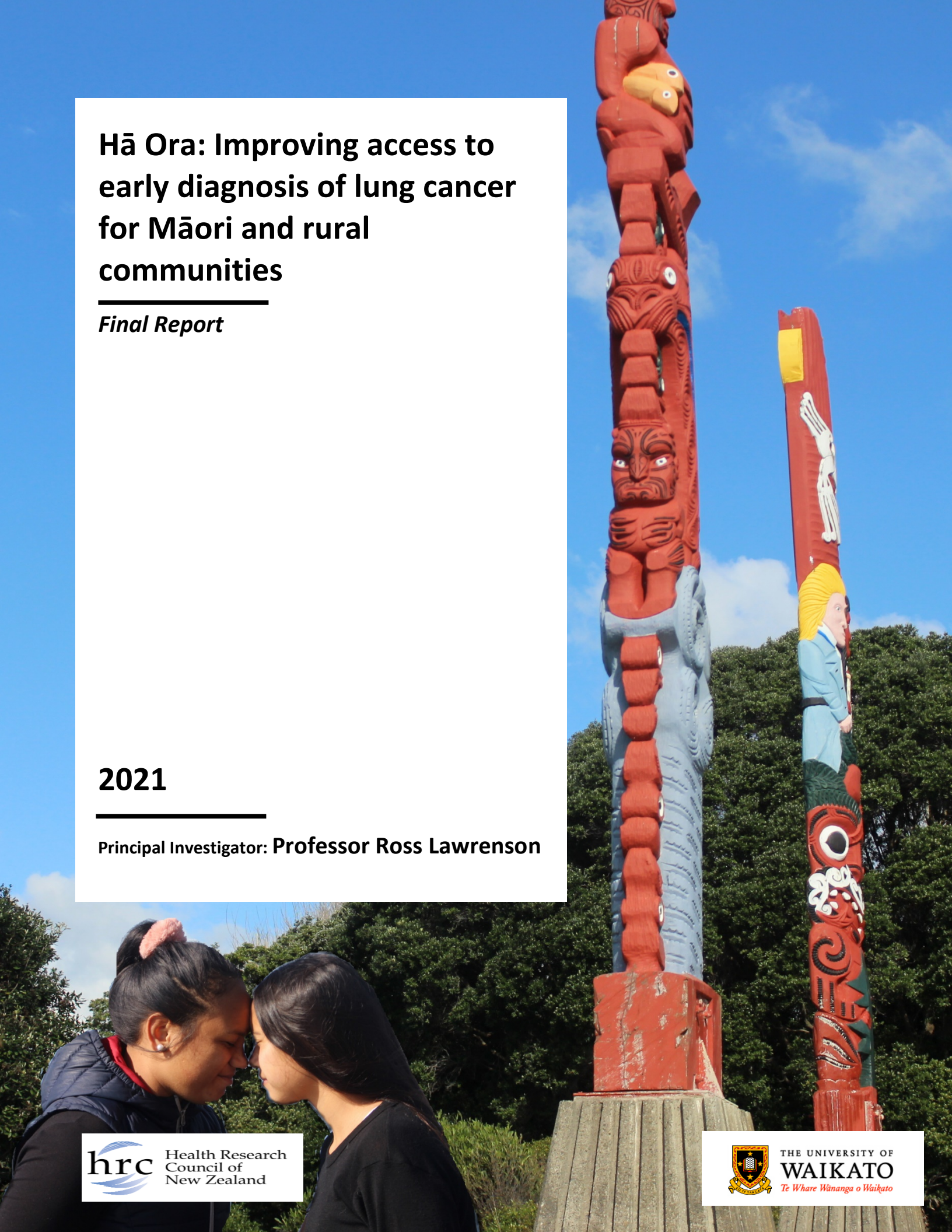


# Hā Ora: Improving access to early diagnosis of lung cancer for Māori and rural communities

*Final Report*

**2021**

Principal Investigator: **Professor Ross Lawrenson**



**Citation:** Lawrenson, R., Cassim, S., Keenan, R., Aitken, D., Kidd, J., Rolleston, A., Hokowhitu, B., Chepulis, L., Lao, C., Brown, L., Firth, M., Wong, J. (2020). *Hā Ora: Improving early diagnosis of lung cancer for rural Māori communities. Final report.* Hamilton, New Zealand: University of Waikato

# Final Report

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

Health Research Council Reference: 17/438

The University of Waikato



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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.*

---

**Prepared for:**

Health Research Council,  
Ministry of Health &  
Te Aho o Te Kahu, Cancer Control  
Agency

**Prepared by:**

Professor Ross Lawrenson  
Dr Shemana Cassim

**Date:** 2021

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## Message from Principal Investigator

Lung cancer is NZ's most important cause of cancer death. Mortality rates for Māori are 3-4 times greater than for non-Māori. It is therefore a high priority for our health care system to try and reduce the impact of the deadly disease and to reduce the inequity in health outcomes for Māori. The main reason for the poor outcomes in people with lung cancer is that over 80% will present with advanced disease that cannot be cured. Yet we know that if diagnosed at an early stage, lung cancer can be cured. Thus this project was aimed at trying to better understand barriers to earlier cancer diagnosis for Māori. This would help suggest ways of improving access for Māori and hopefully ensure earlier diagnosis and a greater likelihood of patients having the opportunity to have successful treatment of their cancer. This project has been based heavily on a codesign methodology working with Māori patients and whānau. The stories we have heard are powerful and a call to action to address the barriers that patients and whānau face in having a diagnosis and treatment for their cancer.

I would like to thank the HRC for their support in funding this project, the fantastic Hā Ora team of investigators, our Kaumātua Mr Hemi Curtis for his guidance throughout the project, but most importantly, I would like to thank our community partners and the patients and whānau who have given up their time and shared their knowledge and expertise that has made this project possible.

Ngā mihi nui



Ross Lawrenson

---

# Governance Structure & Stakeholders

## ***Academic and Clinical Steering Group***

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Anna Rolleston  
Lynne Chepulis  
Rawiri Keenan  
Brendan Hokowhitu  
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Nicolette Sheridan  
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## ***Project Partners***

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***

Phyllis Tangitu – *Rotorua*  
Eru George  
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Hariata Vercoe  
Yvonne Rogers  
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Mahina Joseph-Small – *Te Kuiti*  
Maryanne Thompson  
Tania Te Wano  
Reweti Ropiha – *Gisborne*  
Dallas Poi  
Shirley Keown



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# Executive Summary

There were three main objectives for this project. The first was to engage in cleaning and verification of the data in the Midland Lung Cancer Register, and to identify predominantly Māori rural communities with higher rates of lung cancer in the Midland Region. The second was to identify the barriers to early diagnosis of lung cancer experienced by Māori lung cancer patients and whānau. Third was to co-design a multi-pronged intervention alongside rural Māori communities to improve early diagnosis of lung cancer for whānau in their localities.

First, to understand the characteristics of lung cancer cases in the Midland Region, the team created a combined dataset based on the New Zealand Cancer Register data and the Midland Lung Cancer Register data. The combined lung cancer dataset included all cancer cases in the Midland Region and the additional verified lung cancer cases diagnosed in 2011-2015 and recorded in the New Zealand Cancer Register. Second, the team carried out qualitative research 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 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 identified through the Midland Lung Cancer Register: 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 project 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 (resourced and self-help), a series of lung cancer awareness videos (aimed at whānau of different age groups), a kaiawhina training programme (upskilling health staff) and a ‘pou pupuru oranga’ (cancer navigator).

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# 1. Background

Lung cancer is a priority cancer in New Zealand (NZ) as it is a large volume cancer, with poor survival and large inequities. It is the leading cause of cancer deaths in NZ with approximately 1650 deaths per year [1]. Overall lung cancer survival in NZ is poor with 34.3% of patients being alive at 1-year post diagnosis and 11% at 5 years [2]. Māori men have double the incidence and Māori women have 3.4 times the incidence of lung cancer compared to NZ European men and women [3]. For Māori the survival percentages are 33.5% at one year but only 6.5% at 5 years [3]. With Māori having both a higher incidence and poorer survival the age standardised mortality rate for Māori is thus 3.5 times that of non-Māori [4-6]. Internationally many countries achieve better survival outcomes than NZ including Canada, Australia and Sweden where 5-year survival is between 16 to 18% [7]. There are also gender differences in survival: 5-year survival for men of 9.5% and 11% for women compared with Australia (NSW men 13% and women 15%) and Canada (men 14% and women 18%) [8, 9]. There are also significant variations in outcomes across NZ, with 5-year relative survival ranging from approx. 5% to 14% [9].

There is some evidence from previous studies that there are differences in the presentation and management of Māori. Māori were more likely to present with advanced disease and less likely to receive potentially curative treatment [10]. In the Midland Cancer Network Region 27% of patients are Māori and of the 350 new cases

of lung cancer that occur each year 33% cases occur in Māori.

Much of the reason for the poor outcomes in lung cancer is that it is typically diagnosed at a late stage. In the 2010 HRC funded study, Stevens et al showed 51% of cases with Non-Small Cell Lung Cancer (NSCLC) had metastatic disease at diagnosis and 72% of those with Small Cell Lung Cancer (SCLC) had extensive disease [11]. But localised lung cancer can be cured if found early enough. In the US, lobectomy for early stage lung cancer shows an 80% cure rate [12]. In NZ 63% of localised lung cancer cases are alive at 5 years [2]. In the Midland Cancer Network Region in 2015 only 5% of patients on the Faster Cancer Treatment pathway were treated with surgery. Poorer outcomes have been noted for Māori men and women. This is due to a combination of factors, but late stage at diagnosis is a critical one. Māori are more likely to present with late-stage and incurable disease [2, 6]. Many Māori live in rural areas where GP shortages and a lack of continuity of care mean poorer access. Between 24% and 36% of patients with lung cancer presented directly to ED as the first presentation, without evidence of a GP referral [13]. In the UK, patients who have not got a GP or are regular users of hospital services, those with low socio-economic status and males are all more likely to be diagnosed through the emergency department [14].

Late diagnosis can be due to a variety of factors including patient factors, system factors and the characteristics of the cancer. The Model of Pathways to Treatment recognises four key intervals to treatment as: symptom appraisal, the help-seeking interval, diagnostic interval and

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pre-treatment interval [15]. Walter et al developed this internationally recognised model for examining pathways to cancer diagnosis, which they adapted from the seminal work of Andersen et al [16]. Awareness of cancer warning signs and symptoms by individual patients affects the time between the development of symptoms and the realisation that these may be serious and need investigation [17]. In some cases, this interval may be substantial [18]. Additionally, symptoms of 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. In 2019, the NZ Guidelines Group produced useful guidelines for GPs on the common symptoms of lung cancer and investigation and referral guidance. These include a list of signs and symptoms identified from primary studies of lung cancer aimed at informing general practitioners. These guidelines were widely distributed to doctors but whether their content is known either to doctors or patients has not been researched [19]. Once the symptom has been recognised by the patient as needing assessment – the next interval is from the point of recognition to actually attending a health professional. In NZ with its well-developed primary care sector the health professional is usually a general practitioner, although a significant proportion of patients first present to the hospital emergency department. Research using qualitative methods has been fruitful in understanding how patients recognise possible symptoms and signs of cancer and why they make often complex decisions to seek or not to seek health care practitioner advice [20, 21]. For instance, it has been shown that patients are

more likely to present late with cancer if they are registered in a practice where it is hard to get an appointment [22]. Recent research with Māori patients has indicated continuity of care with a trusted GP is needed if Māori patients are to engage with general practice [23, 24]. Such findings have the potential to inform future interventions to reduce the time to cancer diagnosis.

There is very limited NZ research into the reasons for delay in presentation in patients with lung cancer [25]. Consequently, the understanding of barriers for Māori with lung cancer is limited. Indeed, this is true for all cancers [26]. Findings from the University of Auckland study based on patients attending an ED suggested many patients had minimised or misinterpreted symptoms. Following recognition of symptoms, some self-treated before seeking medical attention. Others mentioned shame about smoking, fear of treatment and fatalism that cancer treatment would have little benefit all as reasons for delay in attending a health professional [25]. Once the patient does attend for assessment further delay can occur. For instance, in the NZ qualitative study above, most participants [10, 13] said they had visited their practice several times over weeks and in some cases months before being diagnosed. Similarly, in a UK study, many lung cancer patients reported visiting their GP on more than one occasion before referral [27]. For patients with a symptom that may be due to lung cancer after a clinical examination the usual first investigation is a chest X-ray. If there is any further suspicion, then a computed tomogram (CT) or bronchoscopy may be needed.

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Within NZ, GPs have poorer access to diagnostic technology and are less likely to refer patients for investigation [11]. The Health & Disability Commissioner (HDC) noted in their report on Delayed Diagnosis of Cancer in Primary Care that issues around a lung cancer diagnosis was one of the commonest causes of complaint [28]. Reasons for delay by GPs included the presence of comorbidities drawing focus away from the lung cancer diagnosis, and inappropriate reliance on a test. Thus a negative chest X-ray is likely to reassure a GP that lung cancer is not possible whereas it is not uncommon on CT to discover cancer that was not apparent on X-ray [28, 29]. In the US lung cancer screening trial, low dose CT identified twice as many early stage lung cancers as did chest X-rays [30]. The propensity to refer patients with suspected cancer varies between practices. It has been shown that patients from practices that refer more patients have a better survival [31]. We have recently shown that NZ GPs are less likely than GPs in other countries to take definitive action in investigating patients who have a moderate or high index of suspicion for lung cancer [32]. The nihilistic attitudes of some GPs to early diagnosis and treatment of lung cancer may also be a barrier. The development of guidelines for the management of suspected cancer by the NZ Guideline Group (NZGG) was an attempt to improve early diagnosis of cancer [19]. The Faster Cancer Treatment (FCT) programme, established by the NZ MOH is designed to reduce waiting times for appointments, tests and treatment and standardise care pathways for cancer patients. Targets for patients with a High Suspicion Cancer (HSC) have been implemented including a 31-

day target from diagnosis to first treatment and a 62-day target from referral from a GP to time to receive their first treatment. However, the FCT initiative does not address the crucial first step of improving early diagnosis. GP referrals are triaged by a secondary care clinician and HSC and/or urgency level recorded by GP may be altered at the secondary care triage. Across all of NZ, many HSC cases are admitted through ED or referred from elsewhere in the system. In the Midland Cancer Network only one third of patients with lung cancer enter the FCT pathway after referral from their GP.

A qualitative study in patients with lung cancer showed that patient delay was common and that for those referred to outpatients there were often long waits [25]. This study was in Auckland where access to key modalities such as CT, endobronchial ultrasound or PET-CT is probably easier than in the Midland Cancer Network where many patients live in rural communities or in small urban areas where access to these diagnostic aids requires referral to the Waikato Cancer Centre in Hamilton. With regards to treatment, access to thoracic surgery and radiotherapy have both been highlighted as being less than optimal [33] but these issues are being addressed by the Midland Cancer Network.

The need for early diagnosis through timely access to diagnostics is well established, and will form the basis of a proposed multi-pronged intervention. Previous studies have noted four key barriers: 1) failing to interpret the symptom/s as requiring medical attention 2) perceived service barriers e.g. difficulty getting an appointment 3) practical barriers e.g. time,

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transport cost 4) emotional barriers e.g. fear of receiving bad news [20]. It may be for Māori there are also cultural barriers [24]. This project involved working primarily Māori communities in the Midland Cancer Network region to co-design and test an intervention to promote the early detection of lung cancer. This included promoting increased awareness of signs and symptoms of the disease among patients and health care providers, and identifying and addressing the perceived, practical and emotional barriers.

## 1.1 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).

The Midland Respiratory Group have been collecting data on all newly diagnosed cases of lung cancer who are referred to their multidisciplinary review meetings onto an access database: Midland Lung Cancer Register (MLCR). It has maintained a register of all patients seen since 2004 and the centre has relatively complete recording of cases for the Midland Region (Lakes, Waikato, Tairāwhiti and Bay of Plenty District Health Boards (DHBs)) since 2007. These four DHBs serve a combined population of 700,000 and generate approximately 400 new cases of lung cancer a year. The region has 27% Māori population and of the over 2000 cases on the register 600 are Māori. The register includes data on date and source of presentation, results

of investigations including CT and spirometry, date of diagnosis and pathological reporting. All patients are staged and mode of treatment is then recorded (radiotherapy, chemotherapy or surgery). Accordingly, the team created a combined dataset based on the New Zealand Cancer Register data and the MLCR data.

The qualitative phases of this project 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



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kaumātua Hemi Curtis. We extend our sincere thanks to members for their time and invaluable contributions to this project.

## **1.2 Research impact**

We believe this project will generate an increase in the number of diagnostic tests for lung cancer and referrals to specialist care. In the longer term we expect to see an increase in the proportion of patients diagnosed with early stage disease and receiving potentially curative treatment. The long term impact is an improvement in survival especially for Māori. There is a strong change orientation within the project which was enhanced by the involvement of end-user stakeholders such as Māori communities, Māori health care providers, GPs and DHBs. This ensured rapid knowledge transfer of any findings because the required local solutions were already in place. Dissemination plans included targeted information sharing for Māori communities, GPs and other health professionals in addition to the hands-on experiences that were generated through the co-design approach. Wider dissemination occurred through the influence of the Midland Cancer Network and the National Lung Cancer Working Group.

## **1.3 Research aims**

The initial phase of this project (Study 1) involved cleaning and verifying data on the Midland Lung Cancer Register, and aimed to identify the

characteristics of newly diagnosed lung cancer cases in the Midland Cancer Network Region, and to understand the factors that influence whether patients receive potentially curative treatment for their lung cancer. The Register was also used to identify rural communities with higher rates of lung cancer in the Midland Region for the next phase of the project.

The latter phases of this project (Studies 2-5) aimed to understand the barriers to early diagnosis of Māori at risk of lung cancer in four rural communities identified from the Register. 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.

The following chapters of this report are structured as separate sections based on, and detailing the six-step research process of this study: Midland Cancer Register, systematic literature review, qualitative interviews with Māori lung cancer patients, community engagement, hui with primary healthcare providers and intervention development. These sections are followed by a general discussion and conclusion.

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## 2. Study One

### Midland Cancer Register

#### 2.1 Sub-study one: Comparison of the Midland Cancer Register and New Zealand Cancer Registry

##### Reference:

Lawrenson, R., Lao, C., Leonie, B., Wong, J., Middleton, K., Firth, M. & Aitken, D. (2018). Characteristics of lung cancers and accuracy and completeness of registration in the New Zealand Cancer Registry, *NZMJ*, 131(1479).

##### 2.1.1 Aim

This study aims to report the characteristics of newly diagnosed lung cancer cases in the Midland Cancer Network region, and to examine the data accuracy of registrations in the NZCR in 2011-2015.

##### 2.1.2 Introduction

The New Zealand Cancer Registry (NZCR) is a population-based tumour registry, collecting and storing cancer incidence data. The new cancer registrations are mainly based on the pathology reports sent by reporting laboratories electronically. Other sources include discharge reports from publicly funded and private hospitals, death certificates and autopsy reports.[34, 35] Data collected in the NZCR includes demographic information (such as date of birth, gender and ethnicity), and tumour

information (such as cancer site and extent of disease). The NZCR is the major source of 'information on the incidence of, and mortality from, cancer' and 'a basis for cancer survival studies and research programmes'.[36] Its completeness and accuracy are vital for cancer control in New Zealand.

The completeness and accuracy of registrations in the NZCR have been reported to be diverse for different cancers.[10, 35, 37, 38] Approximately 88% of the breast cancer cases recorded in the NZCR have information on disease extent with a 94% accuracy rate in those with disease extent.[35] For colon cancer 96% cases have disease extent with a 87% accuracy rate,[37] but only 31% prostate cancer cases have disease extent with a 89% accuracy rate.[38] An audit was conducted to assess the lung cancer data in NZCR using the data recorded in the Auckland and Northland regional databases in 2004.[10] Of the 565 audit cases, 66 (12%) cases were not included in the NZCR, and 1 duplicate registration and 78 (14%) ineligible cases were identified in the NZCR. Only 58% of the lung cancer cases recorded in the NZCR have information on disease extent with a 79% accuracy rate in those with disease extent.[10] The audit of the lung cancer data in the NZCR was conducted a decade ago, and improvement on data quality may have been achieved. An updated quality assessment on the lung cancer data is needed.

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### 2.1.3 Methods

#### **Data cleaning and verification**

Experienced clinicians validated the lung cancer cases diagnosed in 2011-2015 in the MLCR by comparing the clinical records and the data recorded in the MLCR. Lung cancer (ICD code: C33, C34)[39] diagnosed in the Lakes, Waikato, Tairāwhiti and Bay of Plenty DHBs in 2011-2015 were extracted from the NZCR and the MLCR.

Registration duplications were removed from the two datasets. Then they were linked together by the National Health Index (NHI) number, a unique identifier assigned to every person who uses health and disability support services in New Zealand. We classified all the combined cases into three groups: 1) matching cancer cases in both datasets, 2) cancer cases identified in the MLCR only, 3) registrations identified in the NZCR only. For registrations identified in the NZCR only, clinical records were examined by clinicians to verify the lung cancer diagnosis: 1) lung cancer diagnosed in 2011-2015, 2) lung cancer diagnosed before 2011 or after 2015, 3) not lung cancer, 4) cannot confirm due to insufficient information.

#### **Combined lung cancer dataset**

To understand the characteristics of lung cancer cases in the Midland Cancer Network region, we created a combined dataset based on the NZCR data and the MLCR data. The combined lung cancer dataset included all cancer cases in the MLCR and the additional verified lung cancer cases diagnosed in 2011-2015 and recorded in

the NZCR. We have categorised the cancer cell types into six groups: small cell, NSCLC, NSCLC-other, malignant carcinoid, others and unknown. The characteristics of these patients by ethnicity (Māori, Pacific and others) was explored, and the differences were examined by Chi-Square tests, with a p-value of less than 0.05 considered significant. The odds ratio of having small cell lung cancer compared to non-small cell lung cancer between Māori patients and non-Māori patients was estimated using the logistic regression model after adjustment for age, gender, smoking status (recorded in the MLCR), DHB and year of diagnosis.

#### **Accuracy and completeness of the NZCR**

The accuracy of demographic data of the verified lung cancer cases in the NZCR including cancer extent/stage, date of diagnosis, DHB, gender and ethnicity (Māori, Pacific, Asian, European and others) were compared with the MLCR data and clinical record. As demonstrated in the audit[10] on lung cancer data in NZCR in 2004, the difference on date of diagnosis between the NZCR and regional dataset may be due to difference regarding the definition of date of diagnosis. The NZCR may collect the date of diagnosis from 1) date of operation or biopsy, 2) date of admission, 3) date of death if diagnosed at autopsy, or 4) 'approximate time between onset and death' as reported by certifying doctor on the death certificate if the only notification of a cancer comes from the death certificate.[10] However, a regional dataset may record the date of diagnosis from 1) date of issue of the first report confirming malignancy, 2) the date of

final report suggesting invasive malignancy, or 3) the first documentation of the diagnosis in the clinical records.[10]

The MLCR records the cancer stage using the Tumour Node Metastases (TNM) staging system,[40] while the NZCR applies the Surveillance Epidemiology and End Results (SEER) programme cancer staging definitions.[41] The TNM classification was updated by the American Joint committee on Cancer. ‘T’ describes the extent of the primary tumour. ‘N’ describes the extent of regional lymph node metastasis. ‘M’ describes the occurrence of distant metastasis.[40] The SEER staging definition was developed by the American National Cancer Institute. Extent at diagnosis in the NZCR is coded as B (limited to organ of origin), C (Extension to adjacent organs), D (Extension to regional lymph nodes), E (distant metastases) and F (unknown).[41]. In this study, stage IA and IB in the TNM system were considered to be extent B, stage IIA, IIB, IIIA and IIIB were comparable to extent C and D, and stage IV were extent E.[10] All data analyses were performed in IBM SPSS statistics 25 (New York, United States).

#### 2.1.4 Results

##### **Data cleaning and verification**

We identified 2125 lung cancer registrations in the NZCR, and 1572 lung cancer registrations in the MLCR (Table 1) in 2011-2015. We found 4 duplicate lung cancer registrations in the NZCR (Figure 1). Of the cancer cases recorded in the

MLCR, 1482 (94.3%) lung cancer cases were also registered in the NZCR. There are 639 lung cancer registrations recorded in the NZCR that were not identified in the MLCR. After examining the clinical records of these 639 patients, 485 (75.9%) were confirmed to be diagnosed with lung cancer in 2011-2015, 22 (3.4%) were diagnosed with lung cancer before 2011 or after 2015, 72 (11.3%) did not have lung cancer, and 60 (9.4%) could not be verified due to lack of information in the clinical records. Of the 485 lung cancer cases recorded in the NZCR but not in the MLCR, 20 (4.1%) were stage I, 9 (1.9%) stage II, 39 (8.0%) stage III, 341 (70.3%) were stage IV, and 76 (15.7%) with unknown stage. Of the 90 lung cancer cases recorded only in the MLCR, 43 (47.8%) had clinical diagnosis only without any pathology report. Twenty-six patients (28.9%) had stage I lung cancer, 7 (7.8%) stage II, 16 (17.8%) stage III, 36 (40.0%) stage IV and 5 (5.6%) with unknown cancer stage.

Table 1. Number of cancer cases by year of diagnosis and DHB

Categories	MLCR	NZCR
<b>Year of diagnosis</b>		
2011	300	417
2012	293	410
2013	297	398
2014	315	436
2015	367	460
<b>DHB</b>		
Bay of Plenty	403	681
Lakes	223	306
Tairāwhiti	85	140
Waikato	861	994
<b>Total</b>	<b>1572</b>	<b>2121</b>

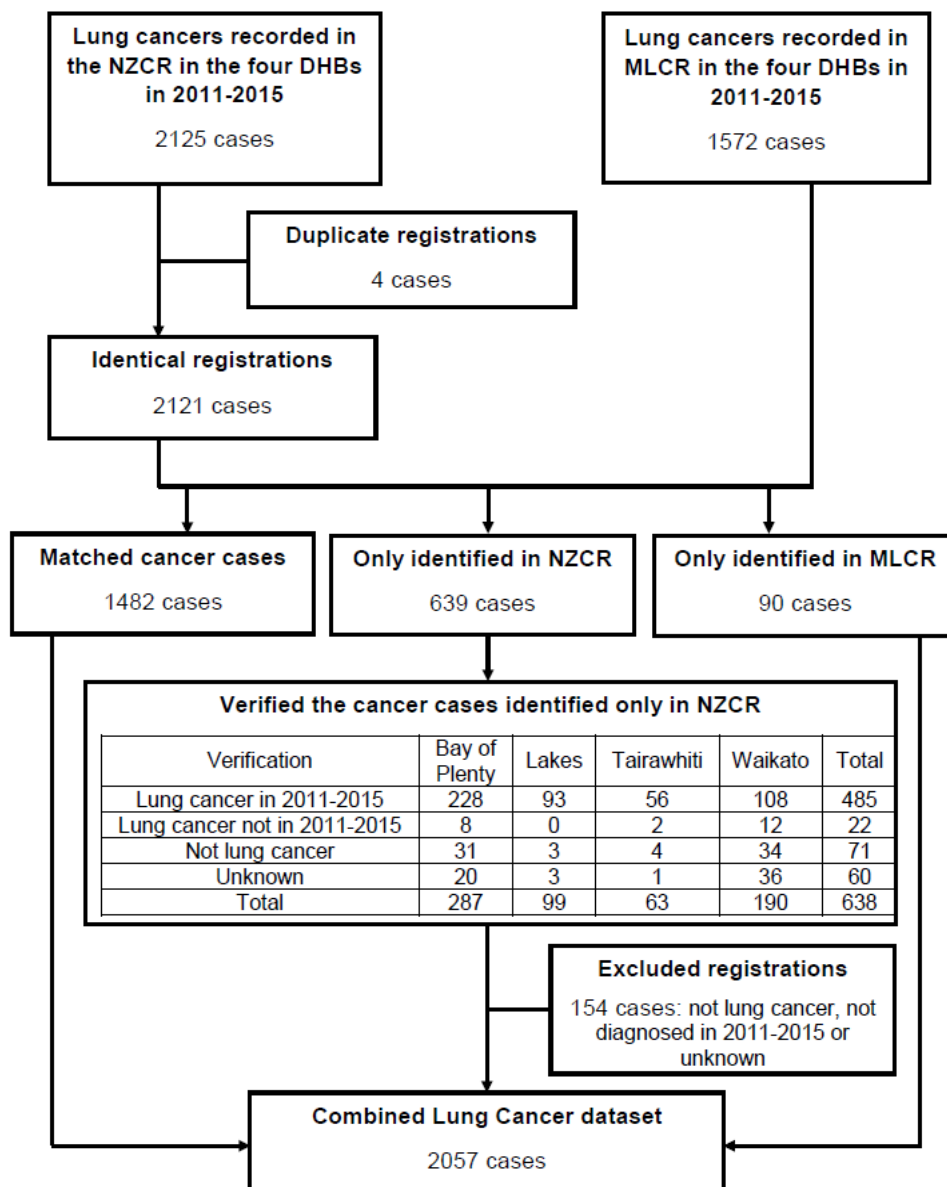


Figure 1. Flow chart of the Combined Midland Lung Cancer Dataset

### Combined Midland Lung Cancer Dataset

The combined dataset included 2057 lung cancer cases (Table 2). The mean age of the cohort was 70 years old at diagnosis, and 52.7% of the patients were male. There were 656 (31.9%) Māori patients, 22 (1.1%) Pacific patients and 1379 (67.0%) patients of other ethnicities. Waikato DHB has the largest number of lung cancer cases, followed by Bay of Plenty, Lakes

and Tairawhiti DHB. Sixty one percent of patients were diagnosed with metastatic cancer, while 11.0% of those who had been staged had stage I disease. Eighty percent of patients had NSCLC, while 16.9% had small cell lung cancer. Māori patients were more likely to be diagnosed at a younger age ( $p$ -value  $<0.001$ , mean age: 66 years for Māori and 72 years for non-Māori), and more likely to be female ( $p$ -value  $<0.001$ ) than others. The difference of cancer stage at diagnosis

between Māori and others was not significant (p-value =0.137). Almost 50% Māori patients were current smokers, another 47.8% were ex-smokers and only 2.6% had never smoked,

compared to 27.4% current smokers, 61.9% ex-smokers and 10.7% never smoked for non-Māori patients (p-value <0.001). The proportions of missing data in smoking status, cancer stage and

Table 2. Characteristics of lung cancer patients between Māori and non-Māori in the combined dataset

Factors	Māori		Non-Māori		P-value (chi-square test)	Total	
	N	%	N	%		N	%
<b>Year of diagnosis</b>					0.907		
2011	122	18.6%	274	19.6%		396	19.3%
2012	136	20.7%	272	19.4%		408	19.8%
2013	126	19.2%	259	18.5%		385	18.7%
2014	132	20.1%	281	20.1%		413	20.1%
2015	140	21.3%	315	22.5%		455	22.1%
<b>DHB</b>					<0.001		
Bay of Plenty	179	27.3%	448	32.0%		627	30.5%
Lakes	138	21.0%	182	13.0%		320	15.6%
Tairāwhiti	83	12.7%	58	4.1%		141	6.9%
Waikato	256	39.0%	713	50.9%		969	47.1%
<b>Age (years)</b>					<0.001		
<50	33	5.0%	45	3.2%		78	3.8%
50-59	158	24.1%	145	10.3%		303	14.7%
60-69	230	35.1%	370	26.4%		600	29.2%
70-79	179	27.3%	485	34.6%		664	32.3%
80+	56	8.5%	356	25.4%		412	20.0%
<b>Gender</b>					<0.001		
Female	363	55.3%	610	43.5%		973	47.3%
Male	293	44.7%	791	56.5%		1084	52.7%
<b>Smoking status</b>					<0.001		
Current smoker	252	49.6%	288	27.4%		540	34.7%
Ex-smoker	243	47.8%	650	61.9%		893	57.3%
Never smoked	13	2.6%	112	10.7%		125	8.0%
Unknown	148		351			499	
<b>Cancer stage</b>					0.137		
I	63	10.0%	154	11.5%		217	11.0%
II	34	5.4%	75	5.6%		109	5.5%
III	161	25.4%	278	20.8%		439	22.3%
IV	375	59.2%	830	62.1%		1205	61.2%
Unknown	23		64			87	
<b>Cell type</b>					<0.001		
NSCLC	403	73.9%	945	83.5%		1348	80.4%
NSCLC-other	8	1.5%	22	1.9%		30	1.8%
Small cell	126	23.1%	157	13.9%		283	16.9%
Malignant Carcinoid	0	0.0%	3	0.3%		3	0.2%
Others	8	1.5%	5	0.4%		13	0.8%
Unknown	111		269			380	
<b>Total</b>		<b>656</b>		<b>1401</b>			<b>2057</b>

cell type between Māori and non-Māori were similar: 22.6% and 25.1% for smoking status; 3.5% and 4.6% for cancer stage; and 16.9% and 19.2% for cell type.

After adjustment for age, gender, year of diagnosis and DHB (Table 3), the odds ratio of having small cell lung cancer for Māori patients compared to non-Māori patients was 1.55 (95% CI: 1.17-2.05). The odds ratio of having small cell lung cancer was 4.06 (95% CI: 1.72-9.60) for current smokers and 2.68 (95% CI: 1.14-6.30) for ex-smokers compared to patients who never smoked. Patients in Bay of Plenty DHB were less likely to have small cell lung cancer compared to patients in Waikato DHB (odds ratio: 0.66, 95% CI: 0.48-0.92). Age, gender and year of diagnosis did not have a significant impact on the risk of being diagnosed with small cell lung cancer.

### **Accuracy and completeness of the NZCR**

The demographic data in the NZCR has high accuracy, with 99.2% accuracy for gender, 97.0% for ethnicity, 98.4% for DHB and 99.9% for date of birth among the 1967 verified lung cancer cases in the NZCR (Table 4). For the date of cancer diagnosis, 21.5% of the cancer cases were on the same date and another 65.5% were within one month difference. However, the recording of cancer extent in the NZCR is poor, with 1041 (55.3%) cancer cases recorded with correct cancer extent.

*Table 3. Adjusted odds ratios of having small cell lung cancer compared to non-small cell lung cancer*

<b>Factors</b>	<b>P-value</b>	<b>Adjusted odds ratio (95% CI)</b>
<b>Smoking status</b>		
Never smoked	Ref	
Ex-smoker	0.024	2.68 (1.14-6.30)
Current smoker	<0.001	4.06 (1.72-9.60)
Unknown	-	-
<b>DHB</b>		
Waikato	Ref	
Bay of Plenty	0.014	0.66 (0.48-0.92)
Lakes	0.571	0.89 (0.60-1.32)
Tairāwhiti	0.815	1.06 (0.64-1.76)
<b>Ethnicity</b>		
Non-Māori	Ref	
Māori	0.002	1.55 (1.17-2.05)
<b>Age (Continuous)</b>		
	0.075	0.99 (0.98-1.00)
<b>Gender</b>		
Female	Ref	
Male	0.402	0.89 (0.68-1.16)
<b>Year of diagnosis (Continuous)</b>		
	0.480	0.97 (0.88-1.06)

### **2.1.5 Discussion**

Lung cancer in the Midland Cancer Network region is relatively common with over 400 new cases per year. There has been a 15% increase in the number of lung cancer cases between 2011 and 2015. This has implications on the capacity of the cancer services to manage the increasing workload. Sixty-one percent of patients present with stage IV disease at diagnosis, while only 17% had potentially curative stage I or II disease.

Table 4. Accuracy of characteristics of lung cancer patients in NZCR

Demographics	Accuracy	Details						
<b>Gender</b>	<b>99.2%</b>	Gender in NZCR		Gender in MLCR/clinical records			Total	
				Female	Male			
		Female		928	12		940	
		Male		3	1024		1027	
Total		931	1036		1967			
<b>Ethnicity</b>	<b>97.0%</b>	Ethnicity in NZCR		Ethnicity in MLCR/clinical records				Total
		Māori	Pacific	Asian	European	Others	Unknown	
		623	1		37	1		662
		2	18	1	2			23
			1	35	1			37
		6		1	1227	1		1235
					1	3		4
		1	1		1		3	6
Total		632	21	37	1269	5	3	1967
<b>DHB</b>	<b>98.6%</b>	DHB in NZCR		DHB in MLCR/clinical records			Total	
				Bay of Plenty	Lakes	Tairāwhiti		Waikato
		Bay of Plenty		604	15		3	622
		Lakes		1	296		3	300
		Tairāwhiti		1		132		133
		Waikato		1	2	2	907	912
Total		607	313	134	913	1967		
<b>Date of birth</b>	<b>99.9%</b>	Differences of date of birth in both dataset			Number of Records			
		0 day			1965			
		6 days			1			
		731 days			1			
		Total			1967			

Early diagnosis is the key to improving the prognosis for lung cancer patients. Reasons for diagnostic delay in New Zealand are complex and multifactorial.[42] Previous New Zealand research has demonstrated that patient delay is common and many are diagnosed in the Emergency Department, although most patients had seen a general practitioner (GP) before diagnosis. Possible interventions to improve early diagnosis include ‘community initiatives to educate and resource at-risk patients to seek help, supporting and resourcing primary care to increase timely referral and implementing strategies to reduce system complexity for GPs and patients, and the employment of care coordinators’.[42]

Māori patients were younger (mean age: 66 years) compared to non-Māori patients (mean

age: 72 years). More Māori with lung cancer were women (55.3%), whereas in non-Māori the majority of cancers were in men (56.5%). This is likely due to differences in smoking status. In 2009, the smoking prevalence for Māori was 44% compared to 18% for non-Māori.[43] Māori women have the highest smoking prevalence rate (48% in 2009).[43, 44] It is worth noting that 10.7% of non-Māori patients and 2.6% Māori patients diagnosed with lung cancer had never smoked.

We found no difference in the risk of diagnosing metastatic lung cancer between Māori and non-Māori patients, but Māori patients are more likely to have small cell lung cancer than others. Small cell lung cancer is strongly associated with smoking.[45] This study showed that Māori patients are more likely to be smokers or ex-



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smokers than others. However, after adjustment for smoking status and other factors, Māori patients are still 1.55 times more likely to have small cell lung cancer than non-Māori patients. Reasons for this need further investigation. A 2010 audit conducted in the Auckland and Lakes region showed no significant difference in having small cell lung cancer between Māori and non-Māori patients.[11] This study only included 57 Māori patients and may have been underpowered to show the difference,[11] while our study has 656 Māori patients and 126 of them have small cell lung cancer.

The NZCR and MLCR are both of great value in understanding the epidemiology of lung cancer in the Midland Cancer Network region. There was some under-reporting in both the NZCR (4%) and the MLCR (24%), and a 5% misrecording in the NZCR. The quality of demographic data of the lung cancer registrations in the NZCR is excellent, but the completeness and accuracy of lung cancer extent has not improved much since 2004: 35% with unknown cancer extent in this study and 42% in the 2004 audit; 81% of accuracy in this study and 77% in the 2004 audit among those with known cancer extent in the NZCR.[10] Further efforts will be needed to improve the cancer extent recording that will be critical for lung cancer research and cancer control in New Zealand.

Around 87% (1713) of the registrations in the NZCR had a date of diagnosis within one month difference compared with the MLCR/clinical records. Though the definition of date of diagnosis in the MLCR is considered to be more reasonable by clinicians, it is more feasible for NZCR to collect the date of diagnosis based on

their definition: 1) date of operation or biopsy, 2) date of admission, 3) date of death if diagnosed at autopsy, or 4) 'approximate time between onset and death' as reported by certifying doctor on the death certificate.[10] For the other 10% registrations whose date of diagnosis in the NZCR was more than one month different from that in the MLCR, the influence of this discrepancy may be substantial especially when these data are used for survival analysis.

The strengths of this study include that records were reviewed by experienced clinicians to ensure the accuracy of lung cancer registrations, cancer stage and cell type. Both sources of data were combined to explore the tumour characteristics between Māori and non-Māori patients. However, this study has some limitations. In the combined dataset, smoking status was not recorded in 24% of the lung cancer cases, cell type was unknown in 18% of the cases, and cancer stage was unavailable in 4% of the cases.

### *2.1.6 Conclusion*

The MLCR provides excellent clinical data on newly diagnosed lung cancer cases. However, there is some under-reporting compared with the NZCR. Combining the two sources of data gives a more complete picture of the incidence and tumour characteristics of lung cancer in our region. Our combined dataset suggests that Māori patients are more likely to have small cell lung cancer than non-Māori patients.

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## 2.2 Sub-study two: Management of patients with early stage lung cancer

### ***Reference:***

Lawrenson, R., Lao, C., Brown, L. et al. (2020). Management of patients with early stage lung cancer – why do some patients not receive treatment with curative intent?. *BMC Cancer*, 20, 109. doi: <https://doi.org/10.1186/s12885-020-6580-6>

### 2.2.1 Aim

This study aims to understand the factors that influence whether patients receive potentially curative treatment for their lung cancer, to understand which patients receive surgical management, and to examine the outcomes in those receiving surgery, other forms of treatment compared to those patients who receive palliative care.

### 2.2.2 Background

Patients with early stage disease can be considered curable with successful surgery, or stereotactic ablative body radiotherapy (SABR).[46] Some stage II and III patients also have successful outcomes with radical radiotherapy and chemo radiotherapy. Surgical resection rates for lung cancer vary between countries and even between centres in a particular country.[47] Overall, 14.7% of NSCLC patients receive surgery in New Zealand compared to 19.1% in Victoria, Australia.[48, 49] Previous studies in New Zealand have reported

lower surgical rates in Māori.[50] New Zealand is looking to improve the proportion of lung cancer patients diagnosed with early stage through the use of an educational campaign. However, we have limited data on how early stage lung cancer is currently managed? There are also limited data on the outcomes of treatment of early stage disease.

Tertiary lung cancer management in the Midland Cancer Network region is principally based at Waikato Hospital.[51] Waikato Hospital provides both surgical services and radiotherapy services for cancer patients for the region; with radiotherapy services also available in the Bay of Plenty DHB.

### 2.2.3 Methods

We analysed lung cancer data from the Midland Lung Cancer Register between January 2011 and December 2018.[51] Patients diagnosed with stage I and II lung cancer (ICD code: C33, C34) and resident in the Midland Cancer Network region in 2011-2018 were included. Patients that were not discussed at an MDM were identified by the NZCR, and missing data was included from examination of their clinical records. For those who did not have a record of treatment, patient notes were searched to ascertain the reasons for no treatment. These were categorised into: comorbidities, poor lung function, poor Eastern Cooperative Oncology Group (ECOG) performance status (2+),[52] high risk of surgical complications, patient refusal or unknown reasons.

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Data collected on individual patients included age, sex, ethnicity, DHB of domicile, type of lung cancer (NSCLC, small cell, others and unknown), stage of cancer, lung function (FEV1 measurement), ECOG status, and presence of known co-morbidities as measured by Charlson Index.[53] We then identified the treatment received by patients, including curative surgery (lobectomy, partial resection of lung and pneumonectomy), curative radiotherapy (radical radiotherapy), SABR, curative chemo radiation or palliative treatment which could include palliative chemo radiation, palliative chemotherapy, or symptomatic palliative care only. Mortality data were derived from the Midland Lung Cancer Register, New Zealand Cancer Registry and hospital system (iPM) with a censor date of 25 June 2019. Statistical analyses were then performed on this Combined Lung Cancer Register.

In order to determine if there is an ethnic basis to inequity of care, patient demographics, tumour characteristics and treatment were compared between Māori and non-Māori patients. The difference was examined with Chi-square test. Reasons for not having potentially curative surgery as the primary treatment were also explored and classified into comorbidity, lung function problems, poor ECOG status, surgical complications, patient refusal and unknown/other reasons. Logistic regression model was used to estimate the odds ratios of having curative treatment for Māori patients compared with non-Māori patients after adjustment for patient demographics and tumour characteristics. We also examined the factors that influence whether patients received

alternative curative treatment compared to surgery.

The Kaplan Meier method was used to examine the all-cause survival by treatment option and by ethnicity (Māori vs non-Māori). For survival analyses, patients without mortality information were considered to be censored on 25 June 2019. Cox proportional hazard model was used to estimate the hazard ratio of death for Māori compared to non-Māori after adjustment for age, sex, year of diagnosis, stage, comorbidities and treatments. All data analyses were performed in IBM SPSS statistics 25 (New York, United States).

#### *2.2.4 Results*

The Combined Lung Cancer Dataset included 3,331 resident cases (1,050 Māori and 2,281 non-Māori) between 2011 and 2018. This study included 583/3,331 (17.5%) with early stage disease (Table 5). This was made up of 169/1,050 (16.1%) Māori and 414/2,281 (18.1%) non-Māori patients. Over 90% of the early stage patients were either a current smoker (30.9%) or ex-smoker (60.1%). Among the lung cancer patients, 47.7% had a history of chronic obstructive pulmonary disease (COPD). There were 452 cases of NSCLC, 14 cases of small cell lung cancer, and 106 patients did not have a pathology report. A record of unknown pathology was associated with significant

Table 5. Patient demographics and tumour characteristics

Subgroup	Māori		Non-Māori		P-value (Chi-square test)	Total	
<b>Sex</b>							
Female	104	61.5%	220	53.1%	0.064	324	55.6%
Male	65	38.5%	194	46.9%		259	44.4%
<b>Age (years)</b>							
<60	35	20.7%	53	12.8%	<0.001	88	15.1%
60-69	65	38.5%	120	29.0%		185	31.7%
70-79	57	33.7%	170	41.1%		227	38.9%
80+	12	7.1%	71	17.1%		83	14.2%
<b>Smoking status</b>							
Current smoker	63	40.4%	104	27.0%	<0.001	167	30.9%
Ex-smoker	91	58.3%	234	60.8%		325	60.1%
Never smoked	2	1.3%	47	12.2%		49	9.1%
Unknown	13		29			42	
<b>Charlson Comorbidity</b>							
0	37	21.9%	119	28.7%	<0.001	156	26.8%
1	44	26.0%	147	35.5%		191	32.8%
2	51	30.2%	99	23.9%		150	25.7%
3	29	17.2%	33	8.0%		62	10.6%
4+	8	4.7%	16	3.9%		24	4.1%
<b>COPD</b>							
No	57	39.9%	207	57.2%	<0.001	264	52.3%
Yes	86	60.1%	155	42.8%		241	47.7%
Unknown	26		52			78	
<b>Cell type</b>							
NSCLC	124	91.2%	328	96.2%	<0.001	452	94.8%
Others	2	1.5%	9	2.6%		11	2.3%
Small cell	10	7.4%	4	1.2%		14	2.9%
Unknown	33		73			106	
<b>FEV1</b>							
<50%	46	30.3%	63	17.4%	<0.001	109	21.2%
50%~80%	70	46.1%	139	38.4%		209	40.7%
80%+	36	23.7%	160	44.2%		196	38.1%
Unknown	17		52			69	
<b>ECOG</b>							
0	51	32.3%	157	40.6%	0.194	208	38.2%
1	73	46.2%	158	40.8%		231	42.4%
2+	34	21.5%	72	18.6%		106	19.4%
Unknown	11		27			38	
<b>Total</b>	<b>169</b>		<b>414</b>			<b>583</b>	

comorbidities in 37 (34.9%) patients, frailty/high risk – ECOG 2+ 10 (9.4%) and very poor lung function 25 (23.6%). The 169 Māori patients

were younger, more likely to be current smokers, have a diagnosis of COPD and have NSCLC-other and small cell lung cancer, and

more likely to have FEV1 of <50% than non-Māori patients.

In total 419/583 (71.9%) of patients with Stage I and II disease were treated with curative intent - 272 (46.7%) patients had curative surgery, including 199 lobectomies, 59 partial resection of lung, and 14 pneumonectomy (Table 6). Another 64 (11.0%) patients were treated with SABR, 67 (11.5%) received curative radical radiotherapy, and 16 (2.7%) had curative chemo/radiotherapy. Amongst those not having curative treatment (164 (28.1%)), 33 (5.7%) had palliative radiotherapy, 14 (2.4%) had palliative chemotherapy, and 117 (20.1%) had best supportive care alone. Māori patients appeared to be less likely to have curative surgery (39.6% vs 49.5%, p-value=0.027), but were as likely to have curative treatment as non-Māori patients

(70.4% vs 72.5%, p-value=0.618). The principal reason recorded in the patient records indicating why these lung cancer patients did not have curative treatment included significant comorbidities in 37 (22.6%) patients, 24 (14.6%) poor lung function, 24 (14.6%) poor ECOG status, 19 (11.6%) high risk of surgical complications, 16 (9.8%) patient refusal and 43 (26.2%) unrecorded.

The logistic regression model showed that age, year of diagnosis, cancer stage, cancer cell type, FEV1 and ECOG status had an impact on the likelihood of having curative treatment (Table 7). Patients who were younger, were diagnosed in more recent years, had stage I disease, had NSCLC, had FEV1 of 80%+, and had an ECOG score of 0 were more likely to receive curative treatment. Amongst those who received

Table 6. Primary treatment for lung cancer patients by ethnicity

Primary treatment	Māori		Non-Māori		Total	
<b>Curative surgery</b>	67	39.6%	205	49.5%	272	46.7%
Lobectomy	49	29.0%	150	36.2%	199	34.1%
Partial resection of lung	16	9.5%	43	10.4%	59	10.1%
Pneumonectomy	2	1.2%	12	2.9%	14	2.4%
<b>SABR</b>	22	13.0%	42	10.1%	64	11.0%
<b>Radical radiotherapy</b>	23	13.6%	44	10.6%	67	11.5%
<b>Curative chemo/radiotherapy</b>	7	4.1%	9	2.2%	16	2.7%
<b>Palliative radiotherapy</b>	14	8.3%	19	4.6%	33	5.7%
<b>Palliative chemotherapy</b>	4	2.4%	10	2.4%	14	2.4%
<b>Supportive care</b>	32	18.9%	85	20.5%	117	20.1%
<b>Total</b>	<b>169</b>		<b>414</b>		<b>583</b>	

curative treatments, younger patients were more likely to have surgery as the primary treatment (odds ratio: 0.91, 95%:0.87-0.95). Current smokers and ex-smokers were less likely to have surgery and more likely to be treated with radiotherapy and chemotherapy than people who never smoked (respective odds ratio: 0.11 (95% Confidence interval (CI): 0.02-0.46); 0.23 (95% CI: 0.06-0.89)). Patients who had NSCLC, had FEV1 of 80%+, and had an ECOG score of 0 were more likely to undergo surgery. After adjustment for other factors we did not find a difference in access to curative treatment and curative surgery between Māori and non-Māori patients (respective odds ratio: 0.80 (95% CI: 0.46-1.38); 1.03 (95% CI: 0.53-2.00)).

There were 217 deaths (37.3%) in this cohort with a median follow-up time of 27 months and a mean follow-up time 34 months. Outcomes in patients with stage I and II lung cancer varied depending on the treatment received (Figure 2). Those who were treated with surgery had a 2-year survival of 87.8% (95% CI: 83.8%-91.8%) and 5-year survival of 69.6% (95% CI: 63.2%-76.0%). SABR has only been available in the region since mid 2015 but outcomes are similar to surgery in the first two years post treatment (2-year survival: 85.2%, 95% CI: 75.8%-94.7%, log-rank test p-value=0.556). Prior to the use of SABR, some patients were offered radiotherapy with curative intent and in this group of patients 2-year survival is only 65.3% (95% CI: 53.1%-77.4%)

Table 7. Adjusted odds ratios from logistic regression model

Subgroup	Having curative treatment vs no curative treatment			Having surgery vs other curative treatment		
	Odds ratio	95% CI	p-value	Odds ratio	95% CI	p-value
<b>Sex</b>						
Female	Ref			Ref		
Male	0.85	(0.51 - 1.41)	0.536	1.26	(0.70 - 2.29)	0.446
<b>Ethnicity</b>						
Māori	0.80	(0.46 - 1.38)	0.424	1.03	(0.53 - 2.00)	0.932
Non-Māori	Ref			Ref		
<b>Age (Continuous)</b>	0.92	(0.89 - 0.95)	<0.001	0.91	(0.87 - 0.95)	<0.001
<b>Smoking status</b>						
Current smoker	0.40	(0.12 - 1.38)	0.149	0.11	(0.02 - 0.46)	0.003
Ex-smoker	0.49	(0.15 - 1.57)	0.229	0.23	(0.06 - 0.89)	0.033
Never smoked	Ref			Ref		
<b>Charlson Comorbidity</b>						
0	Ref			Ref		
1	0.82	(0.36 - 1.87)	0.644	0.43	(0.17 - 1.11)	0.080
2	1.06	(0.45 - 2.50)	0.902	0.35	(0.13 - 0.93)	0.035
3	0.93	(0.34 - 2.54)	0.894	0.20	(0.06 - 0.73)	0.015
4+	0.55	(0.15 - 2.02)	0.365	0.10	(0.02 - 0.56)	0.009
<b>Year of diagnosis (Continuous)</b>	1.15	(1.03 - 1.28)	0.015	0.75	(0.65 - 0.88)	<0.001
<b>Stage</b>						
I	Ref			Ref		
II	0.29	(0.17 - 0.48)	<0.001	0.58	(0.31 - 1.08)	0.088
<b>Cell type</b>						
NSCLC	Ref			Ref		
Others	0.29	(0.17 - 0.51)	<0.001	0.08	(0.03 - 0.23)	<0.001
<b>FEV1</b>						
<50%	0.35	(0.16 - 0.77)	0.009	0.04	(0.01 - 0.12)	<0.001
50%-80%	0.70	(0.36 - 1.38)	0.304	0.42	(0.20 - 0.85)	0.016
80%+	Ref			Ref		
<b>ECOG</b>						
0	Ref			Ref		
1	0.52	(0.26 - 1.02)	0.056	0.57	(0.30 - 1.09)	0.091
2+	0.13	(0.06 - 0.28)	<0.001	0.14	(0.05 - 0.40)	<0.001

and 5-year survival was 50%. Patients offered palliative treatment only had a 2-year survival of 45.0% (95% CI: 37.0%-53.0%) and 5-year survival of 31.8% (95% CI: 23.9%-39.6%).

ratio: 0.77, 95% CI: 0.37-1.61). The all-cause survival for stage I and II lung cancer patients has improved over time (hazard ratio: 0.94, 95% CI: 0.87-1.00).

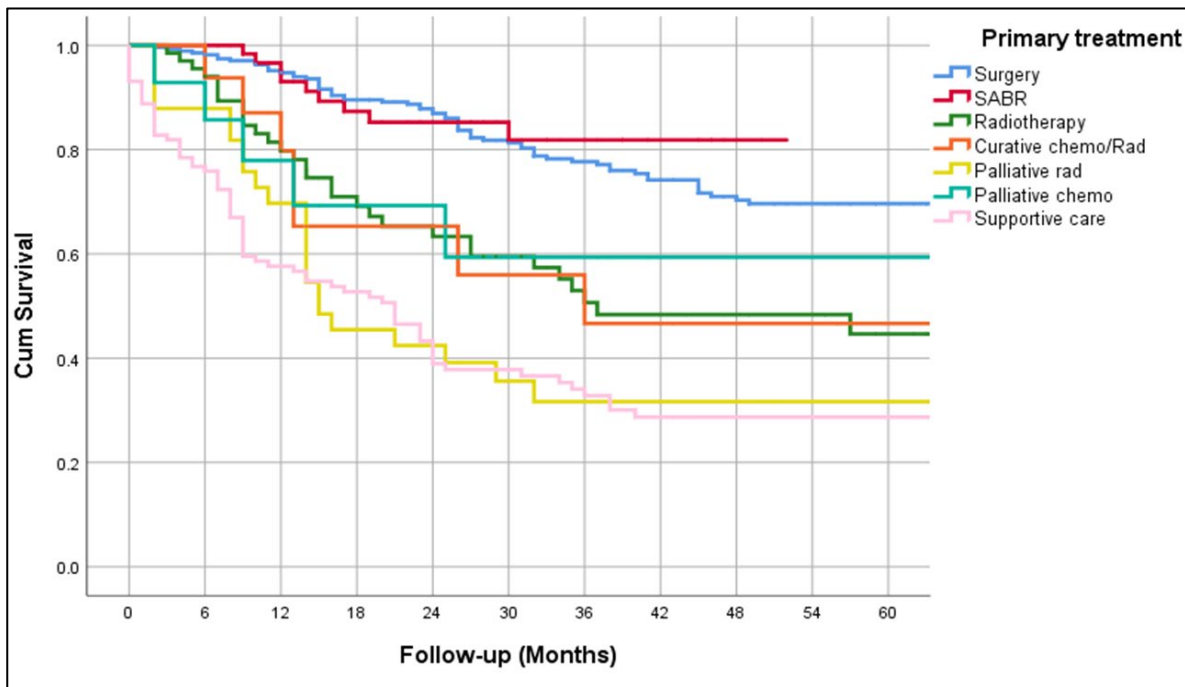


Figure 2. All-cause survival by treatment type in patients with stage 1 and 2 lung cancer

Māori patients had a similar survival to non-Māori patients. The 2-year and 5-year survival for Māori patients was 69.4% (95% CI: 62.2%-76.7%) and 47.1% (95% CI: 37.8%-56.4%), compared to 73.5% (95% CI: 69.1%-77.9%) and 59.3% (95% CI: 53.9%-64.8%) for non-Māori patients.

The hazard ratio (Table 8) of all-cause mortality for Māori patients compared to non-Māori patients was 1.25 (95% CI: 0.92-1.69, p-value=0.150). SABR has equivalent effect on survival compared to curative surgery (hazard

### 2.2.5 Discussion

We found that 71.9% of early stage lung cancer patients in our region were treated with potentially curative treatment. The commonest form of treatment was surgery. Thus in the Midlands Region a total of 272/3331 (8.2%) of lung cancer patients were treated with curative surgery. This low rate of surgical treatment is similar to that found in the UK but lower than the rate reported in Australia and some European countries.[54, 55] While the advent of SABR has coincided with an increasing proportion of early stage patients being offered curative treatment,

Table 8. Adjusted hazard ratio for overall survival from Cox proportional hazard model.

Factors	Hazard ratio	95% CI of hazard ratio	P-value
<b>Sex</b>			
Female	Ref		
Male	1.21	(0.91 - 1.62)	0.195
<b>Ethnicity</b>			
Māori	1.25	(0.92 - 1.69)	0.151
Non-Māori	Ref		
<b>Age (Continuous)</b>	1.01	(0.99 - 1.03)	0.172
<b>Charlson Comorbidity</b>			
0	Ref		
1	1.10	(0.70 - 1.75)	0.673
2	1.07	(0.66 - 1.73)	0.794
3	1.02	(0.55 - 1.86)	0.959
4+	1.19	(0.58 - 2.44)	0.640
<b>Smoking status</b>			
Current smoker	2.51	(1.06 - 5.94)	0.037
Ex-smoker	2.24	(0.96 - 5.22)	0.061
Never smoked	Ref		
<b>Year of diagnosis (Continuous)</b>	0.94	(0.87 - 1.00)	0.068
<b>Stage</b>			
I	Ref		
II	1.35	(1.02 - 1.80)	0.039
<b>Primary treatment</b>			
Curative surgery	Ref		
SABR	0.77	(0.37 - 1.61)	0.486
Radiotherapy	1.94	(1.23 - 3.07)	0.005
Curative chemo/Rad	1.80	(0.80 - 4.03)	0.153
Palliative rad	2.89	(1.72 - 4.85)	<0.001
Palliative chemo	1.69	(0.66 - 4.32)	0.270
Supportive care	3.35	(2.26 - 4.96)	<0.001

significant improvement will only be achieved when the proportion of patients with early stage disease at diagnosis is increased. This can either be achieved through greater awareness of symptoms of lung cancer e.g. through social media campaign[56] and through the introduction of lung cancer screening.[57, 58]

We have shown that there are a number of reasons why patients do not receive curative treatment. Overall, less than half of patients with stage I and II disease in our region 272/583 (46.7%) were treated with surgery. This figure has not improved from the findings in a similar New Zealand study in 2004 which reported a surgery rate of 56% of stage I and II NSCLC.[49]



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Another 147/583 (25.2%) of patients in our study were treated with alternative potentially curative treatment while 164/583 (28.1%) were treated with palliative care only. Patients with stage I and II NSCLC receiving palliative care were older than those who had curative treatment (mean age of 73 years vs 68 years). Other reasons included cancer stage –(stage II cases were less likely to be treated curatively than stage I), cancer cell type (small cell tumours were less likely to be treated than NSCLC), and those with COPD or poor respiratory function who were less likely to receive surgery or curative treatment as were those with a poor ECOG status. These findings are similar to the findings from a Danish study[59] of stage I lung cancer and the historical New Zealand study.[49]

SCLC proliferates more rapidly and has a high propensity to metastasise. Most cases will present with locally advanced or metastatic disease. On rare occasions, patients are identified with small cell lung cancer (SCLC) histology but with early stage disease potentially suitable for resection.[60] Overall our cohort had 440/3331 (13%) small cell lung cancers. There were only 14 small cell lung cancer cases in our group of stage I and II diseases, and only one had curative surgery. In a large cohort of 45,848 patients with SCLC only 1% were treated surgically.[61] The 5-year survival in this cohort from the turn of the century was only 31% and the HR compared with NSCLC was 1.47.[61] Our findings suggest that surgical intervention for SCLC is a rare event, partly because few cases present with early stage disease and other treatment modalities are more likely to be taken up.

Our study also shows that patients who identify as Māori are less likely to receive curative surgical resection of stage I and II lung cancer than those who do not identify as Māori. This finding was based on the unadjusted analysis, and the difference disappeared after adjustment for other factors. This could suggest that the New Zealand healthcare system is ensuring equity of access to curative surgical resection for patients. Māori presenting with early stage disease are younger than non-Māori, and more likely to have COPD, be a current smoker, have an FEV1 less than 50% and have small cell histology. Māori generally have lower socioeconomic status which is associated with poor survival.[62, 63] After adjustment for these factors it appears that Māori are not less likely to receive curative treatment (odds ratio 0.80, 95% CI 0.46 – 1.38) or surgery (odds ratio 1.03, 95% CI: 0.53-2.00). It maybe this finding is a Type 2 error and if we had a bigger sample then potentially we might show a difference. This means that we need to continue to monitor access to curative treatments for Māori if we are to reduce the inequities in outcomes that we know are present.[49, 64]

Our findings show that the all-cause survival from surgery in this group of patients are 85% at 2 years and 70% at five years. This is similar to the survival reported in a 2004 study where the 2-year survival was 81%.[49] This supports the assertion that early stage lung cancer can be “cured”. [65] Indeed if we look just at the 199 NSCLC patients treated with lobectomy we find the 5-year survival is over 70% which is comparable with the findings from studies in major centres in the USA.[65]

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Patients with stage I and II NSCLC treated with SABR have comparable outcomes to those treated with surgery. This is despite the finding that those treated with curative intent with SABR tended to have additional risk factors including older age, higher ECOG status score, more comorbidities and more smokers. The numbers of patients treated with SABR is relatively small and further follow up of a greater number of patients is needed to confirm this finding but the initial results are very encouraging. A systematic review [66] reported that the overall and cancer-specific survival between SABR and lobectomy for stage I NSCLC were similar after 1-year follow-up, but lobectomy appeared to have more favourable outcomes after 3-year and 5-year follow-up. However, this systematic review only included one randomised clinical trial [67] and the other six included studies were cohort studies which may have been subject to bias.[68-73]

Outcomes in patients managed with palliative care are relatively poor where only 30% of palliative patients with Stage I and II disease are surviving 5 years. Many of these patients are older and have significant comorbidities which impact on overall survival. The small number of patients offered palliative chemotherapy appear to be doing better with a 2-year survival of 60%. However, overall survival in this group of patients managed with supportive/palliative care is higher than previous reports. Stevens et al [49] only showed 20% survival with 2 years follow-up, while our study has shown similar improvement year by year during the study period.

One of the strengths of our study is that it was based on the comprehensive lung cancer register, with relatively complete data on patient demographics, tumour characteristics and treatment. The limitations of this study included the small number of patients and short follow-up time in some treatment group, e.g. SABR. Also as an observation study, this study is prone to selection bias.

### *2.2.6 Conclusions*

The majority of patients with stage I and II lung cancer are managed with potential curative treatment – mainly surgery and increasingly SABR. After adjustment for key variables such as smoking, comorbidities and lung function status, the likelihood of Māori patients having curative treatment was similar to non-Māori. This suggest that outcomes for Māori patients can be improved by addressing smoking and the management of comorbidities. While the outcomes of those being diagnosed with stage I and II disease and receiving treatment is positive with 70% surviving 5 years, the next target is to substantially increase the population of lung cancer patients diagnosed with early stage disease.

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## 3. Study Two

### Systematic Literature Review

#### Reference:

Cassim, S., Chepulis, L., Keenan, R., Kidd, J., Firth, M. & Lawrenson, R. (2019). Patient and carer perceived barriers to early presentation and diagnosis of lung cancer: A systematic review, *BMC Cancer* 19(1), 25. doi: 10.1186/s12885-018-5169-9.

#### 3.1 Aim

The aim of this systematic review of literature was to synthesise our knowledge of barriers to early presentation and diagnosis of lung cancer, identified by patients and carers internationally (including those specific to Indigenous and ethnic minority groups).

#### 3.2 Method

##### *Search strategy and selection criteria*

Three major databases, Scopus (1960–2017), PubMed (1945–2017) and EBSCOhost (1888–2017), were searched from 23<sup>rd</sup> November to 8<sup>th</sup> December 2017, for papers published in English prior to December, 2017. Text words or keywords used in the search were “lung cancer” and “barrier”, “obstacle”, “difficult\* (difficulty)”, “problem”, or “diagnos\* (diagnosis/diagnostic)” combined with (i.e., AND) “general practi\* (general practice/ practitioner)”, “primary care”, or “family practice”. Inclusion criteria for the

extraction of articles from the databases were original, qualitative studies, published in peer reviewed journals, and a focus on patient and family or carer perceptions of barriers to early presentation and diagnosis of lung cancer. Accordingly, our exclusion criteria were literature reviews, quantitative analyses, studies focusing solely on prevention (e.g. screening) and a focus only on GP or health care provider perceptions of barriers to lung cancer diagnosis. It should be noted here, that our focus on only qualitative analyses was to identify key themes relating to patient perceived barriers to lung cancer diagnosis. By including quantitative studies in our review, we would have risked being in danger of leaving out important themes voiced by patients themselves, as barriers identified based on quantitative surveys or questionnaires tend to be predetermined. Furthermore, our search did not extend to non-English language studies or grey literature. References cited in the selected studies and any literature reviews with broadly similar search criteria were searched for further relevant articles.

##### *Categorisation of perceived barriers*

Walter et al’s [74] model for examining pathways to cancer diagnosis was used as a guide for identifying and grouping barriers to diagnosis in the studies selected. We particularly focused on the “contributing factors” section of the model, which indicates that healthcare provider and system factors, patient factors and disease factors contribute to delays in cancer diagnosis and initiation of treatment. It should

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be noted, however, that while co-morbidities are listed under patient factors in Walter et al's [74] model, we included them as disease factors in our review due to the nature of symptom presentation particular to lung cancer, as discussed previously.

### *Data extraction*

The selected articles were reviewed and the following data were extracted and compiled into a table: general information about the article (authors' names, year of publication, and methodology); study location; participant information (participant group, ethnicity, and number of participants); and a brief description of the findings, specifically the barriers to early presentation and diagnosis of lung cancer relating to health care system, patient and disease factors. A number of studies that had multiple participant groups (i.e. patients, family members, GPs and other service providers), explored multiple types of cancer (i.e. lung, prostate, breast and colorectal), used mixed methods (both qualitative and quantitative), and had a primary focus that went beyond identifying barriers to early presentation and diagnosis (e.g. developing an intervention) were included, but noted accordingly.

### **3.3 Results**

We identified 908 publications through our database search, and an additional 20 from a manual reference list search. By screening article

titles, 870 were deemed to be duplicates or irrelevant based on topic. The abstracts of the remaining 58 articles were screened, from which 21 were excluded as they examined other cancers, not including lung cancer. Full articles were assessed on the remaining 37 potential publications. Of these, 23 were excluded as they focused on lung cancer screening, they did not examine patient and carer perspectives of barriers to diagnosis and/or they were literature reviews or quantitative analyses. The remaining 14 articles were included in our review.

Six studies were undertaken in the United Kingdom [20, 75-79], six in Australia [80-85], one in the United States [86], and one in New Zealand [25]. The ethnicities of the populations studied were European (New Zealand European, "White British", "White"), Māori, Aboriginal and Torres Strait Island peoples, "Black/Black British", "Asian/British Asian", Chinese, "mixed" and other. Seven studies reported that they recruited participants from hospitals, four from community or other support groups, three from General Practices and one from a cancer register.

Five studies included multiple participant groups including patients, family and/or community members, GPs and other service providers [77, 80, 82, 83, 85]. However, as the purpose of this review was to identify barriers to early presentation and diagnosis of lung cancer specifically by patients and families or carers, only the statements made by these participants were included in our analysis. Two studies focused on multiple types of cancer including lung cancer [78, 81] – only statements by participants with a lung cancer diagnosis were

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included in this analysis. One study had a primary focus on the development of an intervention to reduce time to presentation with symptoms of lung cancer alongside barriers to early presentation and diagnosis [77] - the present review considered only the barriers, rather than the intervention discussed in this article. One study included patients with symptoms suggestive of lung cancer, including patients who had not yet received a lung cancer diagnosis and patients post lung cancer diagnosis [20] – this review considered only the barriers specific to patients post lung cancer diagnosis. Two studies used mixed methods (both qualitative and quantitative) for data collection [79, 81] – only qualitative data from these studies were considered for the present review. Healthcare provider and system factors as barriers to early presentation and diagnosis were identified in 13 articles, patient factors in 12 and disease factors in five.

The age and gender of participants were reported by most articles. When reported, age was provided either as an age range or mean age. Accordingly, participant age ranged from 39 to 86 years, with mean age ranging from 60 to 79 years. A good gender mix was also included in the studies reviewed.

Our findings were grouped into three categories: healthcare provider and system factors, patient factors and disease factors that serve as barriers to early presentation and diagnosis of lung cancer. These categories were based on the “contributing factors” section of Walter et al’s [74] model, as discussed previously. The following sub-sections present our results for each category.

### *Healthcare provider and system factors*

Healthcare provider and system factors included issues relating to delivery and healthcare policy, and barriers to access. Primarily, the quality of the relationship between GPs and patients was a recurring theme reported in many of the articles. For instance, a lack of an established relationship between patient and GP affected the quality of care provided to the patient. The quality of communication between the patient and GP resulted in a lack of established trust between patient and GP, a lengthy period of time before GPs took the patient’s concerns seriously and inadequate information provided to patients [25, 80, 84-86]. Such barriers were also exacerbated by a lack of GP continuity [25, 86]. Specific barriers identified were, GPs’ ‘nihilism’ towards lung cancer [25], and inability to understand or relate to tobacco addiction [84]. A New Zealand study also reported that a lack of openness to other (indigenous/ ethnic minority) worldviews was a barrier to diagnosis of lung cancer [25].

Broader system factors were also identified as barriers (regardless of country level contexts), including difficulty making or accessing appointments, discontinuity of care (relating to GPs, specialists and/or other healthcare providers), long waiting times, patients getting delayed in the system or difficulty faced by GP to get referrals for specialists [25, 77, 79, 85, 86]. Patients additionally observed that limited access to health care (provider and services) was a barrier to diagnosis and care [20, 25, 81, 85].

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Patients and carers also stated that GPs had inadequate knowledge of lung cancer symptoms and treatment options available. A number of studies indicated that GPs lacked knowledge about interpreting symptoms and accessing appropriate treatment pathways [25, 76]. According to Black et al. [78], patients indicated that their health care professional's appraisal led to an inaccurate re-evaluation of self-diagnosed symptoms (e.g. symptoms of lung cancer being diagnosed as asthma).

Finally, Scott et al. [82] observed that in Australia, an increased societal awareness of lung cancer as being smoking related and being the 'fault of the individual', increased stigma related to the condition and smoking, thus serving as a barrier to seeking help. Moreover, according to Tod et al. [75] in the United Kingdom, media messages reinforced the fact that people should not use primary care services unless a problem was extreme.

### *Patient factors*

Patient factors included demographic, psychological, social and cultural factors and previous experience. A key patient related barrier recurrent in the literature was normalisation, misinterpretation, misattribution, minimization or low risk perception of symptoms relating to lung cancer [20, 25, 75, 76, 80, 81, 84, 86]. For instance, while many patients felt that respiratory symptoms and generalized ill-health were normal for smokers, others felt that protective behaviours such as exercise or diet could offset health risk.

Consequently, patients engaged in self-management of symptoms rather than seeking medical advice [20, 25, 86].

Fatalistic beliefs and fear of death and/or cancer diagnosis were additionally reported as preventing patients from seeking help, often due to patients' lack of awareness of lung cancer treatments [25, 75, 82, 84, 86]. Patients also indicated that perceived blame, stigma, guilt and shame related to smoking and diagnosis functioned as barriers [25, 75, 79, 82, 84]. Patients were put off visiting healthcare professionals by perceptions that they would be lectured or reprimanded to cease smoking [84]. 'Stoicism' was also reported as a barrier, particularly amongst men, where patients did not wish to complain, instead, putting on a 'brave face' [75, 81].

Finally, barriers related to the financial aspects of cancer care, and thus patients' socioeconomic status, such as the high cost of health insurance or treatment and care (e.g. in the United States and Australia), lack of transport to healthcare centre (e.g. in rural Australia) and competing responsibilities (e.g. in the United Kingdom) were identified as barriers to symptom presentation and diagnosis [20, 80, 83, 85, 86].

### *Disease factors*

Disease factors included site, size and tumour growth rate as well as symptom presentation. Five articles reported disease factors. All of these studies indicated that symptom presentation, specifically, the wide variation in

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lung cancer symptoms and therefore a lack of a clear symptom profile or a lack of symptom presentation overall, made both GP diagnosis and patient awareness difficult [25, 75, 76, 81]. For example, Birth et al. (in 2014) [20] reported that the existence of co-morbidities masked many of the symptoms indicative of lung cancer (e.g. pain symptomatic of lung cancer was attributed to a kidney infection based on patient's history of gallstone related pain, cough attributed to patient's existing chronic respiratory symptoms or allergy).

### 3.4 Discussion and Conclusion

This systematic literature review provided evidence that the reasons for delays in early presentation and diagnosis of lung cancer are complex and multifaceted. It is also clear that all these factors (i.e. healthcare provider and system, patient and disease) overlap. For instance, a key patient and carer perceived barrier relates to the relationship between patients and GPs. Such relationships are crucial to presentation and diagnosis of lung cancer, as they affect the level of trust between GPs and patients, patient attitudes towards their GP and vice versa, and patient perceived blame, stigma, lecturing and reprimanding by GPs [25, 80, 84, 86]. Thus, barriers relating to the relationship between patients and GPs span both healthcare provider and system factors as well as patient factors. Additionally, this review provided evidence that issues relating to access, spanning both healthcare provider and system factors and patient factors, was another key area that posed barriers to patients' help-seeking behaviour [20, 25, 77, 79, 83, 85]. A lack of awareness of lung

cancer symptoms and treatment was also identified as a significant barrier. Issues relating to a lack of awareness spanned healthcare provider and system factors, patient factors as well as disease factors, and affected patients, GPs and the general public [25, 75, 76, 78, 82, 83].

There is a clear indication in the research of the pressing need to increase lung cancer awareness, and to provide resources and knowledge regarding symptoms and treatment to patients, healthcare providers and the general public. In particular, research by Tod et al. (2008) [75], included in this review, indicates that some information campaigns relating to lung cancer were seen to contribute to fatalistic views due to a focus on death rather than treatment and/or survival. Since then, however, various awareness campaigns about the early diagnosis and/or detection of lung cancer have been trialled in New Zealand, Australia [87], Scotland [77] and Doncaster, United Kingdom [88], some of which have resulted in an increase in at-risk patients' intentions to see a GP and request a chest X-ray (e.g. [88]). The programme implemented in Doncaster, additionally involved a brief GP education intervention for primary care practices in high lung cancer risk localities, resulting in an increase in chest X-rays and lung cancer diagnosis [88]. In many countries, clinical guidelines and optimal care pathways specific to lung cancer exist, aimed at increasing GP awareness of the disease (e.g. according to the Ministry of Health, New Zealand [89]). While such initiatives are promising, there is a need for replication, rigorous outcome evaluation [90], and to create a multi-pronged approach to raise lung cancer awareness [25]. The findings of this review, as well as that of quantitative, population level studies identifying patient

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perceived barriers to lung cancer diagnosis, both indicate that an inability to recognize symptoms and the stigma associated with lung cancer posed significant barriers to early diagnosis [91-94]. Thus, there is also a need to provide education to patients about the risks and symptoms of lung cancer, to dispel negative (fatalistic and stigmatising) beliefs about the disease and outcomes, and to empower at-risk patients to get checked in primary care [25]. Such an approach needs to also involve a GP training or education element, as an increase in lung cancer awareness needs to occur in patients, the general public as well as GPs and other healthcare professionals.

Delays within the system were also identified as a major barrier to presentation and diagnosis of lung cancer. For instance, delays in getting appointments, in waiting times, in getting referrals, or getting a diagnosis, the distance and access to health care providers, as well as the financial aspects of cancer care (e.g. cost of treatment, patients' socioeconomic status) hindered access to services, and thus timely diagnosis and treatment [20, 25, 79-81, 85, 86]. Similar findings were reported by Sood et al's (2009)[95] review of patients' clinical records identifying barriers to diagnosis of lung cancer. Delay, irrespective of reason, can be frustrating for many patients, and when combined with difficulties accessing information and services, could increase distress [96]. It is clear that a more patient-centred and accessible approach to cancer diagnosis and care is needed.

Furthermore, many studies in our review did not report the ethnicity, or rather the ethnic variation, of their participants. In particular, Sharf et al. (in 2005)[86] and Tod et al. (in 2008)[75] indicated that the fact that their participant bases comprised primarily 'white'

patients, rather than 'black' or minority groups, was a limitation of their research. Considering the poorer outcomes relating particularly to ethnic minority and indigenous populations diagnosed with lung cancer [3-5, 97, 98], the findings of this review imply that more qualitative research needs to be conducted and published with a specific focus on ethnic minority and indigenous groups. These findings also hold implications for broader arguments emphasizing the importance of culture, and of acknowledging and respecting diverse worldviews, particularly in cancer care. For example, research from Australia (not included in this review), indicates that a lack of cultural competence by GPs was a significant barrier to early presentation and diagnosis of cancer [99-102]. Such conclusions are consistent with the statements of Māori participants in Walton et al's [25] New Zealand study, which indicated that a GP's lack of respect for, and openness to other (indigenous/ethnic minority) worldviews posed a significant barrier to help-seeking behaviour.

Accordingly, the New Zealand Medical Council has made cultural competency training a specific core expectancy in ongoing medical education for doctors and specialty training programmes, partly to address such issues with indigenous communities [103]. In saying this, it is important to recognise that a healthcare professional's cultural understanding of, and engagement with a patient should not be reduced to a simple set of technical skills acquired solely through cultural competency training [104]. Accordingly, the findings of this review reiterate the importance of the need for a focus on building relationships between patient and GP. As such, the Australian studies report that many Aboriginal Australians hold differing health beliefs of cancer causation [99-102]. For



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instance, this can include a belief that cancer is contagious, or simply the lack of a word for 'cancer', resulting in the diagnosis and its implications not being understood by many of these groups [101]. Accordingly, these researchers indicate that there needs to be an acknowledgement of such differing worldviews by the broader healthcare system, and that GPs need to also be aware of the significance of traditional healing methods germane to each of these communities [100, 102]. While we acknowledge that not all indigenous communities are the same, there is need for health professionals to have knowledge of, and/or experience in, not only medicine, but also the communities they serve, which goes beyond a simple set of skills acquired through cultural competency training. Overall, more attention needs to be paid to identifying and addressing barriers to early presentation and diagnosis of lung cancer among indigenous communities.

A number of studies in this review also indicated that patients, or potential participants of their research, died prior to the commencement of interviews as a result of lung cancer (e.g. [76, 80, 81]). This was listed as a limitation of such studies. The fact that lung cancer patients passed away within the short timeframe of a recruitment process reinforces the importance and urgency of identifying and addressing the barriers to early presentation and diagnosis of lung cancer.

In conclusion, early presentation and detection of symptoms relating to lung cancer is critical to improving survival. Delays in early presentation and diagnosis of lung cancer might be avoided if various barriers relating to healthcare provider and system factors as well as patient and disease factors are addressed. This paper provides a complete, exhaustive summary

of current patient-centred evidence identifying the existent barriers to early diagnosis of lung cancer, by bringing together and reviewing 14 qualitative studies from various countries. According to the findings of our review, a good starting point to addressing patient and carer perceived barriers, is to focus on the three key areas of relationship building between GP and patient, improving patient access to services and care, and increasing awareness of lung cancer symptoms and treatment, particularly among disadvantaged communities.

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## 4. Study Three

### Interviews with Māori lung cancer patients and whānau

#### 4.1 Aim

The aim of this sub-study was to identify the barriers to early diagnosis of lung cancer experienced by Māori lung cancer patients and whānau in the Midland region.

#### 4.2 Method

##### 4.2.1 Recruitment and data collection

Study three was underpinned by a kaupapa Māori approach. Semi-structured, Kanohi-ki-te-kanohi (face-to-face) interviews were carried out with a total of 23 newly diagnosed Māori lung cancer patients and whānau (comprising 16 patients, and 7 whānau members). Nine participants were male, and 14 were female. Participants were recruited from three districts in the Midland region (comprising both rural and urban localities): Waikato, Bay of Plenty and Lakes. Recruitment was carried out by respiratory or cancer nurse specialists (CNS) based at the hospitals of each district. The nurses initially 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 our researcher. The 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. Key areas covered in the interviews

included participant experiences leading up to, and following their diagnosis, how they were diagnosed, and barriers or enablers they may have experienced through their lung cancer journey (from appraisal and diagnosis through to treatment).

It should be noted here, that while we anticipated that the patient interviews would provide a contextual basis for, and thus be completed before commencing study four, delays in patient recruitment resulted in study three spanning years 1-2 of the project. Therefore, study four was carried out concurrent to study three.

##### 4.2.2 Analysis

Interviews were recorded via an audio-recorder and as field-notes. Audio recordings were transcribed. Pseudonyms were used to maintain anonymity of participants. Walter et al's [74] model for examining pathways to cancer diagnosis was used to carry out framework analysis on research data. Walter et al's model was derived from the Andersen Model of total patient delay [16], and provides a framework to identify delays in the cancer diagnosis and treatment pathway, and enabled the grouping and categorising of barriers to early diagnosis of lung cancer. We particularly focused on the "intervals" section of the model, which allowed us to categorise barriers to diagnosis occurring in the "appraisal", "help-seeking", "diagnostic" and "pre-treatment" stages of the pathway.

Coding was carried out on qualitative data by Jacquie Kidd and Shemana Cassim independently and then together, to ensure a rigorous analysis process. Codes were developed

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into categories, and the categories were allocated into the four stages of the pathway.

### 4.3 Findings

#### *Appraisal*

The appraisal stage involved patient appraisal and self-management of symptoms. A key barrier in this stage was the ambiguity of lung cancer symptoms.

#### **(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. The ambiguity of lung cancer symptoms was a barrier that spanned both the appraisal stage and the diagnostic stage. For instance, some participants indicated that their symptoms included pain and a swollen stomach:

*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, female, Waikato)*

Other participants also reported flu-like symptoms and swollen legs, thus delaying patients from going to see their GPs assuming that the symptoms would pass, or attributing their symptoms to other pre-existing conditions such as past sports injuries.

#### *Help-seeking*

Once participants had decided that it was important to see their GP with their symptoms, they entered the help-seeking stage. Barriers in this stage included accumulating costs and difficulty getting GP appointments, whereas positive GP-patient relationships served as an enabler.

#### **(1) Accumulating costs**

Accumulating financial cost was a barrier for Karaitiana. Additionally, the lack of a proper diagnosis despite going to the doctor multiple times, and ambiguous symptom presentation were additional factors that delayed his lung cancer diagnosis. Karaitiana was initially diagnosed with Deep Vein Thrombosis given his symptoms presented as swollen legs:

*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, male, Lakes)*

#### **(2) Difficulty getting appointments**

For Hariata the delay in help-seeking was due to both patient factors as well as HCP/system factors. Such barriers included inability to get an appointment, and the fact that she preferred to see her doctor:

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*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, female, Waikato)*

### **(3) GP-patient relationship**

Interestingly, while trust and relationships between patients and GPs caused delays in the help-seeking stage 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:

*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, female, Waikato)*

## **Diagnostic**

The diagnostic stage involves appraisal by the GP or healthcare provider, investigations and referrals. Barriers in the diagnostic stage included delayed diagnosis and referral.

### **(1) Delayed diagnosis**

Some participants indicate that despite promptly going to see their GP, there were delays in diagnosis and referral by the GP:

*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, male, Lakes)*

Overall, delays occurred throughout this diagnostic stage, ranging from referral for an x-ray, to negative x-ray results, to referral for a CT scan, and delays in receiving the CT results.

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## (2) Delayed referral

Even once the GP sent through a referral, there were occasions where x-ray results did not pick up the cancer:

*I've been spitting blood for a couple of years. And I took that complaint down to the doctor... I told them even I was getting tired just walking. Just going to get the letters out the mailbox... She got me to just go and have an x-ray. And the results of the x-ray came back negative. So she just left it at that after that. I kept telling her I'm still coughing up blood. And she didn't seem like she cared. And well this carried on for a couple of years that I've been doing that. And I changed my physician. Then she got me onto the MRI. (Doug, male, Waikato)*

### Pre-treatment

Following diagnosis, patients and whānau enter the pre-treatment stage. This stage involves planning and scheduling of treatment in secondary care. Barriers in the pre-treatment stage related to coordination of appointments and communication from HCPs. Enablers in this stage included helpful and supportive CNSs, whānau and whānau hui.

#### (1) Coordination

Many participants highlight that a key barrier in the pre-treatment stage 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:

*They just make him a million appointments a week. Some sessions get booked on the same day and on the same time. So we have to re-book them. Like his hospice booked the same time yesterday as his diabetes doctor so we had to put the diabetes doctor off and wait for a couple of hours and stuff. (Rewi's son, male, Waikato)*

#### (2) Communication

During the pre-treatment stage, patients received verbal communication from their HCPs, involving discussions of the ensuing stages of their treatment plans. The mode of communication here, 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 like Rewi was, then this served as a barrier:

*The day after...the doctor they rung up and wanted to talk to [Dad] about this and he wasn't feeling the best and I said to him 'I'm his son', and they said 'but we still need to talk to him'...and I gave him the phone and he doesn't take nothing in. And I asked him 'what did they say?' and he said 'I don't know'. I knew that was gonna happen. So I tried to tell them that you know and they just didn't listen. As long as they had done what they had to do.... Was just contact [Rewi] you know, whereas*

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*instead of giving the information to the right people. They have to make sure that he understands it well. Cause they're not gonna sit down and explain it to him to the point where he understands and they can't see if he understands or hear if he understands. So that's frustrating. (Rewi's son, male, Waikato)*

### **(3) Whānau hui**

In contrast, the HCPs 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, which served as an enabler:

*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, female, Waikato)*

### **(4) Role of whānau**

Additionally, whānau play an active role as carers, and serve as enablers by often maintaining meticulous notes, and keeping 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, Waikato)*

### **(5) 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:

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*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**, female, Waikato)*

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.

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## 5. Study Four

### Community engagement and hui with Māori at risk of lung cancer

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#### 5.1 Aim

Study four comprised two phases and focused on establishing relationships with rural communities at a grass-roots level. This included Māori whānau with an interest in lung cancer, smaller Iwi health providers and special interest groups such as local support group.

Study four was underpinned by a kaupapa Māori co-design approach. The aim of study four was

to (1) identify barriers to early diagnosis of lung cancer from local community perspectives, and (2) identify a group of community members in each locality who would be involved in co-designing the interventions (Study Six) for this project.

#### 5.2 Phase one: Community Engagement

##### 5.2.1 The communities

The team worked with four rural localities in the Midland region of New Zealand: Opōtiki, Te Kuiti, Rotorua and Gisborne.

Opōtiki is a small, relatively remote rural community, situated around 45 mins away (by road) from Whakatāne hospital and 3.5 hours away from Waikato hospital. The team worked closely with a member of the community who was Māori and a community-based health professional. This individual was a pivotal member in our Māori stakeholder group, and was instrumental in organizing community hui and getting the community members together to participate in the research.

Te Kuiti is also a small rural community, located an hour away from Waikato hospital. While Te Kuiti also had its own rural hospital, many community members have to travel to Waikato hospital regularly for (cancer) care and treatment. Te Kuiti has a relatively central location, being close to other rural towns such as Otorohanga, and therefore has access to the healthcare services of these towns. The team worked with two Māori stakeholders in this



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community, who were active members in the healthcare space.

Rotorua is a larger rural community, with its own well-equipped hospital. Rotorua is located 1.5 hours away from Waikato hospital. Despite being considered a rural community on a national scale, this locality had a larger population compared to the others that we worked with, and had a relatively central location with smaller neighbouring communities regularly accessing the Rotorua hospital. In this community, the team worked with three prominent Māori activists in the healthcare and cancer spaces, who were key figures in supporting and promoting Māori health in general, and cancer in particular.

Gisborne is also a larger rural community, with its own hospital. However, this community is very remote in its location, being a little over 5 hours away from Waikato hospital. The stakeholder group in Gisborne comprised a Māori community organisation active in the healthcare space, who were key figures in supporting and promoting Māori health. While the team worked with this organisation as a whole, our regular correspondence was with three particular individuals within the organisation.

### *5.2.2 The process(es): Community engagement*

Initial engagement involved the members of the team approaching key contacts, Māori Health teams in the local DHBs (District Health Boards)

or prominent individuals actively working within the healthcare space in each locality. Most of these connections were made prior to the funding application for the project being submitted, which was vital for the project to succeed. After the funding was received, members of the team met *kanohi-ki-te-kanohi* with these individuals or groups primarily for *whakawhanaungatanga* and to also provide a background of the project and its aims. During these initial hui, the team asked these individuals if they would like to be part of this research project, if they would be happy for the project to include their locality, and to assist with organizing the community hui, recruit participants and form part of the team's broader stakeholder group. These hui were held either in Hamilton (where the majority of the team were based), or in each community. Overall, there were 1-2 preliminary hui carried out during the initial conception of the project (prior to receiving funding), and another 1-2 hui following the receipt of funding.

Following these initial hui, Shemana was responsible for maintaining the relationship with stakeholders from each community and coordinated the organization of a community hui in each location. Shemana and the team worked with stakeholders to recruit participants for each hui. It is important to note, had Shemana acted on her own without the sanctioned support of initial stakeholders, the community members would likely not have had the opportunity to know and trust the research team sufficiently to want to attend the hui. The co-design methodology supported each stakeholder, who vouched for the team members and the process

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of the project, to personally recruit participants within their communities and to ensure their attendance. In addition, the flyer included the name of the stakeholder or the organisation they worked with. It was important that the flyers said ‘...in partnership with...’ or ‘..with support from...’ all the stakeholders involved and/or their affiliated organization(s). The significance of establishing such a link was twofold. First, it was vital that the stakeholders trusted the team, for their communities to also then trust the team. Therein lay the significance of the initial hui between the team and each stakeholder. This is a key consideration when working with Māori communities, as well as for Māori researchers, where the stakeholders’ reputation is linked to that of the team. Second, establishing relationships was a way of acknowledging and appreciating the time, help and support provided by each stakeholder to the team. Overall, taking time to build trust was a vital part of the research process. ‘Trust’ is an important component of any research carried out with Māori [105]. Mistrust of research among Māori is common due to a history of racism, negative stereotyping, mistreatment and oppression that resulted from Aotearoa’s colonial past, and the role of Western ‘research’ approaches in that past [105-108].

Coordination further involved Shemana working closely with stakeholders to design recruitment flyers, to organize dates, times, venues, kai and koha for hui. Such tasks involved repeated interactions between Shemana and each stakeholder over several months until all hui details were finalized. Flyers were circulated by the stakeholders. Some stakeholders also

devised additional initiatives that they thought would work best in their communities, to publicize the hui. For instance, the stakeholder in Opōtiki created a Facebook event linked to the Whakatōhea community page to recruit participants, and a stakeholder in Rotorua included the recruitment flyer and information about the hui in the Aroha Mai community newsletter.

### *5.2.3 Other communities*

The process of approaching and establishing trust relationships with Opōtiki, Te Kuiti, Rotorua and Gisborne was relatively straightforward. However, there was also a community that were approached, who were not willing to be involved with the project: Te Puke. An initial introductory hui was organized with whānau in Te Puke, and the team travelled to attend. Following whakawhanaungatanga and an initial overview of the project and its aims, it became apparent that those present were very cautious about the project and the effect it would have on their community. It was clear by the end of the hui that the Te Puke whānau were not keen to proceed with the project. A kaupapa Māori approach respects the rights of individuals and groups to choose (either directly or indirectly) that a project or process is not right for them; we therefore did not progress with Te Puke from this point.

Conversely, the team encountered Te Kaha, who had heard about the project from Opōtiki, and requested that a hui be organized in their locality. A community hui was planned with the

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help of two Māori health professionals, and was well attended by community members. However, based on the discussion with whānau at this hui, it became clear that for Te Kaha, the barriers to early diagnosis were predominantly related to secondary and/or specialist care. Te Kaha had an active primary care team, who played a strong advocacy role to ensure that their patients got the best treatment and support possible. Te Kaha had strong enablers in place for early diagnosis of lung cancer and the team did not want to change or affect what was already being successfully undertaken. The team did not proceed onto the co-design phase in Te Kaha. Rather, the team agreed to re-visit Te Kaha 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.

#### *5.2.4 Governance and advisory groups*

On carrying out a kaupapa Māori, community engaged research project, a key consideration that turned out to be different from the project plan, was the structure of our governance and/or advisory groups. Early on in the project, we had already established two governance groups: a Māori Advisory Group (MAG) comprising various leading Māori researchers working in the field of health, as well as an Academic and Clinical Steering Group (ACSG) comprising relevant clinicians and senior academics. From a clinical, healthcare research point of view, having such higher level co-governance was vital to ensure our findings, outputs and outcomes were effective in the

broader clinical, healthcare setting. However, our formal governance groups did not involve members from the communities we were working with. This is not to say that our stakeholders and members of our co-design groups were not involved at a co-governance capacity in our project. Rather, despite not being considered ‘advisors’ or members of a formal ‘governance group’, our interactions with community groups ensured that they had a say in the research process. Therefore, our community groups acted as governors of the research process, in conjunction with the formal MAG and ACSG.

Regular meetings with our official governance groups (the MAG and ACSG) served a different function, and occupied a different space to that of our unofficial community governors. As such, having the MAG and ACSGs in the way we did, had a korowai effect for our community groups. Specifically, when worn, a korowai can enhance the mana of the wider whānau who own it. Thus, we found ourselves taking information (findings, points of discussion, issues raised etc.) from our community groups, and presenting them to the MAG and ACSG as evidence, which then ‘legitimised’ such information, for the purpose of an institution led research project. Here, we do not aim to imply that Māori communities need to prove the legitimacy or validity of their whakaaro. Rather, having the community’s views validated in this manner, allowed us to ensure that we brought their best interests, thoughts and views to the fore throughout the project.

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### 5.3 Phase two: Community hui

In the four communities the team worked with, hui were carried out at either local marae or meeting rooms organized by the stakeholders. The team members who attended all the community hui were Jacquie, Anna Rolleston, Shemana, Hemi Curtis and Ross Lawrenson or Rawiri Keenan. The stakeholders had organized for the participants to attend each hui and the seating arrangements in, and kai for each hui. At this stage, the team only had to arrive at each location and commence the hui. Figure 3 shows a sign at the entrance of the meeting room where the hui in Opōtiki occurred, set up by the stakeholder in that community. The team tailored their approach according to where hui were held (e.g. on a marae versus in a meeting room). In particular, hui that were held on marae involved an adherence to tikanga such as commencing with a pōwhiri. Consequently, the team wore appropriate attire as dictated by local tikanga, prepared waiata for these hui, and Hemi (as Kaumātua) led the team onto the marae. The community hui carried out in meeting rooms were less formal. For all hui, irrespective of the space within which they occurred, the team began with a karakia by Hemi or a representative of the community, and whakawhanaungatanga with each team member introducing themselves with a mihi, often in te reo.

Following whakawhanaungatanga, Jacquie explained the aims of Hā Ora, what we wanted to discuss with the community, and the process we proposed to follow (figure 4 depicts an image of Hemi, Jacquie and Ross at a community hui). The GP in the team (Ross or Rawiri) provided a brief overview of lung cancer, including

incidence, mortality and survival rates and acted as ‘medical liaison’. Ross and Rawiri had differing



Figure 3. Sign at entry of a meeting room for a community hui

styles of engagement with hui participants. Ross is English, a senior academic, and an experienced medical practitioner who has worked in rural general practice in Aotearoa over many years. Ross contributed specialist knowledge in medicine. Rawiri is Māori, a GP, and an emerging researcher. Rawiri acted as a whānau member navigating the healthcare space when some topics were discussed and also as ‘medical liaison’. The roles undertaken by Ross and Rawiri, particularly their ability to respond to medical questions, was an essential part of the team’s engagement with communities. Anna and Shemana’s roles involved recording field notes at each hui, including audio recording the discussion, following consent from participants. Accordingly, research data comprised Anna and Shemana’s field notes, alongside transcripts of the hui.

The team were equipped with a semi-structured topic guide for the hui, this document was seldom used, and topics were brought up by Jacquie only as prompts if required. The aim of each hui was for the communities to direct and

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lead the conversations with topics centring on their experiences within the healthcare system. The team took a back seat in these conversations enabling participants to raise what they felt needed to be heard. It was noteworthy that whānau who attended the hui talked about their experiences relating to an array of illnesses, not just lung cancer. They shared their experiences with other types of cancer (e.g. breast cancer, prostate cancer, stomach cancer etc.) and other respiratory conditions (e.g. emphysema, COPD etc.). We realized that many of the barriers and experiences discussed by whānau were also applicable to a lung cancer context, and it was agreed that whānau sharing their varied experiences of illness was a strength within our project. More importantly however, the purpose of the hui was to document whānau stories of navigating the healthcare space, irrespective of whether they were specific to lung cancer or not. Important here, was that whānau came, and shared their stories, which were often very personal. Some even shared stories that they

had never shared before. Therefore, the team deemed it crucial to value and respect these kōrero, and to treat them with dignity.

Overall, all the communities were curious about what the project hoped to achieve. They were also very interested to know when the team would return to discuss results, to progress with the project and to generally work with them again. It was important that the team did not carry out 'drive by' engagements with these whānau. Rather, we often held 2-3 hui with each community, in addition to regular updates and interactions with stakeholders, allowing us to build a working relationship with them, which paved the way for the ensuing co-design process. At the end of each series of community hui, the team invited anyone who would be interested in progressing onto the next stage of co-designing an intervention. Following the design and pilot of each intervention, the team carried out a final series of hui with each community as a thank you, closing off and handing over gathering. This final hui was symbolic of giving whānau in each community ownership of their interventions, where they could carry them forward even following the completion of the official HRC funded project.



Figure 4. The team facilitating a community hui at a local marae

### 5.3.1 Method

A total of nine community hui (CH) were carried out. Each community hui comprised of between 8-21 participants, which included cancer patients, whānau, and anyone else in the community who may be affected by (lung) cancer.

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Data was gathered as field notes and via an audio recorder. Audio recordings were transcribed and anonymized. Transcripts and field notes were thematically analysed [109] by Jacquie and Shemana.

Participants in these hui were invited to join co-design groups for each locality and contribute to the following phase of the project.

## 5.4 Findings

The barriers and enablers to early diagnosis of lung cancer experienced by Māori communities in the five rural localities were identified both in primary care and secondary care. Findings from Study Four were grouped into 5 themes: GP relationship and position in the community, health literacy, pathways to diagnosis, specialist services and treatment, and whānau journey.

### 5.4.1 GP relationships and position in the community

The relationship between patients and GPs can serve as enablers or barriers to early diagnosis of lung cancer in primary care. Here, the existence of a longstanding positive relationship often served as an enabler, whereas a lack thereof served as a barrier.

#### (1) GP's position in the community

The GP- patient relationship is affected by the GP's position in the community, as perceived by community members:

*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. 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)*

#### (2) 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 than prevented the establishment of familiarity and trust between Māori patients and their GPs:

*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)*

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*One of the issues with the GP model of practice these days is that you go into the practice and it used to be that you always had a doctor that was OUR doctor. That doesn't happen anymore because of a lack of GPs and the turnarounds and stuff. So for us to go and talk to a total stranger that we don't have a relationship with is a big barrier. And so the model of work is not helpful because if we don't have a relationship with our doctor, you're not gonna tell him about the things that are really worrying you. (CH#7)*

### **(3) Communication**

Communication and a lack of understanding was also raised as an issue by participants, where GPs did not understand what Māori patients 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 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)*

### **(4) Positive relationships with patients**

However, some patients had positive experiences with their GPs, which served as enablers to early diagnosis of lung cancer. Some of these experiences came from positive 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)*

#### **5.4.2 Health Literacy**

How and when information is given and received is a key part of health literacy, and involves the health care professional as well as the patients and whānau.

In each of our community hui we took care to ensure that a health care expert on the topic of lung cancer was available to respond to 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 detect lung cancer earlier, the availability of a screening tool, and prevalence. In response to our questions about the symptoms of lung cancer, most people

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answered that they associated a persistent cough and blood in the sputum with the need to seek health care. They also identified smoking as the primary risk factor for developing lung cancer.

However, it was also clear that due to previous experiences of losing their whānau to cancer, community members perceived lung cancer as a disease that could not be cured.

### **(1) Lung Cancer as a death sentence**

Most people associated a lung cancer diagnosis with 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)*

### **(2) Fear**

Fear was identified as a barrier preventing people from help-seeking:

*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)*

### **(3) Language**

Patients and whānau described the use of unclear and overly complex language on the part of the health professionals, as demonstrated by the following exchange:

*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)*

The issue of language also emerged as a problem with communication:

*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*



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*what this was about', or, 'where do I go to next'. (CH#1)*

### 5.4.3 Pathway to diagnosis

This section focuses on the time from when a patient is aware of symptoms through until they receive a diagnosis of lung cancer.

#### (1) Cost

A barrier identified was the mounting cost of attending GP appointments:

*Lots of times they can't go to the doctor because they haven't got the money to pay for the doctors' fee which is now, I think it's reaching on \$35. And you know, we're continually having patients who are meant to have help for things, that can't even go to the pharmacy. (CH#4)*

*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)*

#### (2) Symptom ambiguity

Symptoms of lung cancer presented a barrier to some participants. Patients at times were diagnosed opportunistically and had few, if any, symptoms that were consistent with messages about 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)*

#### (3) Diagnosis as a fight

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)*

The following sections discuss barriers and enablers to early diagnosis of lung cancer in secondary care.

### 5.4.4 Specialist services and treatment

The barriers and enablers that participants experienced in relation to specialist services and treatment occurred in the areas of access to care, communication with specialist services and cultural values and respect.

#### (1) Waiting times

Many participants highlighted barriers related to secondary care that they experienced leading up to, or immediately following initial diagnosis. These barriers included long waiting times:

*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)*

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*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)*

## **(2) Communication and information delivery**

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

*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 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. 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)*

The context of the previous two quotes highlights the ineffective interactions that frustrated patients and whānau. In the first quote the specialists did not identify the whānau gap in knowledge, so the whānau believed that radiotherapy was an almost certain cure and chemotherapy was a death sentence. The result of this misunderstanding was that the patient did not continue with treatment. In the second,

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the specialist appeared to be focusing on the limitations of a narrow area of treatment and did not understand that whānau expected to be guided more generally about what they could do for the patient after curative treatment was unsuccessful. It is interesting also that the whānau did not appear to receive any information about accessing palliative care services.

### **(3) Coordination**

A lack of communication and coordination among specialist services within a hospital as well as across hospitals or DHBs was another key concern that whānau discussed:

*The left arm didn't know what the right arm was doing, so the communication in the same ward didn't happen. An example, was that my husband had a drug rash. A real bad drug rash from a particular type of antibiotic. So bad that he couldn't even lie on the bed. Two days later, a nurse turned up with exactly the same drug, and she put it up there and I said, 'oh no no no, you're not giving him that. He's allergic to that'. She took the chart and said, 'not on here'. I said, 'I don't care. You're not giving that to him'. Another doctor said, 'no water for this patient'. And then when the specialist had his days off, he [husband] gained something like 8 kilos in about 2 days. Too much water. So again, I intervened and said, 'no more. Stop'. It's not rocket science. (CH#6)*

*I didn't know that [hospital A] couldn't share information with [hospital B]. So like*

*that's really frustrating... It's like they don't talk to each other.... And the cancer centre there, where he did his PICC line a couple of times. The processes are different. Why are they different? Why isn't there a standard for something like flushing those PICC lines? (CH#6)*

### **(4) Cultural values and respect**

Participants in the community hui discussed the importance of having hospitals value tikanga 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:

*. . . 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, but that they need to be there and their koro's, 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)*

### **(5) Institutional discrimination**

Some whānau described experiences of discrimination that resulted in fierce protectiveness of the patient. Most stories

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stemmed from institutional rules and expectations about how patients and whānau should behave that were not conducive to a Māori form of manaaki:

*Our koros and our kuias; their mana gets tramped on. Their wishes don't get respected. If you are tūturu to your Māoriness, 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)*

#### 5.4.5 Whānau journey

Whānau are a central part of the diagnosis and treatment journeys of many Māori lung cancer patients.

##### (1) 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:

*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)*

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## **(2) Proactive whānau**

As carers, whānau were proactive, and many recounted how they had to actively fight the system and advocate for patients in secondary care:

*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)*

## **(3) 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:

*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)*

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

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## 6. Study Five

### Interviews and hui with local health care providers

#### References

Cassim, S., Kidd, J., Rolleston, A., Keenan, R., Aitken, D.,...Lawrenson, R. (2020). Hā Ora: Barriers and enablers to early diagnosis of lung cancer in primary healthcare for Māori communities, *European Journal of Cancer Care*. doi: 10.1111/ecc.13380

Kidd, J., Cassim, S., Rolleston, A., Chepulis, L., Hokowhitu, B.,... Lawrenson, R. (2021). Hā Ora: Secondary care barriers and enablers to early diagnosis of lung cancer for Māori communities, *BMC Cancer*, 21. doi: [10.1186/s12885-021-07862-0](https://doi.org/10.1186/s12885-021-07862-0)

#### 6.1 Aim

Study Five focused on establishing relationships with local GP practices. The aim of study four was to identify barriers to early diagnosis of lung cancer from the primary care provider perspective.

#### 6.2 Method

Interviews or hui (depending on the number of staff in a practice) were carried out in five rural localities: Opōtiki, Te Kaha, Rotorua, Te Kuiti and Gisborne.

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 Practitioner (GP), nurses and/or other staff.

Data was recorded as field notes, anonymized and sent back to the HCPs for comment and approval prior to analysis. Notes were analysed thematically [109].

#### 6.3 Findings

The barriers and enablers to early diagnosis of lung cancer identified by local HCPs in the five rural localities were identified both in primary care and secondary care. Findings from this sub-study were grouped into 3 themes: GP relationship and position in the community, pathways to diagnosis and specialist services and treatment.

##### *6.3.1 GP relationships and position in the community*

The relationship between local GPs and their patients/communities was also perceived as a barrier or enabler to early diagnosis of lung cancer by HCPs.

##### **(1) Positive relationships with patients**

Some HCPs reported positive relationships with their patients, serving as enablers to earlier diagnosis:

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

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

## **(2) Community relationships**

HCPs reported occasions where they have accessed the power of community relationships to enhance their care:

*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)*

## **(3) Longstanding GP – patient relationships**

However, longstanding GP-patient relationships were not always a positive in terms of early diagnosis. One GP noted that knowing his patients for a long time could serve as a barrier to diagnosis:

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

## **(4) GP continuity**

GP – patient relationships are affected by barriers relating to resourcing for rural localities/communities. The most frequently discussed issue was the lack of continuity among GPs:

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

## **(5) HCP's perception of patients**

The HCPs' perceptions of their patients and the communities that they work in can serve as barriers or enablers to early presentation and diagnosis. Some of these perspectives showed consideration of the broader context, compassion and a desire to ensure that patients get the best possible care:

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

Yet, some had a more judgemental and blame-based view of Māori. Statements included;

*Māori are more tolerant of things not being quite right.*

*They've got an "I don't wanna know" attitude.*

*Māori are not as precious about their health.*

*Māori are surrounded by people who are unwell or unhealthy. So they tend to be complacent.*

*There are higher rates of unhealth in Māori because of a lack of awareness.*

*It's more than the money or the cost. It's the mind-set of people at the bottom of society.*

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### 6.3.2 Pathway to diagnosis

This section focuses on the time from when a patient is aware of symptoms through until they receive a diagnosis of lung cancer.

#### (1) Cost

Some HCPs 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)*

#### (2) Symptom ambiguity

Symptoms of lung cancer presented a barrier to some participants. Patients at times were diagnosed opportunistically and had few, if any, symptoms that were consistent with messages about lung cancer:

*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)*

### (3) HCPs closing their books

Health professionals describe their perceptions of the diagnostic pathway from the frustration of seeing colleagues close their books to new patients:

*[Our practice] picks up the slack as iwi [tribe] provider, so we keep stretching ourselves to make it work. Screening is a luxury that we don't have the capacity to provide" (HCP#1)*

### 6.3.3 Specialist services and treatment

The barriers and enablers that participants experienced in specialist services and treatment occurred in relation to access to care.

#### (1) Waiting times

Many participants highlighted barriers related to secondary care that they experienced leading up to, or immediately following initial diagnosis. These barriers included long waiting times:

*I had a patient who came in with back pain, referred for a Chest X-Ray, it was three 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)*

*Referral depends on symptoms, background of age, smoking etc. I've sent through lots of requests for high suspicion of lung cancer. The majority are acted*



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*upon quickly, some were declined. As the person dealing with the client, I feel like the request should go ahead and not be declined. If it's haemoptysis, I tend to do a Chest X-Ray, and then follow up to see if it's cleared. At the back of your mind you wish they'd approve the CT referral. They have a category for 'high suspicion' [of cancer]. So the referral being approved depends on the hospital's interpretation of the background information we provide. (HCP#5)*

## **(2) Access to diagnostic tests**

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:

*I've sent through lots of requests for high suspicion of lung cancer. The majority are acted upon quickly, some were declined. As the person dealing with the client, I feel like the request should go ahead and not be declined. (HCP#5)*

*We use [respiratory e-referral pathway]. You have to meet criteria to get a CT. For example, a Chest X-Ray abnormality, haemoptysis, pleural fusion, or something like that. If you don't have any of these, then you can't refer for a CT... The system has improved from before, but it's still a hoop [we have to jump through]. (HCP#2)*

## **(3) GP tactics**

Some GPs however, describe strategies to actively overcome barriers to progressing to CT scans in the diagnostic pathway:

*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)*

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## 7. Study Six: Outcomes

### Intervention development and evaluation

#### 7.1 Aim

This study aimed to develop a multi-pronged lung cancer awareness intervention through a process of co-design and involved repeated interactions between members of the team and four co-design groups, based in Opōtiki, Gisborne, Rotorua and Te Kuiti.

#### 7.2 The interventions

During the conception of the project, the 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 of the four groups (co)produced four different ideas for interventions. The interventions included a Hā ora: Let's Talk Lung Health website, a series of lung cancer awareness video clips, a kaiawhina training programme and a 'pou pupuru oranga' (cancer navigator) role. Each intervention will be discussed in detail in the following sections.

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

The website can be accessed via:

[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 alongside whānau in the Opōtiki community with the assistance of 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 funded Summer Scholarship programme. The graphic images for the website were created by a graphic designer, Hakopa Pore. Throughout each step of website development, the community was consulted for feedback and approval.

This community indicated that their intervention should target people having an array of lung related diseases including lung cancer. Accordingly, the website focused on overall lung health, rather than being limited to lung cancer – See figure 5 for screenshot of the homepage of the Hā Ora website. The Hā Ora website consisted of four main areas as requested by the community: my lung health, access support, planner, lung conditions. The 'my lung health' area comprises a short questionnaire to check the health of the user's lungs. It involved a series of simple yes or no questions relating to symptoms for various lung diseases. On completion of the questionnaire, a report was generated with a list of the symptoms that users put in, recommendations to see their GPs and/or to quit smoking, and further resources and information on various lung diseases (e.g. Bronchitis, Asthma, Emphysema, COPD, Pneumonia, Lung Cancer). The 'access support' provides a list of local services including HCPs and community support services in and around



Figure 5. Screenshot of Hā Ora website homepage

Opōtiki (marae, Iwi and community providers etc.) that users can access. The ‘planner’ area links through to either the ‘Manage My Health’ log in page, or to a calendar which users can download and maintain details on their GP appointments and/or other notes. Finally, the ‘lung conditions’ area provides further information, including YouTube videos on various lung diseases including Bronchitis, Asthma, Emphysema, COPD, Pneumonia, Lung Cancer.

The intervention was piloted in Opōtiki for 3 months. Publicity for the pilot involved posters and information cards handed out to whānau at their local HCP, Iwi providers and pharmacies. The local stakeholder also publicized the website at a regional kapa haka competition hosted in Opōtiki (see figures 6 and 7).



Figure 6. Publicity tent for Hā Ora website at the kapa haka competition



Figure 7. Ross at publicity tent at the kapa haka competition

## Evaluation

The website pilot was evaluated using both questionnaires and by tracking website usage.

Questionnaires were handed out to whānau who were involved in the co-design process and also whānau in the community who did not have an input into the website design, to assess their familiarity with the website, and to evaluate how useful they found the website. The questionnaire was shared as a Google Docs link.

A total of six participants responded to the evaluation questionnaire, of whom three were part of the co-design process, and three were not.

Results of the evaluation indicated that four participants (67%) were very familiar with the Hā Ora website, while two indicated that they were 'neither familiar nor unfamiliar'. All participants had used the website. Three participants had heard about the website, through being part of

the research and co-design process, whereas two had heard of the website from their local pharmacist, and one from their co-worker. All six participants reported that they:

- Found the Hā Ora website very helpful,
- Definitely know more about lung cancer after accessing the website,
- Would definitely recommend the website to others.

Five respondents (100%) indicated that the website was especially useful to them as Māori. All participants reported that Hā Ora was a practical way of learning about lung cancer, and for accessing help and support (five responded 'yes, definitely' [83%], and one responded 'yes').

Of the three participants who were part of the co-design process of developing the website, all found the experience to be a positive one. Participant statements include:

*Really interesting being able to hear other people's stories. Learning about other places we could get help. Really makes us realize that even though we think our journey has been hard, that there are actually whānau worse off than us. It's hard that we have had to find out things for our self, as opposed to people or resources available to inform us instead. Some people don't know how to ask those questions or find out for themselves. Some will just agree and nod their heads.*

*To be included from the beginning has given me a sense of pride and investment in the resource that we now know as Hā*

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*Ora, but also to increase my own knowledge of the disease and its progression, and to be amongst whānau who have shared similar journeys with me, I would say - emotional, empowering and yet rewarding.*

*It didn't feel like a process, I was there and gave input and the team from Waikato turned it into something great for us to use.*

*The process was managed very well, because we as whānau felt included in decision making all the way through, and it was our thoughts and ideas that were taken on board and made to feel that each of those thoughts and ideas mattered.*

Most participants indicated that the website captured what they envisioned for their community and whānau: three responded 'yes, definitely' (75%), and one responded 'I don't know'. The particular participant who responded 'I don't know', followed up by stating:

*I chose ['I don't know'] above because some of us aren't good on computers - but like a book, which we could have done. But this is cool too - I think the doctors need to take patients through it.*

Two respondents further indicated that they hoped that the website would get nationwide coverage and reach more people to educate and help them.

Overall, respondents were happy with the website, and those who were involved in the co-design phase of the project were very pleased

with the process and result. Additional comments from respondents include:

*It has meant so much working with the team from Waikato. Why? Because they listened and they explained things to us and they made us part of it. And then when you see each other again it's like meeting up with old friends!*

*Just thank you. Thank you to the amazing team that led this entire project, we thank you for making it possible for the journeys of our families to be heard.*

Basic usage of the website was also tracked using Google Analytics. Usage data indicated in the 3 month pilot period of the website (16 Dec 2019 – 16 Mar 2020), there were a total of 43 users. Within this period, 74.5% of users (n=38) were new visitors, whereas 25.5% of users were returning users.

Extended analysis of user data spanning the 8 months following pilot (Dec 2019 – Sep 2020), indicated a total of 112 users, where 81.1% were new users (n=107), and 18.9% were returning users.

### **7.2.2 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, a local Māori community organization in Gisborne who are key figures in supporting and promoting Māori health. The team worked with Turanga Health to develop a training workshop for their kaiawhina and clinical staff.

Two training workshops were organized: one for kaiawhina and one for clinical staff (nurses). The workshops were facilitated by Respiratory Cancer Nurse Specialists (CNSs) at the Waikato Hospital, and members of the extended team: Karen Middleton and Leonie Brown – see figures 8 and 9. Additionally, the local CNS at the Gisborne hospital as well as a member of the local Hospice team in Gisborne contributed brief sessions at the workshop.

The workshops covered:

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



Figure 8 Karen facilitating a workshop



Figure 9. Leonie facilitating a training workshop

The training workshops highlighted overall that when working with clients who exhibit symptoms that could be attributed to lung cancer, such as a persistent cough, then kaiawhina and nurses should advocate for, patients to promptly go and see their GP, and patients at risk of lung cancer to have a chest X-ray.

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

### *Evaluation*

An evaluation was carried out immediately following the two workshops to assess the uptake and effect of the training. Attendees were given a survey to complete following the training workshops.

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There were a total of 21 participants in the workshops (12 kaiawhina and nine clinical staff), who responded to the evaluation questionnaire.

Focusing on the evaluation of the kaiawhina training workshop, all participants indicated that they found the workshop very helpful. All felt that they knew more about lung cancer following the workshops, that they would recommend the training to others, and that they thought the training would help them support whānau on their lung cancer journeys (10 responded 'yes, definitely' [83%], and two responded 'yes' to each of these questions). Most participants indicated that they thought the training was a practical/effective way of learning about how to identify whānau who may have lung cancer (10 responded 'yes, definitely' [83%], one responded 'yes', and one responded 'I don't know'). A majority of participants also reported that they thought the training would help them support whānau with lung cancer on their journey (11 responded 'yes, definitely' [92%], and one responded 'I don't know').

On evaluating the clinical staff training workshop, all participants indicated that they:

- Found the training workshop very helpful
- Felt they definitely know more about lung cancer after the training
- Thought the training was definitely a practical/effective way of learning about how to identify whānau with lung cancer.

All participants also reported that they would recommend the training to others (eight responded 'yes, definitely' [89%], and one responded 'yes'), and that they thought the

training would help them support whānau with lung cancer on their journey (eight responded 'yes, definitely' [89%], and one responded 'yes').

Overall, responses to the surveys for both the kaiawhina and clinical staff workshops indicated that the workshops were positively received, and considered beneficial to all staff involved.

### 7.2.3 Pou pupuru oranga cancer navigator

The aim of the intervention in Rotorua was to demonstrate the value of a health navigator for cancer patients.

The third community intervention was a pou pupuru oranga cancer navigator in Rotorua, based at Aroha Mai Cancer Support Services, a local organization providing advocacy and support services for cancer patients. Here, the co-design group requested that the intervention be located outside of the mainstream healthcare space (e.g. hospitals), and thus the navigator worked alongside Bubsie McFarlane at Aroha Mai – see figures 10 and 11.



Figure 10 The CE of Aroha Mai Cancer Support Services



Figure 11. Aroha Mai publicising the pou pupuru oranga

The project funded the pilot of the role for a period of 12 weeks. The role was publicized by Aroha Mai, where publicity comprised posters and business cards being made available at local HCPs (GP practices, the hospital) and other Māori community organisations.

The pou pupuru oranga role overlapped with the services already being provided by Aroha Mai, and included a diverse array of 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.

During the duration of the 12 week pilot, the navigator worked with five cancer patients, two male, and 3 female. Three clients were Māori lung cancer patients, whereas the others were non-Māori, and had various other cancers including breast, colon and stomach cancers.

### *Evaluation*

The navigator’s interaction with each patient and whānau comprised an in-built goal-setting and evaluation process. Here, the navigator began their relationship/interaction with the client by asking a series of questions and setting a series of goals based on the client’s expectations of how the relationship/interaction should proceed. This initial phase of questions covered why clients sought out a navigator, what barriers they may have faced with their HCP, and what they hope to get out of their time with the pou pupuru oranga. Towards the end of the client’s treatment journey and/or their journey with the pou pupuru oranga, the navigator asked them another series of questions to evaluate how the process went. This final phase of questions covered whether or not the goals set previous have been successfully achieved, services/aspects that worked best, and services/aspects that could be improved.

Overall evaluation results indicated that all clients were very pleased with their interactions with the pou pupuru oranga. They were



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provided with a range of services during the pilot of the intervention including:

1. Transport to appointments and treatment

For instance, as indicated by Mr A, a male getting treatment for colon cancer:

*When you take out Aroha Mai, then how do I get to [the regional hospital for treatment]? That's the problem...that journey on my own was not really an option... you take the worry away, the stress. (Mr A)*

2. Providing petrol vouchers

3. Acting as an interpreter, or sourcing and providing funding for an interpreter

4. Providing a space to talk and a listening ear.

For instance, as indicated by two patients:

*They let you come here and just talk you know, to be able to just come somewhere and feel good to be able to talk about what you're going through and all that. .. a space to talk and be myself. (Mrs A)*

*Listening. Non-judgemental listening. That is one of [the pou pupuru oranga]'s gifts. (Ms P)*

5. Support

Here it is clear that the support provided by the pou pupuru oranga was wide-ranging and did not only extend to physical health, and the healthcare space. Rather it encompassed holistic health and wellbeing. The holistic support

provided by the pou pupuru oranga and Aroha Mai was discussed by clients:

*Unwellness is a long journey to battle. It requires a lot of support and aroha, manaakitanga, whanaungatanga, wairuatanga, and I believe [the pou pupuru oranga] provides that to people like myself. (Ms P)*

*We have come a long way since we have been here [with Aroha Mai] and the support here. Without it I probably would not have survived. (Ms F)*

*Manaakitanga that leaves me with my mana intact. That's rare to find in a service. (Ms P)*

Overall, clients indicated that the pou pupuru oranga went above and beyond to support them along their cancer journeys. As stated by Ms F, who was getting treatment for breast cancer:

*It's been great with the kai [food] and the vouchers here and there and that's a big help. I wasn't able to get help from WINZ for clothing like bras, and Aroha Mai helped me. The pick-ups and the tautoko getting me to the hospital, that's been a big part of my survival. Even housing, moving into the house. I was never able to get a house because I have never been vouched for, you know. Over and beyond. I don't have to worry now. (Ms F)*

When asked what aspects of the role/service could be improved, many clients stated nothing

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at all. However, some also indicated that they would have liked to see Aroha Mai, and the pou pupuru oranga receive more funding, so they could help patients at a greater capacity:

*At the end of the day it, it comes down to putea [funding]. A pou can only do as much as they can do within their financial restrictions. (Ms P)*

Overall, clients saw the pou pupuru oranga and the overall Aroha Mai team as family, who supported them through their cancer journeys:

*To me the pou pupuru oranga gave me the support needed throughout treatment and later became like family (Mr H)*

Finally, it is clear that the pou pupuru oranga role, alongside the services provided by Aroha Mai serve a vital function for these whānau, in this rohe. Many whānau have received support not only directly relating to their cancers and treatment, but also relating to the broader aspects for their lives (e.g. support for broader whānau, emotional support, funding for kai and clothing etc.) that are also key factors in their lung cancer journeys.

#### **7.2.4 “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 developed with the Te Kuiti community group. This intervention also featured a waiata composed by members of the community. The co-design group reached out to their whānau who lived locally, to compose and perform the waiata, and also enacted brief skits for the videos. The team supported the co-design group to develop the awareness videos from the material the community provided.

The process began with the facilitation of a Media workshop with the co-design group and wider community. The workshop was led by our local stakeholders, alongside Dr Mary Simpson, a media communications expert at the University of Waikato and Rangimahora Reddy, the CEO of Rauawaawa Kaumātua Charitable Trust, who both had considerable experience developing and leading media campaigns (see figures 12 and 13). The workshop aimed to assist community members to start thinking of how they could develop a media communication plan to improve early diagnosis of lung cancer for their community. Key questions of focus included:

1. What issue do you most want to address?
2. Who are the people you most want to engage with?
3. What are your objectives with the people identified (awareness, acceptance, action)?
4. What are the best communication channels/formats to achieve your objective?

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Following the workshop, the co-design group worked together to develop and record 4 short videos comprising scenarios and exemplars of people being asked to go and see their doctor if they had a persistent cough. The message was reinforced through the lyrics of the waiata. The project team enlisted the help of Tom Goulter, a professional video editor, to develop the series of videos.

Throughout each step of video development, the community was consulted for feedback and approval. The team organized a hui with all the stakeholders and leading figures of interest in Ngāti Maniapoto Marae Pact Trust and Maniapoto Whānau Ora Centre alongside other members of the Te Kuiti Community to ‘launch’ the video intervention.



Figure 12. Community stakeholders contributing to the media workshop

### Evaluation

An evaluation was carried out at the community hui immediately following the ‘launch’ of the video interventions to assess the response to the

intervention. Attendees were given a survey to complete towards the end of the hui.



Figure 13. Stakeholders leading the media workshop

There were a total of 10 participants in the hui, of whom six responded to the evaluation questionnaire.

All respondents indicated that they found the videos very helpful. All felt that they knew more about lung cancer after seeing the videos (three responded ‘yes, definitely’ [50%] and three responded ‘yes’). All respondents felt that the videos were especially useful to them as Māori, that the videos convinced them to ask their whānau to go and see the doctor with worrying symptoms and that the videos were a practical way of encouraging whānau to go and see the doctor (four responded ‘yes, definitely’ [66.6%], and two responded ‘yes’ to each of these questions).

All respondents indicated that they were very pleased with their engagements with the team and the co-design process (responses included: ‘excellent’, ‘very good’ and ‘bloody awesome’).

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Two respondents provided suggestions for improvements to the process and intervention. Both respondents stated that they would also like a focus on lung cancer prevention, targeting all age groups (pepi, tamariki, pakeke, kaumātua). Overall, all participants stated that the videos definitely captured what they envisioned for their community and whānau.

### 7.2.5 HCP intervention

The team also facilitated a series of lung cancer awareness workshops with primary care staff (GPs, nurses, social workers, other staff) at each of the 4 communities (Opōtiki, Gisborne, Rotorua and Te Kuiti) to complement each intervention.

In Opōtiki, the team facilitated a workshop inviting all staff at the three local GP clinics. In Rotorua and Gisborne, the team facilitated the workshop as part of the broader Joint Clinical Council meetings – organized by the Rotorua Area Primary Health Services (RAPHS), and the GP compliance, monitoring and enforcement (CME) meetings – organized in Gisborne. The HCP intervention was facilitated in Te Kuiti, with staff at the local Māori health provider, alongside community members concurrent with the ‘launch’ of the ‘wharo wharo wharo’ lung cancer awareness videos.

The HCP lung cancer awareness workshops were led by Ross, and comprised an overview of lung cancer statistics in NZ (including cancer registrations, mortality and survival rates), information on symptoms and the diagnostic pathway, an overview of the findings of studies

1-4, and an introduction to the interventions for each community.

The information presented to HCPs at the workshops in relation to the diagnostic pathway for lung cancer were derived from the following booklet (see figure 14): <https://www.midlandcancernetwork.org.nz/assets/Lung-cancer-booklet-FINAL-October-2017.pdf>

The team also provided HCPs with copies of this booklet. It should be noted that the ‘A guide to help you understand your lung cancer and treatment’ booklet was initially prepared by Leonie and Karen (Respiratory CNSs at the Waikato Hospital, and members of the extended team). This booklet was then updated by them for use and dissemination as part of the Hā Ora project.

However, the team was aware that despite the HCP intervention, we were unsuccessful in changing GP attitudes.

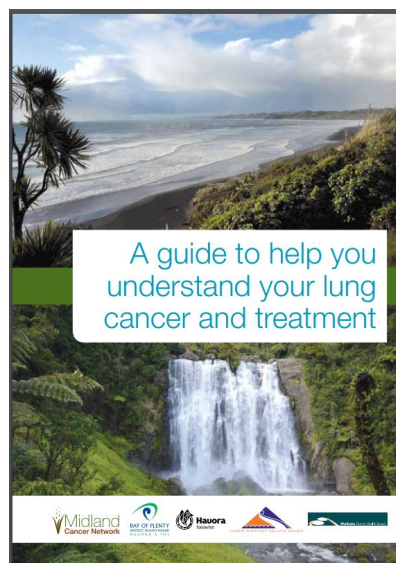


Figure 14. Cover page of the lung cancer booklet used for HCP workshops

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### *7.3 Te Kaha*

It should be noted here, that an intervention was not co-designed with community members in Te Kaha, because for this community the barriers to early diagnosis were predominantly related to secondary and/or specialist care. The Te Kaha community had an active primary care team, who played a strong advocacy role to ensure that their patients got the best treatment and support possible. This community had strong enablers in place for early diagnosis of lung cancer and the team did not want to change or affect what was already being successfully undertaken. Therefore, rather than proceeding onto co-designing an intervention with the Te Kaha community, 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.

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## 8. Discussion & Conclusion

### 8.1 Barriers to early diagnosis

This study has identified the key barriers for Māori patients and their whānau in their diagnostic pathway. Findings suggest that several barriers were similarly reported by patients, community members as well as HCPs. For instance, symptom ambiguity, accumulating cost, long waiting times, delayed diagnosis and referral and GP-patient relationship were barriers identified by all participant groups. Whereas fear and the important role of whānau were key issues identified by patients, whānau and community members.

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.

### 8.2 Community interventions

Overall, the community interventions designed as part of the current project, were 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.

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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.

## **8.3 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.

## **8.4 Recommendations**

From the study we have some suggested recommendations to the Cancer Control Agency (CCA) to promote 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.

### *8.4.1 Recommendations to support HCPs*

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 the CCA consider advocating for funding for regular lung health checks for high risk

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- patients and have a low threshold for ordering chest X-rays in primary care.
2. We recommend that the CCA support HCPS across primary and secondary care to 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.
  3. We recommend that the CCA support PHOs and DHBs to increase their efforts in providing cultural safety training for all staff.
  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 the CCA support better and direct access to diagnostic tests for lung cancer such as CT scans in primary care, in particular for at risk Māori and ex-smokers.
  5. We recommend that the CCA support PHOs and DHBs to work together at ensuring better access for patients at risk of lung cancer to both primary and specialist services.
  6. We recommend that the CCA support DHBs to engage with the communities they are working with on ways of achieving earlier diagnosis for patients at highest risk of lung cancer.
  7. We recommend that the CCA support sustained funding and support for culturally safe initiatives developed locally by Māori communities, such as targeted lung cancer

screening, cancer navigators, health literacy resources and other lung cancer awareness campaigns.

#### *8.4.2 Recommendations to support whānau*

1. We recommend that the CCA encourage HCPs to consider and include whānau as part of the patient interaction, as whānau are significant influencers in patient behaviour.
2. We recommend that the CCA supports whānau to 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 is caught early enough.
3. We found evidence that community interventions like the Hā Ora website and the 'wharo wharo wharo' videos are equally important to tamariki as well as people at risk of lung cancer. We recommend that the CCA share such community interventions with people of all ages.



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## 9. Acknowledgements

The team would like to sincerely thank all those who provided support, help and advice throughout the project, as well as those who worked generously and tirelessly to bring the interventions to life:

- All our participants (Lung Cancer patients, whānau, community members, co-design groups, primary care staff at our 5 localities)
- Health Research Council of New Zealand
- Ministry of Health
- The University of Waikato
- Waikato District Health Board
- The Midland Cancer Network
- Te Puna Oranga
- Lakes District Health Board
- Aroha Mai Cancer Support Services
- Turanga Health
- Hei Pa Harakeke
- Ngāti Maniapoto Marae Pact Trust
- Maniapoto Whānau Ora Centre
- Piki Tiaroa and Kokiri Trust
- Whakatōhea Trust
- Te Arawa Whānau Ora
- Mātua Hemi Curtis
- Mātua Eru George
- Phyllis Tangitu
- Bubsie MacFarlane
- Haley Richards
- Ngaroma Grant
- Lydia Rickard
- Mahina Joseph-Small and whānau
- Maryanne Thompson
- Tania Te Wano
- Mariana Hudson and all our Opōtiki whānau
- Toma Walker
- Rachel Thomson
- Dallas Poi
- Reweti Ropeha
- Shirley Keown
- Nina Scott
- Jade Sewell
- Rawinia Hohua
- Karen Middleton, LeeAnn Shaw, David Boles (CNSs)
- Josh Fellingham
- Hakopa Pore
- Tom Goulter
- The interviewers (Tamati Peni, Haupai Puke, Jo O'Brien, Stella Black, Tepora Emery, Tama Hata-Tipene, Cherie Paekau)
- Mary Simpson
- Rangimahora Reddy
- Janette Ngahe
- Gill Hunn

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## Appendix 1: List of student projects supported by the team

Name	Title	Programme	Institution	Completion date
Chloe Corbett	Ethnic Inequities in Lung Cancer Outcomes in the Midland Region	Master of Public Health	University of Auckland	2020
Janette Ngaheu	Improving early access to a lung cancer diagnosis for rural Māori communities – A Kaupapa Māori study within one rural location of the Midland region to explore the barriers faced by Māori with a self-identified risk of lung cancer	Master of Nursing	Wintec	2019
Joshua Fellingham	HāOra: Designing a website for improving awareness of lung health	Summer Research Scholarship Programme	University of Waikato	2019/2020
Brittany Ryan	Characteristics of lung cancer patients receiving psychosocial support in urban New Zealand	Summer Research Scholarship Programme	University of Waikato	2018/2019



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## Appendix 2: List of Publications

### Project summary reports

Lawrenson, R., Cassim, S., Kidd, J., Rolleston, A., Hokowhitu, B., Chepulis, L., Firth, M., Aitken, D., Wong, J., Keenan, R. (2020). *Hā Ora: Improving early diagnosis of lung cancer for rural Māori communities. Understanding whānau experiences*. Hamilton, New Zealand: University of Waikato. Retrieved from <https://haora.cms.waikato.ac.nz/about/>

Lawrenson, R., Cassim, S., Kidd, J., Rolleston, A., Hokowhitu, B., Chepulis, L., Firth, M., Aitken, D., Wong, J., Keenan, R. (2020). *Hā Ora: Improving early diagnosis of lung cancer for rural Māori communities. Understanding patient experiences in general practice*. Hamilton, New Zealand: University of Waikato. Retrieved from <https://haora.cms.waikato.ac.nz/about/>

### Publication list

Kidd, J., Cassim, S., Rolleston, A., Keenan, R., Lawrenson, R., Sheridan, N., Warbrick, I., Ngahe, J. & Hokowhitu, B. (2021). Hā Ora: Reflecting on a Kaupapa Māori community engaged co-design approach to lung cancer research, *International Journal of Indigenous Health*, 16(2). doi: <https://doi.org/https://doi.org/10.32799/ijih.v16i2.33106>

Cassim, S., Lawrenson, R., Keenan, R., Middleton, K., Rolleston, A.,...Kidd, J. (2021). Indigenous perspectives on breaking bad news: Ethical considerations for healthcare providers, *Journal of Medical Ethics*. doi: <http://dx.doi.org/10.1136/medethics-2020-106916>

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Rolleston, A., Cassim, S., Kidd, J., Lawrenson, R., Keenan, R. & Hokowhitu, B. (2020). Seeing the unseen: Evidence of Kaupapa Māori health interventions, *AlterNative*. doi: 10.1177/1177180120919166

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<p>Lawrenson, R., Lao, C., Brown, L. et al. (2020). Management of patients with early stage lung cancer – why do some patients not receive treatment with curative intent?. <i>BMC Cancer</i>, 20, 109. doi: <a href="https://doi.org/10.1186/s12885-020-6580-6">https://doi.org/10.1186/s12885-020-6580-6</a></p>
<p>Kidd, J., Cassim, S., Rolleston, A. &amp; Keenan, R. (2019). Co-opting or valuing the indigenous voice? A question of ethics, <i>Ethnographic Edge</i> 3(1). doi: <a href="https://doi.org/10.15663/tee.v3i1.52">https://doi.org/10.15663/tee.v3i1.52</a></p>
<p>Cassim, S., Chepulis, L., Keenan, R., Kidd, J., Firth, M. &amp; Lawrenson, R. (2019). Patient and carer perceived barriers to early presentation and diagnosis of lung cancer: A systematic review, <i>BMC Cancer</i> 19(1), 25. doi: 10.1186/s12885-018-5169-9.</p>
<p>Chepulis, L, Ryan, B, Blackmore, T, Burrett, V, McCleery, J, Lawrenson, R. (2019) Characteristics of lung cancer patients receiving psychosocial support in urban New Zealand. <i>Psycho-Oncology</i>, 28, 1588-1590. doi: <a href="https://doi.org/10.1002/pon.5137">https://doi.org/10.1002/pon.5137</a></p>
<p>Lawrenson, R., Lao, C., Leonie, B., Wong, J., Middleton, K., Firth, M. &amp; Aitken, D. (2018). Characteristics of lung cancers and accuracy and completeness of registration in the New Zealand Cancer Registry, <i>NZMJ</i>, 131(1479).</p>
<p><b>Forthcoming publications</b></p>
<p>Kidd, J., Cassim, S., Rolleston, A., Keenan, R., Hokowhitu, B.,.... Lawrenson, R. (forthcoming). Hā Ora: Community driven interventions to promote early diagnosis of lung cancer</p>
<p>Lawrenson, L., Cassim, S., Rolleston, A., Keenan, R., Aitken, D.,..Kidd, J. (forthcoming). Hā Ora: Barriers and enablers to early diagnosis of Lung Cancer for Māori patients and whānau</p>
<p>Lawrenson, R., Keenan, R. (forthcoming). Deliberating GP responses to community driven interventions. <i>NZMJ Editorial</i></p>

## List of Conference and Hui Presentations

Title	Presenter	Team	Conference/Hui
<b>Hā Ora: Community driven interventions to promote early diagnosis of lung cancer for Māori communities</b>	SC		Whānau centred care team meeting, Te Aho o Te Kahu -Cancer Control Agency November 2020
<b>HāOra: Designing a website for improvidng awarenss of lung health</b>	JF	SC, MM, LC	Poster presented at the Summer Research Scholarship Programme Closing Function, University of Waikato, Hamilton, New Zealand February 2020
<b>Barriers in accessing health care for Māori patients with lung cancer</b>	RL		6th New Zealand Lung Cancer Conference, Christchurch, New Zealand October 2019
<b>Hā Ora: Reflecting on a Kaupapa Māori community engaged co-design approach to lung cancer research</b>	SC	JK, AR, RK, JN, RL	Academic General Practice & Primary Care Research Symposium, University of Waikato, Hamilton, New Zealand September 2019
<b>Equity of lung cancer outcomes for Māori</b>	RL		GP Education Evening, Gisborne September 2019
<b>What needs to be done to reduce lung cancer mortality?</b>	RL		Cancer Society Meeting, Hamilton August 2019

<b>What needs to be done to reduce lung cancer mortality?</b>	RL	CL, LC, LB, KM, RK, DA, JW, SC	Grand Round – Tauranga Hospital March 2019
<b>Review of the Midland Lung Cancer Register</b>	RL	CL, LB, LC, SC, JK, JW, DA, KM, RK	Poster presented at the Cancer Care at a Crossroads Conference, University of Otago, Wellington, New Zealand. January 2019
<b>Co-opting or valuing the indigenous voice? A question of ethics</b>	JK	SC, TP, AR, RK, BH	Contemporary Ethnography Across the Disciplines Conference, University of Santiago, Chile November 2018
<b>What needs to be done to reduce lung cancer mortality?</b>	RL		9th Waikato Regional Lung Cancer conference, Hamilton November 2018
<b>Update on: Lung and colorectal cancer research</b>	SC, LC		Hei Pa Harakeke Meeting, Cancer Society, Hamilton August 2018
<b>Improving early access to lung cancer diagnosis for Maori and rural Communities</b>	RL	RK, JK, SC, CL, JW, KM	E-poster presented at the Ca-PRI 2018 Conference “Building Bridges”, Groningen, The Netherlands April 2018

<b>A community based intervention for rural Maori at risk of lung cancer.</b>	RL	JK, CL, RK, AR, BH, DA, JW	National Rural Health Conference, Auckland April 2018
<b>Improving early access to lung cancer diagnosis for Māori &amp; rural communities</b>	SC		Hei Pa Harakeke Meeting, Cancer Society, Hamilton March 2018

<p><b>LEGEND:</b>          DA: Denise Aitken          LB: Leonie Brown          LC: Lynne Chepulis          SC: Shemana Cassim          JF: Joshua Fellingham          MF: Melissa Firth          BH: Brendan Hokowhitu          JK: Jacquie Kidd          JN: Janette Ngaheu          RK: Rawiri Keenan          CL: Chunhuan Lao          RL: Ross Lawrenson          KM: Karen Middleton          TP: Tamati Peni          AR: Anna Rolleston          JW: Janice Wong          MM: Michael Mayo</p>
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## **Appendix 3: Research Outputs**





# Characteristics of lung cancers and accuracy and completeness of registration in the New Zealand Cancer Registry

Ross Lawrenson, Chunhuan Lao, Leonie Brown, Janice Wong, Karen Middleton, Melissa Firth, Denise Aitken

## ABSTRACT

**AIMS:** This study aims to report the characteristics of newly diagnosed lung cancer cases, and to examine the data accuracy of registrations in the New Zealand Cancer Registry (NZCR) in 2011–2015.

**METHODS:** The accuracy and completeness of lung cancer registrations in the NZCR was explored using the Midland Lung Cancer Register (MLCR, including Lakes, Waikato, Tairāwhiti and Bay of Plenty District Health Boards) and clinical records. A combined Midland Lung Cancer Dataset was created based on the NZCR and the MLCR. The characteristics of lung cancer cases was described and compared between Māori and non-Māori patients. The subgroup differences were examined by Chi-Square tests. The odds ratio of having small cell lung cancer compared to non-small cell lung cancer between Māori patients and non-Māori patients was estimated using the logistic regression model.

**RESULTS:** The combined Midland Lung Cancer Dataset included 2,057 verified lung cancer registrations, including 656 (31.9%) Māori patients and 1,401 (68.1%) non-Māori patients. Māori patients were more likely to be diagnosed at a younger age, more likely to be female, more likely to be a current or ex-smoker and more likely to have small cell lung cancer than non-Māori. The difference of cancer stage at diagnosis between Māori and others was not significant. After adjustment, the odds ratio of having small cell lung cancer for Māori patients compared to non-Māori patients was 1.55 (95% CI: 1.17–2.05). The adjusted odds ratio of having small cell lung cancer was 4.06 (95% CI: 1.72–9.60) for current smokers and 2.68 (95% CI: 1.14–6.30) for ex-smokers compared to patients who never smoked.

**CONCLUSIONS:** Combining the two sources of data gives a more complete picture of the incidence and tumour characteristics of lung cancer in our region. Our dataset suggests that Māori patients are more likely to have small cell lung cancer than non-Māori patients.

Lung cancer is the leading cause of cancer death in New Zealand with approximately 1,500 deaths per year.<sup>1</sup> It has a significant impact due to the high rates of morbidity and mortality associated with the disease.<sup>2</sup> Survival from lung cancer in New Zealand is poor with a five year survival of 9.5% for men and 11% for women.<sup>3,4</sup> Internationally many countries achieve better survival outcomes than New Zealand, including Canada, Australia and Sweden where five-year survival is between 16–18%.<sup>5</sup> Māori

have a greater incidence of lung cancer, with Māori men having 2.0 times the incidence and Māori women having 3.4 times the incidence of Europeans/others.<sup>1,6</sup> The age standardised mortality rate for Māori is 3.5 times that of non-Māori.<sup>7</sup> One of the key reasons for the poor prognosis for newly diagnosed patients with lung cancer is that most patients present with advanced stage disease. Treatment is therefore generally palliative, with few patients being suitable for potentially curative treatment such as surgery

or stereotactic ablative body radiotherapy (SABR).<sup>8,9</sup> Another important influence in patient outcome is the tumour biology, for instance those with small cell lung cancer have a poorer prognosis.<sup>10,11</sup> Non-small cell lung cancer (NSCLC) and those who are epidermal growth factor receptor (EGFR) positive have a better outcomes.

The New Zealand Cancer Registry (NZCR) is a population-based tumour registry, collecting and storing cancer incidence data. The new cancer registrations are mainly based on the pathology reports sent by reporting laboratories electronically. Other sources include discharge reports from publicly funded and private hospitals, death certificates and autopsy reports.<sup>12,13</sup> Data collected in the NZCR includes demographic information (such as date of birth, gender and ethnicity) and tumour information (such as cancer site and extent of disease). The NZCR is the major source of “information on the incidence of, and mortality from, cancer” and “a basis for cancer survival studies and research programmes”.<sup>14</sup> Its completeness and accuracy are vital for cancer control in New Zealand.

The completeness and accuracy of registrations in the NZCR have been reported to be diverse for different cancers.<sup>13,15–17</sup> Approximately 88% of the breast cancer cases recorded in the NZCR have information on disease extent with a 94% accuracy rate in those with disease extent.<sup>13</sup> For colon cancer 96% cases have disease extent with a 87% accuracy rate,<sup>15</sup> but only 31% prostate cancer cases have disease extent with a 89% accuracy rate.<sup>16</sup> An audit was conducted to assess the lung cancer data in NZCR using the data recorded in the Auckland and Northland regional databases in 2004.<sup>17</sup> Of the 565 audit cases, 66 (12%) cases were not included in the NZCR, and one duplicate registration and 78 (14%) ineligible cases were identified in the NZCR. Only 58% of the lung cancer cases recorded in the NZCR have information on disease extent with a 79% accuracy rate in those with disease extent.<sup>17</sup> The audit of the lung cancer data in the NZCR was conducted a decade ago, and improvement on data quality may have been achieved. An updated quality assessment on the lung cancer data is needed.

The Midland Respiratory Group has been collecting data on all newly diagnosed cases of lung cancer who are referred to their multidisciplinary review meetings onto an access database: Midland Lung Cancer register (MLCR). It has maintained a register of all patients seen since 2004 and the centre has relatively complete recording of cases for the Midland Cancer Region (Lakes, Waikato, Tairāwhiti and Bay of Plenty District Health Boards (DHBs)) since 2007. These four DHBs serve a combined population of 700,000 and generate approximately 400 new cases of lung cancer a year. The region has 27% Māori population and of the over 2,000 cases on the register, 600 are Māori. The register includes data on date and source of presentation, results of investigations including CT and spirometry, date of diagnosis and pathological reporting. All patients are staged and mode of treatment is then recorded (radiotherapy, chemotherapy or surgery).

This study aims to report the characteristics of newly diagnosed lung cancer cases in the Midland Cancer Network region, and to examine the data accuracy of registrations in the NZCR in 2011–2015.

## Methods

### Data cleaning and verification

Experienced clinicians validated the lung cancer cases diagnosed in 2011–2015 in the MLCR by comparing the clinical records and the data recorded in the MLCR. Lung cancer (ICD code: C33, C34)<sup>18</sup> diagnosed in the Lakes, Waikato, Tairāwhiti and Bay of Plenty DHBs in 2011–2015 were extracted from the NZCR and the MLCR.

Registration duplications were removed from the two datasets. Then they were linked together by the National Health Index (NHI) number, a unique identifier assigned to every person who uses health and disability support services in New Zealand. We classified all the combined cases into three groups: 1) matching cancer cases in both datasets, 2) cancer cases identified in the MLCR only, 3) registrations identified in the NZCR only. For registrations identified in the NZCR only, clinical records were examined by clinicians to verify the lung cancer diagnosis: 1) lung cancer diagnosed in 2011–2015, 2) lung cancer diagnosed

before 2011 or after 2015, 3) not lung cancer, 4) cannot confirm due to insufficient information.

### Combined lung cancer dataset

To understand the characteristics of lung cancer cases in the Midland Cancer Network region, we created a combined dataset based on the NZCR data and the MLCR data. The combined lung cancer dataset included all cancer cases in the MLCR and the additional verified lung cancer cases diagnosed in 2011–2015 and recorded in the NZCR. We have categorised the cancer cell types into six groups: small cell, NSCLC, NSCLC-other, malignant carcinoid, others and unknown. The characteristics of these patients by ethnicity (Māori, Pacific and others) was explored, and the differences were examined by Chi-Square tests, with a p-value of less than 0.05 considered significant. The odds ratio of having small cell lung cancer compared to non-small cell lung cancer between Māori patients and non-Māori patients was estimated using the logistic regression model after adjustment for age, gender, smoking status (recorded in the MLCR), DHB and year of diagnosis.

### Accuracy and completeness of the NZCR

The accuracy of demographic data of the verified lung cancer cases in the NZCR including cancer extent/stage, date of diagnosis, DHB, gender and ethnicity (Māori, Pacific, Asian, European and others) were compared with the MLCR data and clinical records. As demonstrated in the audit<sup>17</sup> on lung cancer data in NZCR in 2004, the difference on date of diagnosis between the NZCR and regional dataset may be due to difference regarding the definition of date of diagnosis. The NZCR may collect the date of diagnosis from 1) date of operation or biopsy, 2) date of admission, 3) date of death if diagnosed at autopsy or 4) 'approximate time between onset and death' as reported by certifying doctor on the death certificate if the only notification of a cancer comes from the death certificate.<sup>16</sup> However, a regional dataset may record the date of diagnosis from 1) date of issue of the first report confirming malignancy, 2) the date of final report suggesting invasive malignancy or 3) the first documentation of the diagnosis in the clinical records.<sup>17</sup>

The MLCR records the patient characteristics at the time of diagnosis including date of birth, gender, ethnicity and patient domicile. These data are taken from the patient's hospital records at the time of diagnosis. Cancer stage is recorded after discussion at the multi-disciplinary meeting, using the Tumour Node Metastases (TNM) staging system.<sup>19</sup> The NZCR applies the Surveillance Epidemiology and End Results (SEER) programme cancer staging definitions.<sup>20</sup> The TNM classification was updated by the American Joint committee on Cancer. 'T' describes the extent of the primary tumour. 'N' describes the extent of regional lymph node metastasis. 'M' describes the occurrence of distant metastasis.<sup>19</sup> The SEER staging definition was developed by the American National Cancer Institute. Extent at diagnosis in the NZCR is coded as B (limited to organ of origin), C (Extension to adjacent organs), D (Extension to regional lymph nodes), E (distant metastases) and F (unknown).<sup>20</sup> In this study, stage IA and IB in the TNM system were considered to be extent B, stage IIA, IIB, IIIA and IIIB were comparable to extent C and D, and stage IV were extent E.<sup>17</sup> All data analyses were performed in IBM SPSS statistics 25 (New York, US).

## Results

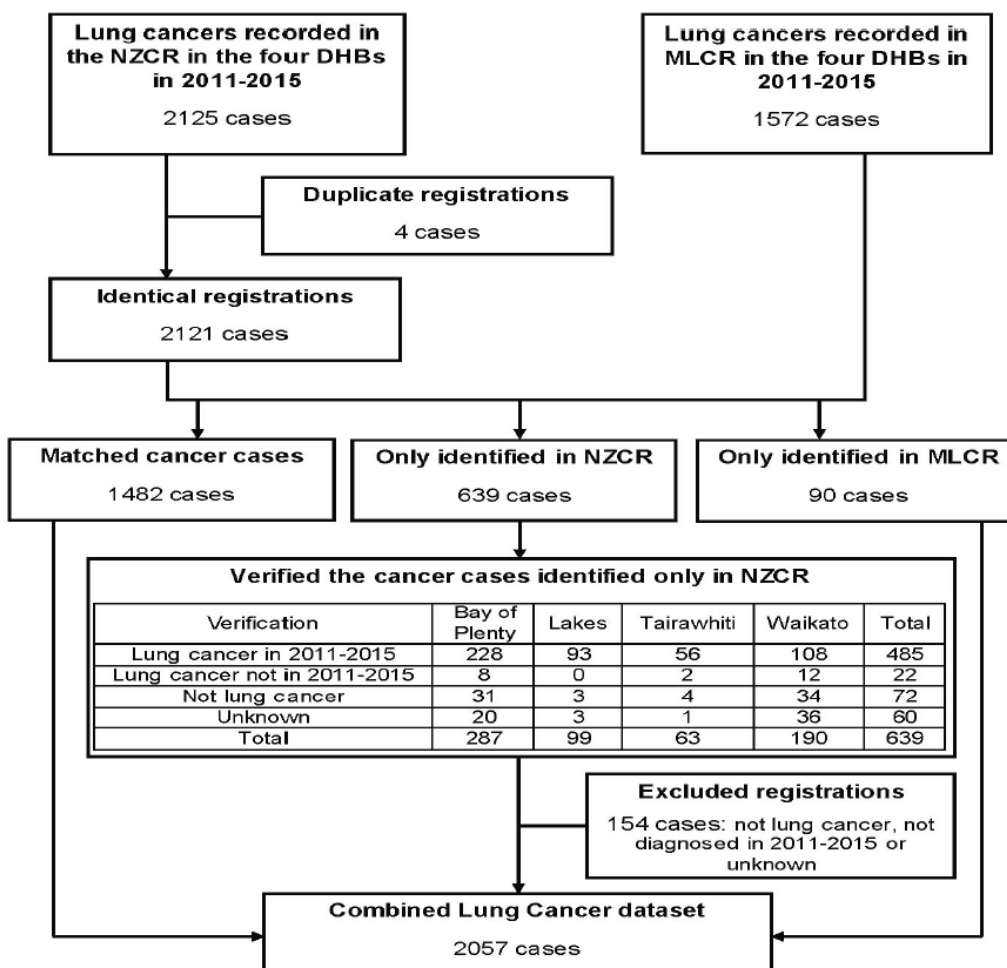
### Data cleaning and verification

We identified 2,125 lung cancer registrations in the NZCR, and 1,572 lung cancer registrations in the MLCR (Table 1) in 2011–2015. We found four duplicate lung cancer registrations in the NZCR (Figure 1). Of the cancer cases recorded in the MLCR, 1,482 (94.3%) lung cancer cases were also registered in the NZCR. There are 639 lung cancer registrations recorded in the NZCR that were not identified in the MLCR. After examining the clinical records of these 639 patients, 485 (75.9%) were confirmed to be diagnosed with lung cancer in 2011–2015, 22 (3.4%) were diagnosed with lung cancer before 2011 or after 2015, 72 (11.3%) did not have lung cancer, and 60 (9.4%) could not be verified due to lack of information in the clinical records. Of the 485 lung cancer cases recorded in the NZCR but not in the MLCR, 20 (4.1%) were stage I, 9 (1.9%) stage II, 39 (8.0%) stage III, 341 (70.3%) were stage IV and 76 (15.7%) with unknown stage. Of the

**Table 1:** Number of cancer cases by year of diagnosis and DHB.

Categories		MLCR	NZCR
<b>Year of diagnosis</b>			
	2011	300	417
	2012	293	410
	2013	297	398
	2014	315	436
	2015	367	460
<b>DHB</b>			
	Bay of Plenty	403	681
	Lakes	223	306
	Tairāwhiti	85	140
	Waikato	861	994
<b>Total</b>		<b>1,572</b>	<b>2,121</b>

**Figure 1:** Flow chart of the Combined Midland Lung Cancer Dataset.



**Table 2:** Characteristics of lung cancer patients between Māori and Non-Māori in the combined dataset.

Factors		Māori		Non-Māori		P-value (chi-square test)	Total	
		N	%	N	%		N	%
Year of diagnosis						0.907		
	2011	122	18.6%	274	19.6%		396	19.3%
	2012	136	20.7%	272	19.4%		408	19.8%
	2013	126	19.2%	259	18.5%		385	18.7%
	2014	132	20.1%	281	20.1%		413	20.1%
	2015	140	21.3%	315	22.5%		455	22.1%
DHB						<0.001		
	Bay of Plenty	179	27.3%	448	32.0%		627	30.5%
	Lakes	138	21.0%	182	13.0%		320	15.6%
	Tairāwhiti	83	12.7%	58	4.1%		141	6.9%
	Waikato	256	39.0%	713	50.9%		969	47.1%
Age (years)						<0.001		
	<50	33	5.0%	45	3.2%		78	3.8%
	50–59	158	24.1%	145	10.3%		303	14.7%
	60–69	230	35.1%	370	26.4%		600	29.2%
	70–79	179	27.3%	485	34.6%		664	32.3%
	80+	56	8.5%	356	25.4%		412	20.0%
Gender						<0.001		
	Female	363	55.3%	610	43.5%		973	47.3%
	Male	293	44.7%	791	56.5%		1,084	52.7%
Smoking status						<0.001		
	Current smoker	252	49.6%	288	27.4%		540	34.7%
	Ex-smoker	243	47.8%	650	61.9%		893	57.3%
	Never smoked	13	2.6%	112	10.7%		125	8.0%
	Unknown	148		351			499	
Cancer stage						0.137		
	I	63	10.0%	154	11.5%		217	11.0%
	II	34	5.4%	75	5.6%		109	5.5%
	III	161	25.4%	278	20.8%		439	22.3%
	IV	375	59.2%	830	62.1%		1,205	61.2%
	Unknown	23		64			87	
Cell type						<0.001		
	NSCLC	403	73.9%	945	83.5%		1,348	80.4%
	NSCLC-other	8	1.5%	22	1.9%		30	1.8%
	Small cell	126	23.1%	157	13.9%		283	16.9%
	Malignant carcinoid	0	0.0%	3	0.3%		3	0.2%
	Others	8	1.5%	5	0.4%		13	0.8%
	Unknown	111		269			380	
<b>Total</b>		<b>656</b>		<b>1,401</b>			<b>2,057</b>	

**Table 3:** Adjusted odds ratios of having small cell lung cancer compared to non-small cell lung cancer.

Factors		P-value	Adjusted odds ratio (95% CI)
Smoking status	Never smoked	Ref	
	Ex-smoker	0.024	2.68 (1.14–6.30)
	Current smoker	<0.001	4.06 (1.72–9.60)
	Unknown	-	-
DHB	Waikato	Ref	
	Bay of Plenty	0.014	0.66 (0.48–0.92)
	Lakes	0.571	0.89 (0.60–1.32)
	Tairāwhiti	0.815	1.06 (0.64–1.76)
Ethnicity	Non-Māori	Ref	
	Māori	0.002	1.55 (1.17–2.05)
Age (continuous)		0.075	0.99 (0.98–1.00)
Gender	Female	Ref	
	Male	0.402	0.89 (0.68–1.16)
Year of diagnosis (continuous)		0.480	0.97 (0.88–1.06)

90 lung cancer cases recorded only in the MLCR, 43 (47.8%) had clinical diagnosis only without any pathology report. Twenty-six patients (28.9%) had stage I lung cancer, 7 (7.8%) stage II, 16 (17.8%) stage III, 36 (40.0%) stage IV and 5 (5.6%) with unknown cancer stage.

### Combined Midland Lung Cancer Dataset

The combined dataset included 2,057 lung cancer cases (Table 2). The mean age of the cohort was 70 years old at diagnosis, and 52.7% of the patients were male. There were 656 (31.9%) Māori patients, 22 (1.1%) Pacific patients and 1,379 (67.0%) patients of other ethnicities. Waikato DHB has the largest number of lung cancer cases, followed by Bay of Plenty, Lakes and Tairāwhiti DHB. Sixty-one percent of patients were diagnosed with metastatic cancer, while 11.0% of those who had been staged had stage I disease. Eighty percent of patients had NSCLC, while 16.9% had small cell lung cancer. Māori patients were more likely to be diagnosed at a younger age (p-value <0.001, mean age: 66 years for Māori and 72 years for non-Māori), and more likely to be female (p-value <0.001) than others. The difference of cancer stage

at diagnosis between Māori and others was not significant (p-value =0.137). Almost 50% Māori patients were current smokers, another 47.8% were ex-smokers and only 2.6% had never smoked, compared to 27.4% current smokers, 61.9% ex-smokers and 10.7% never smoked for non-Māori patients (p-value <0.001). The proportions of missing data in smoking status, cancer stage and cell type between Māori and non-Māori were similar: 22.6% and 25.1% for smoking status; 3.5% and 4.6% for cancer stage; and 16.9% and 19.2% for cell type.

After adjustment for age, gender, year of diagnosis and DHB (Table 3), the odds ratio of having small cell lung cancer for Māori patients compared to non-Māori patients was 1.55 (95% CI: 1.17–2.05). The odds ratio of having small cell lung cancer was 4.06 (95% CI: 1.72–9.60) for current smokers and 2.68 (95% CI: 1.14–6.30) for ex-smokers compared to patients who never smoked. Patients in Bay of Plenty DHB were less likely to have small cell lung cancer compared to patients in Waikato DHB (odds ratio: 0.66, 95% CI: 0.48–0.92). Age, gender and year of diagnosis did not have a significant impact on the risk of being diagnosed with small cell lung cancer.

**Table 4:** Accuracy of characteristics of lung cancer patients in NZCR.

Demographics	Accuracy	Details								
Gender	99.2%	Gender in NZCR		Gender in MLCR/clinical records			Total			
				Female	Male					
		Female		928	12	940				
		Male		3	1,024	1,027				
		Total		931	1,036	1,967				
Ethnicity	97.0%	Ethnicity in NZCR		Ethnicity in MLCR/clinical records				Total		
				Māori	Pacific	Asian	European		Others	Unknown
		Māori		623	1		37	1	662	
		Pacific		2	18	1	2		23	
		Asian			1	35	1		37	
		European		6		1	1,227	1	1,235	
		Others					1	3	4	
		Unknown		1	1		1		3	6
		Total		632	21	37	1,269	5	3	1,967
DHB	98.6%	DHB in NZCR		DHB in MLCR/clinical records				Total		
				Bay of Plenty	Lakes	Tairāwhiti	Waikato			
		Bay of Plenty		604	15		3	622		
		Lakes		1	296		3	300		
		Tairāwhiti		1		132		133		
		Waikato		1	2	2	907	912		
Total		607	313	134	913	1,967				
Date of birth	99.9%	Differences of date of birth in both dataset			Number of records					
		0 day			1,965					
		6 days			1					
		731 days			1					
		Total			1,967					

**Table 4:** Accuracy of characteristics of lung cancer patients in NZCR (continued).

<b>Date of diagnosis</b>	87.0% (within one month difference)	Number of days: Difference between date of diagnosis in NZCR and MLCR/clinical records		Number of records	Percentage				
		0 days		423	21.5%				
		1–30 days		1,289	65.5%				
		31–182 days		159	8.1%				
		183–364 days		27	1.4%				
		≥365 days		10	0.5%				
		No date of diagnosis in clinical records		59	3.0%				
		Total		1,967					
<b>Cancer extent and cancer stage</b>	55.3%	Extent in NZCR	Stage in MLCR/clinical records						
			I	II	III	IV	Unknown	Total	
		B: Localised to organ of origin		80	16	2	1	3	102
		C: Invasion of adjacent tissue or organ		14	8	9	16	0	47
		D: Regional lymph nodes		4	24	118	82	10	238
		E: Distant		11	8	74	802	2	897
		F: Unknown		79	46	220	266	72	683
		Total		188	102	423	1,167	87	1,967

### Accuracy and completeness of the NZCR

The demographic data in the NZCR has high accuracy, with 99.2% accuracy for gender, 97.0% for ethnicity, 98.6% for DHB and 99.9% for date of birth among the 1,967 verified lung cancer cases in the NZCR (Table 4). For the date of cancer diagnosis, 21.5% of the cancer cases were on the same date and another 65.5% were within one month difference. However, the recording of cancer extent in the NZCR is poor, with 1,041 (55.3%) cancer cases recorded with correct cancer extent.

## Discussion

Lung cancer in the Midland Cancer Network region is relatively common with over 400 new cases per year. There has been a 15% increase in the number of lung cancer cases between 2011 and 2015. This has implications on the capacity of the cancer services to manage the increasing workload. Sixty-one percent of patients present with stage IV disease at diagnosis, while only 17% had potentially curative stage I or II disease.

Early diagnosis is the key to improving the prognosis for lung cancer patients. Reasons for diagnostic delay in New Zealand are complex and multifactorial.<sup>21</sup> Previous New Zealand research has demonstrated that patient delay is common and many are diagnosed in the emergency department, although most patients had seen a general practitioner (GP) before diagnosis. Possible interventions to improve early diagnosis include ‘community initiatives to educate and resource at-risk patients to seek help, supporting and resourcing primary care to increase timely referral and implementing strategies to reduce system complexity for GPs and patients, and the employment of care coordinators’.<sup>21</sup>

Māori patients were younger (mean age: 66 years) compared to non-Māori patients (mean age: 72 years). More Māori with lung cancer were women (55.3%), whereas in non-Māori the majority of cancers were in men (56.5%). This is likely due to differences in smoking status. In 2009, the smoking prevalence for Māori was 44% compared to 18% for non-Māori.<sup>22</sup> Māori



women have the highest smoking prevalence rate (48% in 2009).<sup>22,23</sup> It is worth noting that 10.7% of non-Māori patients and 2.6% Māori patients diagnosed with lung cancer had never smoked.

We found no difference in the risk of diagnosing metastatic lung cancer between Māori and non-Māori patients, but Māori patients are more likely to have small cell lung cancer than others. Small cell lung cancer is strongly associated with smoking.<sup>24</sup> This study showed that *Māori patients are more likely to be smokers or ex-smokers* than others. However, after adjustment for smoking status and other factors, Māori patients are still 1.55 times more likely to have small cell lung cancer than non-Māori patients. Reasons for this need further investigation. A 2010 audit conducted in the Auckland and Lakes region showed no significant difference in having small cell lung cancer between Māori and non-Māori patients.<sup>25</sup> This study only included 57 Māori patients and may have been under powered to show the difference,<sup>25</sup> while our study has 656 Māori patients and 126 of them have small cell lung cancer.

The NZCR and MLCR are both of great value in understanding the epidemiology of lung cancer in the Midland Cancer Network region. There was some under-reporting in both the NZCR (4%) and the MLCR (24%), and a 5% misrecording in the NZCR. The quality of demographic data of the lung cancer registrations in the NZCR is excellent, but the completeness and accuracy of lung cancer extent has not improved much since 2004: 35% with unknown cancer extent in this study and 42% in the 2004 audit; 81% of accuracy in this study and 77% in the 2004 audit among those with known cancer extent in the NZCR.<sup>17</sup> Further efforts will be needed to improve the cancer extent recording that will be critical for lung cancer research and cancer control in New Zealand.

Around 87% (1712) of the registrations in the NZCR had a date of diagnosis within one month difference compared with the MLCR/clinical records. Though the definition of date of diagnosis in the MLCR is considered to be more reasonable by clinicians, it is more feasible for NZCR to collect the date of diagnosis based on their definition: 1) date of operation or biopsy, 2) date of admission, 3) date of death if diagnosed at autopsy or 4) 'approximate time between onset and death' as reported by certifying doctor on the death certificate.<sup>17</sup> For the other 10% registrations whose date of diagnosis in the NZCR was more than one month different from that in the MLCR, the influence of this discrepancy may be substantial especially when these data are used for survival analysis.

The strengths of this study include that records were reviewed by experienced clinicians to ensure the accuracy of lung cancer registrations, cancer stage and cell type. Both sources of data were combined to explore the tumour characteristics between Māori and non-Māori patients. However, this study has some limitations. In the combined dataset, smoking status was not recorded in 24% of the lung cancer cases, cell type was unknown in 18% of the cases and cancer stage was unavailable in 4% of the cases.

## Conclusion

The MLCR provides excellent clinical data on newly diagnosed lung cancer cases. However, there is some under-reporting compared with the NZCR. Combining the two sources of data gives a more complete picture of the incidence and tumour characteristics of lung cancer in our region. Our combined dataset suggests that Māori patients are more likely to have small cell lung cancer than non-Māori patients.

**Competing interests:**

All authors report grants from Waikato Medical Research Foundation during the conduct of the study. Dr Lawrenson and Mrs Firth report grants from Health Research Council during the conduct of the study.

**Acknowledgements:**

We would like to acknowledge the financial support from the Health Research Council of New Zealand, the Waikato, Bay of Plenty Division of the Cancer Society and the Waikato Medical Research Foundation. We also thank Lakes, Waikato, Tairāwhiti and Bay of Plenty District Health Boards for their support in this study. We appreciate the help from Ms Suzanne Bull and Ms Jennifer Goodson in examining the clinical records.

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<http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2018/vol-131-no-147927-july-2018/7641>


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## CLINICAL CORRESPONDENCE

# Characteristics of lung cancer patients receiving psychosocial support in urban New Zealand

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## KEYWORDS

cancer research, lung cancer, psychological support, psychosocial, New Zealand

## 1 | INTRODUCTION

Lung cancer is a leading cause of cancer death in New Zealand (NZ), with approximately 2200 cases and around 1600 deaths per year.<sup>1</sup> Survival from lung cancer in NZ is poor, with 5-year survival rates (1994-2003) of 9.5% for men and 11% for women; rates that are lower than those reported in Australia, Canada, the United Kingdom, and Sweden during the same period.<sup>2</sup> Further, the incidence of lung cancer in Māori (the indigenous people of NZ) is 2 to 3 times higher than that of non-Māori,<sup>3</sup> which corresponds to worse health and reduced life expectancy in this population. Indeed, ethnic disparities for Māori cancer patients are well documented in NZ,<sup>3,4</sup> and are associated with both patient factors (such as later cancer stage at diagnosis and higher levels of comorbidity) and health system factors (eg, barriers/unequal access to cancer services and a lower quality of cancer care offered).<sup>3-5</sup> Cultural perception can also influence an individual's cancer experience and it has been suggested that an unmet need for psychosocial support for Māori may also exist.<sup>6</sup>

Because of high rates of morbidity and mortality and the fact that only 20% of lung cancer cases are eligible for curative surgery,<sup>7</sup> lung cancer patients have one of the highest risks for psychological distress among cancer patients.<sup>8</sup> The National Comprehensive Cancer Network (NCCN) defines distress as a range of emotions (behavioural, cognitive, emotional) relating to a cancer diagnosis and treatment,<sup>9</sup> and for lung cancer patients, this distress can be exacerbated by any history of smoking because of a persistent societal perception that lung cancer is a preventable and self-inflicted disease.<sup>10</sup>

In 2014, the NZ Ministry of Health committed to improving cancer psychosocial support services and in 2016, the Cancer Psychological and Social Support Service (CPSSS) initiative was established to better meet the supportive care needs of cancer patients, with a particular focus on improving access to health services and equity of outcomes for Māori.<sup>6</sup> However, little is currently known about the characteristics of lung cancer patients utilising this service nor their reasons for referral. The aim of this study was to compare the demographic and clinical characteristics of lung cancer patients from a mostly urban (Waikato) region of NZ who were and were not referred to CPSSS.

## 2 | METHODS

We retrospectively reviewed the clinical records of patients who were diagnosed with lung cancer and recorded in the Midland Lung Cancer Register (MLCR), a regional database containing data from Jan 1st 2016 to Nov 30th 2018. Psychosocial support information was obtained from the CPSSS and linked via National Health Number to the Waikato MLCR data. Referrals are made to CPSSS after completion of a "distress" and an "impact of distress" tool,<sup>11</sup> modified from the NCCN distress thermometer with the addition of an impact thermometer. The distress thermometer has good internal consistency ( $\alpha = .81$ )<sup>11</sup> and validity<sup>12</sup> and corresponds well with other measures, such as the Hospital Anxiety and Depression Scale (HADS).<sup>11,12</sup> To be accepted by CPSSS, patients are generally required to score greater than 5 out of 10 on both distress and impact, although those with

lower distress but higher impact scores are also accepted at the clinician's discretion.

Ethnicity was categorised as Māori or non-Māori based on hospital recorded ethnicity. Urban-rural profiling used the NZ Department of Statistics database. Patient domicile codes were obtained from clinical records and used to estimate socioeconomic deprivation by using the New Zealand deprivation (NZDep2013) score, with 1 representing the least socially deprived decile.<sup>13</sup> Student *t* tests were used to compare age at diagnosis and Pearson chi square tests were used to compare characteristics of those who did and did not receive psychosocial support. All data were analysed using SPSS version 25.

Reason(s) for referral to CPSSS were analysed using qualitative thematic analysis and categorised into five common themes: depressed/low mood, future concerns, lack of social support, financial concerns, and distress regarding diagnosis/treatment.

Ethical approval for the study was obtained from the New Zealand Health and Disability Ethics Committee (16/STH/167/AM02).

### 3 | RESULTS

A total of 602 patients were recorded in the Waikato MLCR, and 39 (6.5%) of these were referred to CPSSS (Table S1). The majority of referrals were made by a cancer nurse specialist (*n* = 14; 35.9%), and the majority of patients were referred during treatment (*n* = 17; 43.6%) or at the time of diagnosis (*n* = 14; 35.9%).

Overall, patients referred to CPSSS were significantly younger (62.7 vs 71.4 years; *P* < .01), more likely to be female (74.4% vs 47.6%;  $\chi^2 = 10.5$ ; *P* < .001), and had never smoked (20.5% vs 6.1%;  $\chi^2 = 11.7$ ; *P* < .001) compared with those not referred. Those referred were also more than three times as likely to have received curative surgery (20.5% vs 6.1%;  $\chi^2 = 11.6$ ; *P* < .001), and were less likely to have metastatic (stage 4) disease (42.9% vs 60.0%;  $\chi^2 = 4.4$ ; .04). The proportion of patients with early stage disease (stage 1 and 2) was not significantly different between those referred or not referred.

Fewer Māori were referred to CPSSS compared with those not referred (17.9% vs 25.3%) but this was not statistically significant (*P* = .3). Patients referred to CPSSS were less likely to live in social deprivation (SES 6.3 vs 5.2; *P* = .02). No differences were observed with regards to rurality.

Overall, 6.5% of lung cancer patients were referred to CPSSS because of distress regarding diagnosis and/or treatment. This included concerns about aggressive treatment, associated side effects, recovery from surgery, and minimal treatment options for those with advanced disease. In addition, 43.6% of referred patients reported feelings of depression and/or low mood. Other referral reasons included concerns about the future (23.1%), lack of support (20.5%), and financial worries (7.7%). Feelings of depression/low mood were more common in Māori than non-Māori (71.4% vs 43.8%—but this was not significant). Māori patients were also a third less likely to be

#### Key Points

- Lung cancer is a leading cause of cancer death in New Zealand, with approximately 1600 deaths per year.
- Approximately 6.5% of Waikato lung cancer patients were referred to the Cancer Psychological and Social Support Service during 2016 to 2018.
- Lung cancer patients receiving psychosocial support were more likely to be younger, female, never smokers, and requiring curative surgery.
- Ethnic disparity exists with respect to CPSSS referrals, with fewer Māori than non-Māori patients being referred
- The most common reason for psychosocial referral in lung cancer patients was because of distress regarding diagnosis and/or treatment (61.5%).

referred because of distress about diagnosis and treatment (42.9% vs 65.6%).

### 4 | DISCUSSION

There appears to be key differences in the characteristics of patients who are and are not referred for psychosocial support with CPSSS. Patients were more likely to be younger and more likely to be female, which is in accordance with other research.<sup>8</sup> Further, referred patients were significantly less likely to have previously smoked, supporting the relationship between patient distress and the perception—both at an individual and a societal level—that lung cancer is a self-inflicted disease associated with smoking behaviour.<sup>10</sup>

Despite the incidence of lung cancer in Māori being 2 to 3 times higher than that of non-Māori,<sup>3</sup> we showed that fewer Māori patients in the Waikato region were referred to CPSSS for lung cancer-related distress. Only 17.9% of referred patients were Māori, which is lower than the proportion of Māori patients on the cancer register for this region. In contrast, a NZ Ministry of Health commission interim report indicated higher proportions of Māori than were on the cancer register were referred to CPSSS in other regions of NZ (this report only evaluated the Auckland and Northland regions).<sup>6</sup> Whilst there is insufficient data to draw definitive conclusions about why fewer Māori with lung cancer received psychosocial support in the Waikato region, our data supports other research highlighting inequities between indigenous and non-indigenous cancer populations in NZ.<sup>14</sup> Indeed, the NZ Ministry of Health report indicated that both the clinical workforce and stakeholders have specifically indicated a desire to increase the number of Māori accessing the CPSSS programme.

Lastly, whilst this study has not quantified the efficacy of the CPSSS in alleviating patient psychological distress, the service is a positive addition, particularly given the highly distressing nature of lung cancer, the poor prognosis<sup>7</sup> and stigma<sup>10</sup> associated with the disease.

However, with only 6.5% of lung cancer patients in the Waikato region being referred during the study period, the number of patients being referred is lower than reported in other countries<sup>15,16</sup> and may represent an unmet need in NZ, particularly for Māori. Thus, it is imperative that psychosocial support services continue to be made accessible (and be appropriately delivered to) both Māori and non-Māori lung cancer patients within the Waikato region of NZ.

## ACKNOWLEDGEMENT

We would like to thank the University of Waikato for a summer student scholarship to allow B.R. to undertake this project.

## CONFLICT OF INTEREST

None.

## AUTHORSHIP

B.R. collected the data. L.C. analysed the data and drafted the initial manuscript. R.L. conceived the initial idea. All authors contributed to the writing and revision of the manuscript.

## DATA AVAILABILITY

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available because of privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.


**How to cite this article:** Chepulis L, Ryan B, Blackmore T, Burrett V, McCleery J, Lawrenson R. Characteristics of lung cancer patients receiving psychosocial support in urban New Zealand. *Psycho-Oncology*. 2019;1-3. <https://doi.org/10.1002/pon.5137>

RESEARCH ARTICLE

Open Access



# Patient and carer perceived barriers to early presentation and diagnosis of lung cancer: a systematic review

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## Abstract

**Background:** Lung cancer is typically diagnosed at a late stage. Early presentation and detection of lung cancer symptoms is critical to improving survival but can be clinically complicated and as yet a robust screening method for diagnosis is not available in routine practice. Accordingly, the barriers to help-seeking behaviour and diagnosis need to be considered. This review aimed to document the barriers to early presentation and diagnosis of lung cancer, based on patient and carer perspectives.

**Methods:** A systematic review of databases was performed for original, English language articles discussing qualitative research on patient perceived barriers to early presentation and diagnosis of lung cancer. Three major databases were searched: Scopus, PubMed and EBSCOhost. References cited in the selected studies were searched for further relevant articles.

**Results:** Fourteen studies met inclusion criteria for review. Barriers were grouped into three categories: healthcare provider and system factors, patient factors and disease factors.

**Conclusions:** Studies showed that the most frequently reported barriers to early presentation and diagnosis of lung cancer reported by patients and carers related to poor relationships between GPs and patients, a lack of access to services and care for patients, and a lack of awareness of lung cancer symptoms and treatment. Addressing these barriers offers opportunities by which rates of early diagnosis of lung cancer may be improved.

**Keywords:** Barrier to diagnosis, Early presentation, Lung cancer, Cancer care, Primary care, Delay to diagnosis

## Background

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) [8, 9]. Consequently, symptoms

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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 [10–14]. Cross-cultural variations across nine countries have shown differences in the delay in reporting symptoms, ranging from 7 days to 6 months [15]. Early recognition of lung cancer symptoms combined with early medical help-seeking behaviour can have the potential to increase survival and decrease mortality from lung cancer [11, 16–18]. However, the proportion of patients who are identified with early stage cancer and receive curative surgery is low, with studies showing a prevalence of between 15 and 20% [19–22].

In saying this, recent research also points out that, although shortening of diagnostic intervals can result in clinical benefits for some patient groups (e.g. in terms of diagnosis and post-diagnosis cancer management in primary care), for others, it may not necessarily translate to improved outcomes. This can be due to various broader reasons including the symptom signature of lung cancer [9] or the patients' perception of their experience within the healthcare system [23].

Overall, to maximise patient survival from lung cancer, early detection remains an imperative factor, alongside prompt referral. It is therefore necessary to increase the proportion of patients diagnosed with early stage disease. However, numerous studies indicate that there are significant barriers towards help-seeking behaviour and diagnosis. The objective of this systematic review was to explore and document the barriers to early presentation and diagnosis of lung cancer, identified by patients and carers (including those specific to indigenous and ethnic minority groups).

## Methods

### Search strategy and selection criteria

Three major databases, Scopus (1960–2017), PubMed (1945–2017) and EBSCOhost (1888–2017), were searched from 23rd November to 8th December 2017, for papers published in English prior to December, 2017. Text words or keywords used in the search were “lung cancer” and “barrier”, “obstacle”, “difficult\* (difficulty)”, “problem”, or “diagnos\* (diagnosis/diagnostic)” combined with (i.e., AND) “general practi\* (general practice/ practitioner)”, “primary care”, or “family practice”. Inclusion criteria for the extraction of articles from the databases were original, qualitative studies, published in peer reviewed journals, and a focus on patient and family or carer perceptions of barriers to early presentation and diagnosis of lung cancer. Accordingly, our exclusion criteria were literature reviews, quantitative analyses, studies focusing solely on prevention (e.g. screening) and a focus only on GP or health care provider perceptions of barriers to lung cancer diagnosis. It should be noted here, that our focus on only qualitative

analyses was to identify key themes relating to patient perceived barriers to lung cancer diagnosis. By including quantitative studies in our review, we would have risked being in danger of leaving out important themes voiced by patients themselves, as barriers identified based on quantitative surveys or questionnaires tend to be predetermined. Furthermore, our search did not extend to non-English language studies or grey literature. References cited in the selected studies and any literature reviews with broadly similar search criteria were searched for further relevant articles. Figure 1 shows a flow chart of the process of selecting and including relevant studies for this review according to the PRISMA guidelines [24].

The inclusion of articles published only in peer reviewed journals was our first method of assessing the quality each study reviewed. The quality of each study was also assessed using the CASP checklist for qualitative research [25]. All studies yielded generally strong scores in the domains of validity, results and local relevance or value.

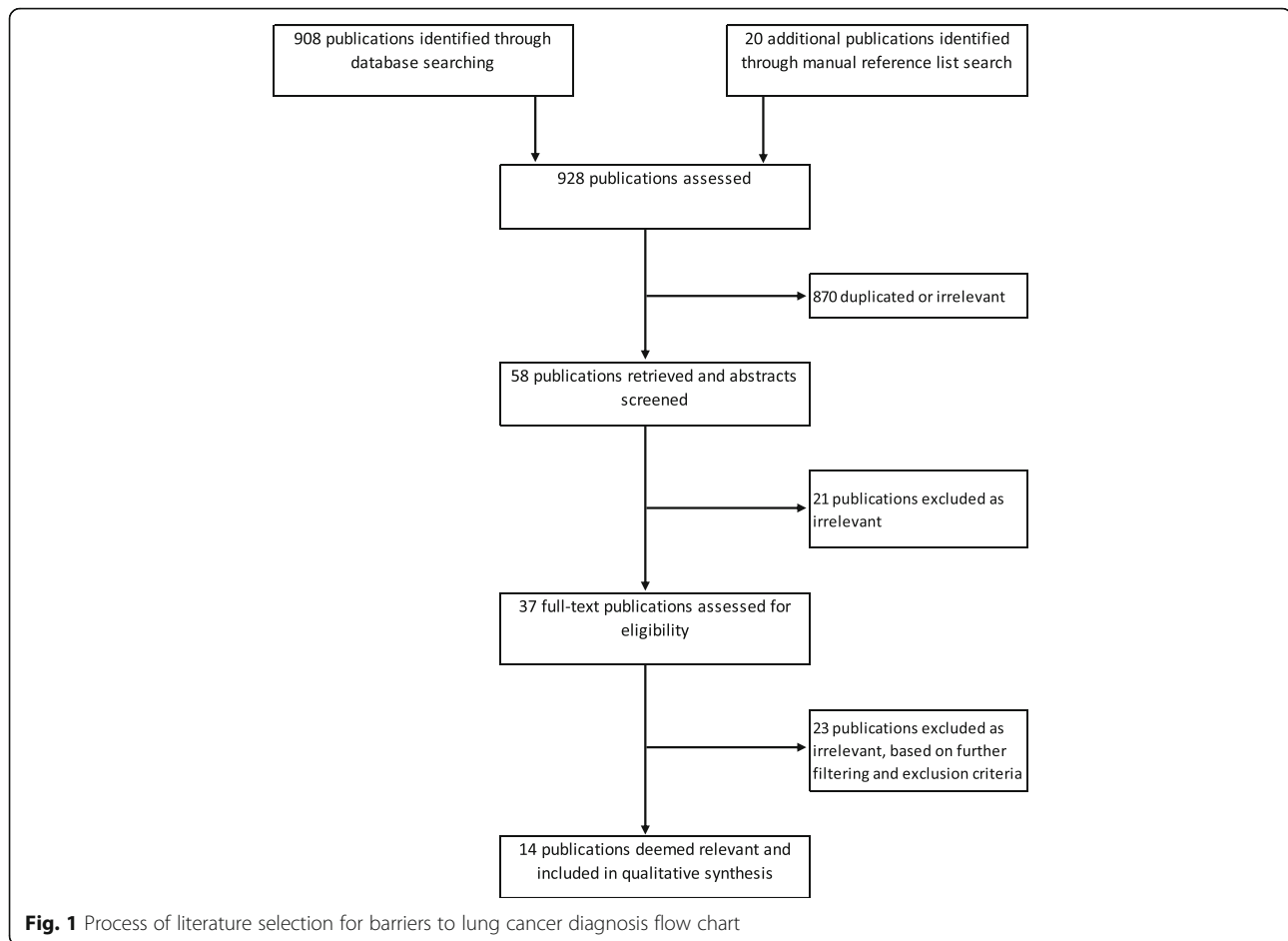
### Categorisation of perceived barriers

Walter et al's [7] model for examining pathways to cancer diagnosis was used as a guide for identifying and grouping barriers to diagnosis in the studies selected. We particularly focused on the “contributing factors” section of the model, which indicates that healthcare provider and system factors, patient factors and disease factors contribute to delays in cancer diagnosis and initiation of treatment. It should be noted, however, that while co-morbidities are listed under patient factors in Walter et al's [7] model, we included them as disease factors in our review due to the nature of symptom presentation particular to lung cancer, as discussed previously.

### Data extraction

The selected articles were reviewed and the following data were extracted and compiled into a table: general information about the article (authors' names, year of publication, and methodology); study location; participant information (participant group, ethnicity, and number of participants); and a brief description of the findings, specifically the barriers to early presentation and diagnosis of lung cancer relating to health care system, patient and disease factors. A number of studies that had multiple participant groups (i.e. patients, family members, GPs and other service providers), explored multiple types of cancer (i.e. lung, prostate, breast and colorectal), used mixed methods (both qualitative and quantitative), and had a primary focus that went beyond identifying barriers to early presentation and diagnosis (e.g. developing an intervention) were included, but noted accordingly.





## Results

We identified 908 publications through our database search, and an additional 20 from a manual reference list search. By screening article titles, 870 were deemed to be duplicates or irrelevant based on topic. The abstracts of the remaining 58 articles were screened, from which 21 were excluded as they examined other cancers, not including lung cancer. Full articles were assessed on the remaining 37 potential publications. Of these, 23 were excluded as they focused on lung cancer screening, they did not examine patient and carer perspectives of barriers to diagnosis and/or they were literature reviews or quantitative analyses. The remaining 14 articles were included in our review. The characteristics and results of the studies are summarised in Table 1.

Six studies were undertaken in the United Kingdom [10–12, 26–28], six in Australia [29–34], one in the United States [35], and one in New Zealand [36]. The ethnicities of the populations studied were European (New Zealand European, “White British”, “White”), Māori, Aboriginal and Torres Strait Island peoples, “Black/Black British”, “Asian/British Asian”, Chinese, “mixed” and other. Seven studies reported that they

recruited participants from hospitals, four from community or other support groups, three from General Practices and one from a cancer register.

Five studies included multiple participant groups including patients, family and/or community members, GPs and other service providers [26, 29, 31, 32, 34]. However, as the purpose of this review was to identify barriers to early presentation and diagnosis of lung cancer specifically by patients and families or carers, only the statements made by these participants were included in our analysis. Two studies focused on multiple types of cancer including lung cancer [27, 30] – only statements by participants with a lung cancer diagnosis were included in this analysis. One study had a primary focus on the development of an intervention to reduce time to presentation with symptoms of lung cancer alongside barriers to early presentation and diagnosis [26] - the present review considered only the barriers, rather than the intervention discussed in this article. One study included patients with symptoms suggestive of lung cancer, including patients who had not yet received a lung cancer diagnosis and patients post lung cancer diagnosis [10] – this review considered only the barriers specific

**Table 1** Characteristics and results of studies relating to barriers to lung cancer diagnosis

Study	Study design				Findings (Barriers)			
	Methodology & sampling	Country	Ethnicity	Participant group	Number of participants	Healthcare provider and system factors	Patient factors	Disease factors
Sharf, Stelijes & Gordon (2005) [35]	M: qualitative (interviews) S: Hospital - participants recruited through pulmonary conference for ongoing cohort study, and review of pathology reports	United States	Not reported	Patients	9	Inadequate information provided to patients; i.e. regarding what to expect in relation to the disease and treatment; Lack of established relationship between physician and patient; discontinuity of care; long waiting times.	Patients took action to improve their suspected lung problems or health in general on their own, as an alternative to physician's recommendations; Patients minimizing risk factors, possibility of a cancer diagnosis, or severity of illness. Patient relies on positive experiences with illness or treatment experienced by self or others; Fatalism and faith: patient's emphasis on the importance of powers that outweigh self-control, i.e. fate or God; Patient's distrust and suspicion of health information, medical procedures, motives of doctors or other health authorities. Patient focuses on negative experiences and expectations, past, present and future; Patient's capacity or desire to live without knowing their diagnosis; Patient's denial or questioning of the utility of treatment or procedure; Patient postponing treatment or delays seeking medical treatment after self-recognition of symptoms; Patient	

**Table 1** Characteristics and results of studies relating to barriers to lung cancer diagnosis (Continued)

Study	Study design				Findings (Barriers)			
	Methodology & sampling	Country	Ethnicity	Participant group	Number of participants	Healthcare provider and system factors	Patient factors	Disease factors
Tod et al. (2008) [11]	M: qualitative (interviews) S: community & hospital - respiratory physician and lung cancer nurse specialists	United Kingdom	Not reported	Patients and survivors	20 (18 patients, 2 survivors)	Media messages interacting with cultural tendencies to reinforce the belief that people should not use primary care services unless a problem was extreme.	wanting to avoid pain or discomfort caused by medical procedures; Patient prioritizing his/her remaining quality of life; patient not being able to afford private insurance, thus limiting options for seeing specialists and obtaining medications.  Tendency to attribute symptoms to other acute and chronic conditions; Patient's poor knowledge and awareness of lung cancer risks, symptoms and treatments; fatalistic beliefs and fear of death and cancer diagnosis (due to lack of awareness of lung cancer treatments); Patient's fear of a medical consultation and being seen as a timewaster further prompted delay; previous bad experiences; Non- or ex-smokers delayed in reporting symptoms because of an expectation, based on previous experience, that they would be stigmatized as a smoker and blamed for their illness; patient placing great value on stoicism, not complaining and "putting on a brave face"; Lifelong patterns of	Symptom experience: wide variation in symptoms and therefore lack of a clear symptom profile.

**Table 1** Characteristics and results of studies relating to barriers to lung cancer diagnosis (*Continued*)

Study	Study design				Findings (Barriers)			
	Methodology & sampling	Country	Ethnicity	Participant group	Number of participants	Healthcare provider and system factors	Patient factors	Disease factors
S. E. Hall et al. (2008) <sup>a</sup> [29]	M: qualitative (interviews) S: cancer notifications in Western Australia Cancer Registry	Australia	Not reported	Patients and GPs	41 (14 patients)	Quality of care: quality of communication from and between care providers and communication skills in general.	poor healthcare utilization resulted in patient's reluctance to see a GP unless symptoms were severe. Misinterpretation or minimization of symptoms; financial aspects of cancer care (rural patients); transport costs and time.	
Smith et al. (2012) <sup>a,b</sup> [26]	M: qualitative (focus groups) S: General Practice and 'Breathe Easy' group - specialist lung cancer nurses	Scotland	Not reported	Patients, families, GPs and other service providers (psychologists, sociologists, respiratory physician, health services researcher)	7 patients (plus spouses/partners)	Difficulty in making appointments due to lack of advice on making appointments and exactly what to ask when contacting GP; lack of involvement of the entire GP team in the process (eg. receptionist as first point of contact, triage by practice nurses, GPs)		
Emery et al. (2013) <sup>c</sup> [30]	M: mixed methods (medical records & interviews) S: rural cancer nurse coordinator, Cancer Registry and treating clinician	Australia	Not reported	Patients	66 (8 lung cancer patients)	Distance to health care	Misinterpretation or minimization of symptoms; low risk perception; stoicism (particularly of men)	Symptom experience
Walton et al. (2013) [36]	M: qualitative (interviews and focus groups) S: Hospital -primary physician and hospital physician	New Zealand	New Zealand European, Māori	Patients and family members	39	Access to services - patient getting delayed in the system (hospital booking systems, difficulties faced by GPs in obtaining referrals for specialists, schedule inflexibility, workforce issues etc. - as opposed to an expedited entry into secondary care via	Misinterpretation or minimization of symptoms; smoking beliefs and health expectancies (many felt respiratory symptoms and generalized ill-health were the norm for smokers, or others felt that protective behaviours e.g. exercise, diet could offset health risk); individual	Symptom experience: lack of symptom presentation

**Table 1** Characteristics and results of studies relating to barriers to lung cancer diagnosis (Continued)

Study	Study design			Findings (Barriers)				
	Methodology & sampling	Country	Ethnicity	Participant group	Number of participants	Healthcare provider and system factors	Patient factors	Disease factors
Birt et al. (2014) <sup>d</sup> [10]	M: qualitative (interviews) S: Hospital – email invitation sent to patients referred via urgent, routine and diagnostic routes	England	“white” and other	Patients (with lung cancer diagnosis and other respiratory conditions)	35 (17 lung cancer patients)	presentation of severe symptoms at ED); perceived time pressure in consultations and lack of GP continuity leading to ineffective communication; GPs lack of knowledge about interpreting symptoms and accessing the appropriate pathways; regional differences to access in services (specialist numbers, distance to medical centre); GPs’ nihilistic attitude towards lung cancer; lack of respect for and openness to other (indigenous/ethnic minority) worldviews; lack of cultural competence and interpersonal skills	beliefs about cancer (denial of risk, avoidance of unpleasant knowledge, shame about smoking, fears about treatment and fatalism that cancer treatment will have little benefit)	Symptom experience: co-morbidities masking respiratory changes, difficulty in recognising symptoms.
Scott, Crane, Lafontaine, Seale & Currow (2015) <sup>a</sup> [31]	M: qualitative (interviews) S: lung cancer support networks	Australia	Not reported	Patients and GPs	30 (20 patients)	Limited access to healthcare  Increased societal awareness of lung cancer as smoking related and being the ‘fault of the individual’ (increases stigma).	Views of lung cancer as a ‘death sentence’ and severe health consequence of smoking (as portrayed in some anti-smoking messaging) meant that patients were hesitant to seek medical advice for symptoms;	

**Table 1** Characteristics and results of studies relating to barriers to lung cancer diagnosis (Continued)

Study	Study design				Findings (Barriers)			
	Methodology & sampling	Country	Ethnicity	Participant group	Number of participants	Healthcare provider and system factors	Patient factors	Disease factors
Black et al. (2015) <sup>c</sup> [27]	M: qualitative (interviews) S: EDs – member of the clinical team	England	"White British"	Patients	27 (4 lung cancer patients)	Health care professional's appraisal leading to patients re-evaluating their symptoms inappropriately (e.g. lung cancer misdiagnosed as asthma)	anticipation of stigma and blame from health professionals and general community.	
Page, Bowman, Yang & Fong (2016) <sup>a</sup> [32]	M: qualitative (interviews) S: flyer, approaching people on the street, local meetings, places of employment, community centres, and snowballing	Australia	Aboriginal and Torres Strait Islander peoples	Patients, indigenous health workers and community members	67 (2 patients)		Lack of (public or private) transport to specialist health care; cost incurred in accessing care	
Wagland et al. (2016) [28]	M: mixed methods (questionnaire, clinical records review and interviews) S: GP practices – participants identified via questionnaire mailed to them	England	"White", mixed, "Black/Black British", "Asian/British Asian", Chinese, other	Patients	908 (38 patient interviews)	Difficulty accessing appointments and time wasted in waiting rooms	Participants' 'wait and see' attitudes towards most symptoms; guilt for symptoms perceived as self-inflicted; fear among patients for wasting GP's time; patients not fully reporting true smoking habits or symptoms	Symptom experience
Caswell et al. (2017) [12]	M: qualitative (interviews) S: Hospital – participants identified through previous phase of project (not reported in this paper)	England	Not reported	Patients and carers	23 (13 patients, 10 carers)	Lack of in-depth knowledge of lung cancer signs and symptoms - GP inability to recognise symptoms and thus attributing symptoms to other conditions	Patient's inability to recognise symptoms as pertaining to lung cancer	
Murray et al.	M: qualitative	Australia	Not reported	Patients	20	GP communication:	Patient's fear and	

**Table 1** Characteristics and results of studies relating to barriers to lung cancer diagnosis (Continued)

Study	Study design		Findings (Barriers)					
	Methodology & sampling	Country	Ethnicity	Participant group	Number of participants	Healthcare provider and system factors	Patient factors	Disease factors
(2017) [33]	(interviews) S: General Practice – computerized records					leading to a lack of established trust between GP and patient; GP not understanding or relating to addiction and thereby diagnosis; GP lecturing	fatalism; symptom normalisation; smoking-related guilt and stigma; past GP experiences (patients being put off by perceptions of lecturing or reprimanding to cease smoking); perception of miscommunication between patient and GP (not understanding diagnosis)	
Rankin et al. (2017) <sup>a</sup> [34]	M: qualitative (interviews and focus groups) S: Hospitals – treating clinicians including pulmonologist, medical oncologist, or nurse coordinator	Australia	Not reported	Patients and GPs	30 (19 patients)	Lengthy period of time before GPs took patient concerns seriously; lengthy time intervals between diagnosis and treatment commencement; geographical location (distance) of regional health care services/GPs; lack of psychosocial support for both patient and family member(s)	Patient's financial status	

<sup>a</sup>Study included multiple groups of participants including patients, barriers listed were identified by patients diagnosed with lung cancer (and family and/or carers)

<sup>b</sup>Study discusses intervention to reduce time to presentation with symptoms of lung cancer

<sup>c</sup>Study included multiple types of cancer including lung, prostate, breast and colorectal. For the purpose of this review only the barriers specific to patients diagnosed with lung cancer were included

<sup>d</sup>Study included patients with symptoms suggestive of lung cancer, including patients prior to a lung cancer diagnosis and patients post lung cancer diagnosis. For the purpose of this review only the barriers specific to patients post lung cancer diagnosis were included

to patients post lung cancer diagnosis. Two studies used mixed methods (both qualitative and quantitative) for data collection [28, 30] – only qualitative data from these studies were considered for the present review. Healthcare provider and system factors as barriers to early presentation and diagnosis were identified in 13 articles, patient factors in 12 and disease factors in five.

The age and gender of participants were reported by most articles. When reported, age was provided either as an age range or mean age. Accordingly, participant age ranged from 39 to 86 years, with mean age ranging from 60 to 79 years. A good gender mix was also included in the studies reviewed.

Our findings were grouped into three categories: healthcare provider and system factors, patient factors and disease factors that serve as barriers to early presentation and diagnosis of lung cancer. These categories were based on the “contributing factors” section of Walter et al’s [7] model, as discussed previously. The following sub-sections present our results for each category.

#### **Healthcare provider and system factors**

Healthcare provider and system factors included issues relating to delivery and healthcare policy, and barriers to access. Primarily, the quality of the relationship between GPs and patients was a recurring theme reported in many of the articles. For instance, a lack of an established relationship between patient and GP affected the quality of care provided to the patient. The quality of communication between the patient and GP resulted in a lack of established trust between patient and GP, a lengthy period of time before GPs took the patient’s concerns seriously and inadequate information provided to patients [29, 33–36]. Such barriers were also exacerbated by a lack of GP continuity [35, 36]. Specific barriers identified were, GPs’ ‘nihilism’ towards lung cancer [36], and inability to understand or relate to tobacco addiction [33]. A New Zealand study also reported that a lack of openness to other (indigenous/ ethnic minority) worldviews was a barrier to diagnosis of lung cancer [36].

Broader system factors were also identified as barriers (regardless of country level contexts), including difficulty making or accessing appointments, discontinuity of care (relating to GPs, specialists and/or other healthcare providers), long waiting times, patients getting delayed in the system or difficulty faced by GP to get referrals for specialists [26, 28, 34–36]. Patients additionally observed that limited access to health care (provider and services) was a barrier to diagnosis and care [10, 30, 34, 36].

Patients and carers also stated that GPs had inadequate knowledge of lung cancer symptoms and treatment options available. A number of studies indicated that GPs lacked knowledge about interpreting symptoms

and accessing appropriate treatment pathways [12, 36]. According to Black et al. [27], patients indicated that their health care professional’s appraisal led to an inaccurate re-evaluation of self-diagnosed symptoms (e.g. symptoms of lung cancer being diagnosed as asthma).

Finally, Scott et al. [31] observed that in Australia, an increased societal awareness of lung cancer as being smoking related and being the ‘fault of the individual’, increased stigma related to the condition and smoking, thus serving as a barrier to seeking help. Moreover, according to Tod et al. [11] in the United Kingdom, media messages reinforced the fact that people should not use primary care services unless a problem was extreme.

#### **Patient factors**

Patient factors included demographic, psychological, social and cultural factors and previous experience. A key patient related barrier recurrent in the literature was normalisation, misattribution, misinterpretation, minimization or low risk perception of symptoms relating to lung cancer [10–12, 29, 30, 33, 35, 36]. For instance, while many patients felt that respiratory symptoms and generalized ill-health were normal for smokers, others felt that protective behaviours such as exercise or diet could offset health risk. Consequently, patients engaged in self-management of symptoms rather than seeking medical advice [10, 35, 36].

Fatalistic beliefs and fear of death and/or cancer diagnosis were additionally reported as preventing patients from seeking help, often due to patients’ lack of awareness of lung cancer treatments [11, 31, 33, 35, 36]. Patients also indicated that perceived blame, stigma, guilt and shame related to smoking and diagnosis functioned as barriers [11, 28, 31, 33, 36]. Patients were put off visiting healthcare professionals by perceptions that they would be lectured or reprimanded to cease smoking [33]. ‘Stoicism’ was also reported as a barrier, particularly amongst men, where patients did not wish to complain, instead, putting on a ‘brave face’ [11, 30].

Finally, barriers related to the financial aspects of cancer care, and thus patients’ socioeconomic status, such as the high cost of health insurance or treatment and care (e.g. in the United States and Australia), lack of transport to healthcare centre (e.g. in rural Australia) and competing responsibilities (e.g. in the United Kingdom) were identified as barriers to symptom presentation and diagnosis [10, 29, 32, 34, 35].

#### **Disease factors**

Disease factors included site, size and tumour growth rate as well as symptom presentation. Five articles reported disease factors. All of these studies indicated that symptom presentation, specifically, the wide variation in lung cancer symptoms and therefore a lack of a clear symptom profile or a lack of symptom presentation



overall, made both GP diagnosis and patient awareness difficult [11, 12, 30, 36]. For example, Birth et al. (in 2014) [10] reported that the existence of co-morbidities masked many of the symptoms indicative of lung cancer (e.g. pain symptomatic of lung cancer was attributed to a kidney infection based on patient's history of gallstone related pain, cough attributed to patient's existing chronic respiratory symptoms or allergy).

## Discussion

This systematic literature review provided evidence that the reasons for delays in early presentation and diagnosis of lung cancer are complex and multifaceted. It is also clear that all these factors (i.e. healthcare provider and system, patient and disease) overlap. For instance, a key patient and carer perceived barrier relates to the relationship between patients and GPs. Such relationships are crucial to presentation and diagnosis of lung cancer, as they affect the level of trust between GPs and patients, patient attitudes towards their GP and vice versa, and patient perceived blame, stigma, lecturing and reprimanding by GPs [29, 33, 35, 36]. Thus, barriers relating to the relationship between patients and GPs span both healthcare provider and system factors as well as patient factors. Additionally, this review provided evidence that issues relating to access, spanning both healthcare provider and system factors and patient factors, was another key area that posed barriers to patients' help-seeking behaviour [10, 26, 28, 32, 34, 36]. A lack of awareness of lung cancer symptoms and treatment was also identified as a significant barrier. Issues relating to a lack of awareness spanned healthcare provider and system factors, patient factors as well as disease factors, and affected patients, GPs and the general public [11, 12, 27, 31, 32, 36].

There is a clear indication in the research of the pressing need to increase lung cancer awareness, and to provide resources and knowledge regarding symptoms and treatment to patients, healthcare providers and the general public. In particular, research by Tod et al. (2008) [11], included in this review, indicates that some information campaigns relating to lung cancer were seen to contribute to fatalistic views due to a focus on death rather than treatment and/or survival. Since then, however, various awareness campaigns about the early diagnosis and/or detection of lung cancer have been trialled in New Zealand, Australia [37], Scotland [26] and Doncaster, United Kingdom [38], some of which have resulted in an increase in at-risk patients' intentions to see a GP and request a chest X-ray (e.g. [38]). The programme implemented in Doncaster, additionally involved a brief GP education intervention for primary care practices in high lung cancer risk localities, resulting in an increase in chest X-rays and lung cancer diagnosis [38]. In many countries, clinical guidelines and

optimal care pathways specific to lung cancer exist, aimed at increasing GP awareness of the disease (e.g. according to the Ministry of Health, New Zealand [39]). While such initiatives are promising, there is a need for replication, rigorous outcome evaluation [40], and to create a multi-pronged approach to raise lung cancer awareness [36]. The findings of this review, as well as that of quantitative, population level studies identifying patient perceived barriers to lung cancer diagnosis, both indicate that an inability to recognize symptoms and the stigma associated with lung cancer posed significant barriers to early diagnosis [41–44]. Thus, there is also a need to provide education to patients about the risks and symptoms of lung cancer, to dispel negative (fatalistic and stigmatising) beliefs about the disease and outcomes, and to empower at-risk patients to get checked in primary care [36]. Such an approach needs to also involve a GP training or education element, as an increase in lung cancer awareness needs to occur in patients, the general public as well as GPs and other healthcare professionals.

Delays within the system were also identified as a major barrier to presentation and diagnosis of lung cancer. For instance, delays in getting appointments, in waiting times, in getting referrals, or getting a diagnosis, the distance and access to health care providers, as well as the financial aspects of cancer care (e.g. cost of treatment, patients' socioeconomic status) hindered access to services, and thus timely diagnosis and treatment [10, 28–30, 34–36]. Similar findings were reported by Sood et al's (2009) [45] review of patients' clinical records identifying barriers to diagnosis of lung cancer. Delay, irrespective of reason, can be frustrating for many patients, and when combined with difficulties accessing information and services, could increase distress [46]. It is clear that a more patient-centred and accessible approach to cancer diagnosis and care is needed.

Furthermore, many studies in our review did not report the ethnicity, or rather the ethnic variation, of their participants [10–12, 26, 29–31, 33–35]. In particular, Sharf et al. (in 2005) [35] and Tod et al. (in 2008) [11] indicated that the fact that their participant bases comprised primarily 'white' patients, rather than 'black' or minority groups, was a limitation of their research. Considering the poorer outcomes relating particularly to ethnic minority and indigenous populations diagnosed with lung cancer [47–52], the findings of this review imply that more qualitative research needs to be conducted and published with a specific focus on ethnic minority and indigenous groups. These findings also hold implications for broader arguments emphasizing the importance of culture, and of acknowledging and respecting diverse worldviews, particularly in cancer care. For example, research from Australia (not included in this review),

indicates that a lack of cultural competence by GPs was a significant barrier to early presentation and diagnosis of cancer [53–56]. Such conclusions are consistent with the statements of Māori participants in Walton et al's [36] New Zealand study, which indicated that a GP's lack of respect for, and openness to other (indigenous/ethnic minority) worldviews posed a significant barrier to help-seeking behaviour.

Accordingly, the New Zealand Medical Council has made cultural competency training a specific core expectancy in ongoing medical education for doctors and specialty training programmes, partly to address such issues with indigenous communities [57]. In saying this, it is important to recognise that a healthcare professional's cultural understanding of, and engagement with a patient should not be reduced to a simple set of technical skills acquired solely through cultural competency training [58]. Accordingly, the findings of this review reiterate the importance of the need for a focus on building relationships between patient and GP. As such, the Australian studies report that many Aboriginal Australians hold differing health beliefs of cancer causation [53–56]. For instance, this can include a belief that cancer is contagious, or simply the lack of a word for 'cancer', resulting in the diagnosis and its implications not being understood by many of these groups [55]. Accordingly, these researchers indicate that there needs to be an acknowledgement of such differing worldviews by the broader healthcare system, and that GPs need to also be aware of the significance of traditional healing methods germane to each of these communities [54, 56]. While we acknowledge that not all indigenous communities are the same, there is need for health professionals to have knowledge of, and/or experience in, not only medicine, but also the communities they serve, which goes beyond a simple set of skills acquired through cultural competency training. Overall, more attention needs to be paid to identifying and addressing barriers to early presentation and diagnosis of lung cancer among indigenous communities.

A number of studies in this review also indicated that patients, or potential participants of their research, died prior to the commencement of interviews as a result of lung cancer (e.g. [12, 29, 30]). This was listed as a limitation of such studies. The fact that lung cancer patients passed away within the short timeframe of a recruitment process reinforces the importance and urgency of identifying and addressing the barriers to early presentation and diagnosis of lung cancer.

The strengths of this review were that it assessed 14 high quality studies from respected journals, bringing together statements from a total of 240 patients from five countries and diverse populations. A limitation of this review was that it only examined studies published in

English. However, the consistency of results identified in these studies provides some reassurance as to their validity. Studies reviewed were also from a limited number of countries. Research from countries that are not considered First World nations may have contributed significantly to our findings. Moreover, we documented only the perceived barriers identified by patients and carers. Patients and carers are the most valid source for identifying barriers to early presentation and diagnosis of lung cancer. However, understanding GP views alongside population level data may be necessary in order to introduce effective interventions.

## Conclusion

Early presentation and detection of symptoms relating to lung cancer is critical to improving survival. Delays in early presentation and diagnosis of lung cancer might be avoided if various barriers relating to healthcare provider and system factors as well as patient and disease factors are addressed. This paper provides a complete, exhaustive summary of current patient-centred evidence identifying the existent barriers to early diagnosis of lung cancer, by bringing together and reviewing 14 qualitative studies from various countries. According to the findings of our review, a good starting point to addressing patient and carer perceived barriers, is to focus on the three key areas of relationship building between GP and patient, improving patient access to services and care, and increasing awareness of lung cancer symptoms and treatment, particularly among disadvantaged communities.

## Abbreviations

CASP checklist: Critical Appraisal Skills Programme checklist; GP: General Practitioner; LDCT: Low Dose Computerised Tomography; PRISMA guidelines: Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines

## Acknowledgements

Not applicable

## Funding

This work was supported by the Health Research Council of New Zealand [HRC grant number 17/438, entitled 'Improving early access to lung cancer diagnosis for Māori and Rural Communities']. The funding body did not play a role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

## Availability of data and materials

All data generated or analysed during this study are included in this published article.

## Authors' contributions

SC: Design of study, acquisition of data, interpretation of data, manuscript writing and revision; LC: Design of study, interpretation of data, manuscript writing; RK: Original conception of study, manuscript revision; JK: Original conception and design of study, manuscript revision; MF: Original conception of study, manuscript revision; RL: Original conception and design of study, interpretation of data, manuscript revision. All authors read and approved the final manuscript.

## Ethics approval and consent to participate

Not applicable.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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Received: 14 August 2018 Accepted: 2 December 2018

Published online: 08 January 2019

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**Volume 3, Issue 1, 2019**

**Co-opting or Valuing the Indigenous Voice Through Translation?  
A Decision for Research Teams**

Jacquie Kidd, Shemana Cassim, Anna Rolleston and Rawiri Keenan

**Editors: Robert E. Rinehart and Jacquie Kidd**

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**To cite this article:** Kidd, Jacquie, Shemana Cassim, Anna Rolleston and Rawiri Keenan. 2019. "Co-opting or Valuing the Indigenous Voice Through Translation? A Decision for Research Teams". *The Ethnographic Edge* 3, (1): 53-62. <https://doi.org/10.15663/tee.v3i1.52>

**To link to this volume** <https://doi.org/10.15663/tee.v3i1>

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## Co-opting or valuing the Indigenous voice through translation? A decision for research teams

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### Abstract

*Although te reo Māori is an official language of Aotearoa New Zealand, translation of research material such as information sheets, consent forms and questionnaires into te reo Māori remains highly variable. Translation tends to occur in research projects where Māori lead the work and that exclusively focus on Māori communities and topics. Translations are not offered or undertaken as a matter of course for all research. As a team of Māori and Indigenous researchers working within the health sector, we believe that there are important questions that need to be explored around the practice of using Indigenous languages, rich in similes and metaphors, to convey English/Western concepts/constructs/ideologies. In this paper, we draw on the story of one project to deconstruct and challenge the hegemonic terms through which translation of research material occurs. We explore the messages that translated material sends to potential research participants.*

*We contend that the choice about whether to translate research material into te reo Māori is one that should be undertaken within a robust decision-making framework that considers the reasons for a translation and its impact on the participants. Translation should not be undertaken primarily to attract Māori participants, but should reliably signal that the research is being undertaken in a way that honours a Māori worldview.*

### Keywords

Māori; Indigenous; translation; ethics

### Introduction

This paper is set within the context of a mixed-cultural research team who have minor or advisory-only roles on a project about colorectal cancer in Aotearoa New Zealand. The authors are all Indigenous, with three of Māori (the Indigenous peoples of Aotearoa New Zealand) descent (Jacquie, Anna, and Rawiri) and one (Shemana) from Sri Lanka.

The colorectal cancer research project took a mixed method approach, utilising a researcher-assisted validated survey and personal interviews to capture information from people from a range of ethnicities



from the Aotearoa New Zealand population. Ethical approval for the study was granted through the Southern Health and Disability Ethics Committee (reference: 16/STH/167). While this project was not grounded in te ao Māori (the Māori world), the inclusion of Māori data is an important component of investigating population-based health outcomes.

This paper draws on snippets of conversations to recreate discussions that took place as we tried to decide whether the research materials associated with our project should be translated from English into te reo Māori (the Māori language). After deliberating on the te ao Māori context, we consider whether our decisions align with Shemana's experiences in Sri Lanka and further afield in the international Indigenous space.

## Background

Aotearoa New Zealand came into contemporary existence with the signing of a treaty (Te Tiriti o Waitangi [Te Tiriti]) in 1840. Te Tiriti set the terms of engagement between the many tribes of the Indigenous Māori peoples and the Crown including colonial institutions, businesses and settlers. However, the first systemic problem with translations between te reo Māori and English is found within Te Tiriti because there are signed versions in both languages and the two versions differ significantly in key areas when interpreting the document (Waitangi Tribunal 2016). Importantly, the concepts of sovereignty and governance are confused between the versions and what constitutes a valued or treasured possession is meaningfully different in the Māori compared to the English version. These language-based differences in the understanding of concepts within Te Tiriti has been compounded by the many deliberate breaches of Te Tiriti by the Crown and persistent processes of colonisation that have been the cause of a great deal of pain and anger for Māori over the last 180 years (Berghan et al. 2017, Tawhai and Gray-Sharp 2011). Research in Aotearoa New Zealand operates in an environment where the motivation of Crown-based institutions (universities and health care services) is therefore often viewed with mistrust by Māori.

The Aotearoa New Zealand health system is inequitable for Māori, with significant disparities in access, diagnosis, treatment and outcomes (Robson and Harris 2007). From a research perspective, projects relating to improving Māori health are important to impact equity and therefore Māori participation and the inclusion of Māori researchers and advisors in university and government funder-based requirements for projects has increased in recent years.

However, in our experience the desire of Māori to participate in non-Māori led research can be limited, which can result in researchers being unable to attract the required number of participants for a western-centric sample size. Researchers sometimes use strategies to make their projects seem more meaningful to Māori, including the use of Māori imagery and language. The Māori language, however, is diverse, with different dialects arising from different tribal areas and this makes using the language and in particular translating documents not as straightforward as it may seem.

Jacque speaks:

In many conversations over the last decade, I have spoken to fluent te reo Māori speakers about how they learned the language. During those times I frequently heard variations of this: "I learned te reo Māori from when I was a baby, listening to the old people talking. I grew up speaking it. My cousin learned at uni after she left school. Sometimes she talks and I have no idea what she's saying." Alternatively, people would say, "I wouldn't say I was fluent. When the *kaumātua* (elders) speak I can't understand some of the words." My own experience of te reo Māori involves attending classes that were taught using the local tribal dialect. I not only found it difficult to understand the variations in words and sentences, I also resisted learning my own language in the dialect of an iwi (tribe) that is not my own. As an adult learner who has lived in their lands for almost two decades, I was surprised at my need to struggle against the teacher.

These interactions highlight the diversity within te reo Māori and therefore some of the challenges faced with providing an effective translation of complex English documents such as participant information sheets, consent forms and surveys.

*Te Ara Tika* (Hudson et al. 2010) provides a framework for health researchers working with Māori participants and communities. It sits alongside other guidelines for conducting ethical research, such as those published by the Centre for Social Research and Evaluation: Te Pokapū Rangahau Arotake Hapori (2004) and Health Research Council of New Zealand (2010). These documents all highlight the importance of research teams that are recruiting Māori including investigators and advisors who have a good understanding of te reo Māori. They also assert that participants should have the opportunity to express themselves in te reo Māori if they wish. However, it is important to note that these documents do not suggest that research materials are translated into te reo Māori, but instead focus on the relationship between the research team and Māori participants. We suggest that there is a gap when it comes to guidelines for research teams about what is required at the interface between themselves as researchers and Māori as participants in relation to how te reo Māori is acknowledged and imbedded. Consideration of how diverse Māori participants perceive and understand research information in te reo Māori is also needed.

### Defining translation: Lessons from te ao Māori

Writing this paper has involved taking a somewhat shallow dive into areas that we are not expert in, such as the nature of translation itself and the best-practice process of translating a validated survey.

Firstly, we had to consider what constitutes te reo (language) for Māori. A generic definition of language proposes that it is a culturally bound system of ‘verbal habits’ which are interconnected, symbolic, highly specialised and constantly changing (Nida 1991, 11). This fits with our collective understanding of te reo Māori; it is rich in symbolism and metaphor, has dialects and jargon, and is dynamic. New words are created and old ones repurposed to meet the demands of our contemporary lives. Native and fluent speakers of te reo Māori invoke whakataukī (proverbs) and *kīwaha* (idioms), they use pūrākau (stories) and whakapapa (genealogy), and they speak directly about an issue only after these practices have been used to gather their audience together in shared anticipation. Our understanding of te reo is far more complex than the words and phrases that make up the Māori language. Nida’s definition includes the term ‘culturally bound’, meaning that terms are so tied to their own time and place they have to be placed into a greater context before they can be translated into another language (Dictionary.com). One example is a t-shirt that Jacquie wears sometimes; it has the combination of English and Māori words ‘be autaiā’ on the front. The most likely translation the maker of the shirt intended is ‘be extraordinary’. However, it can also mean to be ‘pretty good’, or ‘a problem’. All these translations are technically correct, but it takes the wider context of knowing that the shirt is a part of a university campaign to empower Māori academics before the first definition can be accepted.

We would take Nida’s (1991) definition a little further by adding that some terms are so embedded and embodied by a culture that no amount of a wider context would be sufficient for an effective translation. One of those terms, *taonga*, appears in te Tiriti and has been the focus of generations of cross-cultural misunderstandings. The English version of te Tiriti lists “Lands and Estates Forests Fisheries and other properties” in Article Two in a clear indication that tangible belongings are under discussion when the term *taonga* is used. However, the Māori version lists “*o ratou wenua o ratou kainga me o ratou taonga katoa*”, meaning their land (wenua/whenua), their homes (kainga), and all their treasures (taonga katoa) (Kawharu 1989). *Taonga* is therefore defined as property and goods, but also “anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques” (Māori Dictionary). *Taonga* is a frequently used word in te reo, referring to a person, an ornament, an idea, health, a gathering, the environment and even the air. There is a world of difference between a tangible object, such as land, and the intangible nature of anything that is *considered to be* of value. Of course, there are further issues about whose opinion about value should be paramount and what value means as a concept. This illustrates one of the difficulties encountered when a translation is under consideration.



We turn now to the act of translating a text. The definition of translation differs according to the purpose by the original author, the type of text and the intentions held for the translated version. We have already indicated that the pain and anger associated with colonisation is still being played out in Māori communities, and that when considering translation researchers must be mindful of the historical context of the interactions between government organisations and Māori. Translation scholar Anthony Pym (2014) recognises the long history and dynamic nature of translation, contending that translation is culturally and historically bound, and that the translator must also be located as a part of the translation of text. For Indigenous populations worldwide, the colonising people created written language and performed translations which in effect allowed them to progress colonisation (Jackson 1992). Here we add the notions of history, dynamism, and the translator as a person to our discussion of language as culturally bound.

The notion that the translator is integral to the translation is an interesting one to reflect on. Our project team already had a relationship with a Māori colleague who was fluent in te reo and would be a part of the interview team. However, he had no formal training as a translator and was not a native speaker having learned te reo Māori at university. We did not take those factors into consideration during our discussions about translating the research documents, but with hindsight they were important. He had other contributions to make:

Jacque: What do you think about the idea of translating the research materials?

Translator: I could do it, yes. But do you think we need to have them in te reo? I mean, most of the participants will speak English.

Jacque: True. But maybe we should do it anyway because some people might be more comfortable talking about cancer in te reo? It would act as a signal that it's OK.

Translator: Well, I usually translate the bits they don't understand anyway. I just do it as we go.

Wait, what? Now we start to have a discussion about 'code switching', which is when a bilingual speaker uses elements (not only words) from both languages in a single interaction (Nilep 2006). Our colleague was describing code switching as a standard part of his interview repertoire, and the rest of the team had been unaware. After a brief flurry of exclamations, the conversation continued.

Shemana: If we translate the documents, will that change how you interview?

Translator: It will. I don't know if it's a good idea because a lot of the medical jargon we use just won't translate, you know? I actually tried to take part in an online survey that was offered in te reo Māori and I couldn't follow half of it. They used words that I hadn't come across before. It was an awful experience, to be honest. I think that as long as the interviewer is able to offer translations of the bits the participant doesn't understand, we shouldn't do a full translation. I like being able to use the real-world situation of people being able to choose which language suits their kōrero.

Jacque: I'm hearing that your relationship with the person you're interviewing actually guides your translation?

Translator: Exactly. I wouldn't be effective without forming the relationship through whakawhanaungatanga (a process building relationships). I guess that's one reason I found the online survey so frustrating—it was impersonal.

This exchange highlighted the notion that the translator *as a person* was a vital part of the translation process, with his ability to understand and respond to the participants' language needs as they emerged. Our colleague's relationship with the participants enhanced his ability to respond to their need for code-switching, and his ability to code-switch in turn enhanced his relationship with the participants.

## A political decision

The project under discussion here was conceived and largely carried out by non-Māori researchers. Most of the Māori involvement in the project was in the form of advice and guidance. As mentioned, te Tiriti is the document that establishes the terms of engagement between Māori and the Crown. It follows, therefore, that the Māori researchers advising the research team would view decisions regarding the use of te reo and strategies for inviting Māori to participate in the research as inherently political. Ensuring the honouring of te Tiriti obligations was a priority. This was highlighted through a series of conversations with members of the wider Māori advisory group who pointed out that any Māori who were considering taking part in the research “have the right to have the choice to have the research explained in their own reo”. This related not only to the Tiriti-based right to self-determination, but also to the understanding that te reo and health are viewed by Māori as taonga: treasures that are protected by te Tiriti. From some points of view, even if most of the Māori participants did not speak te reo fluently it was their right to have access to it within the research. Including te reo Māori was seen as a gesture of respect as well as meeting the team’s obligations under te Tiriti.

However, the long standing impacts of colonisation means that many Māori are not confident speakers of te reo Māori, and in fact feel significant shame about their lack of knowledge (Ka’ai-Mahuta 2011). One of the key components of colonisation is to deny and erase the Indigenous language (Jackson 1992). For Māori, that erasure of te reo Māori started in 1867 with the imposition of English as the sole language used in state schools (Ka’ai-Mahuta 2011). The policy was rigorously enforced, including beating children for using te reo Māori at school, well into the mid-1900s. Consequently, te reo Māori became a language that was only used extensively in small Māori communities, with the attendant loss of fluent speakers who moved away from their homes of origin to seek work in the cities. Living with the shame and grief of the systematic removal of their Indigenous language has had a devastating impact on Māori identity, including removing access to traditional wisdom and the inability to feel in control of one’s destiny (Jackson 1992). Making the choice to translate the research materials into te reo Māori could act as a deterrent or even be perceived as intimidating or shaming for some potential participants (see Kidman 2018). The over-arching purpose of considering a translation within this project was to uphold the values within te Tiriti, to pay respect to te reo Māori and to provide an avenue for self-determination for Māori participants. Regardless of these intentions, colonisation means that some of our Māori participants may be made to feel shame and grief if they are spoken to in te reo Māori and provided with a Māori translation when they are not competent users of the language.

## Voice and representation

The project needed to recruit a certain number of Māori participants in order to meet the criteria for successful data analysis, as well as wanting to make a difference to Māori health outcomes. However, we had to consider the implications of both not translating, because it would seemingly be a breach of our te Tiriti obligations, and also the implications of actually performing the translation as a somewhat mercenary means to entice reluctant participants to engage. A further issue we considered was whether providing a translation implied for Māori participants that the project itself was grounded in te ao Māori. The use of a European-based medical survey as the main data collection tool with subsequent semi-structured interviews located this project’s western bio-medical underpinnings. The researchers doing the everyday work of managing and analysing the data were non-Māori. As advisors we were able to add a relatively strong Māori view to the process, although this stopped short of ensuring that the ‘story’ of Māori, their strengths, risks, needs and preferred ways of being, were fully and fairly represented (Reid et al. 2017). Our concern was two-fold; for Māori participants to be able to feel that the research process would be respectful of them as Māori, and for the early research documents to accurately reflect what would happen to the data throughout the analysis and dissemination aspects of the project. Through our roles as advisors or minor players in this project, and our trust in our non-Indigenous colleagues, we were assured that the data and dissemination activities would be respectful. However, we needed to ensure that by translating we were not giving the impression that the analysis would be performed and interpreted in a way that reflected te ao Māori.

Our discussions about translation were consistently recognising that there were both benefits and potential harms to our participants no matter which language we chose, although it seemed that having a code-switching interviewer could mitigate the harmful effects that might arise from either translating or not translating. Looking further afield, such issues were not unique to Māori. Rather, issues relating to translation have also been expressed by a number of researchers internationally.

## Internationally

One of our Indigenous researchers, Shemana, took our discussions further by contributing her experiences. She conducted her research in Sri Lanka and considered that the issues we were working through around translation were also relevant to other cultures.

### Shemana's story

A few years ago, I embarked on my first research project to explore the ways in which people from Sri Lanka worked to address the disruption to their life narratives caused by the loss of loved ones as a result of the 2004 Indian Ocean Tsunami. My project involved interviewing five key informants in the rural fishing town of Hikkaduwa, who were affected by the tsunami. Given that my academic base was Aotearoa New Zealand, I had obtained ethical approval for the project from a human research ethics committee at the academic institution with which I was affiliated.

In particular, the ethics application recommended that I translate all my research material (aka participant information sheets and consent forms) into Sinhala—the 'native' language spoken by my participants, and also my first language. Despite Sinhala being my first language, however, direct translation of these documents was difficult. Writing them up in English was easier as there were pre-designed templates that I could follow and add to. I was not able to say the same when composing the Sinhala translation, as I had no template to aid my efforts. Therefore, I had to engage the help of my mother's work colleague (who lived in Sri Lanka). This individual had completed his tertiary education in Sinhala as well, whereas I had only considered Sinhala my first language up to the end of high school, and upon embarking on university education, I had switched to English. Nonetheless, we constructed Sinhala translations of my research material, and thus ticked the box on the ethics application.

On my first interaction with a participant, despite handing him my carefully constructed PIS, and offering to go through it page by page (as ethical research conventions dictated), he did not spare the document more than a passing glance and politely kept it aside. He also politely indicated that he did not want me to read the document out to him, but that he would prefer if I simply verbally told him what was in it, and what he should know. While I was confused and slightly unnerved about breaching ethical guidelines, I did as he requested. The other participants reacted in a similar manner to these conventions pertaining to the initial, introductory part of an interview.

Upon later reflection and further reading, I realised that first, when I verbally explained the purpose of the project and its aims to the participants, the verbal Sinhala that I used was quite different to the language in the actual documents. Something that I did not consciously realise until later, was the complexity around the Sinhala language. The verbal language is very informal and varies in dialect based on where the speaker is from. Whereas the written language is very formal and conveys a level of power, status and hierarchy, as only people of higher status (based on social standing and/or educational achievement) tend to use this version of the language. This is further complicated by the fact that many people from rural communities (like the one I worked in) do not often know how to read or write. The problem I faced was that many of the English words that I had used to appease the ethics committee could not be translated

directly into verbal Sinhalese (e.g. words like psychology, or monument). Thus, for the purpose of translation, they had to be translated into the formal, written Sinhalese. And so, it was not surprising that many of my participants did not even attempt to read those documents, or the ones who did attempt to read it often looked up at me with blank faces as they did not understand what the documents said exactly. Verbally explaining the research by using informal, verbal Sinhala, and even Singlish (a combination of English and Sinhala, or by pointing out/extensively explaining ideas, things or objects that I could not directly translate) was much more conducive.

Through her story, Shemana is alluding to three key messages: the intricate distinctions between written (formal) and spoken (informal) language and dialects, the occasionally problematic nature of often prescriptive mainstream research conventions, and a need to consider the complexities relating to translation and analysis of research material (Li 2011, Maclean 2007). It is important to note that the decision she came about how to manage the translations was consistent with the practice of verbal explanation in the language chosen by the participants that our Māori colleague employed.

Although we have not focused particularly on ethics committee approval in this discussion, the impact of the largely Western paradigm on Indigenous consent is undeniable (Tomaselli 2017). In addition to imposing the templates and ‘standardisation’ Shemana describes, the very act of signing a paper to indicate consent is problematic for peoples who have experienced the full force of colonialism. It is an issue of trust, and as researchers from institutions we are the colonial ‘other’, regardless of our own cultures of origin.

Returning then, to our discussion on translation, Spivak’s words resonate for us, when she talks about the “forced simplicity of plain English” that has imposed itself as the “norm” (Spivak 2012, 313). She also notes, as we did above, that direct translation loses the cultural embeddedness and the transmission of meaning that is afforded through Indigenous languages. In our framing of this issue for our project we discussed ‘te wairua o te reo Māori’ (the spiritual connectedness of our language), which manifests itself in the use of culturally specific metaphor to portray complex and culturally embedded information. We see considerable similarities between Spivak’s academic language as she reflects on translating Sanskrit and ours as we consider the use of te reo Māori in this English academic paper. Similarly, these arguments about the loss of meaning are being made by academics from other indigenous nations such as Africa (Tomaselli 2017), China (Li 2011) and Bolivia (Maclean 2007). As Shemana found, when Sinhalese is translated it loses a whole wealth of meaning in the process. As our translator found, when Māori is translated it can become such a different language that all meaning itself is lost. Clearly there is an international awareness of the complexities of the process of translation, the damage that can be done through the imposition of a colonisers’ language, and the ethical imperative that translation be considered through an Indigenous lens.

## Discussion and conclusion: Making the decision

According to *Te Ara Tika* (Hudson et al. 2010), the research project we are discussing in this paper is characterised as “research involving Māori” (23) because the project was conceived and carried out according to Western perspectives but included Māori participants. This positioning of the research embodied te Tiriti o Waitangi as the underpinning framework for defining and operationalising the relationship between the Western researchers and research, and any potential Māori participants (Health Research Council of New Zealand 2010). This relationship became the field of interest for us as we considered the use of te reo Māori in the research documents. The key points in our discussion were about the absolute right of tino rangatiratanga (self-determination) Māori hold under te Tiriti, the embeddedness of te reo as the Indigenous language of Aotearoa and a protected *taonga*, and the ongoing negative impact of colonisation on Māori. This latter included the systematic removal of te reo Māori from public life, and the subsequent grief and shame of Māori who are still unable to speak their own language (Ka’ai-Mahuta 2011). We conceptualised the enforced addition of translated materials as potentially retraumatising some participants as they would represent the losses associated with colonisation. This would almost certainly not be the case for all participants, but we considered it to be too risky since we did not know who the participants would be.

The Māori authors of this paper are all in varying stages of our own journey relating to te reo Māori, which includes our own experiences of the current effects of colonisation on us and our whānau (family). It is important to acknowledge that none of us felt able to step into the role of bilingual researcher for this project, whether because we literally cannot speak te reo Māori to the level our potential participants would need, or because we do not trust in our ability to make ourselves understood. The different ways of understanding fluency within the context of colonisation is a topic for another paper but is one that needs further exploration.

As a group of Indigenous researchers, we support the normalisation of te reo in academic spaces. However, this paper has presented an important opportunity to more fully understand the complexities around code-switching and the use of technical or academic language in translations (Nilep 2006, Pym 2014). Furthermore, there are important nuances relating to translating te reo involving how metaphor, kīwaha (idiomatic phrases) and culturally bound information is shared with another language with its own cultural embeddedness (Spivak 2012). We have a new appreciation of the theoretical and technical expertise of translators.

The research materials in our study were not translated into te reo Māori. Ultimately, we had three reasons for this. 1) The project itself was not based on te ao Māori, and we believed that translations would inaccurately represent the western process that was embedded in the research; 2) the process of verbal translations that were based on the needs of the participants at the time of the data collection had worked previously for our translator in the field; and 3) the research materials contained medical and institutional based language (such as symptom tracking and clinic appointments) that would not readily translate into te reo Māori. Ultimately, we wanted to avoid using translated documents as a means to make Māori participants feel comfortable in a non-Māori space. In this decision we were cognisant that “kaupapa Māori knowledge is not to be confused with Pākehā knowledge ... that has been translated into Māori” (Tuakana Nepe, cited in Smith and Reid 2000, 3). Despite wanting to see te reo used in research settings, we believed that in this situation it was important to preserve the integrity of te reo Māori as a portal into the unique space of te ao Māori.

The process of decision-making and writing this paper to explain our process has resulted in learnings that could be applied in other research settings, particularly where non-Indigenous researchers are working with Indigenous populations and participants. Most importantly, it is uncomfortably necessary to understand what the desired outcome of translation is. This involves a candid examination of the role Indigenous participants have in the research. Are they required in order to meet external requirements of, for example, ethics committees or government funders? Is their data important to add credibility and relevance to the findings? Is the translation simply a means of attracting participants who would otherwise not engage? If this is the case, how can the researchers adapt the project so they are respectful of the data, its analysis and the need for culturally acceptable dissemination activities? We propose that the involvement of an oral translator who is culturally aligned with the Indigenous population and proficient at code-switching is likely to mitigate these issues.

Understanding the context of the Indigenous participants is the precursor to being able to treat their data with respect and integrity. What are the processes the team will use to ensure that such data is understood from within its own context? What is the ongoing impact of colonisation on the Indigenous participants and how can the researchers avoid traumatising them further? This may mean involving and resourcing Indigenous researchers or advisory groups.

Finally, we would urge any research team who conclude that translating their materials is a necessity to engage a qualified and experienced translator to undertake the task.

## Glossary

Iwi: tribe

Kaumātua: elders

Kaupapa Māori: Māori ideology

Kīwaha: idioms

Kōrero: speak, talk

Pūrākau: stories

Taonga: treasured item, concept or action

Te ao Māori: the Māori world

Te reo Māori: Māori language

Te Tiriti o Waitangi: founding treaty between Māori and the English Crown

Tino rangatiratanga: self-determination, sovereignty, right to exercise authority

Wairua: spirit, soul, spirit of a person

Whakapapa: genealogy

Whakataukī: proverbs

Whakawhanaungatanga: a process of introduction where family, area or experience-based connections are sought

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RESEARCH ARTICLE

Open Access



# Management of patients with early stage lung cancer – why do some patients not receive treatment with curative intent?

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## Abstract

**Backgrounds:** This study aims to understand the factors that influence whether patients receive potentially curative treatment for early stage lung cancer. A key question was whether indigenous Māori patients were less likely to receive treatment.

**Methods:** Patients included those diagnosed with early stage lung cancer in 2011–2018 and resident in the New Zealand Midland Cancer Network region. Logistic regression model was used to estimate the odds ratios of having curative surgery/ treatment. The Kaplan Meier method was used to examine the all-cause survival and Cox proportional hazard model was used to estimate the hazard ratio of death.

**Results:** In total 419/583 (71.9%) of patients with Stage I and II disease were treated with curative intent - 272 (46.7%) patients had curative surgery. Patients not receiving potentially curative treatment were older, were less likely to have non-small cell lung cancer (NSCLC), had poorer lung function and were more likely to have an ECOG performance status of 2+. Current smokers were less likely to be treated with surgery and more likely to receive treatment with radiotherapy and chemotherapy. Those who were treated with surgery had a 2-year survival of 87.8% (95% CI: 83.8–91.8%) and 5-year survival of 69.6% (95% CI: 63.2–76.0%). Stereotactic ablative body radiotherapy (SABR) has equivalent effect on survival compared to curative surgery (hazard ratio: 0.77, 95% CI: 0.37–1.61). After adjustment we could find no difference in treatment and survival between Māori and non-Māori.

**Conclusions:** The majority of patients with stage I and II lung cancer are managed with potentially curative treatment – mainly surgery and increasingly with SABR. The outcomes of those being diagnosed with stage I and II disease and receiving treatment is positive with 70% surviving 5 years.

**Keywords:** Lung cancer, Non-small cell lung cancer, Thoracic surgery, Stereotactic ablative body radiotherapy, Smoking

## Background

Lung cancer is the leading cause of cancer death in New Zealand [1]. Mortality in Māori, the indigenous people in New Zealand, is 2.6 times greater than in New Zealand Europeans [1]. Overall, outcomes from lung cancer in New Zealand are poor with a 5-year survival of only 11% [2]. This is mainly because the majority of lung cancer patients are diagnosed at late stage. In a recent study of lung

cancer patients in our New Zealand region, only 16.5% were diagnosed with early stage (stage I and II) lung cancer [3].

Patients with early stage disease can be considered curable with successful surgery, or stereotactic ablative body radiotherapy (SABR) [4]. Some stage II and III patients also have successful outcomes with radical radiotherapy and chemo radiotherapy. Surgical resection rates for lung cancer vary between countries and even between centres in a particular country [5]. Overall, 14.7% of non-small cell lung cancer (NSCLC) patients receive surgery in New Zealand compared to 19.1% in Victoria, Australia [6, 7]. Previous studies in New Zealand have reported lower

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surgical rates in Māori [8]. New Zealand is looking to improve the proportion of lung cancer patients diagnosed with early stage through the use of an educational campaign. However, we have limited data on how early stage lung cancer is currently managed? There are also limited data on the outcomes of treatment of early stage disease.

The Midland Lung Cancer Register collects data from four District Health Boards (DHB) with a combined population of 800,000 residents. Tertiary lung cancer management is principally based at Waikato Hospital [3]. Waikato Hospital provides both surgical services and radiotherapy services for cancer patients for the region; with radiotherapy services also available in the Bay of Plenty DHB. This study aims to understand the factors that influence whether patients receive potentially curative treatment for their lung cancer, to understand which patients receive surgical management, and to examine the outcomes in those receiving surgery, other forms of treatment compared to those patients who receive palliative care.

## Methods

We analysed lung cancer data from the Midland Lung Cancer Register between January 2011 and December 2018 [3]. The Midland Lung Cancer Register is derived from data collected at multidisciplinary meetings (MDMs) within the region and complemented by data sourced from the New Zealand Cancer Registry (NZCR). Patients diagnosed with stage I and II lung cancer (ICD code: C33, C34) and resident in the Midland Cancer Network region (including Waikato, Lakes, Bay of Plenty and Tairāwhiti District Health Board) in 2011–2018 were included. Patients that were not discussed at an MDM were identified by the NZCR, and missing data was included from examination of their clinical records. For those who did not have a record of treatment, patient notes were searched to ascertain the reasons for no treatment. These were categorised into: comorbidities, poor lung function, poor Eastern Cooperative Oncology Group (ECOG) performance status (2+) [9], high risk of surgical complications, patient refusal or unknown reasons.

Data collected on individual patients included age, sex, ethnicity, DHB of domicile, type of lung cancer (NSCLC, small cell, others and unknown), stage of cancer, lung function (FEV1 measurement), ECOG status, and presence of known co-morbidities as measured by Charlson Index [10]. We then identified the treatment received by patients, including curative surgery (lobectomy, partial resection of lung and pneumonectomy), curative radiotherapy (radical radiotherapy), SABR, curative chemo radiation or palliative treatment which could include palliative chemo radiation, palliative chemotherapy, or symptomatic palliative care only. Mortality data were derived from the Midland Lung Cancer Register, New Zealand Cancer Registry and hospital system (iPM) with a

cursor date of 25 June 2019. Statistical analyses were then performed on this Combined Lung Cancer Register.

In order to determine if there is an ethnic basis to inequity of care, patient demographics, tumour characteristics and treatment were compared between Māori and non-Māori patients. The difference was examined with Chi-square test. Reasons for not having potentially curative surgery as the primary treatment were also explored and classified into comorbidity, lung function problems, poor ECOG status, surgical complications, patient refusal and unknown/other reasons. Logistic regression model was used to estimate the odds ratios of having curative treatment for Māori patients compared with non-Māori patients after adjustment for patient demographics and tumour characteristics. We also examined the factors that influence whether patients received alternative curative treatment compared to surgery.

The Kaplan Meier method was used to examine the all-cause survival by treatment option and by ethnicity (Māori vs non-Māori). For survival analyses, patients without mortality information were considered to be censored on 25 June 2019. Cox proportional hazard model was used to estimate the hazard ratio of death for Māori compared to non-Māori after adjustment for age, sex, year of diagnosis, stage, comorbidities and treatments. All data analyses were performed in IBM SPSS statistics 25 (New York, United States).

## Results

The Combined Lung Cancer Register included 3331 resident cases (1050 Māori and 2281 non-Māori) between 2011 and 2018. This study included 583/3331 (17.5%) with early stage disease (Table 1). This was made up of 169/1050 (16.1%) Māori and 414/2281 (18.1%) non-Māori patients. Over 90% of the early stage patients were either a current smoker (30.9%) or ex-smoker (60.1%). Among the lung cancer patients, 47.7% had a history of chronic obstructive pulmonary disease (COPD). There were 452 cases of NSCLC, 14 cases of small cell lung cancer, and 106 patients did not have a pathology report. A record of unknown pathology was associated with significant comorbidities in 37 (34.9%) patients, frailty/high risk – ECOG 2+ 10 (9.4%) and very poor lung function 25 (23.6%). The 169 Māori patients were younger, more likely to be current smokers, have a diagnosis of COPD and have NSCLC-other and small cell lung cancer, and more likely to have FEV1 of < 50% than non-Māori patients.

In total 419/583 (71.9%) of patients with Stage I and II disease were treated with curative intent - 272 (46.7%) patients had curative surgery, including 199 lobectomies, 59 partial resection of lung, and 14 pneumonectomy (Table 2). Another 64 (11.0%) patients were treated with SABR, 67 (11.5%) received curative radical radiotherapy,

**Table 1** Patient demographics and tumour characteristics

Subgroup	Māori	Non-Māori	P-value (Chi-square test)	Total
Sex				
Female	104 (61.5%)	220 (53.1%)	0.064	324 (55.6%)
Male	65 (38.5%)	194 (46.9%)		259 (44.4%)
Age (years)				
< 60	35 (20.7%)	53 (12.8%)	< 0.001	88 (15.1%)
60–69	65 (38.5%)	120 (29.0%)		185 (31.7%)
70–79	57 (33.7%)	170 (41.1%)		227 (38.9%)
80+	12 (7.1%)	71 (17.1%)		83 (14.2%)
Smoking status				
Current smoker	63 (40.4%)	104 (27.0%)	< 0.001	167 (30.9%)
Ex-smoker	91 (58.3%)	234 (60.8%)		325 (60.1%)
Never smoked	2 (1.3%)	47 (12.2%)		49 (9.1%)
Unknown	13	29		42
Charlson Comorbidity				
0	37 (21.9%)	119 (28.7%)	< 0.001	156 (26.8%)
1	44 (26.0%)	147 (35.5%)		191 (32.8%)
2	51 (30.2%)	99 (23.9%)		150 (25.7%)
3	29 (17.2%)	33 (8.0%)		62 (10.6%)
4+	8 (4.7%)	16 (3.9%)		24 (4.1%)
COPD				
No	57 (39.9%)	207 (57.2%)	< 0.001	264 (52.3%)
Yes	86 (60.1%)	155 (42.8%)		241 (47.7%)
Unknown	26	52		78
Cell type				
NSCLC	124 (91.2%)	328 (96.2%)	< 0.001	452 (94.8%)
Others	2 (1.5%)	9 (2.6%)		11 (2.3%)
Small cell	10 (7.4%)	4 (1.2%)		14 (2.9%)
Unknown	33	73		106
FEV1				
< 50%	46 (30.3%)	63 (17.4%)	< 0.001	109 (21.2%)
50%~ 80%	70 (46.1%)	139 (38.4%)		209 (40.7%)
80%+	36 (23.7%)	160 (44.2%)		196 (38.1%)
Unknown	17	52		69
ECOG				
0	51 (32.3%)	157 (40.6%)	0.194	208 (38.2%)
1	73 (46.2%)	158 (40.8%)		231 (42.4%)
2+	34 (21.5%)	72 (18.6%)		106 (19.4%)
Unknown	11	27		38
Total	169	414		583

and 16 (2.7%) had curative chemo/radiotherapy. Amongst those not having curative treatment (164 (28.1%)), 33 (5.7%) had palliative radiotherapy, 14 (2.4%) had palliative chemotherapy, and 117 (20.1%) had best supportive care alone. Māori patients appeared to be less likely to have

curative surgery (39.6% vs 49.5%,  $p$ -value = 0.027), but were as likely to have curative treatment as non-Māori patients (70.4% vs 72.5%,  $p$ -value = 0.618). The principal reason recorded in the patient records indicating why these lung cancer patients did not have curative treatment

**Table 2** Primary treatment for lung cancer patients by ethnicity

Primary treatment	Māori	Non-Māori	Total
Curative surgery	67 (39.6%)	205 (49.5%)	272 (46.7%)
Lobectomy	49 (29.0%)	150 (36.2%)	199 (34.1%)
Partial resection of lung	16 (9.5%)	43 (10.4%)	59 (10.1%)
Pneumonectomy	2 (1.2%)	12 (2.9%)	14 (2.4%)
SABR	22 (13.0%)	42 (10.1%)	64 (11.0%)
Radical radiotherapy	23 (13.6%)	44 (10.6%)	67 (11.5%)
Curative chemo/radiotherapy	7 (4.1%)	9 (2.2%)	16 (2.7%)
Palliative radiotherapy	14 (8.3%)	19 (4.6%)	33 (5.7%)
Palliative chemotherapy	4 (2.4%)	10 (2.4%)	14 (2.4%)
Supportive care	32 (18.9%)	85 (20.5%)	117 (20.1%)
Total	169	414	583

included significant comorbidities in 37 (22.6%) patients, 24 (14.6%) poor lung function, 24 (14.6%) poor ECOG status, 19 (11.6%) high risk of surgical complications, 16 (9.8%) patient refusal and 43 (26.2%) unrecorded.

The logistic regression model showed that age, year of diagnosis, cancer stage, cancer cell type, FEV1 and ECOG status had an impact on the likelihood of having curative treatment (Table 3). Patients who were younger, were diagnosed in more recent years, had stage I disease, had NSCLC, had FEV1 of 80%+, and had an ECOG score of 0 were more likely to receive curative treatment. Amongst those who received curative treatments, younger patients were more likely to have surgery as the primary treatment (odds ratio: 0.91, 95% CI: 0.87–0.95). Current smokers and ex-smokers were less likely to have surgery and more likely to be treated with radiotherapy and chemotherapy than people who never smoked (respective odds ratio: 0.11 (95% Confidence interval (CI): 0.02–0.46); 0.23 (95% CI: 0.06–0.89)). Patients who had NSCLC, had FEV1 of 80%+, and had an ECOG score of 0 were more likely to undergo surgery. After adjustment for other factors we did not find a difference in access to curative treatment and curative surgery between Māori and non-Māori patients (respective odds ratio: 0.80 (95% CI: 0.46–1.38); 1.03 (95% CI: 0.53–2.00)).

There were 217 deaths (37.3%) in this cohort with a median follow-up time of 27 months and a mean follow-up time 34 months. Outcomes in patients with stage I and II lung cancer varied depending on the treatment received (Fig. 1). Those who were treated with surgery had a 2-year survival of 87.8% (95% CI: 83.8–91.8%) and 5-year survival of 69.6% (95% CI: 63.2–76.0%). SABR has only been available in the region since mid 2015 but outcomes are similar to surgery in the first 2 years post treatment (2-year survival: 85.2, 95% CI: 75.8–94.7%, log-rank test  $p$ -value = 0.556). Prior to the use of SABR, some patients were offered radiotherapy with curative intent and in this group of patients 2-year survival is

only 65.3% (95% CI: 53.1–77.4%) and 5-year survival was 50%. Patients offered palliative treatment only had a 2-year survival of 45.0% (95% CI: 37.0–53.0%) and 5-year survival of 31.8% (95% CI: 23.9–39.6%).

Māori patients had a similar survival to non-Māori patients (Fig. 2, Log-rank test  $p$ -value = 0.091). The 2-year and 5-year survival for Māori patients was 69.4% (95% CI: 62.2–76.7%) and 47.1% (95% CI: 37.8–56.4%), compared to 73.5% (95% CI: 69.1–77.9%) and 59.3% (95% CI: 53.9–64.8%) for non-Māori patients.

The hazard ratio (Table 4) of all-cause mortality for Māori patients compared to non-Māori patients was 1.25 (95% CI: 0.92–1.69,  $p$ -value = 0.150). SABR has equivalent effect on survival compared to curative surgery (hazard ratio: 0.77, 95% CI: 0.37–1.61). The all-cause survival for stage I and II lung cancer patients has improved over time (hazard ratio: 0.94, 95% CI: 0.87–1.00).

## Discussion

We found that 71.9% of early stage lung cancer patients in our region were treated with potentially curative treatment. The commonest form of treatment was surgery. Thus in the Midlands Region a total of 272/3331 (8.2%) of lung cancer patients were treated with curative surgery. This low rate of surgical treatment is similar to that found in the UK but lower than the rate reported in Australia and some European countries [11, 12]. While the advent of SABR has coincided with an increasing proportion of early stage patients being offered curative treatment, significant improvement will only be achieved when the proportion of patients with early stage disease at diagnosis is increased. This can either be achieved through greater awareness of symptoms of lung cancer e.g. through social media campaign [13] and through the introduction of lung cancer screening [14, 15].

We have shown that there are a number of reasons why patients do not receive curative treatment. Overall, less than half of patients with stage I and II disease in our region 272/583 (46.7%) were treated with surgery. This figure has not improved from the findings in a similar New Zealand study in 2004 which reported a surgery rate of 56% of stage I and II NSCLC [7]. Another 147/583 (25.2%) of patients in our study were treated with alternative potentially curative treatment while 164/583 (28.1%) were treated with palliative care only. Patients with stage I and II NSCLC receiving palliative care were older than those who had curative treatment (mean age of 73 years vs 68 years). Other reasons included cancer stage – (stage II cases were less likely to be treated curatively than stage I), cancer cell type (small cell tumours were less likely to be treated than NSCLC), and those with COPD or poor respiratory function who were less likely to receive surgery or curative treatment as were those with a poor ECOG status. These findings are

**Table 3** Adjusted odds ratios from logistic regression model

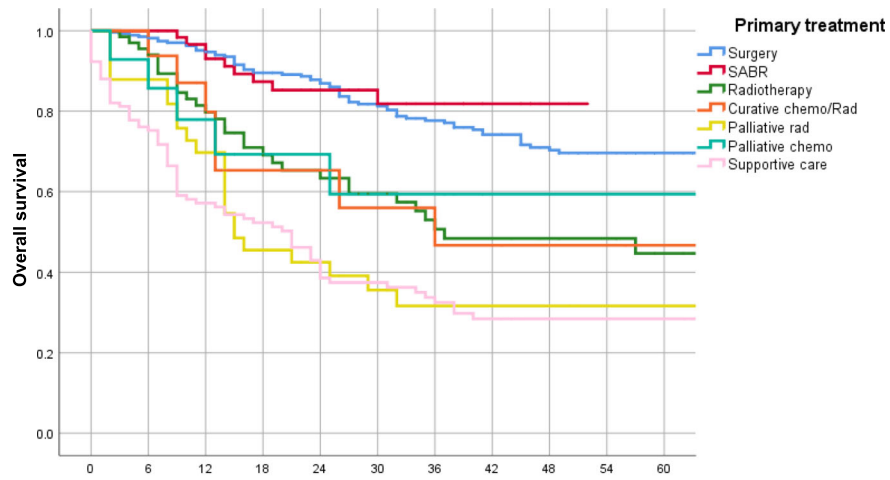
Subgroup	Having curative treatment vs no curative treatment			Having surgery vs other curative treatment		
	Odds ratio	95% CI	p-value	Odds ratio	95% CI	p-value
Sex						
Female	Ref			Ref		
Male	0.85	(0.51 - 1.41)	0.536	1.26	(0.70 - 2.29)	0.446
Ethnicity						
Māori	0.80	(0.46 - 1.38)	0.424	1.03	(0.53 - 2.00)	0.932
Non-Māori	Ref			Ref		
Age (Continuous)	0.92	(0.89 - 0.95)	< 0.001	0.91	(0.87 - 0.95)	< 0.001
Smoking status						
Current smoker	0.40	(0.12 - 1.38)	0.149	0.11	(0.02 - 0.46)	0.003
Ex-smoker	0.49	(0.15 - 1.57)	0.229	0.23	(0.06 - 0.89)	0.033
Never smoked	Ref			Ref		
Charlson Comorbidity						
0	Ref			Ref		
1	0.82	(0.36 - 1.87)	0.644	0.43	(0.17 - 1.11)	0.080
2	1.06	(0.45 - 2.50)	0.902	0.35	(0.13 - 0.93)	0.035
3	0.93	(0.34 - 2.54)	0.894	0.20	(0.06 - 0.73)	0.015
4+	0.55	(0.15 - 2.02)	0.365	0.10	(0.02 - 0.56)	0.009
Year of diagnosis (Continuous)	1.15	(1.03 - 1.28)	0.015	0.75	(0.65 - 0.86)	< 0.001
Stage						
I	Ref			Ref		
II	0.29	(0.17 - 0.48)	< 0.001	0.58	(0.31 - 1.08)	0.088
Cell type						
NSCLC	Ref			Ref		
Others	0.29	(0.17 - 0.51)	< 0.001	0.08	(0.03 - 0.23)	< 0.001
FEV1						
< 50%	0.35	(0.16 - 0.77)	0.009	0.04	(0.01 - 0.12)	< 0.001
50%~ 80%	0.70	(0.36 - 1.38)	0.304	0.42	(0.20 - 0.85)	0.016
80%+	Ref			Ref		
ECOG						
0	Ref			Ref		
1	0.52	(0.26 - 1.02)	0.056	0.57	(0.30 - 1.09)	0.091
2+	0.13	(0.06 - 0.26)	< 0.001	0.14	(0.05 - 0.40)	< 0.001

similar to the findings from a Danish study [16] of stage I lung cancer and the historical New Zealand study [7].

SCLC proliferates more rapidly and has a high propensity to metastasise. Most cases will present with locally advanced or metastatic disease. On rare occasions, patients are identified with small cell lung cancer (SCLC) histology but with early stage disease potentially suitable for resection [17]. Overall our cohort had 440/3331 (13%) small cell lung cancers. There were only 14 small cell lung cancer cases in our group of stage I and II diseases, and only one had curative surgery. In a large cohort of 45,848 patients with SCLC only 1% were treated surgically [18]. The

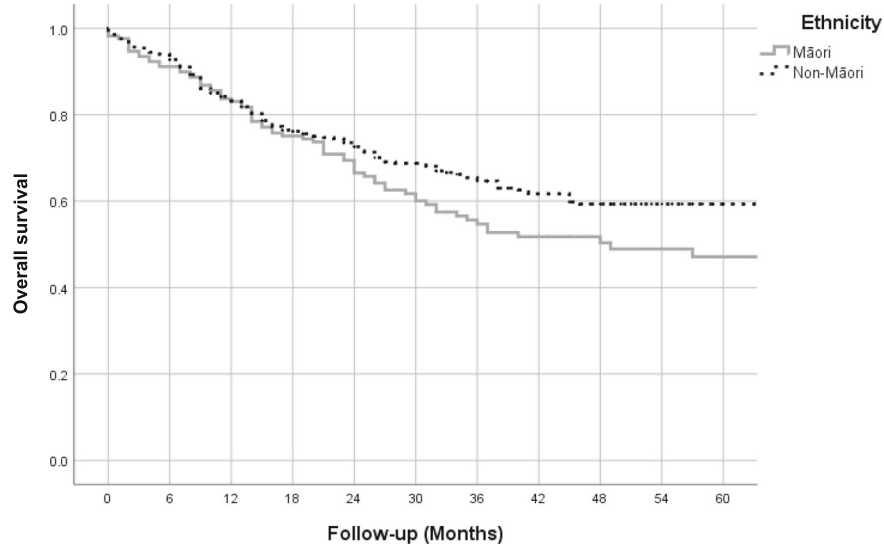
5-year survival in this cohort from the turn of the century was only 31% and the HR compared with NSCLC was 1.47 [18]. Our findings suggest that surgical intervention for SCLC is a rare event, partly because few cases present with early stage disease and other treatment modalities are more likely to be taken up.

Our study also shows that patients who identify as Māori are less likely to receive curative surgical resection of stage I and II lung cancer than those who do not identify as Māori. This finding was based on the unadjusted analysis, and the difference disappeared after adjustment for other factors. This could suggest that the New Zealand



Primary treatment	Number of patients at risk by follow-up time (Months)										
	0 M	6 M	12 M	18 M	24 M	30 M	36 M	42 M	48 M	54 M	60 M
Surgery	272	267	244	220	197	165	141	121	105	87	72
SABR	64	64	54	43	35	25	17	9	3	0	0
Curative chemo/Rad	16	16	12	8	8	6	6	5	3	3	2
Radiotherapy	67	64	49	38	34	29	23	20	18	15	11
Palliative chemo	14	13	9	7	7	6	6	3	3	2	2
Palliative rad	33	29	23	15	13	10	8	8	8	5	5
Supportive care	117	89	60	51	40	32	27	20	15	15	15

Fig. 1 All-cause survival by treatment option



Primary treatment	Number of patients at risk by follow-up time (Months)										
	0 M	6 M	12 M	18 M	24 M	30 M	36 M	42 M	48 M	54 M	60 M
Māori	169	154	129	109	95	74	59	51	37	30	24
Non-Māori	414	388	322	273	239	199	169	135	118	97	83

Fig. 2 All-cause survival between Māori and non-Māori

**Table 4** Adjusted hazard ratio for overall survival from Cox proportional hazard model

Factors	Hazard ratio	95% CI of hazard ratio	P-value
Sex			
Female	Ref		
Male	1.21	(0.91 - 1.62)	0.195
Ethnicity			
Māori	1.25	(0.92 - 1.69)	0.151
Non-Māori	Ref		
Age (Continuous)	1.01	(0.99 - 1.03)	0.172
Charlson Comorbidity			
0	Ref		
1	1.10	(0.70 - 1.75)	0.673
2	1.07	(0.66 - 1.73)	0.794
3	1.02	(0.55 - 1.86)	0.959
4+	1.19	(0.58 - 2.44)	0.640
Smoking status			
Current smoker	2.51	(1.06 - 5.94)	0.037
Ex-smoker	2.24	(0.96 - 5.22)	0.061
Never smoked	Ref		
Year of diagnosis (Continuous)	0.94	(0.87 - 1.00)	0.068
Stage			
I	Ref		
II	1.35	(1.02 - 1.80)	0.039
Primary treatment			
Curative surgery	Ref		
SABR	0.77	(0.37 - 1.61)	0.486
Radiotherapy	1.94	(1.23 - 3.07)	0.005
Curative chemo/Rad	1.80	(0.80 - 4.03)	0.153
Palliative rad	2.89	(1.72 - 4.85)	< 0.001
Palliative chemo	1.69	(0.66 - 4.32)	0.270
Supportive care	3.35	(2.26 - 4.96)	< 0.001

healthcare system is ensuring equity of access to curative surgical resection for patients. Māori presenting with early stage disease are younger than non-Māori, and more likely to have COPD, be a current smoker, have an FEV1 less than 50% and have small cell histology. Māori generally have lower socioeconomic status which is associated with poor survival [19, 20]. After adjustment for these factors it appears that Māori are not less likely to receive curative treatment (odds ratio 0.80, 95% CI 0.46–1.38) or surgery (odds ratio 1.03, 95% CI: 0.53–2.00). It maybe this finding is a Type 2 error and if we had a bigger sample then potentially we might show a difference. This means that we need to continue to monitor access to curative treatments for Māori if we are to reduce the inequities in outcomes that we know are present [7, 21].

Our findings show that the all-cause survival from surgery in this group of patients are 85% at 2 years and 70% at 5 years. This is similar to the survival reported in a 2004 study where the 2-year survival was 81% [7]. This supports the assertion that early stage lung cancer can be “cured” [22]. Indeed if we look just at the 199 NSCLC patients treated with lobectomy we find the 5-year survival is over 70% which is comparable with the findings from studies in major centres in the USA [22].

Patients with stage I and II NSCLC treated with SABR have comparable outcomes to those treated with surgery. This is despite the finding that those treated with curative intent with SABR tended to have additional risk factors including older age, higher ECOG status score, more comorbidities and more smokers. The numbers of patients treated with SABR is relatively small and further follow up of a greater number of patients is needed to confirm this finding but the initial results are very encouraging. A systematic review [23] reported that the overall and cancer-specific survival between SABR and lobectomy for stage I NSCLC were similar after 1-year follow-up, but lobectomy appeared to have more favourable outcomes after 3-year and 5-year follow-up. However, this systematic review only included one randomised clinical trial [24] and the other six included studies were cohort studies which may have been subject to bias [25–30].

Outcomes in patients managed with palliative care are relatively poor where only 30% of palliative patients with Stage I and II disease are surviving 5 years. Many of these patients are older and have significant comorbidities which impact on overall survival. The small number of patients offered palliative chemotherapy appear to be doing better with a 2-year survival of 60%. However, overall survival in this group of patients managed with supportive/palliative care is higher than previous reports. Stevens et al. [7] only showed 20% survival with 2 years follow-up, while our study has shown similar improvement year by year during the study period.

One of the strengths of our study is that it was based on the comprehensive lung cancer register, with relatively complete data on patient demographics, tumour characteristics and treatment. The limitations of this study included the small number of patients and short follow-up time in some treatment group, e.g. SABR. Also as an observation study, this study is prone to selection bias.

## Conclusions

The majority of patients with stage I and II lung cancer are managed with potential curative treatment – mainly surgery and increasingly SABR. After adjustment for key variables such as smoking, comorbidities and lung function status, the likelihood of Māori patients having

curative treatment was similar to non-Māori. This suggests that outcomes for Māori patients can be improved by addressing smoking and the management of comorbidities. While the outcomes of those being diagnosed with stage I and II disease and receiving treatment is positive with 70% surviving 5 years, the next target is to substantially increase the population of lung cancer patients diagnosed with early stage disease.

#### Abbreviations

CI: Confidence interval; COPD: Chronic obstructive pulmonary disease; DHB: District Health Boards; ECOG: Eastern Cooperative Oncology Group; FEV1: Forced Expiratory Volume; MDM: Multidisciplinary meeting; NSCLC: Non-small cell lung cancer; NZCR: New Zealand Cancer Registry; SABR: Stereotactic ablative body radiotherapy; SCLC: Small cell lung cancer

#### Acknowledgements

The Midland Cancer Register is maintained by the Midland Cancer Network and this study has been supported by grants from the New Zealand Cancer Society, the Waikato Medical Research Foundation and the Health Research Council of New Zealand (grant number: 17/438). The funders did not play any role in the research design, data analyses or results interpretation.

#### Authors' contributions

RL, PC, JW and DA conceived of and designed the study. LB, LM and KM collected the data. CL and LB did the data cleaning and analyses. RL, CL, RK, CG, LC and JK were involved in the interpretation of data. All the authors were involved in the drafting of the manuscript and the critical revisions. All the authors approved the submitted version and have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

#### Funding

Funding has been received from the New Zealand Cancer Society, the Waikato Medical Research Foundation and the Health Research Council of New Zealand (grant number: 17/438). While the overall study has been peer reviewed by the funding bodies, they have had no role in the design of the study and collection, analysis, and interpretation of data and or writing the manuscript.

#### Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due to the confidentiality of patient data but are available from the corresponding author on reasonable request.

#### Ethics approval and consent to participate

Ethical approval for the study was granted through the Southern Health and Disability Ethics Committee (HDEC reference: 16/STH/167). As this was a retrospective observational study using anonymised data, individual patient consent was not deemed a requirement by HDEC.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare that they have no competing interests.

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Received: 29 October 2019 Accepted: 27 January 2020

Published online: 10 February 2020

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# Seeing the unseen: evidence of kaupapa Māori health interventions

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DOI: 10.1177/1177180120919166

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## Abstract

Māori in Aotearoa have higher incidence, prevalence and mortality from chronic disease. The dominant narrative in Aotearoa about the reasons for Māori ill health neglects to acknowledge the history of colonisation and failures of the health system, alongside the holistic view of health taken by Māori focusing on collective, whānau-based outcomes. In this article, we review health interventions for chronic disease that have a kaupapa Māori philosophical basis. Our findings demonstrate that there is no clear process in health service design, delivery, research and funding that values and understands mātauranga Māori. Western knowledge systems are inadequate for collecting and presenting Māori knowledge. Overall, we highlight that the tension between acknowledging that a “by Māori, for Māori” approach is best, and the difficulty in defining appropriate evidence collection methodology and outcome measures when funders and policy makers continue to require Western-centric interventions is an obstacle to improving Māori health outcomes.

## Keywords

kaupapa Māori, health, intervention, review

## Background

The effects of colonisation on the well-being of Indigenous cultures, communities and individuals are well known, researched and documented and are, unsurprisingly, consistent across colonial contexts (Durie, 2003; Hokowhitu et al., 2010; Kauanui, 2008; Laenui, 2000; Marrone, 2007; Moreton-Robinson, 2016; Simpson, 2014; Simpson & Smith, 2014; Tobias et al., 2009). As a recent article bringing together practitioners and health scholars from multiple colonial contexts summarises, “Globally, health disparities between Indigenous and non-Indigenous populations are ubiquitous and pervasive, and are recognized as being unfair, avoidable, and remediable” (Jones et al., 2019, p. 512). Similarly, the negative impact of colonisation on Indigenous lifespan is internationally endemic. Typically, Indigenous peoples die considerably earlier than their non-Indigenous compatriots, creating a great sense of loss and source of pain for cultures that view their elders as bearers of knowledge critical to survivance (Vizenor, 2008).

Māori are Indigenous to Aotearoa (New Zealand) and have higher incidence, prevalence and mortality from chronic disease compared to non-Māori. Life expectancy at birth for Māori is 73 years for males and 77.1 years for females compared to 80.3 and 83.9 years for non-Māori males and females, respectively. Cardiovascular disease mortality rate among Māori is more than twice as high as that among non-Māori, cancer mortality is more than 1.5 times as high for Māori as for non-Māori adults and diabetes

prevalence is more than twice the rate of non-Māori (Ministry of Health, 2015). These disparities are perpetual and the result of colonisation and the associated loss of culture and identity that comes with colonial influence on Indigenous civilisations (Paradies et al., 2015; P. Reid & Robson, 2007). The extent and longevity of health disparities is unacceptable and provides clear evidence of the failure of the health system in Aotearoa to deliver health in an equitable manner (Waitangi Tribunal, 2019). Achieving equitable health outcomes for Māori is therefore a priority.

The majority of health research on Indigenous peoples simply fails to acknowledge the causative effects of colonisation. That is, the loss of Indigenous lands, cultures, languages and identities as an advent of colonisation remains largely unacknowledged in the majority of health literature focused on Indigenous peoples (Jones et al., 2019). One of the issues with the majority of current health

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research and Indigenous peoples is that it is often validated via a logic of disparity, where statistics on a certain aspect of Indigenous health are measured against a non-Indigenous baseline. While the logic of disparity helps to define the problem, in doing so, it simultaneously defines Indigenous peoples as “the problem” to be fixed and, consequently, falls into the trap of a deficit model framing (Coulthard, 2014). Yet, we argue it is the structural discrimination within the health system itself that contributes significantly to reduced access and effectiveness of health interventions and health services (Dyall et al., 2013; Levack et al., 2016) across the lifespan for Māori (New Zealand Medical Association, 2011; Robson & Harris, 2007). The dominant narrative in Aotearoa about the reasons for Māori ill health implies that Māori have disproportionately high incidences and mortality due to non-compliance (Leventhal et al., 2005), poor-quality health behaviours and poor lifestyle choices (McCreanor & Nairn, 2002). However, such perceptions are unfounded and neglect to acknowledge the history of colonisation and the coterminous failures of the health system. Māori are in fact engaged and proactive about their health but from a worldview that reflects Māori values and principles (Penney et al., 2011). The Māori view of health is holistic, considering more than just the physical realm of bodily illness and disease. Rather, the Māori view of health acknowledges broader social, cultural and economic factors which focus on collective, whānau-based outcomes (Kidd et al., 2013; Moore, 2014).

Māori models of health exist and are well known within the Aotearoa health system (Durie, 1994, 1999; Pere, 1991). The most commonly used model is Mason Durie’s Te Whare Tapa Wha (Durie, 1985) which describes Māori health as analogous to a house with four walls. The four walls of the house represent the realms of tinana (physical), hinengaro (mental and emotional), whānau (family) and wairua (spiritual) health. For a person to be well, and thus for the house to be strong, all four realms of health must be addressed. Despite acknowledgement of Māori models of health and their existence since the early 1980s, the practical implementation of the principles expressed in such models does not often occur.

While Durie’s model is popular and often cited, the reason for this is possibly because the four cornerstones merely reflect Western holistic models of health, and thus simplistic translations of “wairua” to “spirituality”, for example, allow for conceptual assimilation. In reality, none of these concepts are translatable to Western frameworks, especially wairua, which is akin to a sub-atomic global essence that pervades all things, both living and inanimate (hence, the belief in telekinesis, dream travel, and the visionary ability of tohunga). The point being that, although Durie’s health configuration begins with Indigenous concepts, its production within the broader medical discourse soon disfigures, disassembles and reconfigures it to fit a Western medical taxonomy, and this epistemological disfiguration was a core component of successful colonisation. Yet, for Māori working with Māori there, typically at least, remains a deeper and more authentic understanding of the concepts that Durie amalgamated in

forming Te Whare Tapa whā. The misrepresentation and misinterpretation of Durie’s model by many non-Māori health practitioners follow a history of epistemological subjugation in relation to Māori health and well-being, stemming back to the most significant piece of Aotearoa legislature in relation to the suppression of Māori health practices: the 1907 Tohunga Suppression Act, which banned the practices of tohunga.

The Crown realised that tohunga were able to retain pre-colonial metaphysical belief systems through practices, ritual and systems of knowledge transferal that set them beyond the imperial scope of the colonising machine. Tohunga were of course also leaders of great metaphysical mana and, therefore, threatened the Crown’s desire to either have Māori die off or to produce assimilated brown citizens. Such an analysis resounds with a growing literature that not only foregrounds the effects of colonisation in relation to Indigenous health disparities, but also, assumes a causality between what is now increasingly referred to as colonial “historical trauma” and epistemological violence (e.g. Atkinson, 2013; A. Brown, 2009; Chandler et al., 2003; Chandler & Lalonde, 2008; Durie, 2003; Hallett et al., 2007; Hirini et al., 2005; Oster et al., 2014; Pihama et al., 2014). That is, the “systematic subjugation” (Duran et al., 1998) of an Indigenous culture via punitive and assimilatory methods leading to cultural dissonance (or what Fanon, 1961, would call “self-loathing”) and, in turn, spiritual, psychological, epistemological and physical trauma. Put simply, it is increasingly assumed that there is a correlation between poor Indigenous health colonisation and the resultant cultural dissonance.

At present, the health system in Aotearoa is at a turning point, where attempts at providing equitable health care are a significant cause of disruption in the health space. Recently, the Waitangi Tribunal released its Report on stage one of the Health Services and Outcomes Kaupapa Inquiry: WAI2575 (Waitangi Tribunal, 2019). The central allegation of the inquiry is that the primary health framework has failed to achieve Māori health equity, and further, that the framework is not sufficiently fit for purpose in its current state. In particular, concerns were raised about the role of, and resourcing for, Māori-led primary health organisations and health providers. The report argued that Māori were not able to exercise tino rangatiratanga (self-determination) in the design and delivery of primary services that impact Māori. Māori-centric health service development and delivery need to be driven by Māori. The system should no longer privilege a Western medical model of health for a population plagued by problems that Western medicine has thus far failed to solve. Interventions therefore that are inclusive of Māori worldviews and values, grown from within Māori communities, where Māori are partners, will have more of an effect on the disparity gap than any intervention grown from colonial soil.

Kaupapa Māori is a methodology that describes a “by Māori, for Māori” approach to service and project development and implementation (Smith, 1998). Kaupapa Māori provides an avenue for Māori to enact health care within a Māori worldview, while also challenging the

dominant narrative and associated power dynamics, so that Māori are not articulated as “the other”. Such an approach creates solutions to problems identified by Māori, within Māori communities (Kerr et al., 2010; Pitama et al., 2011). Through the use of kaupapa Māori methodological approaches, Māori are empowered to self-determine their own health from within their own cultural value system. Kaupapa Māori approaches can thereby interrogate systems of power and dominance, to illustrate the agency and resilience of Māori. In Aotearoa, Te Tiriti o Waitangi is the founding document of the nation and describes the principles of *kāwanatanga* (decision making), *rangatiratanga* (self-determination), *ōritetanga* (equity) and *wairuatanga* (spirituality) that underpin the relationship between the government and Māori (Berghan et al., 2017). The principles of Te Tiriti o Waitangi have been poorly upheld in many areas of life, but especially so in health (Waitangi Tribunal, 2019). The use of kaupapa Māori methodological approaches to improving Māori health outcomes is an avenue for the government to meet their obligations outlined within Te Tiriti. Kaupapa Māori, by definition, means that only Māori organisations deliver kaupapa Māori services and programmes. Governmental and other non-Māori organisations can however apply a Māori philosophical lens to their services, therefore ensuring that they are responsive to Māori needs.

Health interventions built from within a Māori worldview are slowly becoming more familiar in Aotearoa. Despite general acknowledgement of the need for Māori solutions in health, there are still significant blocks in place that inhibit the widespread use of kaupapa Māori (Came, 2012; Chin et al., 2018). We contend that Western knowledge and systems for collection and analysis of evidence are still privileged over *mātauranga Māori* (Māori knowledge). Therefore, securing funding for Māori health interventions can be difficult because the nature of kaupapa Māori is such that it often does not meet the criteria of the Western knowledge system to be robust for evidence. For example, there is tension between the acceptance that “by Māori, for Māori” interventions are best placed to provide positive health outcomes (Crengle, 2000), and the difficulty in defining and measuring those outcomes when the funder sits within a Western medical paradigm. For instance, the understanding of what an outcome looks like tends to be determined, and thus constrained by Western medical and scientific parameters. Moreover, in service delivery, such outcomes are determined by the funder rather than by the providers or recipients of the service (O’Brien, 2015). Rather, kaupapa Māori interventions have targets and outcomes that align with the holistic and collective nature of the Māori health worldview. Therefore, interventions built from within the Māori world often cannot be measured by a Western standard. The inability to benchmark against this Western standard often means projects are not funded and therefore cannot be implemented. Despite an environment that has inherent barriers to the funding and delivery of kaupapa Māori interventions, there are innovations happening in Aotearoa.

This article demonstrates that there is no clear process in health service design, delivery, research and funding that values and understands *mātauranga Māori*. Furthermore, funders and researchers are thus unable to share, understand and learn from innovations in Māori health. We know that Western knowledge systems are inadequate for collecting and presenting Māori knowledge. This raises the query, how do we have impact on the dominant Western structure of health when kaupapa Māori is not held in the same esteem as Western knowledge? In this article, we utilised the Western literature review process to find health interventions for chronic disease that have a kaupapa Māori philosophical basis. In addition, we used our networks within Māori health to get a sense of the kaupapa Māori interventions and initiatives that are happening in communities. All efforts have been made to canvas academic, governmental and community sources to determine the community health interventions that are having a positive impact for Māori. The intention of this article is not to discuss health outcomes, but to describe and discuss the nature of evidence generated through interventions or initiatives that are kaupapa Māori.

## Methodological process

The methodology used to review evidence attempts to traverse the tensions between Western knowledge and *mātauranga Māori*, including the criteria used for “evidence”. This was purposefully not a systematic review of the literature, but instead involved a search for evidence reported according to non-Māori conventions and *mātauranga Māori*. Accordingly, our process demonstrated that a systematic review privileges Western literature that has been peer-reviewed; therefore, such an approach overlooked or dismissed equally rigorous initiatives and interventions that are based on a Māori worldview.

The review in this article is a synthesis of available literature, evidence and *mātauranga* that describe kaupapa Māori interventions for chronic disease management. Three main search approaches for evidence were used: academic, governmental and Māori communities. The following criteria were used to select interventions for inclusion: (a) describes a health intervention or initiative; (b) kaupapa Māori methodology or philosophical framework used in the development and delivery of the intervention and (c) intervention was for the prevention or management of one or more chronic conditions (cancer, cardiovascular disease, diabetes mellitus, obesity).

## Academic

The Scopus database was searched to access academically published literature. A Google search was also carried out to access additional published literature. Various websites of universities and other academic institutions in Aotearoa (e.g. University of Waikato, University of Auckland, Victoria University, Wintec, Auckland University of Technology, University of Otago) were searched to access relevant dissertations and theses. The search terms used in various combinations were kaupapa Māori,

intervention, community, chronic disease, chronic illness, long term condition, health, cancer, cardiovascular disease, diabetes and obesity.

### **Governmental**

Ministry of Health and District Health Board websites (in Aotearoa) were searched to collect evidence of kaupapa Māori interventions performed within communities but not reported to an academic audience. Where a report or evaluation was identified but not available online, contact was made with the relevant organisation to request access for the purpose of this article. Only interventions that had reports available were included in the findings, which may mean that important kaupapa Māori interventions were missed from this section.

### **Māori community**

There are numerous iwi (tribe), hapū (sub-tribe) and whānau-based (family) organisations that develop and deliver health interventions with Māori. These organisations do not report findings in a Western-centric fashion and therefore the academic and governmental search approaches miss evidence from these organisations. From a Māori worldview, these community approaches are more relevant than interventions built from within academia or governmental sources because they are grounded in those communities. The authors have a wide network within the Māori health world and these networks were used to find community driven kaupapa Māori interventions. This is by no means an exhaustive exploration but is intended to get a sense of the various community-level initiatives existent for Māori. In many cases, these community initiatives do not have standard reporting mechanisms that could be drawn for use in an article such as this. Therefore, when a written report was available for an intervention that met criteria, it was requested for inclusion here. In most cases, a written report was not available, therefore a narrative that describes the types of services and programmes available is included in the findings.

### **Findings**

From academic and governmental sources, 13 kaupapa Māori interventions for chronic disease were found, eight within the academic literature base and five from governmental sources that had reports available.

Table 1 records the interventions found that used a kaupapa Māori methodological framework philosophy in the prevention or management of a chronic condition from academic and governmental sources. The table lists the condition of focus, the intervention and its duration, and the outcome measures used to assess effectiveness. All interventions were reported as successful when assessed against their stated aims. Seven out of the 13 projects were prevention focused, looking at reducing the risk of chronic disease. The majority of the programmes were based on lifestyle change and health promotion and interestingly,

most also had clinical (Western science) outcome measures associated with them.

On canvassing our professional networks for interventions that fell outside the academic and governmental lens, we found that while many and varied interventions exist, written records comprised only contractual reports produced to satisfy funders. Such records were available to be included in this article. In addition, a stock-take of interventions that aimed to improve access to cancer services for Māori was carried out by Cormack et al. (2005). A multi-methods approach was employed that incorporated a literature review, review of data, and interviews with providers and stakeholders. The approach for the stocktake was designed to deliver a comprehensive understanding of issues relevant to access to cancer services for Māori and was intended to be broad rather than exhaustive. The stocktake found very few Māori-specific cancer interventions and only one dedicated Māori cancer support service in Aotearoa. This service is not classified as an intervention or initiative and is more an integrated kaupapa Māori service that supports whānau throughout the cancer journey. Cormack reports that Māori health providers who did offer cancer-specific services offered activities such as working in Māori communities to raise awareness of cancer, cancer support groups pre- and post-operatively, and providing support to patients following a cancer diagnosis. Interestingly, as part of the stocktake, interviews with Māori health providers showed that they had a range of interventions and strategies that they deemed necessary to improve Māori access to cancer services, but little avenue to have these interventions formally recognised, funded and delivered.

Māori health agencies in Aotearoa work within a kaupapa Māori framework. Toi Tangata ([www.toitangata.co.nz](http://www.toitangata.co.nz)) are an example of an agency delivering kaupapa Māori interventions within communities that have an impact on the prevention, and management, of chronic disease. Toi Tangata develops, delivers and champions kaupapa Māori-based approaches to health, movement and nutrition. Te Whānau o Waipareira ([www.waipareira.com](http://www.waipareira.com)) is an agency that has been providing kaupapa Māori services to Māori for more than 30 years with a view to supporting whānau to transform. They work in collaboration with partners in Aotearoa to develop “strong indigenous social, educational, health, economic and spiritual agendas”. Services offered by Te Whānau o Waipareira work alongside whānau to understand their current needs and strengths which leads to the development of a plan and then navigation to and through services. Manawaora, The Centre for Health ([www.thecentreforhealth.co.nz](http://www.thecentreforhealth.co.nz)), is an example of small community organisation that provides kaupapa Māori health services bridging the gap between “medical and non-medical, cultural and western, illness and wellness”. The Centre for Health delivers interventions and performs kaupapa Māori health research in an effort to provide Western-valued evidence for their services. Detailed methodology describing interventions, outcome measures and effectiveness for the work done by these types of organisations can be found through their websites but is of course not readily available (or valued) in an

**Table 1.** Kaupapa Māori interventions from academic and governmental sources.

Project	Condition focus	Intervention	Duration	Outcome measures
A controlled trial of a 12-week exercise and lifestyle management (Rolleston et al., 2019)	Cardiovascular disease (prevention)	Exercise, nutrition, mātauranga Māori	12 weeks	Cardiovascular disease risk factors, Quality of life, Acceptability
12-week exercise and lifestyle management pilot programme (Rolleston et al., 2017)	Cardiovascular disease (prevention)	Exercise, nutrition and education	12 weeks	Cardiovascular disease risk factors, Quality of life
An intervention trial for Māori at risk of diabetes-related lower limb pathology (J. Brown & Barrett, 2010)	Diabetes	Personal care plan	12 months	Podiatry measures, Diabetes knowledge
Community-based participatory research to develop a diabetes prevention documentary (Farmer et al., 2016)	Diabetes (prevention)	Documentary	23-min documentary	Formally evaluated based on Indigenous principles
Ngati and healthy prevent diabetes project (Coppell et al., 2009)	Diabetes (prevention)	Health promotion, community education and monitoring, local environment adaptation	2 years	Insulin resistance
Nurse-led diabetes service (Jansen, 2008)	Diabetes	Māori diabetes nurse educator	9–12 months	Individual and organisational effectiveness, Anthropometry, Cholesterol profile, HbA1c
Project REPLACE (Bay of Plenty District Health Board, 2007)	Long-term conditions (prevention)	Replace an unhealthy behaviour with a healthy one	24 months	Client surveys, Participant interviews
Te Whai mātauranga o te ahua noho (Murphy et al., 2003)	Diabetes	Lifestyle intervention programme	4 months	Formal focus groups Cardiovascular disease, and diabetes clinical and biochemistry Diet records
Community health worker (Simmons et al., 2008)	Diabetes (prevention)	Māori community health worker-based intervention	189 ( $\pm$ 128) days	Weight loss
Health literacy and the prevention and early detection of gout (S. Reid et al., 2014)	Gout (prevention)	Health literacy resources	1 hr education with whānau, Continuing Medical Education session with health practitioners	Resource trialling
Community cancer support services pilot projects (Ministry of Health, 2011)	Cancer	Patient navigation and health promotion	No fixed duration	3-year quantitative and qualitative evaluation
Kaihautu Cancer Hauora navigator (McDonald & Rolleston, 2017)	Cancer	Navigator to support health professionals improve responsiveness to Māori	6 months	Whānau experiences
Ola Ora mHealth Tool (Verbiest et al., 2018)	Non-communicable disease	Mobile phone app and website	12 weeks	Eating habits, weight, activity levels

academic reporting context. These organisations (and the many others like them) which use Māori knowledge to develop and deliver services have a mix of government, private and philanthropic funding and are often unseen in the academic environment.

## Discussion and conclusion

Improvement in health outcomes is the focus of interventional health research and practice. However,

despite Aotearoa's world class health system, informed by high-quality research, Māori remain disproportionately impacted by almost all health conditions compared to non-Māori. While there are many and varied interventions provided by kaupapa Māori services, formal reports are often unavailable or if available, are produced in forms that do not adhere to Western notions of rigorous research. The lack of visibility of "evidence" for kaupapa Māori health interventions to support chronic disease prevention and management is apparent from the findings reported here.

Thirteen projects were found from within academic and governmental sources, and many others were identified through our networks. There is therefore a disconnect between the theoretical assumption that kaupapa Māori programmes are best placed to support Māori health outcomes and the acceptability of the robust evidence for such an approach when such evidence is still critiqued against a non-Māori standard.

The interventions described in Table 1 are attempts to provide validation for Māori approaches within a Western evidence framework. The interventions described used either a kaupapa Māori methodology or a Māori philosophy in the design and implementation. The interventions share a number of commonalities that are implicit in a kaupapa Māori approach. Each acknowledges a Māori holistic view of health, there is a co-design or community partnership aspect, there is Māori knowledge and leadership, and there is a multi-disciplinary approach to intervention development and delivery. There is also, however, definite Western clinical focus to most interventions, and the kaupapa Māori aspects appear to be competing for visibility and respect with Western science. The publications produced that have entered the academic arena do contribute significantly to promoting kaupapa Māori as the best approach to achieve equity in health for Māori. However, the struggle between Western science and mātauranga Māori is still very evident.

Interventions that were included in Table 1 were those that could be academically reported within a Western frame, despite their kaupapa Māori context. In Western science, the quality of an evidence source is assessed based on whether or not it meets some type of inclusion criteria such as the Joanna Briggs Institute (2019) and CASP checklists (Critical Appraisal Skills Programme, 2019). The injustice that then occurs is that Western science remains the benchmark against which quality is measured and despite acknowledgement and efforts to incorporate kaupapa Māori, very few programmes will ever meet such standards. Mātauranga Māori is not clearly evident within the reporting of the interventions described in Table 1, although we acknowledge that this does not mean that mātauranga was not used. The construct and utility of mātauranga Māori means its heart and meaning are lost when they are converted for a Western reporting system and thus it would be inappropriate to fully articulate its mana (prestige and status) in such a format.

The methodology section of this article included the academic process that privileges a Western construct for finding evidence, while also adding evidence that has been missed through such a monocultural lens. When we first conceived of this article, we intended to write a literature review, and we knew that within the findings, there would be a significant imbalance between Western and Māori knowledge. Our initial challenge was negotiating how to highlight that imbalance. However, as the article evolved, we shifted to a direct analysis that demonstrates how “standard” literature reviews in fact perpetuate inequities. Scholars in Indigenous spaces confront this situation continually. There is a need to be able to review knowledge

bases that inform health outcomes and methods of intervention that is a shift away from a mainstream “literature review”. While there is increasing interest in review methodologies such as the integrative review, which includes qualitative and unpublished material (de Souza et al., 2010), the fundamental problem of what constitutes “evidence” remains. Similarly, a systematic review of reviews into the impact of Indigenous health research also questions the nature of evidence (Kinchin et al., 2017). In this study, the authors note that the impact of Indigenous evidence is rarely and poorly reported and call for a review framework that structures the inclusion of Indigenous health principles. We contend that the development of such a framework, while useful, will not fully address the lack of value placed by Western medicine on mātauranga and kaupapa Māori health interventions.

This article provides the forum to raise the following question: Why is kaupapa Māori evidence not accepted as valid in Aotearoa? The tension between acknowledging that a “by Māori, for Māori” approach is best and the difficulty in defining appropriate evidence collection methodology and outcome measures when funders and policy makers continue to require Western-centric interventions is an obstacle to improving Māori health outcomes. Currently however, the health environment within Aotearoa is at a cross-roads, with the Health Outcomes Inquiry finding that the primary health system has failed Māori and that Māori solutions are needed for equity to be achieved (Waitangi Tribunal, 2019). Moreover, the recent Waitangi Tribunal report (Waitangi Tribunal, 2019) recommends the development of a new Māori research agenda. Given this environment and opportunity for disruptive change in Aotearoa, Western science privilege can now be challenged further, and kaupapa Māori in its full effect can be afforded the position of power that is needed to support Māori health and well-being. This certainly calls for the prioritisation of mātauranga Māori health interventions, while also emphasising the need to legitimise reporting styles and formats that privilege mātauranga. Together this may be a step to achieving equitable health care delivery and improving overall health outcomes for Māori. Accordingly, we propose the concurrent development of a kaupapa Māori template for recognising, measuring and reviewing the efficacy of Māori health interventions.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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## Primary Research

# Hā Ora: Reflecting on a *Kaupapa* Māori Community-Engaged Co-design Approach to Lung Cancer Research

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## ARTICLE INFO

*Keywords:*

Community engagement  
Indigenous  
Rural communities  
Health inequities  
Māori  
Kaupapa Māori  
Lung cancer  
Early diagnosis

<https://doi.org/10.32799/ijih.v16i2.33106>

## ABSTRACT

Co-designed research is gaining prominence within the health care space. Community engagement is a key premise of co-design and is also particularly vital when carrying out *kaupapa* Māori research. *Kaupapa* Māori describes a “by Māori, for Māori” approach to research in Aotearoa/New Zealand. This article discusses the research process of Hā Ora: a co-design project underpinned by a *kaupapa* Māori approach. The objective was to explore the barriers to early presentation and diagnosis of lung cancer, barriers identified by Māori. The team worked with four rural Māori communities, with whom we aimed to co-design local interventions that would promote earlier diagnosis of lung cancer. This article highlights and unpacks the complexities of carrying out community-engaged co-design with Māori who live in rural communities. In particular, we draw attention to the importance of flexibility and adaptability in the research process. We highlight issues pertaining to timelines and budgets, and also the intricacies of involving co-governance and advisory groups. Overall, through this article, we argue that health researchers need to prioritise working with and for participants, rather than on them, especially when working with Māori communities.

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## Glossary

**Aotearoa:** New Zealand

**hui:** meeting or focus group

**iwi:** tribe

**kai:** food

**kaiāwhina:** healthcare advocate

**kanohi-ki-te-kanohi:** face-to-face

**karakia:** prayer

**Kaumātua:** respected Elder

**kaupapa Māori:** a Māori focus incorporating the knowledge, skills, attitudes and values of Māori society

**kawa:** protocols

**koha:** gift of thanks

**kōrero:** story

**korowai:** traditional Māori cloak

**mana:** pride and status

**Māori:** Indigenous Peoples of New Zealand

**marae:** Māori meeting space

**mihi:** speech of greeting/introduction that usually includes the recitation of one's family origins

**Pākehā:** New Zealanders of European descent

**pou pupuru ōranga:** a health care advocate and navigator

**pōwhiri:** welcoming ritual/ritual of encounter

**tapu:** sacred, prohibited, restricted, set apart, forbidden

**te reo:** the Māori language

**Te Tiriti o Waitangi:** the Treaty of Waitangi

**tikanga:** traditional protocols/customs

**tino rangatiratanga:** sovereignty and self-determination

**waiata:** song

**whakaaro:** thoughts/opinions

**whakanoa:** to remove tapu/restriction

**whakawhanaungatanga:** relationship building

**whānau:** family, generally related but also includes close social groups

### Acknowledgements

*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 ā rātou kōrero kia tau te rangimarie, te aroha me te whakaponu Paimarire.*

*We are very honoured indeed to acknowledge those who shared their stories and brought to life Hā Ora. We are forever thankful and dedicate this to them, and also to 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.*

The project discussed in this article was funded by the Health Research Council of New Zealand (HRC Grant 17/438, entitled “Improving Early Access to Lung Cancer Diagnosis for Māori and Rural Communities”). We are grateful for the collaboration of Hemi Curtis, Ngaroma Grant, Mariana Hudson, Mahina Joseph-Small, Shirley Keown, Bubsie McFarlane, Dallas Poi, Reweti Ropiha, Phyllis Tangitu, and Maryanne Thompson.

### Introduction

Co-design is gaining prominence within the healthcare space as an approach to service design and delivery that may enable better uptake and outcomes because those impacted have been involved (Bate & Robert, 2007). Ideally, the co-design process involves all stakeholders in the design process of a service, intervention, or other initiative as a way of ensuring that the results meet their needs. However, there is an increasing need to draw a distinction between community consultation versus community-driven engagement as the basis of co-design. To elaborate, project teams often carry out community consultation by capturing people’s experiences regarding a particular issue, and designing a service or intervention that is then implemented in that community. A consultation approach does not reflect a genuine and effective partnership with communities (Bate & Robert, 2007). Rather, the intention of co-design is community-driven engagement, where project teams work together with their stakeholders and/or community members to identify a problem that needs to be addressed, engage people, document their experiences relating to the problem, and then collectively devise a solution (Boyd

et al., 2012; Rodgers, 2018). Similarly, a co-design approach involves researchers working in partnership with communities throughout a research process. As this article will demonstrate, such an approach to co-design enables the co-creation of interventions and ensures effective implementation, dissemination, uptake, and sustainability (Oetzel et al., 2017; Oetzel et al., 2015). Community-driven engagement is particularly vital when carrying out kaupapa Māori research.

*Kaupapa* Māori research describes a “by Māori, for Māori” approach to service and project development and implementation in Aotearoa New Zealand (Smith, 1999). Kaupapa Māori methodological approaches challenge the dominant narrative and associated power dynamics, so that Māori are not articulated as “the other” (Pihama, 2017). In particular, the undermining of Māori sociocultural, economic, and political structures through colonial processes has resulted in a redistribution of power and resources in favour of Pākehā (New Zealanders of European descent). This is reflected in the current economic, sociopolitical, and health inequities between Māori and Pākehā, alongside interventions aimed at addressing these inequities (Cormack et al., 2013; Harris et al., 2015). In Aotearoa, Te Tiriti o Waitangi is the founding document that underpins the relationship between the government and Māori. Te Tiriti guarantees *tino rangatiratanga* (sovereignty and self-determination) and the principles of mutual respect and the freedom to express *tino rangatiratanga*; active protection and being able to manage affairs according to *tikanga* (customary practice), including in mainstream health services; equity; and the right to choose people’s own social and cultural path and exercise authority (Waitangi Tribunal, 2019). Te Tiriti o Waitangi has been poorly upheld in Aotearoa, but especially so in health (e.g., Waitangi Tribunal, 2019). The use of kaupapa Māori methodological approaches to improve Māori health outcomes is an avenue to redress this issue, and to meet obligations outlined within Te Tiriti. Interventions using kaupapa Māori approaches have been associated with improved health outcomes for Māori (Oetzel et al., 2017; Pitama et al., 2011; Tipene-Leach et al., 2013).

The current project, Hā Ora, is underpinned by a kaupapa Māori approach. Our core team comprised a Kaumātua (respected Māori Elder); two general practitioners (RL, who is of European descent, and RK, who identifies as Māori); two senior Māori academics (JK and AR), who were the cultural leads for Hā Ora; and a full-time research fellow (SC, who is an Indigenous researcher of Sri Lankan descent), alongside several other clinicians and researchers involved in an advisory capacity (both Māori and non-Māori). The objective was to explore the barriers to early presentation and diagnosis of lung cancer, as identified by Māori patients and *whānau* (family or close social group), particularly in primary care. We worked with four rural localities in Aotearoa which had relatively high lung cancer rates, aiming to co-design interventions that would promote earlier diagnosis of lung cancer.

This article will discuss the research process of this project to highlight and unpack the complexities and value of carrying out community-engaged co-design with Māori in rural communities. In addition to issues such as confidentiality and rigour, the ethics application for the project involved detailed information about consultation with Māori advisers, the use of

Māori research approaches (detailed in this paper), and the inclusion of Māori researchers and collaborators throughout all stages of research and dissemination. Approval was received from the New Zealand Health and Disability Ethics Committee, reference number 17/STH/158.

### **The Communities**

Four rural localities in the Midland region of the North Island of New Zealand were engaged. To ensure anonymity of the communities in these localities, they are identified as Community A, B, C, and D in this article. A brief profile of each community is presented below (See also Table 1 for a summary).

Community A was a small, relatively remote rural community, situated around 45 minutes away (by road) from the nearest rural hospital and 3.5 hours away from the nearest major regional hospital. The team worked closely with a Māori community-based health professional, an integral member of the community. This individual was a pivotal member in the Māori stakeholder group and was instrumental in organising community *hui* (meetings or focus groups) and getting the community members together to participate in the research.

Community B was also a small rural community, located an hour away from the nearest major regional hospital. While Community B also had its own rural hospital, many community members have to travel to the regional hospital regularly for (cancer) care and treatment. Community B had a relatively central location, being close to other rural towns, and therefore had access to the healthcare services of these towns. The team worked with two Māori stakeholders in this community who were active members in the healthcare space.

Community C was a larger rural community, with its own well-equipped hospital. This community was located 1.5 hours away from the nearest major regional hospital. Despite being considered a rural community on a national scale, this locality had a larger population compared to the others that we worked with, and had a relatively central location with smaller neighbouring communities regularly accessing the hospital in Community C. In this community, the team worked with three prominent Māori activists in the healthcare and cancer spaces, who were key figures in supporting and promoting Māori health in general, and cancer care in particular.

Community D was also a larger rural community, with its own hospital. However, this community was very remote in its location, being a little over 5 hours away from the nearest major regional hospital. The stakeholder group in Community D comprised a Māori community organisation active in the healthcare space and important in supporting and promoting Māori health. While the team worked with this organisation as a whole, our regular correspondence was with two particular individuals within the organisation.

**Table 1***Summary of Community Profiles*

Community	Description	Distance to nearest hospital	Number of stakeholders engaged
Community A	Small, relatively remote rural community	45 minutes from rural hospital, 3.5 hours from regional hospital	One individual
Community B	Small, rural community	Has its own rural hospital; 1 hour away from regional hospital	Two individuals
Community C	Larger rural community	Has well-equipped hospital; regional hospital used for cancer treatment (1.5 hours away)	Three individuals
Community D	Larger rural community	Has well-equipped hospital; regional hospital used for cancer treatment (5 hours away)	One organisation

**The Process(es): Community Engagement****Laying the Groundwork**

Initial engagement involved the members of the team approaching key contacts, Māori health teams in the local district health boards, or prominent individuals actively working within the healthcare space in each locality. Most of these connections were made prior to the funding application for the project being submitted, which was vital for the project to succeed. After the funding was received, members of the team met *kanohi-ki-te-kanohi* (face-to-face) with these individuals or groups primarily for *whakawhanaungatanga* (forming relationships and finding connections) and to also provide a background of the project and its aims. During these initial hui, the team asked these individuals if they would like to be part of this research project, if they would be happy for the project to include their locality, and to assist with organising the community hui, recruiting participants, and forming part of the team's broader stakeholder group. These hui were held either in Hamilton, Aotearoa (where the majority of the team were based), or in each community. Overall, in each community there were one to two preliminary hui carried out during the initial conception of the project (prior to receiving funding), and another one to two hui following the receipt of funding.

Following these initial hui, SC was responsible for maintaining the relationship with stakeholders from each community and coordinating the organisation of a community hui in each location. SC worked with stakeholders to recruit participants for each hui, including designing recruitment flyers and organising dates, times, venues, *kai* (food), and *koha* (contributions/gifts) for hui. Such tasks involved repeated interactions between SC and each stakeholder over several months until all hui details were finalized. Flyers were circulated by the stakeholders. Some stakeholders also devised additional initiatives that they thought would work best in their communities to publicise the hui. For instance, the stakeholder in Community A created a

Facebook event linked to a local *iwi* (tribe) community page to recruit participants, and a stakeholder in Community C included the recruitment flyer and information about the hui in a regular community newsletter.

It is important to note that had SC acted on her own without the sanctioned support of initial stakeholders, the community members would likely not have had the opportunity to know and trust the research team sufficiently to want to attend the hui. The co-design methodology supported each stakeholder, who vouched for the team members and the process of the project, to personally recruit participants within their communities and to ensure their attendance. In all recruitment materials the name of the stakeholder and/or the organisation they worked with was prominently displayed. The significance of establishing such a link was twofold. First, it was vital that the stakeholders trusted the team in order for their communities to also then trust the team. Therein lay the significance of the initial hui between the team and each stakeholder. This is a key consideration when working with Māori communities, as well as for Māori researchers, where the stakeholders' reputation is linked to that of the team. Second, establishing relationships was a way of acknowledging and appreciating the time, help, and support provided by each stakeholder to the team. Overall, taking time to build trust was a vital part of the research process. Mistrust of research among Māori is common due to a history of racism, negative stereotyping, mistreatment, and oppression that resulted from Aotearoa's colonial past, and the role of Western "research" approaches in that past (Cormack et al., 2013; Harris et al., 2015; Harris et al., 2012; Oetzel et al., 2017).

### **Other Communities**

The process of approaching and establishing trust relationships with Communities A to D was relatively straightforward. However, there was also a community (Community E) that was approached and was not willing to be involved with the project. An initial introductory hui was organised with Community E, and the team travelled to attend. Following whakawhanaungatanga and an initial overview of the project and its aims, it became apparent that those present were very cautious about the project and the effect it would have on their community. By the end of the hui, it was clear that Community E was reluctant to proceed with the project. A kaupapa Māori approach respects the rights of individuals and groups to choose (either directly or indirectly) that a project or process is not right for them; we therefore did not progress with Community E from this point.

Conversely, the team encountered Community F, who had heard about the project from Community A and requested that a hui be organised in their locality. A community hui was planned with the help of two Māori health professionals and was well attended by community members. However, based on the discussion with whānau at this hui, it became clear that for Community F, the barriers to early diagnosis were predominantly related to secondary and/or specialist care. Community F had an active primary care team, who played a strong advocacy role to ensure that their patients got the best treatment and support possible. Community F had strong enablers in place for early diagnosis of lung cancer, and the team did not want to change or affect what was already being successfully undertaken. The team did not proceed on to the co-design

phase in Community F. Rather, the team agreed to revisit Community F 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.

### The Community Hui

In the four communities the team worked with, hui were carried out at either local *marae* (traditional meeting places) or meeting rooms organised by the stakeholders. The team members who attended all the community hui were JK, SC, AR, RL, and Kaumatua Hemi Curtis (HC). The stakeholders had organised attendance for each hui, as well as the seating arrangements and kai. At this stage, the team only had to arrive at each location and commence the hui. Figure 1 shows a sign at the entrance of the meeting room where the hui with Community A occurred, set up by the stakeholder in that community. The team tailored their approach according to where hui were held (e.g., on a marae versus in a meeting room). In particular, hui that were held on marae involved an adherence to tikanga, such as commencing with a *pōwhiri* (ritual of encounter). Consequently, the team wore appropriate attire as dictated by local tikanga, they prepared *waiata* (songs) for these hui, and HC (as Kaumātua) led the team onto the marae (see Durie [2007] for in-depth discussions of pōwhiri/marae processes). The community hui carried out in meeting rooms were less formal. For all hui, irrespective of the space within which they occurred, the proceedings began with a *karakia* (prayer) by HC or a representative of the community, and whakawhanaungatanga with each team member introducing themselves with a *mihī* (recitation of one's family origins), often in *te reo* (the Māori language). The use of *te reo* here was important both due to it being consistent with our kaupapa Māori approach, and also as a way of respecting tikanga of the communities we were working with.

### Figure 1

*Sign at Entry of a Meeting Room for Hui with Community A*





Following whakawhanaungatanga, JK explained the aims of Hā Ora, what we wanted to discuss with the community, and the process we proposed to follow (Figure 2 depicts an image of HC, JK, and RL at a community hui). One of the general practitioners in the team (RL or RK) provided a brief overview of lung cancer, including incidence, mortality, and survival rates, and acted as “medical liaison.” RL and RK had differing styles of engagement with hui participants. RL is English, a senior academic, and an experienced medical practitioner who has worked in rural general practice in Aotearoa over many years. RL contributed specialist knowledge in medicine. RK is Māori, a general practitioner, and an emerging researcher. RK acted as a whānau member navigating the healthcare space when some topics were discussed and also as medical liaison. The roles undertaken by RL and RK, particularly their ability to respond to medical questions, were an essential part of the team’s engagement with communities. AR and SC’s roles involved recording field notes at each hui, including audio recording the discussion, following consent from participants. Accordingly, research data comprised AR and SC’s field notes, alongside transcripts of the hui.

## Figure 2

*HC, JK, and RL Facilitating Hui in a Local Marae With Community D*



The team were equipped with a semistructured topic guide for the hui, but this document was seldom used, and topics were brought up by JK only as prompts if required. The aim of each hui was for the communities to direct and lead the conversations with topics centring on their experiences within the healthcare system. The team took a back seat in these conversations, enabling participants to raise what they felt needed to be heard. Noteworthy is that whānau who attended the hui talked about their experiences relating to an array of illnesses, not just lung cancer. They shared their experiences with other types of cancer (e.g., breast cancer, prostate cancer, stomach cancer) and other respiratory conditions (e.g., emphysema, COPD). We realised that many of the barriers and experiences discussed by whānau were also applicable to a lung cancer context, and we agreed that whānau sharing their varied experiences of illness was a strength within our project. More importantly, however, the purpose of the hui was to document whānau *kōrero* (stories) of navigating the healthcare space, irrespective of whether they were specific to lung cancer or not. Important here was that whānau came and shared their *kōrero*, which were often very personal. Some even shared *kōrero* that they had never shared before. Therefore, the team deemed it crucial to value and respect these *kōrero*, and to treat them with dignity.

Overall, all the communities were curious about what the project hoped to achieve. They were also very interested to know when the team would return to discuss results, to progress with the project, and to generally work with them again. Importantly, the team did not carry out “drive by” visits, or rather, one-off quick engagements with these whānau. Rather, we often held two to three hui with each community, in addition to regular updates and interactions with stakeholders, allowing us to build a working relationship with them, which paved the way for the ensuing co-design process. At the end of each series of community hui, the team invited anyone who was interested to progress on to the next stage of co-designing an intervention.

### **Timelines, Budgets, and Koha**

The journey from community engagement to the co-design phase of the project was not short, straightforward, or predictable. Timelines and budgets are a key part of project funding, and our research process had a number of factors that impacted on achieving our stated timeline and budget. In particular, our timeline began prior to the project funding being approved, as mentioned previously. Developing trust relationships with key stakeholders is essential from the very beginning of project initiation and design, including when writing project funding proposals, so that partnerships are genuine. Moreover, project teams cannot assume that one hui to introduce the project and to gather participant *kōrero* is enough to allow communities to decide if they wish to participate in the co-design phase of the project. Rather, the process may involve multiple hui and engagements, to get the communities to a place of co-design. While this could be seen by some researchers and institutions as inefficient or a waste of time (and resources), the additional time taken was an investment in establishing trust and a strong relationship with communities. This in fact is key when working with Māori communities and in

kaupapa Māori research. Indeed, the additional time taken was an expression of our genuine concern for the community and appreciation of their contribution within the co-design process.

Additionally, no two communities were the same. For instance, in Community A, the team had two initial engagements with the key stakeholder (one where a team member approached the stakeholder in person, and the next where the core team organised a hui via video communication) and two hui with the community prior to being able to organise a co-design hui. Here, while the first community hui was successfully organized and facilitated by the team in partnership with the stakeholder, word had travelled, and the community had requested that the team organise a second hui with them, so that they could bring along more people.

Alternatively, as the process with Community C involved working alongside three key stakeholders, the team began the engagement with a series of email exchanges and phone calls between the three stakeholders and RL (before and after funding approval) and SC (after funding approval), followed by a *kanohi-ki-te-kanohi* hui. This resulted in two community hui being organised in Community C. Following the two community hui, word had travelled, and Stakeholder 3 requested that a third hui be organised. Therefore, SC worked with Stakeholder 3 via a series of emails and phone calls to organise the third hui in Community C. Here, while some participants attended all three hui, others only attended one. It was only after these three hui were completed that the team could consider organising a co-design hui with this community.

Accordingly, some key factors that the project budget needed to reflect and incorporate were the cost of multiple community engagements or hui, including the associated costs for kai and koha. Kai, for instance, was a vital part of all our community hui. Hui were always based around morning/afternoon tea and either lunch or dinner. The significance of the kai itself and the timing of when it is brought out is twofold. The first is in its significance as a reciprocal offering to the community, and therefore kai demonstrated our gratitude for their time and effort. More importantly, kai carries with it the ability to *whakanoa* or remove *tapu*, the sacredness and restrictions that accompany the formality of a *pōwhiri* and hui that discuss issues surrounding death and illness. Koha was another important way of acknowledging the participants' time and effort to contribute to this project. The koha provided ranged from fuel vouchers to supermarket gift cards to cash, depending on services available in each community. In most cases we consulted with our stakeholders and asked them what was appropriate to provide as koha. Some forms of koha were easier to legitimise for the project budget and institutional approval than others. For instance, getting institutional approval for fuel vouchers seemed to be relatively easy. In the context of Community C, Stakeholder 2 played a key role in recruiting participants for all three community hui. Therefore, we asked Stakeholder 2 whether she would prefer an individual token of thanks for her time and effort (e.g., a supermarket gift card), or if she would rather receive koha on behalf of her organisation. Stakeholder 2 requested the latter. Accordingly, we sent her organisation a number of fuel vouchers. She responded that these vouchers were immensely helpful over the Christmas period when members of her organisation provided transport assistance to cancer patients travelling to hospital for treatment.

Conversely, the legitimisation and institutional approval process of koha in the form of cash proved to be more complicated, and lacked cultural understanding on the part of the institution. For instance, when the team attended marae-based hui, tikanga meant that the team presented koha in the form of cash during the pōwhiri. However, institutional conventions relating to the use of research funding do not condone researchers making cash withdrawals from project funding pools. Therefore, the team had to devise an alternative process where one of the team had to withdraw cash from their personal bank accounts to provide koha to marae, and then reimburse themselves with supermarket gift cards purchased from research funds. That said, purchasing supermarket gift cards was also a tedious process involving the completion of a “voucher purchase request form.” The form itself was not an issue and completely understandable (and was also the case for purchasing fuel vouchers). However, the complication arose when approval for supermarket gift cards required a condition, statement, or reassurance from the supermarket or the researcher that restricted the purchase of alcohol or cigarettes. The team was not prepared to dictate to participants what they could and could not use koha for.

The point we wish to highlight is that such hurdles imposed by institutional regulations or policies pose ethical and cultural barriers to real-world human research contexts. Funding bodies and institutions need to be more realistic in their approach to research with people and their everyday lives. Accordingly, there needs to be a greater acknowledgement of the cultural and/or ethical requirements of human research, where researchers should not have to devise creative tactics to show respect to and value participant involvement in the research process. Irrespective of such barriers, however, the team presented koha to stakeholders as well as each member of our co-design groups at each co-design hui they attended, as a token of thanks.

### **Governance and Advisory Groups**

On carrying out a kaupapa Māori, community-engaged research project, yet another key consideration that turned out to be different from the project plan was the structure of our governance and/or advisory groups. Early on in the project, we had already established two governance groups: a Māori Advisory Group (MAG) comprising various leading Māori researchers working in the field of health, as well as an Academic and Clinical Steering Group (ACSG) comprising relevant clinicians and senior academics. These were consistent with the requirements from the funders. The terms of reference for these groups included oversight of the project as a whole and, importantly, providing advice and input into the findings and dissemination of the research. From a clinical, healthcare research point of view, having such higher level co-governance was vital to ensure our findings, outputs, and outcomes were effective in the broader clinical, healthcare setting. However, our formal governance groups did not involve members of the communities we were working with. This is not to say that our stakeholders and members of our co-design groups were not involved at a co-governance capacity in our project. Rather, despite not being considered “advisers” or members of a formal “governance group,” our interactions with community groups ensured that they had a say in the

research process. Therefore, our community groups acted as governors of the research process, in conjunction with the formal MAG and ACSG.

Regular meetings with our official governance groups (the MAG and ACSG) served a different function, and occupied a different space to that of our unofficial community governors. As such, having the MAG and ACSGs in the way we did had a *korowai* (traditional cloak) effect for our community groups. Specifically, when worn, a korowai can enhance the *mana* (pride and status) of the wider whānau who own it. Thus, we found ourselves taking information (findings, points of discussion, issues raised, etc.) from community groups and presenting them to the MAG and ACSG as evidence, which then “legitimised” such information for the purpose of an institution-led research project. Here, we do not aim to imply that Māori communities need to prove the legitimacy or validity of their *whakaaro* (thoughts/opinions)—a constant reality within a Pākehā world. Rather, having the community’s views validated in this manner allowed us to ensure that we brought their best interests, thoughts, and views to the fore throughout the project. This also demonstrated a more community-driven approach, rather than a top-down authoritative approach.

### **Initiating the Co-design Process**

The co-design phase of Hā Ora involved repeated interactions between members of the team and co-design groups. AR took the lead with the co-design phase in Communities A and C, whereas JK took the lead with Communities B and D. SC coordinated the co-design interactions alongside the design of interventions for all four communities.

During the conception of the project, the team envisioned that communities would suggest similar interventions that they would co-design with the team. However, the reality of the project was that the four communities (co)produced four different ideas for interventions. The interventions included a Hā Ora website, a health-related media campaign, a *kaiawhina* (healthcare advocate) training programme, and a “*pou pupuru ōranga*” (healthcare advocate/navigator) role. While each of these initiatives took vastly different forms, it was clear that their content or key rationale held a common, linking thread involving messages of health literacy. Thus, all the interventions included an education element, to promote awareness of lung health and respiratory symptoms and illnesses including lung cancer (focused on patients, whānau, kaiawhina, or other healthcare mentors or professionals).

### **Lessons Learned**

This article discusses the methodological processes and intricacies of a community-driven co-design project aimed at improving early diagnosis of lung cancer for rural Māori communities. Our research process highlights three key issues that require us to revisit the issue of community consultation versus community-driven engagement as being the basis of co-design, mentioned in the introduction. First, we highlight the importance of the process of co-production when devising an intervention for a specific community. Second, we advocate for

flexibility in the research process. Finally, we problematise the idea of generalising interventions at a national level.

To focus on the first issue, we emphasise 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. Researchers need to ensure they co-produce the intervention with their communities and/or key stakeholders so that the intervention reflects the realities of the communities involved. Moreover, through this article, we attempt to provide a snapshot of what real community-driven engagement can look like. As such, we demonstrate that this is often a complex process that is almost certainly never straightforward or predictable (cf. Kidd & Edwards, 2016). Community engagement involves walking away if communities indicate that they do not want to work with you. It involves lengthy, often unpredictable time frames, and the formulation of workarounds for any institutional hurdle that may present itself. Community engagement involves taking information and ideas back to the communities and getting their feedback on how the process was for them. Researchers should be wary of laying down their expectations of what communities need to do for them. Rather, as was demonstrated in our project, the communities were encouraged to drive or lead us. This was clear, for instance, in the fact that despite the key focus of our project being early detection of lung cancer, whānau discussed not only lung cancer at the hui, but all cancers and potentially other respiratory conditions as well.

Accordingly, flexibility in a research process in relation to participant engagement, time frames, and expectations for what we gathered as data was a crucial component of our research process specifically, but also relevant to co-design and kaupapa Māori research overall. Within such a research context, a key priority should be respecting and valuing the contribution of the participants. Community-engaged research should prioritise enhancing the mana of the whānau we are working with (cf. Te Morenga et al., 2018). As such, our research experience has led us to ask the question: How do you get the health message about cancer to at-risk, rural communities? The answer: *you* don't. You engage with them, and you work with them to construct the message.

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 often lead to unsatisfactory uptake of such interventions. Rather, the four communities clearly illustrate that what works for one locality may not work at all for another. 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.

Overall, this article encourages researchers and institutions to rethink who our research is for. Who will it benefit? How we can ensure that research agendas reflect the goals of communities, rather than those of a researcher or their institution?

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## ORIGINAL ARTICLE

# Hā Ora: Barriers and enablers to early diagnosis of lung cancer in primary healthcare for Māori communities

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## Funding information

Health Research Council of New Zealand, Grant/Award Number: 17/438

## Abstract

**Objective:** The objective of this research was to document the barriers to early presentation and diagnosis of lung cancer within primary healthcare, identified by Māori whānau (families) and primary healthcare providers in the Midland region of Aotearoa New Zealand.

**Methods:** This project used a kaupapa Māori approach. Nine community hui (focus groups) and nine primary healthcare provider hui were carried out in five rural localities in the Midland region. Each community hui included cancer patients, whānau, and other community members. Each healthcare provider hui comprised staff members at the local primary healthcare centre, including General Practitioners and nurses. Hui data were thematically analysed.

**Results:** Barriers and enablers to early diagnosis of lung cancer were categorised into three key themes: GP relationship and position in the community, health literacy and pathways to diagnosis.

**Conclusion:** This study demonstrates that culturally responsive, patient-centred healthcare, and positive GP–patient relationships are significant factors for Māori patients and whānau serving as barriers and enablers to early diagnosis of lung cancer.

## KEYWORDS

barrier, diagnosis, lung cancer, Māori, primary care

## 1 | INTRODUCTION

Lung cancer is one of the most common causes of death from cancer worldwide (Ferlay et al., 2013). It is the leading cause of cancer deaths in Aotearoa New Zealand (NZ) with approximately 1,650 deaths per year (Ministry of Health, 2016). In particular, Māori (Indigenous peoples of NZ) have both higher incidence and poorer survival rates for lung cancer compared to non-Māori (Ministry of Health, 2015; Robson et al., 2010; Sutherland & Aitken, 2008; Teng et al., 2016). While the main cause of the inequity in lung cancer mortality rates is due to the high rates of smoking in Māori (Walsh &

Grey, 2019) and to differences in the social determinants of health such as occupation (Corbin et al., 2011), variations in health care may also be a factor including institutional racism; research that investigates how to improve health outcomes for Māori therefore takes place in this context (Chin et al., 2018; Harris et al., 2018; Waitangi Tribunal, 2019b).

Globally, lung cancer is typically diagnosed at a late stage. Yet if detected early, patients can receive curative treatment (McPhail et al., 2015; Stevens et al., 2010), with 5-year survival rates being at 70% (Lawrenson et al., 2020). A recent review highlighted that barriers to lung cancer diagnosis within primary care related to

the relationship between General Practitioners (GPs) and patients, access to healthcare, and a lack of awareness of lung cancer symptoms and treatment (Cassim et al., 2019). While this review included one publication from NZ, an important point of discussion was the need to investigate barriers specific to minority and Indigenous groups.

This article discusses findings from the Hā Ora project, funded by the NZ Health Research Council (HRC) for three years (2017–2020). The objective was to explore the barriers to early diagnosis of lung cancer within primary healthcare, identified by Māori whānau (families) and primary healthcare providers (HCPs) in the Midland region of NZ. While approximately 14% of the NZ population are Māori, the Midland region is a predominantly rural farming region in the North Island with a population of 880,000 people of whom 27% are Māori (Ministry of Health, 2019). The Midland region has many small independent urban and rural communities which often have a shortage of GPs and poorer access to healthcare. Despite a funded public health system, primary care in NZ is provided by largely private organisations who receive a partial subsidy, and charge patients a fee. To maximise Māori patient survival from lung cancer, early detection in primary care and prompt referral remains imperative. It is therefore necessary to identify barriers to diagnosis within primary care experienced by Māori. Addressing these barriers will help increase the proportion of Māori patients diagnosed with early-stage disease and improve overall outcomes.

## 2 | METHODS

Understanding the barriers to health care for Indigenous communities requires a culturally appropriate methodology. In NZ, this has led to the use of kaupapa Māori research methodologies which emphasise the Māori world view and self-determination (Cram et al., 2006; Oetzel et al., 2017; Walker et al., 2006). Using a kaupapa Māori approach enabled us to interrogate systems of power and dominance within the health system, and to illustrate the agency and resilience of Māori participants.

The team carried out hui (focus groups) with community members and HCPs in five rural localities in the Midland region. All 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 primary care providers was followed by written materials for distribution to each community, inviting them to participate in hui (see Kidd et al. (in press) for further details).

In total, nine community hui (CH) and nine primary HCP hui were carried out. Each community hui comprised of 8–21 participants, including cancer patients, whānau, and other community members affected by (lung) cancer. Overall, the CH comprised 108 participants across all hui, all of whom either had lung cancer themselves, or had direct experience of caring for someone with lung cancer. Each HCP

hui comprised 1–6 staff at the local primary healthcare centre, including GPs, nurses and other staff. The HCP hui comprised 27 participants in total across all hui.

Data were gathered as field notes and via an audio recorder. Audio recordings were transcribed. Transcripts and field notes were thematically analysed (Braun & Clarke, 2013), and three key themes were identified: GP relationship and position in the community, health literacy and pathways to diagnosis.

## 3 | RESULTS

### 3.1 | GP relationships and position in community

The relationship between patients and GPs can serve as enablers or barriers to early diagnosis of lung cancer. Some patients 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).

These positive relationships were also reciprocated 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).

HCPs reported occasions where they have accessed the power of community relationships to enhance their care:

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).

However, longstanding GP–patient relationships were not always a positive in terms of early diagnosis. One GP noted that knowing his patients for a long time could serve as a barrier to 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 GP's position in the community, as perceived by community members:

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).

Furthermore, the HCPs' perceptions of their patients and the communities that they work in can serve as barriers or enablers to early presentation and diagnosis. Some of these perspectives showed consideration of the broader context, compassion and a desire to ensure that patients get the best possible care:

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

Yet, many had a more judgemental or racist and blame-based view of Māori. Statements included;

Māori are more tolerant of things not being quite right.

They've got an "I don't wanna know" attitude.

Māori are not as precious about their health.

Māori are surrounded by people who are unwell or unhealthy. So they tend to be complacent.

There are higher rates of unhealth in Māori because of a lack of awareness.

It's more than the money or the cost. It's the mind-set of people at the bottom of society.

Patients and whānau also recognised these attitudes. Here, communication was also raised as an issue by participants, where GPs did not understand what Māori were trying to say to them. One whānau member commented:

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 localities/communities. The most frequently discussed issue was 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).

Consequently, levels of familiarity and trust between doctors and patients directly affected whether or not patients went to see their doctor promptly following symptom onset:

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

One of the issues with the GP model of practice these days is that you go into the practice and it used to be that you always had a doctor that was OUR doctor. That doesn't happen anymore because of a lack of GPs and the turnarounds and stuff. So for us to go and talk to a total stranger that we don't have a relationship with is a big barrier. And so the model of work is not helpful because if we don't have a relationship with our doctor, you're not gonna tell him about the things that are really worrying you. (CH#7).

### 3.2 | Health literacy

How and when information is given and received is a key part of health literacy, and involves the HCP as well as the patients and whānau.

In each of our community hui, we took care to ensure that a health care expert on the topic of lung cancer was available to respond to 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 detect lung cancer earlier, the availability of a screening tool, and prevalence. In response to our questions about the symptoms of lung cancer, most people answered that they associated a persistent cough and blood in the sputum with the need to seek help. They also identified smoking as the primary risk factor for developing lung cancer.

Most people associated a lung cancer diagnosis with 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 identified as a factor in preventing people from help-seeking:

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 HCPs and patients and whānau was sometimes inadequate, 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 reported questioning the information they was given, and searching out ways to help themselves:

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

Patients and whānau described the use of unclear and overly complex language on the part of the HCPs, as demonstrated by the following exchange:

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).

The issue of language also emerged as a problem with communication:

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).

### 3.3 | Pathways to diagnosis in primary care

This section focuses on the time from when a patient is aware of symptoms through until they receive a diagnosis of lung cancer. As discussed, participants showed a good knowledge of the importance of symptoms such as a persistent cough and blood in the sputum. However, that knowledge does not always result in prompt attendance at primary care clinic. A further barrier identified was the mounting cost of attending GP appointments:

Lots of times they can't go to the doctor because they haven't got the money to pay for the doctors' fee which is now, I think it's reaching on \$35. And you know, we're continually having patients who are meant to have help for things, that can't even go to the pharmacy. (CH#4).

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).

In contrast, some HCPs 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).

Symptoms of lung cancer presented a barrier to some participants. Patients at times were diagnosed opportunistically and had few, if any, symptoms that were consistent with messages about 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).

However, many participants relayed stories of delayed 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).

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).

HCPs describe their perceptions of the diagnostic pathway from the frustration of seeing colleagues close their books to new patients:

[Our practice] picks up the slack as iwi [tribe] provider, so we keep stretching ourselves to make it work. Screening is a luxury that we don't have the capacity to provide" (HCP#1),

to the restricted availability of diagnostic scans:

I've sent through lots of requests for high suspicion of lung cancer. The majority are acted upon quickly, some were declined. As the person dealing with the client, I feel like the request should go ahead and not be declined. (HCP#5).

Some GPs, however, describe strategies to actively overcome barriers to progressing to CT scans in the diagnostic pathway:

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).

## 4 | DISCUSSION

The findings of our research build on international evidence on barriers to early diagnosis of lung cancer discussed earlier (Cassim et al., 2019) and the impact of racism on health outcomes (Reid et al., 2019). Barriers to early diagnosis of lung cancer experienced by Māori communities include the importance of GP–patient relationships, barriers relating to health literacy and in the pathway to diagnosis.

The importance of GP–patient relationships was evident in the repeated use of the phrase 'our doctor' by patients and whānau. Relationship building, or whakawhanaungatanga is an important part of Māori patient–HCP interactions (Jansen et al., 2008; Levack et al., 2016; Masters-Awatere & Graham, 2019), and have significant implications for earlier diagnosis. However, the high turnover and shortage of GPs in rural and high needs communities make continuity and cultivating enduring relationships problematic. Research from the United States and Denmark support the notion that discontinuity of care and a lack of relationship between physicians and patients affected quality of care provided to patients, and served as a barrier to early diagnosis of medical problems including cancer (Moore et al., 2004; Pedersen et al., 2019; Sharf et al., 2005). Moreover, reciprocity, trust and mutual respect are a key part of the interaction between Māori patient and GP (Jansen et al., 2008; Walton et al., 2013). However, racism remained evident among some HCPs who passed judgement and held biased views of Māori. This inability to engage with cultural conventions and tikanga can lead to misunderstanding and a breakdown in the relationship between GPs and patients. Similarly, research with Indigenous communities in Australia indicates that a lack of cultural competence by GPs was a significant barrier to early presentation and diagnosis of cancer (Davidson et al., 2013; Dunn et al., 2017; Koefler, 2012; Shahid et al., 2016). Therefore, our findings point to the need to re-examine the GP model of practice and training in NZ. This includes reassessing relationship building and communication with Māori patients, a need for anti-racism training, and improvements in cultural responsiveness.

Recent developments in NZ include a revised statement on best practice when providing healthcare to Māori, recommending a change in focus towards cultural safety and HCP reflexivity (Medical Council of New Zealand, 2019). Additional culturally centred guidelines for patient–HCP interactions include the Meihana Model (Pitama et al., 2014) and 'hui process' (Lacey et al., 2011). A key feature of these approaches is getting to know the patient. In particular, whakawhanaungatanga involves establishing connections, and both patient and HCP sharing information such as who they are, and where they are from. However, there is a need to go beyond training HCPs simply with a set of technical skills, towards anti-racism training, promoting culturally safe practice, and fostering better engagement and relationships between GPs and their communities.

Furthermore, Māori patients and whānau are aware of the key symptoms of lung cancer. The prevailing fear and belief that lung cancer is incurable were reflective of past experiences, rather than a lack of awareness of treatment. Contrary to the dominant narrative, Māori patients and whānau do not necessarily lack health literacy (Kidd et al., 2018). Rather, participants engaged in complex health literate behaviour by questioning their GP, searching online for answers and wanting to learn more about lung cancer. Yet, unclear or a lack of communication and information delivery from the HCPs is often a barrier to Indigenous patients understanding more about their disease, and can hinder health literacy (Kidd et al., 2018; Shahid et al., 2016). Clear explanations given to Indigenous patients and families with support as needed in language that is clear and contextually appropriate is necessary. HCPs should also ensure that they use lines of questioning that confirms patients and families have understood the information delivered. In NZ in particular, there needs to be a shift away from the prevailing deficit view of Māori lacking health literacy, and towards more sustained efforts to best equip HCPs to interact and communicate with Māori so they can get the most out of the healthcare system. As such, it is important to acknowledge the rich lived knowledge that Māori possess, particularly from caring for generations of whānau.

Finally, cost is a recurrent theme relating to healthcare access in NZ. Here, financial barriers extend beyond the mounting costs of GP appointments, to include other related costs such as prescriptions, medication, travel and childcare. Difficulty in accessing services, particularly for diagnostic tests, is also a barrier to early diagnosis experienced by patients and HCPs. A recent survey highlighted that prompt access to diagnostic tests must be a priority, given that GPs in NZ took more time to access tests than in most other International Cancer Benchmarking Partnership jurisdictions (Htun et al., 2017). Fostering strong positive GP–specialist relationships and ready access to diagnostic tests could be avenues to smooth the diagnostic pathway.

The findings from this research hold broader implications relating to why Māori may be disengaged from mainstream health systems, partly contributing to delayed diagnosis. Racism and lack of cultural safety on the part of GPs at an individual level could be one reason. Another could be an overall mistrust of the health system by Māori,

when it has repeatedly failed them and continues to do so (Graham & Masters-Awatere, 2020; Jansen et al., 2008). There has been system level acknowledgement of this (Waitangi Tribunal, 2019a), so a change in attitude about health literacy and health awareness of Māori is long overdue. Health services, at individual, practice and systemic levels need to increasingly work *with* Māori communities to acknowledge and value their agency and to collectively battle health inequity.

A strength of this study was the use of a kaupapa Māori, community engaged research process. This approach enabled the establishment of mutual trust between the researchers and participants, and for participants to share what was important to them, on their own terms. Another strength was that we documented a wide range of perspectives from patients, whānau, other community members and HCPs. A limitation is that we only reported barriers identified in primary care. An avenue for further investigation would be to also explore barriers in other areas of the healthcare system such as secondary or supportive care.

In conclusion, this study highlights barriers and enablers to early diagnosis of lung cancer experienced by Māori in primary healthcare. While the factors discussed are most applicable to the NZ setting, many are also likely to be translatable to Indigenous and minority groups globally. Lessons learned include, the significance of culturally safe, patient-centred healthcare and the importance of positive GP–patient relationships.

## 5 | ETHICS APPROVAL STATEMENT

This project received ethical approval from the Health and Disabilities Ethics Committees (HDEC) – Ref 17/STH/158.

## ACKNOWLEDGEMENT

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.

## CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

## AUTHORS CONTRIBUTION

SC involved in acquisition of data, interpretation of data, manuscript writing and revision; JK involved in original conception and design of study, acquisition of data, interpretation of data, manuscript writing and revision; AR involved in original conception and design of study, acquisition of data, and manuscript revision; RK involved in original conception and design of study, and manuscript revision; DA involved in original conception and design of study, and manuscript revision; MF involved in original conception and design of study, manuscript revision, KM involved in original conception and design of study, and manuscript revision; LC involved in management of study, and manuscript revision; JW involved in original conception and design of study, manuscript revision; BH involved in original conception and design of study, and manuscript revision; RL involved in original conception and design of study, manuscript writing and revision. All authors read and approved the final manuscript.

## FUNDING INFORMATION

The project discussed in this article was funded by the Health Research Council of New Zealand [HRC grant number 17/438, entitled 'Improving early access to lung cancer diagnosis for Māori and Rural Communities'].

## DATA AVAILABILITY STATEMENT

All data generated or analysed during this study are included in this published article.

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**How to cite this article:** Cassim S, Kidd J, Rolleston A, et al. Hā Ora: Barriers and enablers to early diagnosis of lung cancer in primary healthcare for Māori communities. *Eur J Cancer Care*. 2020;00:e13380. <https://doi.org/10.1111/ecc.13380>



RESEARCH ARTICLE

Open Access



# Hā Ora: secondary care barriers and enablers to early diagnosis of lung cancer for Māori communities

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## Abstract

**Background:** Lung Cancer is the leading cause of cancer deaths in Aotearoa New Zealand. Māori communities in particular have higher incidence and mortality rates from Lung Cancer. Diagnosis of lung cancer at an early stage can allow for curative treatment. This project aimed to document the barriers to early diagnosis and treatment of lung cancer in secondary care for Māori communities.

**Methods:** This project used a kaupapa Māori approach. Nine community hui (focus groups) and nine primary healthcare provider hui were carried out in five rural localities in the Midland region. Community hui included cancer patients, whānau (families), and other community members. Healthcare provider hui comprised staff members at the local primary healthcare centre, including General Practitioners and nurses. Hui data were thematically analysed.

**Results:** Barriers and enablers to early diagnosis of lung cancer were categorised into two broad themes: Specialist services and treatment, and whānau journey. The barriers and enablers that participants experienced in specialist services and treatment related to access to care, engagement with specialists, communication with specialist services and cultural values and respect, whereas barriers and enablers relating to the whānau journey focused on agency and the impact on whānau.

**Conclusions:** The study highlighted the need to improve communication within and across healthcare services, the importance of understanding the cultural needs of patients and whānau and a health system strategy that meets these needs. Findings also demonstrated the resilience of Māori and the active efforts of whānau as carers to foster health literacy in future generations.

**Keywords:** Lung Cancer, Māori, Barriers, Secondary care, Hospital, Diagnosis

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## Background

*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 hikoi ana te hikoi 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 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.*

Lung cancer is one of the most common causes of death from cancer worldwide [1]. It is the leading cause of cancer deaths in Aotearoa New Zealand (NZ) with approximately 1650 deaths per year [2]. In particular, Māori (Indigenous peoples of NZ) account for 16.5% of the NZ population [3], and have both higher incidence and poorer survival rates for lung cancer compared to non-Māori [4–8]. For instance, mortality rates for Māori from lung cancer are 2.6 times greater than in NZ Europeans [2]. The persisting health disparities between Māori and non-Māori in NZ are of particular concern [9, 10].

Diagnosis of lung cancer at an early stage can allow for curative treatment [11, 12]; however, lung cancer is typically diagnosed at a late stage when treatment tends to be palliative [13]. Barriers to early diagnosis can occur at various stages throughout the diagnostic pathway. Barriers in primary care for Māori in particular are primarily related to General Practitioner (GP) – patient relationships, the health literacy of patients and health providers, and factors such as cost, symptom presentation and delayed diagnosis [14, 15]. 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 [16]. However, this pathway also presents barriers to patients. Walton and colleagues [17] 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 [13, 18]. However, further research is needed to identify the barriers to early diagnosis of lung cancer in secondary care for Māori.

This article discusses the findings from a broader project entitled Hā Ora: Improving early access to lung cancer diagnosis for Māori and rural communities. The objective was to explore the barriers to early presentation and diagnosis of lung cancer, as identified by Māori patients, whānau (families) and primary healthcare providers in the Midland region of NZ. This paper reports on additional findings from the Hā Ora project that relate to the barriers and enablers to early diagnosis and treatment of lung cancer that are specific to the secondary care setting.

## Methods

This qualitative research used a kaupapa Māori methodological approach. Kaupapa Māori approaches emphasise local cultural contexts and self-determination by prioritizing Māori history, development and aspirations [19]. As such, kaupapa Māori initiatives have been associated with improved health outcomes and engagement for Māori (e.g. [19–22]). This approach enabled us to interrogate systems of power and dominance within the health system, and to illustrate the agency and resilience of the Māori communities who collaborated on the research.

The team carried out hui (focus groups/meetings) with community members and healthcare providers in five rural localities in the Midland region. All community hui (CH) were organised in conjunction with key Māori stakeholders in each community and followed local tikanga (protocols). 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. Kidd and colleagues’ [23] publication provides a detailed discussion of the methods used in this research. CH were led by Māori members of the Hā Ora team (JK and AR) and occurred at local meeting rooms or marae (Māori meeting houses), whereas primary healthcare provider hui (HCP) was facilitated by RL, and took place at local GP practices. All facilitators had extensive experience in community engagement.

Hui data was recorded as field notes and via an audio recorder. Audio recordings were transcribed and anonymized. Transcripts and field notes were thematically analysed [24]. Coding was carried out on qualitative data by two researchers (JK and SC) independently and then together, to ensure a rigorous analysis process. Accordingly, codes were developed into categories, and the categories were allocated into two broad themes, each comprising several sub-themes. Rigour was also considered based on the COREQ guidelines ([25]; also see completed COREQ checklist available as [supplementary material](#)).

**Results**

A total of nine CH and nine primary HCP hui were carried out by the Hā Ora team. Each CH comprised of between 8 and 21 participants, which included cancer patients, whānau, and anyone else in the community who may be affected by (lung) cancer. Each HCP hui comprised 1–6 staff members at the local primary healthcare centre or General Practice, which included the GP, nurses and/or other staff. Overall, the CH comprised 108 participants, and the HCP hui comprised 27 participants in total.

Data analysis generated two key themes relating to secondary care settings: “specialist services and treatment”, and “whānau journey”, which will be discussed in the following sections of this article. Figure 1 shows how the results in terms of the themes and sub-themes are structured.

**Specialist services and treatment**

The barriers and enablers that participants experienced in relation to specialist services and treatment are classified by four sub-themes: access to care, engagement with specialists, communication with specialist services and cultural values and respect. Here, we present both community and HCP accounts together, to demonstrate that the issues raised are experienced by both whānau and HCPs.

**Access to care**

Many participants highlighted barriers related to secondary care that they experienced leading up to, or immediately following initial diagnosis. These barriers included long waiting times and GPs having to advocate for 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)*

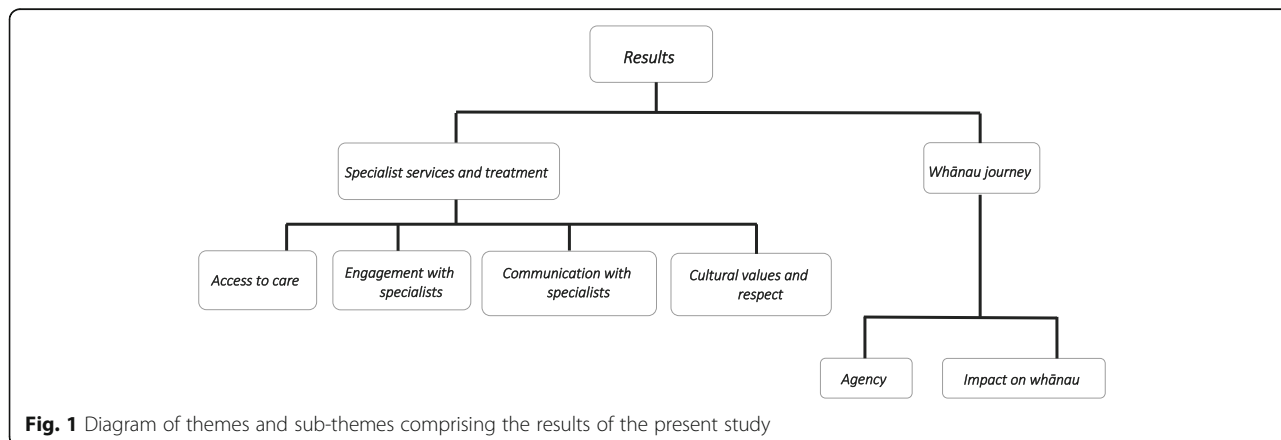
*My whānau, they've had to wait almost an hour for an ambulance to get out to [my uncle's place]. And we lost that uncle... (CH#1)*

*I had a patient who came in with back pain, referred for a chest x-ray, it was three 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)*

*Referral depends on symptoms, background of age, smoking etc. I've sent through lots of requests for high suspicion of lung cancer. The majority are acted upon quickly, some were declined. As the person dealing with the client, I feel like the request should go ahead and not be declined. If it's haemoptysis, I tend to do a chest x-ray, and then follow up to see if it's cleared. At the back of your mind you wish they'd approve the CT referral. They have a category for 'high suspicion' [of cancer]. So the referral being approved depends on the hospital's interpretation of the background information we provide. (HCP#5)*

All the primary care providers we interviewed also described difficulties with secondary care, particularly related to accessing CTs for their patients. While some described frustration with the system, others employed specific tactics to get past the barriers to having a CT referral accepted:

*We use [respiratory e-referral pathway]. You have to meet criteria to get a CT. For example, a chest x-ray abnormality, haemoptysis, pleural fusion, or something like that. If you don't have any of these, then you can't refer for a CT. So I just lie. The system has improved from before, but it's still a hoop [we have to jump through]. Now I can just ring the radiologist that I know and get an endorsement, which lets me*



**Fig. 1** Diagram of themes and sub-themes comprising the results of the present study

*refer for a CT. Still, I'll do a chest x-ray first but if we can't find any of the above criteria, I'll just lie and tick the box. (HCP#2)*

### **Engagement with specialists**

Patients and whānau also discussed negative and stressful experiences relating to their interaction with the specialist. This participant's story relates to waiting to hear what his wife's diagnosis would be, during a manifestly unsatisfactory 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)*

The quote below is representative of several participants' 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 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. 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)*

The context of the previous two quotes highlights the ineffective interactions that frustrated patients and whānau. In the first quote the specialists did not identify the whānau gap in knowledge, so the whānau believed that radiotherapy was an almost certain cure and chemotherapy was a death sentence. The result of this misunderstanding was that the patient did not continue with treatment. In the second, the specialist appeared to be focusing on the limitations of a narrow area of treatment and did not understand that whānau expected to be guided more generally about what they could do for the patient after curative treatment was unsuccessful. It is interesting also that the whānau did not appear to receive any information about accessing palliative care services.

### **Communication within specialist services**

A lack of communication among specialist services within a hospital as well as across hospitals or District Health Boards (DHBs) was another key concern that whānau discussed:

*The left arm didn't know what the right arm was doing, so the communication in the same ward didn't happen. An example, was that my husband had a drug rash. A real bad drug rash from a particular type of antibiotic. So bad that he couldn't even lie on the bed. Two days later, a nurse turned up with exactly the same drug, and she put it up there and I said, "oh no no no, you're not giving him that. He's allergic to that". She took the chart and said, "not on here". I said, "I don't care. You're not giving that to him". Another doctor said, "no water for this patient". And then when the specialist had his days off, he [husband] gained something like 8 kilos in about 2 days. Too much water. So again, I intervened and said, "no more. Stop". It's not rocket science. (CH#6)*

*I didn't know that [hospital A] couldn't share information with [hospital B]. So like that's really frustrating... It's like they don't talk to each other.... And the cancer centre there, where he did his PICC line a couple of times. The processes are different. Why are they different? Why isn't there a standard for something like flushing those PICC lines? (CH#6)*

### **Cultural values and respect**

Participants in the CH discussed the importance of having hospitals value tikanga (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:

*. . . 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 were not conducive to a Māori form of manaaki (respect/care):

*Our koros and our kuias [elders]; their mana [status/authority] 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 [body], but you need to look after the wairua [spirit/soul] 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)*

### **Whānau journey**

Barriers and enablers in secondary care relating to the whānau journey into and through cancer comprised two subthemes: agency and the impact on whānau.

### **Agency**

Participant accounts demonstrated various instances where whānau enacted agency when caring for patients by taking the initiative at various points in the cancer care journey, which served as enablers for patients. Here, agency is enacted when whānau advocate for and act on behalf of patients. For instance, as carers, whānau were proactive, and many recounted how they had to actively fight the system and advocate for patients in secondary care:

*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 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:

*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 [support] and help. (CH#2)*

#### **Impact on whānau**

As discussed, whānau are central enablers in the diagnosis and treatment journeys of Māori lung cancer patients. Accordingly, impacts on whānau members, who often took on the carer role, are significant. Such impacts stretched beyond 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)*

#### **Discussion**

Many of the findings of this study were consistent with previous research identifying secondary care barriers to the diagnosis of lung cancer that led to delays at the primary-secondary care interface [17]. Such barriers include delays for referrals (to diagnostics and/or specialist assessments), declined referrals from primary care (despite being flagged as a 'high suspicion case') and long waiting times in accessing specialist care. These delays were not specific to the lung cancer pathway, but also other forms of cancer [17, 26]. Findings are symptomatic of a health system which is under stress including having a shortage of senior medical staff [27]. For a number of years GP referrals to specialist care have had to be rationed with some patients not being able to be seen. Similarly, GP access to diagnostic tests such as CT are poor in NZ compared to other countries [28]. Our study indicates that barriers in secondary care were experienced by patients as well as GPs. In addition to long waiting times, a lack of communication between departments and/or hospitals was identified by some participants. Here, GPs highlight the need for coordination and collaboration between HCPs when working with patients and whānau. Such delays and hurdles caused barriers to

earlier diagnosis and treatment of lung cancer. GPs admitted to finding workarounds such as sending all referrals through as high suspicion of lung cancer, drawing on endorsements from specialists, or falsely applying the criteria in order to ensure prompt acceptance of their referral.

This study draws attention to the importance of tikanga and the complex involvement of whānau through a Māori patient's lung cancer journey. An acknowledgement of, and adherence to tikanga is certainly vital to ensuring patient engagement and treatment uptake, but also to showing basic respect for Māori patients and whānau in secondary care. The importance of tikanga in the broader healthcare system is not a new finding. For instance, research not specific to the field of lung cancer highlights the importance of whakawhanaungatanga, or culturally meaningful connections and respect in secondary care [29–31]. For other groups, similar cultural understanding and respect is required. This can be a challenge for a health system which is under stress and relies heavily on the use of clinical staff, especially doctors from other countries. Yet, it is an issue that needs to be addressed. While one solution to this can be the provision of intensive cultural training for clinical staff, another solution that has been used is to employ cultural navigators who provide a bridge between patients and staff [32–34]. The Bay of Plenty DHB in New Zealand, for instance, have recently engaged navigators who support Māori whānau through their secondary care journey [35]. Additionally, a workforce strategy has been proposed to train more New Zealanders, especially Māori and those from a Pacific Island (PI) background, in medicine and other clinical roles to better meet the needs of an increasing Māori and PI population [36]. It should be recognised that this strategy will take many years before the current proportion of 3.5% of Māori medical practitioners begins to mirror the proportion of Māori in the population.

Overall, Māori patients are entitled to receive culturally appropriate and respectful care and interactions from secondary care providers and staff. This is important, particularly given the fact that Te Tiriti o Waitangi (the Treaty of Waitangi) has been poorly upheld in NZ, particularly in health, resulting in the unequal distribution of the determinants of health and inaction for Māori in the face of need [37]. As such, in the present context, engaging in kaupapa Māori processes such as whakawhanaungatanga (making meaningful connections), conversing in te reo (Māori language) and taking time to fully answer questions is an avenue to redress this issue. Such steps have also been discussed as modes of increasing provider-patient engagement and to providing higher quality interactions in secondary healthcare [31].

An acknowledgement of whānau involvement in a Māori patient's lung cancer journey comes hand-in-hand with adherence to tikanga and culturally safe care [38]. Research by Jansen and colleagues [30] for instance, demonstrates the vital role that whānau play to support and advocate for patients through their hospital journey. Our study sheds further light on the sheer complexity of whānau involvement, which goes beyond the immediate hospital setting, and the broader implications of being a carer, that are incorporated into their everyday lives. Our participant accounts demonstrate the resilience and agency of patients and whānau to learn, support and advocate for each other. Such demonstrations of agency and health literacy call into question the mainstream misinterpretation of (Māori) patients as being helpless, lacking initiative, not being compliant, and disinterested [39, 40]. This research contributes to the mounting kaupapa Māori evidence in other areas of healthcare (e.g. [31, 41–45]) demonstrating that there needs to be an acknowledgement of the proactive initiatives that Māori engage in to care for their whānau. Participants of this study were also actively teaching or exposing their tamariki (children) to the processes involved in caring for the unwell, thus fostering health literacy in the next generations. These findings demonstrate that a lung cancer journey does not simply involve singular units of individual patients. Rather, a lung cancer journey is taken by entire whānau networks, who go to extreme lengths to support and care for each other, today and also in the future.

The findings of this study raises a number of issues. The NZ healthcare system overall, but certainly in secondary care, needs to ensure that the needs of Māori patients and whānau are met. Primarily, health systems must work towards consistently increasing Māori patient engagement, by supporting patients and providing higher quality, culturally safe care to patients as well as whānau. Additionally, drawing on the Health and Disability Commission's code of rights [46] and research into culturally safe healthcare [37, 47, 48], the health system should look at ways of supporting staff, through more cultural training and the provision of cultural navigators that support patients and staff. In the longer term there needs to be a review of the health workforce strategy that reduces the shortages in the system and helps provide a workforce that more closely mirrors the communities it serves. There also needs to be an improvement in communication between HCPs, and a national standard of care (e.g. in relation to processes for administering PICC lines) irrespective of DHB or region. These issues have been recognised and will be something for the newly formed Cancer Control Agency – Te Aho o Te Kahu to address [49]. Finally, providing GPs with the ability to request for diagnostic tests such as CT scans could also be an avenue to speed up the diagnostic pathway, and overcome barriers in early diagnosis of lung cancer in secondary care.

This study had several strengths and limitations. The strengths of this study include an inherently kaupapa Māori approach, and a holistic view of barriers within secondary care, as perceived by patients and whānau, as well as primary healthcare providers. A limitation of this study was that it has not included the perspective of the secondary care services in the research. Future research could explore the wider perspectives of secondary care services relating to barriers and enablers to diagnosis and treatment of lung cancer, and may provide further information that was not captured in this study.

## Conclusion

This research provided insight into barriers as well as enablers experienced by Māori lung cancer patients and whānau in secondary care. While some barriers and enablers may be more applicable to the NZ context, findings can be relatable and thus applicable to other Indigenous and/or minority groups globally. Lessons learned include the need to improve communication within and across healthcare services; an understanding of the cultural needs of patients and whānau and a health system strategy that meets these needs. We should also acknowledge the resilience and agency of Māori and the active efforts demonstrated by whānau to foster health literacy in the future generations. Other lessons include better access for diagnostic services for primary care practitioners and greater standardisation of care between different secondary care providers.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12885-021-07862-0>.

**Additional file 1.**

**Additional file 2.**

**Additional file 3.**

## Acknowledgements

Not Applicable.

## Authors' contributions

JK: original conception and design of study, acquisition of data, interpretation of data, manuscript writing and revision, SC: acquisition of data, interpretation of data, manuscript writing and revision, AR: original conception and design of study, acquisition of data, manuscript revision, LC: management of study, manuscript revision, BH: original conception and design of study, manuscript revision, RK: original conception and design of study, manuscript revision, JW: original conception and design of study, manuscript revision, MF: original conception and design of study, manuscript revision, KM: original conception and design of study, manuscript revision, DA: original conception and design of study, manuscript revision, RL: original conception and design of study, manuscript writing and revision. All authors read and approved the final manuscript.

## Funding

The project discussed in this article was funded by the Health Research Council of New Zealand [HRC grant number 17/438, entitled 'Improving early access to lung cancer diagnosis for Māori and Rural Communities']. The

funding body did not play a role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

#### Availability of data materials

All data generated or analysed during this study are included in this published article.

#### Ethics approval and consent to participate

This project received ethical approval from the Health and Disabilities Ethics Committees (HDEC) – Ref 17/STH/158. Written consent was obtained from all study participants prior to interviews and focus groups.

#### Consent for publication

Not Applicable.

#### Competing interests

The authors declare that they have no competing interests.

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Received: 20 September 2020 Accepted: 31 January 2021

Published online: 04 February 2021

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# Indigenous perspectives on breaking bad news: ethical considerations for healthcare providers

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Received 16 September 2020

Revised 4 November 2020

Accepted 27 November 2020

## ABSTRACT

Most healthcare providers (HCPs) work from ethical principles based on a Western model of practice that may not adhere to the cultural values intrinsic to Indigenous peoples. Breaking bad news (BBN) is an important topic of ethical concern in health research. While much has been documented on BBN globally, the ethical implications of receiving bad news, from an Indigenous patient perspective in particular, is an area that requires further inquiry. This article discusses the experiences of Māori (Indigenous peoples of New Zealand) lung cancer patients and their families, in order to investigate the ethical implications of receiving bad news. Data collection occurred through 23 semistructured interviews and nine focus groups with Māori lung cancer patients and their families in four districts in the Midland Region of New Zealand: Waikato, Bay of Plenty, Lakes and Tairāwhiti. The findings of this study were categorised into two key themes: communication and context. Avenues for best practice include understanding the centrality of the HCP–patient relationship and family ties in the healthcare journey, and providing patients with the full range of viable treatment options including hope, clear advice and guidance when the situation calls for it. Overall, the findings of this study hold implications for providing culturally safe and humanistic cancer care when BBN to Māori and Indigenous patients.

## INTRODUCTION

Most healthcare providers (HCPs) work from ethical principles based on a Western model of practice, and the Hippocratic tradition. Many Indigenous cultures, however, have a very different framework of values that need to be taken into account in medical care. Breaking bad news (BBN) is an important topic of ethical concern in the fields of health research and medical education. BBN involves delivering bad, serious or significant news to patients and whānau (family), and can include test results or diagnoses of long-term or life-altering conditions.<sup>1</sup> Overall, HCPs are driven by an ethical imperative to do good by their patients. Historically, the paternalistic patient-care model involved the HCP acting as the patient's guardian, and delivering only selected information that steered the patient to what the HCP considered was the best decision.<sup>2</sup> Since then, there has been a turn in focus towards patient-centred care. As such, various expert consensus guidelines were published to aid HCPs in BBN.<sup>1 3 4</sup> The more prominent protocols or guidelines to support best practice in BBN include ABCDE,<sup>5</sup> BREAKS,<sup>6</sup> Kayes 10 steps,<sup>7</sup> Girgis and Sanson-Fischer's consensus guidelines and best practices<sup>3 8</sup> and SPIKES.<sup>9</sup> In oncology, SPIKES is the

most widely used protocol in guidance,<sup>10</sup> teaching programmes<sup>11</sup> and by HCPs in practice.<sup>12</sup> Themes common to all these guidelines involve finding an appropriate setting, establishing rapport, assessing the patient's previous knowledge of the condition, their wish for more information, avoiding medical jargon, supporting patients' emotions, allowing for questions, summarising and discussing the next steps.

The experiences of BBN from both HCP and patient perspectives have been extensively documented.<sup>1 3 4 7 9 10 13–23</sup> However, the ethical dilemmas relating to BBN have only received scant attention. The research in this area tends to mostly focus on HCP perspectives, discussing topics such as patient privacy, autonomy, informed consent, truth-telling and full-disclosure.<sup>24–31</sup> The ethical implications of receiving bad news, from a patient and whānau perspective in particular, is an area that warrants further inquiry.

This article has two main aims. First, we explore the ethical implications of receiving bad news from a general patient perspective. Second, more specifically, we discuss the ethical implications of Māori (Indigenous peoples of New Zealand (NZ)) lung cancer patients and their whānau receiving bad news. Briefly, Māori models of health exist and are well known within the Aotearoa health system.<sup>32 33</sup> The most commonly used model is Mason Durie's Te Whare Tapa Wha,<sup>34</sup> which describes a holistic model of health comprising the realms of tinana (physical), hinengaro (mental and emotional), whānau (family) and wairua (spiritual) health. It is also important to note here, that in the present context, 'bad news' included a lung cancer diagnosis, as well as test results (eg, X-ray, CT scan, PET scan, etc), delivered by various HCPs including general practitioner (GPs) and secondary care physicians, nurses and specialists.

## METHODS

### Recruitment and data collection

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

Semistructured interviews were carried out with a total of 23 Māori lung cancer patients and whānau (comprising 16 patients, and 7 whānau members). Nine participants were male, and 14 were female. Patient recruitment was carried out by respiratory or cancer nurse specialists based at the hospitals of



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**To cite:** Cassim S, Kidd J, Keenan R, et al. *J Med Ethics* Epub ahead of print: [please include Day Month Year]. doi:10.1136/medethics-2020-106916

each district. Interviews were carried out by a Māori researcher, and were 1–2 hours in duration. Interviews commenced with *whakawhanaungatanga* (building connections between the interviewer and participants), and often opened and closed with *karakia* (prayer).

CH were carried out in five rural localities within the four districts mentioned previously. All CH 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 (see work by Kidd *et al*)<sup>35</sup> for further details of the community engagement process). A total of nine CH were carried out, each comprising between 8 and 21 participants, which included patients with cancer, *whānau* and other community members affected by (lung) cancer.

### 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.<sup>36</sup> Analysis was carried out by SC and JK independently and then together, to ensure a rigorous analysis process. Findings were categorised into two broad themes: communication and context.

## FINDINGS

### Communication

Communication by the HCP was a key theme discussed by all participants, and involved how the diagnosis and treatment options were delivered to patients with lung cancer and their *whānau*. Our findings highlighted three subthemes relating to communication, which involved providing an array of options and clear advice, giving patients and *whānau* hope, and the use of analogies and simple language.

### Options and clear advice

Participants indicated that when discussing their diagnosis and treatment, it was important that they were presented with as many options as possible, so they could collectively discuss and decide on the next steps on their lung cancer journey. For instance, participants in CH would have appreciated a ‘smorgasbord’ of options to be presented to them and their *whānau*, without having to specifically ask for it:

A: All [patients] want to hear about is how the hell am I gonna get cured? Because that’s what I asked when my wife was diagnosed. Give us a smorgasbord of opportunity. The person who was there with me was meant to be a liaison person, said oh but it’s too expensive. And I said, I’m not talking to you. Because I was looking for the best—for health. Price shouldn’t be of any consequence.

B: I think it’s about letting us have those options. And how can that smorgasbord be spread before me without me having to make a special case for it. (CH#4)

Moreover, when the diagnosis and treatment options are delivered, Māori patients indicate that the provision of clear advice and direction are important to them. Participants in another CH, for instance, compared the communication styles of the two specialists who discussed treatment options with them following diagnosis:

With that initial meeting with the two surgeons, one surgeon is a professional—explained to us our options. We didn’t know

nothing. Thank god for the other surgeon. Because in order to follow without committing himself illegally, he gave us enough ideas about what action to take. And we were so grateful. We were there for clarity. Not following a checklist or some standard procedure. We didn’t know where to go, or who to turn to. But at that initial meeting we got direction. He was very clear. And we took that advice. (CH# 6)

### Hope

Giving hope was an important aspect of delivering (or receiving) bad news to Māori lung cancer patients and *whānau*. Many participants were diagnosed with late stage, often palliative lung cancer. Thus, while many were aware that their cancers were incurable, their oncology specialist telling them that there is nothing else they can do, was unhelpful:

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 refer you to anything natural. To give it a go. Cause what have we got to lose? Where does he go from here? Give us some hope. It was old Google that helped us in the end. We got on there and had a look at what was being offered naturally. (CH#6)

This account builds on the previous theme, where the options presented by the HCP could include alternative treatments such as natural remedies or *rongoā* (traditional Māori treatments) to make the patient comfortable, ease their pain and most importantly, to give them hope. Despite being at the ‘end of the road’, how an HCP communicates this message can significantly ease patient and *whānau* stress, and can improve quality of life in the time they have left.

### Analogies and simple language

The use of analogies and simple language can also be instrumental in easing stress of the diagnosis and prognosis for patients and *whānau*. Moana’s daughter relates how their specialists explained her lung cancer diagnosis and treatment clearly to them, using common analogies in a way that they could visualise and understand what was going on:

We were told [Mum is] at stage IV, which means it’s not curable and [we got a] really good explanation. The reason why it’s not curable is because it’s not a single cell or solo lump that can be operated on and removed. ...It had little highway nodes to other parts of the body and therefore you can operate and try and get it out, but history has taught that it causes more problems because the cancer has already spread—finds new highways and spreads even more. However, we can treat it to make sure that the cancer doesn’t spread anymore or grow and really improve the quality of life. In reality it’s totally understandable to hear these words, because we want to hear the truth... [They also said] that infusion Chemotherapy acts like a weed killer. And like a weed killer you could spray it on the weed... and it kills the weed but unfortunately it damages other things in its path and can hurt other things as well. (Moana’s daughter, female, Waikato)

Honesty and simple, relatable language were important, and appreciated by Moana and her *whānau*, despite finding out that the cancer was at stage IV and incurable.

### Context

The delivery of a diagnosis can vary considerably based on the situation. For instance, patients may want to know their

diagnosis as quickly as possible. Conversely, others may not be ready for their diagnosis, and want to gather whānau to hear the news. HCPs need to adapt their style of delivery based on different patient realities. Accordingly, our findings highlighted two subthemes relating to context: proactive patients and the role of whānau.

### Proactive patients

Keerehi was very eager to hear the results of her CT scan, and promptly arranged an appointment with her GP, who did not have time to prepare for the delivery of bad news:

After the CT scan... the GP knew nothing about it! It was because I'd pushed for them to come straight to the GP and as soon as they turned up there I rang the GPl walked into the room, she sat there and she goes 'what can I do for you today [Keerehi]?' And I said to her, you can read those CT results up on your screen and tell me what the story is? Anyway she spins around, looked at it for a couple of minutes and then she turned back to me... she was lovely, I mean, I take my hat off to her... she said, '[Keerehi] would you like me to get someone to ring for you? To be with you?' And I said 'no, I've been waiting for 2 weeks for this, you might as well tell me now'. And she even had tears in her eyes telling me. She wasn't expecting to be telling me that. (Keerehi, female, Waikato)

Here, despite being caught off-guard, the HCP adapted to the situation and delivered her test results in a manner that was greatly appreciated by Keerehi. Here, the GP seems to have acted with care and compassion towards Keerehi.

### Role of whānau

Having whānau actively participate with the patient has implications in terms of patient privacy, particularly in mainstream medical care from a predominantly 'Western' approach. However, for Māori patients, whānau play a key role in any health journey. Rewi's whānau, for instance, served as mediators who relayed his late-stage lung cancer diagnosis to him, as Rewi had difficulty listening to and receiving this information:

Rewi Aw it pisses you off doesn't it. You don't know where you stand. And they think you's gonna like sit there and listen. Obviously not. You've got other things in mind. I was like aw well I'm outta here!

Son: We just kinda keep him positive. And we gave him as much information and do as much as we can for him. 'Cause you know he gets a little tongue tied sometimes... this is your worst day and like he's repeating himself over the same things. So we're coming in and finding out what the doctor's talking about and try and get them to understand from his point of view (Rewi and his son, Waikato)

As Rewi's son points out, the day a patient receives a palliative lung cancer diagnosis becomes the 'worst day' in their life. Therefore, some patients not only struggle with their diagnosis, but also refuse to receive it. In such contexts, HCPs can follow the whānau member or carer's directive on how to proceed. At a CH, the wife of a patient explains how she bore the burden of receiving the bad news and relaying it to her husband, who was not ready to hear it from the specialist:

Sometimes [my husband] didn't want to hear the bad news, but I knew 'cause I knew him inside out. So I would leave the room [with the HCPs], and said so what's going on? So they would share that with me. (CH#6)

Additionally, when delivering bad news, including whānau in the discussion is important. Here, the individual patient's

health is seen as being connected with the health of the whānau. Therefore, when bad news is delivered, it impacts on the whole whānau and thus, HCPs need to have care and compassion for everyone who is present for that conversation::

As a [doctor] the first thing you do is start talking to the patient. And tell them you need to do this and this. But they don't talk to the whānau that are sitting there. Telling the whānau that [my wife has] got lung cancer, this is what's gonna happen, you know? That kind of thing can help the whānau. Explain it to them, and making sure that you're not only talking to the patient but to the family there with them as well. And giving something that the family can understand. (Keerehi's husband, male, Waikato)

...the whole tikanga within, within the process... Knowing that we come with many whānau members, children, aunties, uncles, everybody wants to come... they need to be there and their koros [grandfathers], their nans they need them there.... Because this is part of your healing process, this is what is going to make it better for you. (CH# 1)

Participants also highlighted that within a predominantly 'Western' healthcare space, it is whānau who ensure that tikanga is followed, and who look after the wairua (spirit/soul) of (particularly elderly) patients by ensuring that their mana (authority/status) is respected and maintained. At a CH, participants discussed the importance of having whānau support to fill the gap, or address the discrepancy in mainstream healthcare:

If you are tūturu to your Māori-ness [everything is subsumed by your Māori identity], you know that the whānau looks after their own... Their [HCP] job is to look after the tinana [body], but you need to look after the wairua too. Because that's what keeps the person going (CH# 2)

Overall, for Māori, whānau play a central role in, and are as much a part of the lung cancer journey as patients.

## DISCUSSION

The findings of this study are consistent with BBN guidelines such as SPIKES,<sup>9</sup> and extend this knowledge by exploring ethical dilemmas in the specific context of Māori lung cancer patients and whānau. As such, our findings demonstrate that while all the ethical dilemmas raised are important specifically for Māori (and potentially also relevant to other Indigenous communities), many of these concerns may also be relevant to all patients in general. Parallels with existing guidelines include the importance of simple language that are likely useful when interacting with all patients, and HCPs understanding how whānau are placed in the interaction that are important specifically to Māori and Indigenous communities, but also more generally applicable in some contexts. Key areas for additional discussion include communication and context.

Providing patients with clear advice, direction and hope were three key points raised, relating to communication. It is important to note that the establishment of connection (whakawhanaungatanga) is a vital first step in communication for Māori patients and whānau which has been well described elsewhere.<sup>37,38</sup> When receiving bad news, first the delivery of clear information and advice to patients is vital to ensure they understand what is being communicated and to adjust language and the pace of delivery accordingly. Regular checking back with patients and whānau can help ensure they understand the information delivered to them. In NZ, culturally tailored models of communication such as the Hui Model<sup>39</sup> or the Meihana Model<sup>40</sup> have been developed to assist HCPs. Whakawhanaungatanga is also a key part

of the GP–patient relationship, where trust and safety is established. This is important, as the GP is often a patient’s first point of contact when receiving a diagnosis or test results. Similarly, we also wish to highlight the ethical significance of ‘care and compassion’ shown by HCPs towards their patients when delivering bad news. Most importantly, an HCP needs to be able to understand how to be caring and compassionate with patients in general, and with Indigenous patients in particular, where their Indigeneity is an important aspect of the context.

HCPs need to balance their patients’ rights to involvement and choice in their treatment with the desire many have for direction at a critical and traumatic time in their lives. Participants indicate that giving direction is not perceived as coercion. Rather, Māori place a lot of trust in, and respect their HCPs as the expert,<sup>41–43</sup> and as such seek guidance and direction from them. In saying this, it is also important to note that patients may want choice. Therefore, guidance and advice also involves providing patients with a ‘smorgasbord’ of options about the next steps. One area of controversy is whether patients should be advised of scientifically proven options that are not available in the public health system due to cost. HCPs (often oncologists) have to navigate the balance between deciding whether or not the patient can afford certain treatment options and raising expectations that may not be realised, so that patients are not left disappointed that they cannot access expensive drugs or treatments. In the NZ context, oncologists are obliged by the Health and Disabilities Commission to provide full disclosure around what the patients and whānau may benefit from. HCPs should establish whether patients are insured or can otherwise cope with the costs of non-standard treatments when broaching this topic. Sometimes it appears that assumptions about patients’ circumstances are made based on appearance, ethnicity or job status.<sup>44</sup> Clear communication and transparency are key to avoid misunderstandings or misplaced assumptions.

Third, even in the face of mortality, Māori patients and whānau seek some degree of hope from their HCP. Given that for Māori communities specifically, cancer tends to be associated with a death sentence, due to past experiences with whānau members, and the overall inequity in health outcomes,<sup>45</sup> patients require some form of reassurance and hope from HCPs. However, the issue of hope may also be relevant to all patients, rather than being specific only to Māori. Nonetheless, such instances raise the question: is it ethical to give patients seemingly ‘unrealistic’ hope? Certainly, the literature discussing ‘truth-telling’ often indicates that optimal supportive medical care requires honesty, full disclosure and for HCPs to allow patients the chance to finalise affairs and say their goodbyes.<sup>24</sup> Yet, as Whitney *et al*<sup>46</sup> demonstrates, HCPs can maintain an open-ended hopefulness, or offer hope to help patients day-to-day such as natural remedies to ease nausea or pain from treatment. Here, while HCPs may be cautious about the ethics of offering unproven treatment options to patients, it is important to bear in mind that Māori perceptions of health are holistic, and go beyond physical health to also encompass spiritual health (wairuatanga) and connections to the natural world.<sup>32, 34, 47</sup> Thus, when working with Indigenous peoples, HCPs need to consider holistic, natural and spiritual wellness alongside physical outcomes. Overall, providing patients with an array of options to promote holistic wellness is also compatible with an HCP’s obligation to be truthful, and still convey support and caring. Thus, an HCP’s awareness of the roles of hope and hopefulness can help sustain patients and whānau as they adapt to the reality of a palliative illness.<sup>46</sup>

Context was the second theme derived from our findings, and encompassed issues such as the role of whānau and patient’s

privacy. Whānau play an important role in a Māori patient’s cancer care journey, where patient and whānau should be considered as one, rather than as separate units when delivering bad news. Moreover, despite mainstream ‘Western-centric’ medical ethics dictating that a patient’s individual right to privacy takes precedence, when working with Māori, HCPs may find themselves having to follow the lead or direction of whānau members when BBN. Non-disclosure of a diagnosis based on whānau request has been discussed in-depth as an ethical issue in previous research, particularly in ‘non-Western’ and Indigenous contexts. For instance, HCPs felt that non-disclosure carried high psychological costs for patients and whānau.<sup>24</sup> However, medical ethics research from non-Western and/or migrant contexts recognise that this is not an issue of lying to patients or withholding information. Rather, it is about respecting the cultural contexts of patients and whānau.<sup>24, 48, 49</sup> Ultimately, the HCP finds themselves having to reflect and adapt to the (cultural) context of the interaction, and respond in the best interests of the patient and whānau. Importantly, the participants in this study did not advocate for non-disclosure but rather sought to mitigate the trauma of receiving the bad news by delivering it to whānau to act as intermediaries. This, of course, relies on the HCP having established a clear communication process with the patient and whānau in order to effectively assess the most appropriate way to deliver the news.

Overall, the findings of the present study hold implications for providing culturally safe and humanistic cancer care when BBN to Māori and Indigenous patients. However, while the findings indicate that ethical concerns arise in the context of culture, reflecting specifically Māori beliefs and conceptual structures, parallel concerns and experiences might also be found in patient experiences in general. Avenues for best practice include understanding the centrality of the HCP–patient relationship, and providing patients and whānau with the full range of viable treatment options alongside providing hope, clear advice and guidance when the situation calls for it. Additionally, building on existing BBN guidelines, HCPs should consider whānau an equally important a part of the patient-care journey. HCPs could also engage in ongoing reflective practice to hold themselves accountable for providing culturally safe, family-centred care.<sup>50, 51</sup> More broadly, HCPs and medical educators need to emphasise the cultural context of their patients when considering how to break bad news.

This research had several strengths and limitations. The strengths include our focus on ethical dilemmas relating to Indigenous patients and their families. A limitation of this study was its focus on patients with lung cancer and only on Indigenous peoples of NZ. Future research could investigate the experiences of patients from other culturally diverse groups and those with other forms of cancer or chronic disease to gain a more comprehensive understanding of patient perspectives of receiving bad news. The findings of this study are most applicable to HCPs working in NZ, but they can also be relatable and applicable to HCPs working with other Indigenous and culturally diverse groups globally.

**Twitter** Rawiri Keenan @DrRawiri

**Acknowledgements** 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 hikoi ana te hikoi 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.

**Contributors** All authors have contributed significantly to this manuscript. SC: acquisition of data, interpretation of data, manuscript writing and revision. JK: original conception and design of study, acquisition of data, interpretation of data, manuscript writing and revision. RK: original conception and design of study, manuscript revision. KM: original conception and design of study, manuscript revision. AR: original conception and design of study, acquisition of data, manuscript revision. BH: original conception and design of study, manuscript revision. MF: original conception and design of study, manuscript revision. DA: original conception and design of study, manuscript revision. JW: original conception and design of study, manuscript revision. RL: original conception and design of study, manuscript writing and revision. All authors read and approved the final manuscript.

**Funding** This project was funded by the Health Research Council of New Zealand (HRC grant number 17/438, entitled 'Improving early access to lung cancer diagnosis for Māori and Rural Communities').

**Disclaimer** The funding body did not play a role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** This project received ethical approval from the Health and Disabilities Ethics Committees (HDEC) of New Zealand – Ref 17/STH/158.

**Provenance and peer review** Not commissioned; externally peer reviewed.

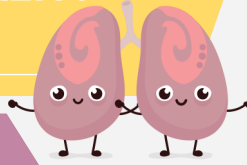
**Data availability statement** All data relevant to this study are included in the article.

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# HĀ ORA: DESIGNING A WEBSITE FOR IMPROVING AWARENESS OF LUNG HEALTH

Joshua Fellingham, Shemana Cassim, Michael Mayo, Lynne Chepulis



## INTRODUCTION

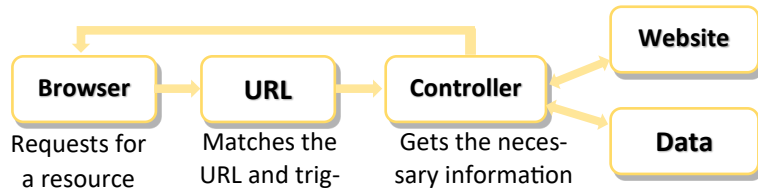
This lung awareness website entitled, “Hā Ora: Let’s talk lung health”, arose from a broader research project entitled Ha Ōra: Improving early diagnosis of lung cancer for Māori and rural communities and was underpinned by a kaupapa Māori approach. The objective of the project was to explore the barriers to early diagnosis of lung cancer, experienced by Māori patients and whanau. The broader project involved four rural localities in the Midland region of New Zealand who each had high lung cancer rates, to identify what they consider barriers to early diagnosis. Four different interventions were designed in partnership with each community to help promote earlier diagnosis of lung cancer.

The website is a result of work with Opotiki. With the purpose to help and support whānau across Aotearoa with lung related conditions including lung cancer, to go and see the doctor as soon as they notice any symptoms or get worried about something not being right.

## DEVELOPMENT

### Back-end

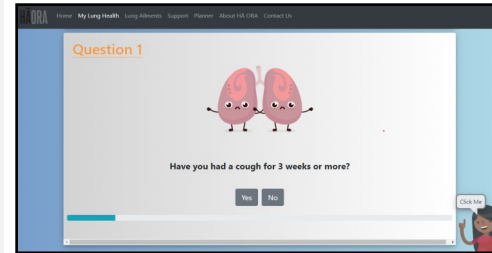
Development was completed using the Django REST Framework. Django is a free and open source web application framework, written in Python. A web framework is a set of components that helps to develop websites faster and easier. The simplified graphic below illustrates how the framework (Django) displays a website on a user’s browser.



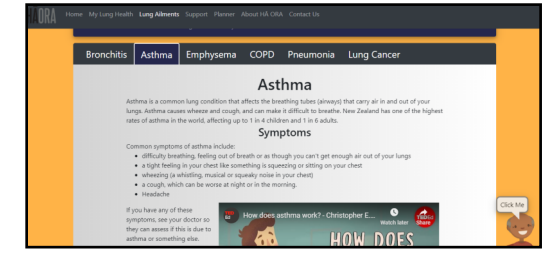
### Front-end

For the front end, the design framework of choice was Bootstrap 4, used for developing responsive mobile first websites. This included templates for typography, forms, buttons, navigation and other interface components. JavaScript (interaction), CSS (layout) and HTML (information) was also used throughout to build the website.

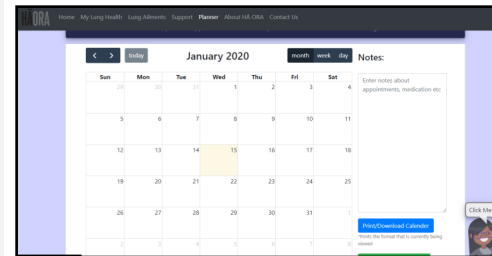
## FEATURES



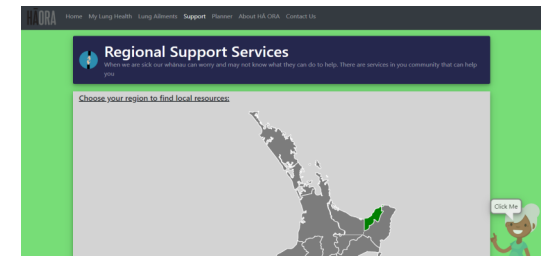
Lung questionnaire with tailored responses



Easy to navigate Lung Ailment info page



Editable calendar to record notes/dates



Find support services in a specific region



Each page shares a true/actual patient story

## CONCLUSION AND NEXT STEPS

The Hā Ora website will be piloted in Opotiki, where the community will have the opportunity to navigate the website and provide feedback on their experience.

## ACKNOWLEDGMENTS

This was made possible thanks to the UOW Summer Research Scholarship Program and the New Zealand Health Research Council. Also a special thank you to my supervisors Shemana, Lynne and Michael.



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