

## **Progress Report**

Bowel Cancer NZ - Focus on achieving equitable outcomes for Māori through the National Bowel Screening Program

**Project:** How the National Bowel Cancer Screening Program Should Be Delivered in Te Tai Tokerau, Aotearoa to Māori - An Equity Focused Kaupapa Māori Qualitative Study

Dr.Moea Nimmo (MBChB) Primary researcher

Dr.Maxine Ronald (FRACS) Study supervisor

### **Project Objectives**

- Highlight the need – for such a programme to improve outcomes for Māori
- Demonstrate – how such a programme could look and roll out an effective pilot
- Drive effective change – by showing what can be achieved in a culturally appropriate way we hope to begin a cascade of multi-year change in the way that health care is delivered to Māori

### **Overview of Project to date**

The purpose of the project is to understand how Māori living in Te Taitokerau think that the National Bowel Screening program should be delivered in order to have optimal uptake and success of the bowel screening program once it is rolled out in Te Taitokerau in October 2021. The purpose has been to support the implementation of a colorectal cancer screening programme which is informed and designed by Māori communities in Northland, is culturally safe and competent, and which will achieve a high level of engagement with the program.

The project recognises that there are a number of barriers to equitable bowel screening for Māori and aims to mitigate some of those barriers. It is hoped that information gained from the project will inform actions to improve access and reduce barriers to the bowel screening program.

The project has been underway for the last 6 months and has involved face to face interviews with the primary researcher and multiple Māori health organisations and iwi and hapu throughout Te Tai Tokerau. The information gained from the interviews has been compiled and analysed and key themes identified. The final interviews have been conducted in late April 2021.

The large geographical area of Northland, pressure on Māori health organisations and iwi and hapu due to Covid-19 and other organisational demands have provided challenges in terms of timeliness of the conducting the interviews.

Both the primary researcher and project supervisor are Māori who have iwi connections to Te Taitokerau and the project has been conducted in close relationship with the Māori Health Directorate of Northland DHB who sponsor the primary researcher's position.

Key themes have emerged from the data provided to date and divided broadly into barriers and enablers to successful engagement with the bowel screening program. Two interviews are yet to be transcribed and analysed.

Barriers accessing the bowel screening program include: embarrassment, concerns about the collection and return of faecal samples (FIT kit) and further investigations including maintaining mana and issues to do with transgressions of tapu, fatalism about dying young, lack of knowledge and information provided in a way that is understandable and acceptable to Māori, distrust of the health system, lack of cultural competency, inappropriate public health messaging and lack of involvement of Māori health providers, socioeconomic barriers to transport.

Potential enablers include: use of Te Reo Māori in information pamphlets, use of Māori health providers to deliver information, education and screening packages, using kaiawhina (Māori support workers) for delivery and pick-up of bowel screening packages, design of local bowel screening program by Māori, linking program with marae based activities and programs.

Secondary outcomes of the project have been increasing education about the bowel screening program and developing stronger relationships between the DHB and Māori communities.

Once the final two interviews are transcribed the data will be analysed. In accordance with Kaupapa Māori principles the information obtained will be given back to the participating groups to ensure that what has been transcribed is correct and that they agree with the conclusions made. The project team will then discuss with the Māori Health Directorate, Māori health providers and iwi and hapu how the funds provided for this project should best be used.

At this stage, no funds have been used as the recommendations are yet to be confirmed. Based on the information gained to date it is anticipated funds may be used to develop information and educational content in Te Reo Māori and to resource Māori health providers, and iwi and hapu workers to provide educational sessions at marae and community centres on bowel screening, and to deliver and collect the FIT kits. Time frames for this would be approximately late May/early June 2021 in anticipation of the bowel screening program starting in October this year.

Once the project is completed it will be submitted for publication. A draft of the project is attached for interest regarding methodology and interim results but is not complete and requires further analysis and finalisation.

DRAFT:

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## Introduction

Poorer access to quality healthcare produces inequitable bowel cancer outcomes amongst Māori in Aoteroa. This poses major breaches to the Treaty of Waitangi and from a New Zealand health policy perspective warrants addressing. With the roll-out of the bowel screening program set to be completed nationally by August 2021, issues pertaining to equitable access for Māori remain outstanding. In fact the literature suggests, current program design is at risk of increasing inequitable outcomes for Māori. Subsequently poorer bowel cancer morbidity and mortality will increase. Already data from the National Bowel Screening Unit of the Ministry of Health show under-screening among Māori in many district health boards around New Zealand. Disregard for the demographic many Māori in New Zealand represent could in part account for diminished access to the program and highlight poor program design. This is particularly true for those living in rural areas. Bearing in mind the nuance of the screening program, the struggles to achieve better access to healthcare and the need to meet Treaty obligations, this study aimed to determine how Māori in Northland would like the bowel cancer screening program delivered.

## Methodology

### The Māori Population

Māori are the indigenous people of New Zealand and self-identification as Māori by ethnicity has become the standard practice for census data collection. Although people can report multiple ethnicities anyone listing Māori is counted as Māori under both prioritised and total response analyses. To identify as Māori the Ministry of Health in New Zealand uses the census ethnicity question and protocol. Māori participants were defined as those who, at interview, confirmed descent and self-identified as New Zealand Māori.

### Māori in Te Tai Tokerau

In New Zealand approximately 15% of people identify as Maori, with the Northland region containing the highest proportion of Maori to non-Maori (Statistics NZ, 2013). Of the total population, there are approximately 33,920 people eligible for the BSP. In this group approximately 5960 Māori were eligible for the BSP in 2018/2019. This has increased to approximately 6260 Māori eligible for the BSP in 2019/2020 (Statistics NZ, 2013; MOH, 2019). The data for specific iwi (tribe) that eligible Māori affiliate to in Northland, is not available.

## Sampling

In efforts to represent Māori across Northland, the study aimed to involve participants from as many iwi as possible and Māori Health providers. Participants included Ngāi Takoto, Te Aupōuri, Ngāti Kahu, Ngāpuhi, Ngāpuhi ki Whāingaroa, Te Rarawa, Te Uri O Hau and Ngāti Whātua. Participants were recruited from local iwi, rūnanga (assembly or council) and Māori health provider groups including Te Runanga O Te Rarawa Te Anga Mua (Kataia), Te Hauora O Te Hiku O Te Ika (Kataia),

Ngati Hine Health Trust / Hauora Whanui (Kawakawa), Te Ha O Te Oranga O Ngatiwhatua (Dargaville), Te Runanga o Whaingaroa (Kaeo) and Te Hau Ora O Ngapuhi (Kaikohe).

## Recruitment

Potential participants were first sent an invitation email and information package to explain the overall study. Those who did not respond to the first email were followed up with a reminder email, then follow-up phone calls. A second round of phone calls were conducted to those who did not respond in the first round. Participants were booked via phone into a scheduled interview appointment. At the beginning of the interview, a brief explanation of the bowel screening program was provided followed by time given for any questions. Participants then signed informed consent and in keeping with data sovereignty any indication to have results emailed to them on completion of the study were made. Interviews were then audio recorded once consent was gained.

## Semi-Structured Focus Groups

The study undertook semi-structured interviews altogether over an approximate 9 month period. Appropriate rangatiratanga and kaupapa Māori protocol distinct to each iwi/hāpu/whanau group were considered at the onset of each interview. Focus groups varied between 5-20 people and lasted between 30 minutes to 2 hours. Socio-demographic information was collected at the start of the interview. In total 55 people were involved in the study. There were 41 women, 14 men and the average age of participants was 59.9 years. Participants in the study affiliated to several iwi - 7 affiliated to Ngāti Kahu, 11 to Te Rarawa, 3 to Te Aupōuri, 26 to Ngā Puhi, 8 to Ngati Whatua, 1 to Te Uri O Hau, 3 to Ngāti Kahu, 3 to Ngāti Kuri, 1 to Ngati Takoto and 3 to Ngāti Hine. (numbers need to be adjusted for final two interviews).

## Kaupapa Māori Methodology

Kaupapa Māori methodology was used for this study. The methodology places Māori beliefs and values at the centre of the research process and when needed recognises the impacts of colonization and power imbalance on Māori health outcomes. The study recognises that previous research relating to Māori health has under-appreciated the historical context in which Māori have developed. Further a lack of an understanding of the macrosystems which Māori are influenced by, inadvertently reinforces stereotypes, creates impasse and fails to explain inequity and unequal health outcomes in a way which leads to transformative change. The methodology focuses on eight principals including: Tino Rangatiratanga (The Principle of Self-determination), Taonga Tuku Iho (The Principle of Cultural Aspiration), Ako Māori (The Principle of Culturally Preferred Pedagogy), Kia piki ake i ngā raruraru o te kainga (The Principle of Socio-Economic Mediation), Whānau (The Principle of Extended Family Structure), Kaupapa (The Principle of Collective Philosophy), Te Tiriti o Waitangi (The Principle of the Treaty of Waitangi) and Ata (The Principle of Growing Respectful Relationships). Data interpreted by this methodology underpins the results, discussion and conclusion. The lead investigator and clinical research supervisor affiliate to Te Tai Tokerau iwi including Ngā Puhi, Ngāti Whatua, Ngāti Hine and Ngāti Wai. Furthermore accountability and collaboration with Te Poutokomanawa Maori Health Services (TPMHS) of the Northland District Health Board (NDHB), ensures that research contributes to Māori health development. TPMHS also provided a significant bridge to local Māori organisations and groups. TPMHS offered cultural advice regarding best practice and tikanga that reflects Te Tai Tokerau iwi, hāpu and communities. Acknowledging rangatiratanga and advances in Māori knowledge, resources and people is a key component of this research project. All questionnaires, interview structure and recruitment approaches were approved by the NDHB Ethics Committee and the New Zealand Health and Disability Ethics Committee (HDEC).

## Qualitative Outcomes/Analysis Methods

Data was transcribed verbatim and themes were identified after both manual review of transcripts and analysis using NVivo 11 software. Three investigators were involved in the identification of themes. Independent coding and coding consistency checks were undertaken to ensure trustworthiness of the data analysis. Data was thematically analysed, incorporating a hybrid approach of both, data-driven general inductive analysis and a deductive a priori template of coding (Crabtree & Miller, 1999; Boyatzis, 1998). Deductive a priori analysis of data confirmed pre-considered themes that were suspected to be raised before the study began. However on the other hand new and emergent themes were also described consistently throughout the study on general inductive analysis.

## Results

After analysis of interviews, data arranged it-self into three common themes- firstly those relating to barriers to access and participation (barriers), secondly changes or adjuncts to aspects of the program which might improve participation (enablers) and thirdly the means by which to accomplish the aforementioned improvements (facilitators). Participants were aware of bowel cancer or knew of family who had been diagnosed with bowel cancer however a majority did not know symptoms in keeping with bowel cancer disease and neither were they aware of the bowel cancer screening program overall.

### Theme One: Barriers

Access describes, whether patients who need care, get into the system or not. While having access is the potential to utilise a service, gaining access is the process toward achieving this. People may have potential access but can encounter many difficulties in utilising services. Difficulties with access are generally described as barriers to healthcare and have been categorized into several overarching themes. They are mainly located to individual and system level barriers and are experienced across a range of situations. In the study participants consistently described several key barriers to access and participating in the program.

### System and Organisational Barriers

System level barriers raised in the study included lack of public health messaging, lack of promotion and education of the program at the community level and among health professionals working in the primary sector, lack of relevant education material about the program for both health professionals and non-healthcare participants, lack of cultural competency among health professionals to appropriately engage Māori participants, lack of engagement of Māori communities and groups in program design, lack of involvement and development of Māori and iwi health providers into delivery of the program and historical grievances through colonisation producing distrust and unwillingness to engage with the health system. Unmet health policy requirements according to Treaty obligations were raised in addition to questionable screening age for Māori and the need to reduce this.

### Public Health Messaging

Participants agreed a lack of public health messaging on a regional and national scale posed a major barrier. Study participants often related the importance of public health messaging back to its positive impacts on the breast and cervical screening programs. It was highlighted that without population level education to improve incentive, participation among the target audience would be low.

## Cultural Design of the Program

Lack of cultural design and a lack of involvement of local or regional Māori communities in designing program components and delivery was described. This was important regarding education material, including the invitation package, the instruction pamphlet and the consent forms. Furthermore participants alluded to the importance of Māori and iwi health providers as absolutely pivotal in successfully delivering the program to Northland Māori. It was postured that the invitation package did not focus on Māori but rather appeared to be designed for tauiwi or non-Māori. It might be surmised that opportunities may be missed without culturally leveraging available resources in a way which could encourage Māori to participate in the program.

## Primary Care Involvement

Onus was placed on the Ministry's lack of involvement of the primary care sector to drive education, promotion and delivery of aspects of the program. As described previously the importance of the primary care sector including Māori and iwi health providers could not be understated. It was described that education gaps in part could only be alleviated with direct involvement of primary level health professionals, like healthcare promoters who were in the most proximal and opportunistic position to achieve this. That is study participants consistently encouraged active involvement of primary level healthcare professionals such as clinical nurse specialists, nurses and health promoters, for both the delivery and pick-up of the FIT. This is particularly important for rural Northland. Moreover much doubt was expressed in the ability for an eligible Māori participant in Northland to complete the FIT by themselves without adequate support. Many of the discussed barriers contribute to this opinion. In addition

## Cultural competency

Cultural competency and a lack thereof was a systemic barrier described by participants and most relevant in highlighting why Māori in some instances fail to engage the health system successfully. It was highlighted that failure to engage Māori in a culturally sensitive manner would deter them from participating in the program altogether and improvements among healthcare professionals in this area were needed. This is described in more detail below.

## Health Policy

Failure to meet Treaty obligations was not commonly discussed during interviews. However its implications towards achieving better Māori health was singularly mentioned. It was acknowledged that without true partnership with Māori at an organizational level in the health sector, seeing improved Māori outcomes would be difficult to realize. In this instance one participant admitted Māori appear to be persistently left out of the discussion and planning of important health program implementation. Consequently program design fails Māori because collaborative approaches are missing. On the other hand reducing the eligible screening age for Māori was suggested a number of times and remains a topic of significant debate in New Zealand's current political arena.

## Individual Barriers

Individual level barriers included behavioural issues pertaining to embarrassment and matakū (fear) surrounding bowel cancer health, resultant avoidance behaviours due to fear of investigating bowel cancer, fatalistic views and perceived lower life expectancy. Cultural barriers included difficulties preserving mana and tapu (personal integrity, dignity) during the screening process, difficulties overcoming taha tinana or physical privacy and the culturally taboo nature of discussing bowel cancer in general. Barriers relating to education gaps included lack of incentive, misunderstanding of

the significance of screening, lack of knowledge bowel cancer and the program and misunderstanding of eligibility. Language barriers and difficulty interpreting the invitation package, FIT instructions and lack of Te Reo Māori in the program instruction material was commonly described. Multiple socioeconomic barriers were discussed including financial and travel restraints and technology barriers preventing reliable connection to the health system, a vital component of short and long term follow-up of care.