

Perspectives of potentially eligible Indigenous Māori on a lung cancer screening programme: a qualitative study

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ABSTRACT

AIMS: Lung cancer causes more deaths than any other cancer, globally and in Aotearoa New Zealand, where it disproportionately affects Māori. We aimed to understand Māori perspectives on lung cancer screening in Aotearoa New Zealand to guide its equity-focussed implementation, including identifying enablers and barriers.

METHODS: We took a Kaupapa Māori based co-design approach to inform future screening, recruiting Māori current/ex-smokers and members of their whānau (family) for three focus group phases held in Auckland, Aotearoa New Zealand in August 2019. Participants responded to a proposed lung cancer screening pathway and shared their attitudes and beliefs about lung cancer and screening. Results were thematically analysed.

RESULTS: The 21 Māori participants supported future lung cancer screening in Aotearoa New Zealand. Perceived benefits included being more informed about lung cancer and screening and enabling healthier future generations. Barriers to screening were previous negative health service experiences; fear; stigma; and access, including time, cost and transport. Enablers included providers' cultural competence; clear communication; a one-stop shop; and support with transport. A range of factors could potentially influence a decision to participate in screening.

CONCLUSIONS: Participants favoured future lung cancer screening and identified key barriers and facilitators of screening.

Lung cancer is the greatest single contributor to the gap in life expectancy between Māori and non-Māori¹ (non-Māori include European, Pacific, Asian and other ethnicities). Māori age-sex standardised mortality rates for lung cancer are over three times that of non-Māori.¹ While higher rates of smoking contribute to inequities, Māori deaths from lung cancer are also associated with having a greater number of comorbidities than non-Māori, being diagnosed later and having worse experiences (including racism) in the health system.¹ Māori develop lung cancer around 6 years earlier than non-Māori, and develop lung cancer with lower smoking exposures.¹

Because lung cancer is often asymptomatic in its earlier stages, most people with lung cancer are diagnosed late and survival is low. Screening for lung cancer is important to ensure people with lung cancer are diagnosed earlier, increasing their chance of a cure. Those who are diagnosed at the earliest stage (stage 1A) have a much improved (at least 70%) 5-year survival. Screening for lung

cancer has been proven internationally to be effective at reducing cancer-specific mortality in a number of high-quality trials.^{2,3} While low-dose computerised tomography (LDCT) screening is increasingly accepted as an evidence-based intervention to decrease lung cancer mortality, other factors contributing to optimal implementation of screening require understanding of local contexts.⁴

Aotearoa New Zealand does not currently have a lung cancer screening (LCS) programme. Introducing a screening programme into the Aotearoa New Zealand context requires an equity focus to ensure that existing inequalities are not exacerbated. Researchers have found that LCS in Aotearoa New Zealand is feasible and likely to be cost-effective,^{5,6} but ethnic-specific information is needed, including Māori perspectives on LCS, to inform future implementation.

Te Oranga Pūkahu: The Lung Cancer Screening Research Programme is a Māori-led approach to ensuring that a future national programme benefits Māori. The research

programme centres Te Ao Māori (the Māori world) and whānau (family) experience, drawing from Kaupapa Māori approaches (research that is done *with, for and by* Māori).⁷ Seeking the voices and experiences of whānau Māori as the first step in programme development, then co-designing the programme itself with whānau, ensures the whole programme is built to achieve Māori health equity.

The proposed LCS process as outlined to participants involves the selection of potentially high-risk individuals, an assessment to determine individual risk, the offer of an LDCT scan to those considered high risk with shared decision making about agreeing to this offer, and then the follow-up of abnormal CT scans as required.

Methods

Kaupapa Māori research locates Māori at the centre of enquiry, aims to be of benefit to Māori, is focussed on equitable health outcomes, considers Māori world views and Māori ways of knowing, being and doing, and centres Māori aspirations. Our research focusses on a significant health issue for Māori: its goal is designing LCS that has excellent Māori participation, reduces lung cancer mortality and inequities, and is culturally safe and acceptable for Māori; and it addresses questions that are important to meet this goal. Our research was *led* by Māori, was done *with* Māori and is *for* Māori health equity gains.

Focus groups took the form of hui including marae protocols. This approach served to ensure that whānau attending felt welcomed, their spiritual needs were taken care of, they experienced manaakitanga, and hui were facilitated to ensure maximum participation by each person in the process. Notes of each hui were sent out to participants after each one and recapped at the beginning of subsequent hui. Facilitation of hui was supported by two Māori facilitators with health research and evaluation experience, particularly in the cancer care areas.

Eligibility

Invited focus group participants were Māori living in the Auckland and Waitemātā regions, potentially eligible for LCS (current smokers, or ex-smokers who had quit within the previous 15 years and were aged between 50 to 75 years) and their whānau members.

Recruitment

Three focus group phases were held in Auckland

between 15 and 29 August 2019. The phase one focus group was held in South Auckland (a home-based whānau group) with participants recruited through snowballing methods (researcher contacts in the first group). This group was predominantly made up of three whānau who could be categorised as “hard to reach”, in that their engagement with the health system was minimal (whānau who the system has failed to engage).⁸ The age range of this group was 25–55 years of age. In phase two, two groups were held at the Waitakere Hospital marae with participants recruited via an existing research database of Māori participants aged over 60 years who had participated in an abdominal aortic aneurysm (AAA) screening project and had consented to be contacted for further research. This cohort had shared risk factors (for example, smoking history) in terms of LCS eligibility. The third, and final, phase involved all participants being invited to the marae to review findings from the prior focus groups and provide feedback on the interpretation of findings. All participants in each phase were encouraged to invite whānau members to attend and participate in the focus groups.

Consent and data collection

After an initial phone call, those who were interested were sent a letter with a participant information sheet and consent form and were invited to attend a focus group session. In each phase, the hui process⁹ was used to structure the session. This process incorporated mihimihi and karakia (traditional Māori welcome, greetings and prayer) and whakawhanaungatanga (relationship building) followed by kai (food) and then discussion relating to LCS (the kaupapa). The focus group then formally concluded with closing karakia. All three focus group phases were concluded by a final karakia.

Data analysis

Field notes and recordings were undertaken at the focus groups, with data coded and organised into preliminary themes by the hui facilitators (KP and MM) and co-author SMC. Transcripts were then coded by co-authors SRC and BB. SRC grouped codes into categories and developed themes, which were informed by the earlier preliminary analysis.¹⁰

Results

Twenty-one potentially eligible Māori (10 males and 11 females) and nine whānau members took

part in the focus groups.

In the third focus group phase, participants confirmed the following key themes: 1) positivity towards LCS, 2) fear of the disease and prior negative experience of the health system, 3) other barriers to screening, including access, 4) enablers for Māori participating in LCS, and 5) influences on LCS decision making. Feedback is presented in Table 1 and summarised below.

The second phase included participants who worked within the health system and group facilitators identified that these participants strongly favoured whānau *knowing* what was available within the health system, including screening.

Positivity towards LCS

After being taken through the proposed process for LCS, in general, Māori participants were positive towards LCS and engaged with the Kaupapa. They were hopeful that it would pave the way for healthier future generations and were altruistically focussed on the future of their whānau. They were positive about the opportunity to be more informed about lung cancer and screening, including understanding the risks and benefits of screening. They were also positive about potentially getting a second chance at life through the earlier diagnosis of lung cancer.

Fear of the disease and prior negative experience of the health system

Some participants were hesitant about LCS, mainly due to fear of the disease and prior negative experiences of the health system and screening. Some of their whānau had not survived lung cancer. Some were generally distrustful of the health system, including their own doctors. They also warned about the potential of the “grapevine” to spread negative experiences.

Other barriers, including access

Access was a significant barrier to Māori participants potentially taking up LCS. This included cost, time to attend appointments and travel. Participants voiced that for Māori, getting time off work to attend the screening was problematic, as was arranging childcare. Furthermore, the inconvenience of having to attend multiple appointments requiring repeated hospital visits was another barrier. A further barrier was the stigma of being a smoker and its association with a lung cancer diagnosis.

Enablers for LCS

On the other hand, factors that could enable Māori to take part in LCS included:

Practical support

Support with transport could take the form of taxi or parking chits, transport to screening or mobile sites in rural communities. Time off work to attend screening and a “one-stop shop” arrangement where participants could address multiple health needs at one time were also favoured.

Kaupapa Māori approaches

Culturally safe practices, specifically a focus on Kaupapa Māori, were very important. Participants valued whānau-friendly processes, such as whānau support at screening and being able to take children to appointments. They also appreciated a culturally competent and kind navigator to walk alongside them. They suggested communication that was grounded in te reo Māori (Māori language) and tikanga (cultural practices), although they did acknowledge limits around eligible people’s resonance with and confidence in te reo Māori due to historical trauma and colonisation. Whakawhanaungatanga was a key aspect of any potential LCS programme. Participants said that they would respond better if those facilitating the programme took time to engage in relationship building, at initial contact as well as throughout delivery of screening services. Trust and friendliness of providers was important.

Clear, meaningful communication

Clear communication that was culturally responsive included accessible study information (written in everyday, non-clinical language) and clear explanations of risk was an enabler. Participants wished to be reassured that taking part in screening did not necessarily mean a death sentence and that there was potential for cure if caught early.

Programme messaging, awareness raising and role modelling

Programme messaging that promoted a “by Māori, for Māori” approach to LCS and that was cognisant of the connotations of specific word choice was an enabler. For example, it was felt that wording needed to be strong yet positive to encourage people to take the invitation to screening seriously while not putting them off. It was important to raise awareness among Māori of

Table 1: Focus group themes.

Theme	Sub-theme	Feedback	Focus group phase
Positivity towards LCS	Personal experience	<i>"We've all experienced cancer."</i>	FG1
	Being informed	<i>"Awareness and some knowledge is awesome I think."</i>	FG1
		<i>"There is actually something that I can do about that."</i>	FG1
		<i>"The confirmation, the knowing that yeah everything is good, which is cool."</i>	FG1
		<i>"Their [FG2 participants] experiences were that whānau need to know—they need to know now. So screening was about knowing what was happening."</i>	FG3
	Whānau–hapū–iwi-focussed	<i>"I'm looking at my mokos [grandchildren] ... and I'm thinking this won't happen to them. And you know... that's what we are doing this for to make it better for the coming generations."</i>	FG1
		<i>"Because each family, if they look after themselves, their hapū [sub-tribe] will be safe and then their iwi [tribe] should be safe. So everything starts in the home, not out there."</i>	FG2
		<i>"I support it simply because it will help us in our future and our iwi you know?"</i>	FG1
	New chance at life	<i>"I feel that this lung cancer scanning would be very positive for me and it would be like I'd be wearing a new korowai [cloak of protection]. Yeah I'd be happy with that."</i>	FG1
	Fear of the disease and prior negative experience of the health system	Fear	<i>"Cancer it's a death sentence. It's basically 'you're gonna die'."</i>
<i>"Our Māori women don't turn up for breast screening because they're scared shit[less] that they will be diagnosed with breast [cancer]."</i>			FG2
<i>"So the fear was that if you get diagnosed with cancer for you that's going to ... carry on forever and it won't ever go away."</i>			FG3
<i>"Ok, if you can't confirm to me that it has no side effects, I have doubts about that."</i>			FG1
Bad experiences		<i>"I've had a bad experience, um, in breast scanning so that's how I feel even after today because I refuse to go back to breast cancer [screening]."</i>	FG1

Table 1 (continued): Focus group themes.

	Distrust/relationships	<i>“That relationship, the way you were treated the last time [can be a] barrier ... it wasn’t last time, it was the last screening of any kind really, and you had a bad experience. I would hesitate to go personally.”</i>	FG2
	Grapevine spreads negative messages	<i>“If something went wrong I would be really riri [angry] and I would tell everybody about my bad experience.”</i>	FG1
		<i>“And some of the kōrero [conversations], that grapevine ... when they don’t like something. And, um, and they will say, no, don’t go there. Don’t go there.”</i>	FG2
Other barriers, including access	Access—cost	<i>“Wouldn’t do it [LCS] if it cost money.”</i>	FG1
	Access—transport	<i>“Too far from home, can’t get there. Access.”</i>	FG2
	Access—time/whānau/work commitments	<i>“Whānau support if you’ve got young kiddies can you take them to your appointment? Somebody needs to look after them—that stops people from screening.”</i>	FG3
		<i>“He has huge concerns about work. He’s there every day. He doesn’t want to take a day off to go to the doctor.”</i>	FG1
	Stigma	<i>“There’s this whole smoking thing around lung cancer ... people like thinking or saying you got lung cancer ‘cause you smoked for this long or just somehow blaming the person for having a disease that literally kills anybody it feels like it.”</i>	FG1
	Inconvenience	<i>“That’s a big one when you go to the hospital and you go to an outpatients area to do all your outpatients stuff and yet you’ve got to go to five different places to talk to people about your screening stuff. Yeah at different times.”</i>	FG3
		<i>“That you’re not coming back to the hospital all the time. It’s just inconvenient you know.”</i>	FG3
Enablers for LCS	Practical support	<i>“Cause diabetes has satellites ... so why can’t the other services have satellite of some sorts, you know, you’ve got, um, cervical, you’ve got breast screening that has the mobile clinics. You have, um, dialysis who transports the patients by taxi and then transport them home. So there’s ... no cost to the patient whatsoever.”</i>	FG2
	One-stop shop	<i>“If someone was going to the hospital, how can they address three different things at one time?”</i>	FG2

Table 1 (continued): Focus group themes.

	Kaupapa Māori approaches	<i>“But when it’s given ... Kaupapa Māori, delivered in a Kaupapa Māori way, in a Kaupapa Māori setting, then we can actually ... I sit there and I look at what’s on the wall and anything Kaupapa Māori I say okay. That makes sense to me.”</i>	FG2
		<i>“I like anything that starts with whakawhanaunga ... so you could ask me to do anything after I know everyone in the room. I know who the people who want my information [are] or who want my opinion. If I knew you and you knew me and you told me who everyone was then I feel fine.”</i>	FG1
	Clear, meaningful communication	<i>“Yeah like ‘nodule’ I have no idea what a nodule is.”</i>	FG1
		<i>“The simple language and having motivation to actually do it ... And if I get really good clear information, I’m happy.”</i>	FG3
	Whānau-focussed	<i>“What’s needed to make a decision so for this group it was if my whānau can be with me throughout the process.”</i>	FG3
		<i>“I’m only going to start with my own whānau at first and then maybe leading by example, the other whānau would actually hop on the band-wagon. But first and foremost, I would take care of my whānau and my health.”</i>	FG2
Promotion	Programme messaging, awareness raising, role modelling	<i>“If my mum did it and my Auntie did it then I [would] just do it just ‘cos they’re doing it.”</i>	FG1
Influences on decision making	Information	<i>“Decision making, what they need is facts. Yeah. What they need is the detail, detailed information. What happened? Why does that happen?”</i>	FG2
	Established relationship with doctor	<i>“I would personally do it [make decision about LCS] with my GP [general practitioner] because I have a relationship with them ... but ... if I didn’t have a GP like I wouldn’t talk to a doctor if it wasn’t my doctor I wouldn’t talk to him.”</i>	FG1
	Key decision maker within the whānau	<i>“You try and you focus on the members of the whānau who do make a decision ‘cos I feel like I could tell him ‘go get a screening’ and he’d go because I told him to.”</i>	FG1
		<i>“You’re not having to do the work to convince this whole whānau to go. You’re just convincing one person to go.”</i>	FG1

Table 1 (continued): Focus group themes.

	Autonomy	<i>“It’s up to you. I like that because it didn’t sound pressuring, it didn’t sound like you should do this, it was just you need to weigh [up] the pros and cons and decide for yourself.”</i>	FG1
		<i>“I’d like to make my own decisions ... and I like to have all the information.”</i>	FG1
	Invitation source	<i>“Because if I got a DHB [District Health Board] letter, I probably wouldn’t open the DHB letter.”</i>	FG1

why screening was necessary. The wider community could role model screening behaviour, influencing the uptake of LCS.

Influences on decision making

Decisions to take part in LCS could be influenced by quality (detailed and factual) information; GP (general practitioner) relationships; a key decision maker within the whānau; autonomy over the decision-making process; and the invitation source. Participants valued being able to make a decision that was right for them and one they were not feeling pressured into by the way the information was framed. Some participants felt they would respond better to an invitation to participate in LCS from their GP rather than a “cold call” letter or phone call. Participants felt the key decision maker within the whānau would need to be involved in decisions for other whānau members to take part in LCS. It was therefore important to appeal to whānau units and whānau decision makers.

Discussion

This study aimed to gain an understanding of Māori perspectives of LCS through a series of focus groups to guide equity-focussed implementation. Our study has identified some of the key barriers and facilitators for Māori participation in LCS. Overall, Māori participants enthusiastically supported future LCS in Aotearoa New Zealand, with perceived benefits including being more informed about lung cancer and screening, and improving the health of future generations. Perceived barriers to screening included fear of the disease and/or a cancer diagnosis; prior negative experience of the health system and screening; stigma from the association with smoking; access barriers, such as time to attend appointments, cost and transport;

as well as inconvenience. Perceived enablers of a culturally acceptable LCS programme were practical support such as transport; a “one-stop shop” health service visit that combined health appointments; culturally competent practices; clear communication; user-friendly processes; and promotion within and among Māori whānau. Participants identified a range of factors influencing a decision to participate in LCS. Anticipated barriers to LCS for Māori are suggestive of racism and echo the results of a recent qualitative review, summarising healthcare experiences of Māori within *“an alienating public health system.”*⁸

The equity focus of our research programme is a novel approach to LCS internationally and to other cancer screening programmes within Aotearoa New Zealand. Other national cancer screening programmes in Aotearoa New Zealand (breast, bowel and cervical) have not been *designed* from an equity perspective. This study’s key strength is that it describes the views of Māori who would potentially be eligible for LCS and of their whānau regarding LCS and the design of a potential LCS programme. Many of those who participated in the early focus group research have gone on to become the programme’s consumer advisory group, Te Hā Kotahi (broadly translated as “united breath”). This group meets regularly, supported by Health New Zealand – Te Whatu Ora kaumātua (respected elders), and has contributed significantly to the framing of the research programme, research questions, participant materials, logo and design, and to the name of the programme. The programme is led by a Māori principal investigator (Professor Sue Crengle) and all data are governed by Māori members of a steering group. Our results are limited by the limited demographic information we have about participants. While efforts have been taken with transcription

and qualitative analysis to ensure data integrity, not all parts of the recordings were able to be transcribed clearly and where this occurred, the discussion was not included in the data analysis and results. Like all qualitative research, these results are not necessarily generalisable outside the context where they were gathered; for example, they may not reflect the views of some Māori who live more rurally.

Our work builds on other Aotearoa New Zealand co-designed participatory research with Māori that identifies enablers and barriers to diagnosis of lung cancer.¹¹ Previous research has focussed on earlier diagnosis of symptomatic lung cancer within primary care. Our research is specific to the setting of a potential national LCS programme. Commonalities between these two strands of qualitative research with Māori participants include: the importance of the GP–patient relationship (potentially either helping or hindering the diagnostic pathway); access, including the cost and availability of health-care/services, travel and childcare; interest from Māori patients in being more informed about lung cancer; fear, and the association of a lung cancer diagnosis with a death sentence; the provision of information about lung cancer in clear and straightforward language; awareness of potential language barriers for people who only speak te reo Māori; and the importance of whakawhanaungatanga and manaakitanga, which includes taking good care of whānau throughout the cancer screening journey.¹¹

Importantly, our research fits within the international research gap specifically concerning LCS and equity, particularly for Indigenous peoples. Over the last few decades, the international evidence base for LCS has expanded, supporting the use of organised LCS programmes across varied health systems.⁴ Currently, national programmes are in place in the United States, Poland, Croatia and South Korea, with smaller-scale programmes underway elsewhere, such as those in Canada, Australia and Europe. In 2022, the United Kingdom recommended targeted LCS.⁴ A recent *Lancet* review summarises the LCS evidence base and identifies opportunities for optimising LCS, including tailoring screening geographically for specific populations and incorporating smoking cessation and assessment for chronic obstructive pulmonary disease (COPD) and cardio-vascular disease (CVD).⁴ The review states that “LCS programmes must focus on health equity”, and highlights that culturally safe approaches are “critical”.⁴

Other pro-equity suggestions for improving access to LCS include mobile CT scanners and offering free ride-shares to screening.⁴

Our results align closely with international evidence concerning barriers to participation in LCS: “poor awareness of LCS, concerns about the risk of false positives, distrust of the health-care system, smoking-related stigma, inconvenience, fear of a cancer diagnosis, and worries about financial cost.”⁴ Our findings add to Australian research that identifies that Indigenous barriers to lung cancer diagnosis and treatment include a lack of public transport and inadequate communication, as well as poor coordination between health services.¹² Similarly, in Scotland (the LUNGSCOT study, focussed on eligible Scottish residents rather than on ethnic inequities), barriers to engaging in LCS included fear, stigma, mistrust towards health systems and professionals and practical constraints including travel, cost, time, and competing priorities; enablers included positive messaging and the use of mobile units to improve accessibility.¹³ Cavers et al.¹³ found that LCS was broadly acceptable to participants, some of whom lived in rural and deprived areas.

Our LCS research programme also aligns with key Aotearoa New Zealand policy directives. Recent national reforms of the Aotearoa New Zealand health system have led to an Interim New Zealand Health Plan, *Te Pae Tata*, which prioritises equity.¹⁴ Explicitly, *Te Pae Tata* states, “We will be committed to achieving equitable health outcomes for Māori.”¹⁴ This includes enabling “The voice of whānau in the design and delivery of services that are culturally safe and produce equitable outcomes.”¹⁴ Health equity for Māori is a key specified outcome of the new *Pae Tū: Hauora Māori Strategy 2023*, with its commitment to honouring Te Tiriti o Waitangi.¹⁵ Similarly, a key goal of the *New Zealand Cancer Action Plan 2019–2029* is that “New Zealanders experience equitable cancer outcomes.”¹⁶

In Aotearoa New Zealand, engaging with Māori specifically around LCS had not been done before. Engaging with Indigenous communities from the very early stages of research or programme design is an important first step for introducing equity into the cancer screening pathway. Co-design of *Te Oranga Pūkahu*, the LCS programme, has included engagement with Māori communities, building long-term relationships, co-creating the screening pathway and its associated resources, ensuring mana motuhake (self-determination, control) and addressing key

aspects of existing stigmatisation, racism and health system inequities.

A key aspect of Te Oranga Pūkahu is participatory involvement of Māori who are potentially eligible for LCS, and their whānau, with their input co-designing the direction and application of the research, ultimately to co-produce a national programme that ensures Māori benefit.

Co-design is becoming more common in health research, with its focus on ensuring that research is meaningful to end-users.¹⁷ Simply put, co-design means “*Designing with, rather than designing for.*”^{18,19} Within other cancer screening programmes in Aotearoa New Zealand, Māori women have been involved in co-design in HPV cervical cancer self-testing, as part of qualitative research specifically concerning acceptability.²⁰ To a certain extent, co-design has influenced recent international qualitative research (Canada, United States, Australia) with Indigenous populations that has sought to understand Indigenous perspectives and experiences of cancer screening programmes, including cervical,^{21,22} breast^{23–25} and colorectal.²⁶ These studies have expanded the evidence base about enablers and barriers to Indigenous participation in cancer screening.

Cancer Australia has recently engaged in LCS co-design workshops with Aboriginal and Torres Strait Island populations in their national

programme preparation;²⁷ however, there is little published evidence specifically concerning LCS and Indigenous co-design. A few qualitative studies discuss LCS research in the context of vulnerable populations and equity, including the use of co-design for smaller programme aspects such as learning materials for health professionals,²⁸ patient-centred research questions²⁹ and providing feedback about the design of LCS, specifically the pathways for engaging people with a biomarker blood test.³⁰

As a result of participatory involvement in our study, Māori participant feedback from the three focus group phases has directly influenced the development of Te Oranga Pūkahu. The focus group findings reported here, alongside surveys (to be reported elsewhere) are the foundational aspects of the programme, which is now offering LDCT to Māori participants.³¹ The focus groups and subsequent survey have informed the central research question of a randomised controlled trial, currently underway, that compares two different invitation approaches to LCS—via GPs or central hub.³¹

Māori are generally supportive of LCS; however, a number of factors need to be taken into account to enable participation in the screening pathway. Our findings lend support to the implementation of LCS in Aotearoa New Zealand.

COMPETING INTERESTS

The authors declare that they have no competing interests.

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