

Kia Piki te Ora o Ngā Whānau
**A study on whānau access to
effective healthcare**

**A Fourth Year Medical Student Project
University of Otago, Wellington**

Arohanui



Manuhiritanga



Matewa



Mahi



Korero



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Abstract

Aim:

This research report aims to identify the barriers and enablers to access to healthcare for a group of marginalized whānau in South Wellington, in order to develop solutions for the Consultancy Advocacy and Research Trust.

Methods:

Interviews using a kaupapa methodology were conducted with whānau, key stakeholders including consultancy advocacy research trust staff, health practitioners and Māori health experts. Whānau narratives were then subject to a qualitative analysis in conjunction with health practitioner and Māori health expert input to examine experiences, explanations and elucidate themes.

Results:

Eight themes emerged, providing an overview of key areas where barriers and enablers were identified. These included affordability, competing priorities, logistics, health literacy, whānau perceptions, discrimination, service design/focus, individual quality of care.

Conclusions:

We need to be dissatisfied with a large health inequity within New Zealand that currently exists. We need to dedicate resources to decreasing the gap between Māori and non-Māori and strive towards giving all New Zealanders equal opportunities to access effective health care and in turn equitable health outcomes. Solutions to reduce barriers and enable health participation include free shuttles, further subsidized GP services, outreach health literacy programs, volunteer community based child care, creating more whānau centred services, changing stereotypical terminology, creating a more whānau based approach to service design and focus and empowering whānau to provide more feedback.

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Introduction

Whānau sometimes struggle to access effective healthcare for a number of reasons, including the costs of transport, prescription. Other barriers may include experiences of discrimination; cultural factors in health service provision, and whānau priorities such as paying rent and buying food, which can compete with healthcare related costs like doctor's fees and prescription charges. There are a wide range of reasons concerning why some whānau do not access effective healthcare and why some providers, although making their best effort to reach these whānau, are unable to get them through the clinic door unless in a state of crisis or facing a medical emergency. Prevention and early intervention may go some way to circumventing health crises, and may lead to better health outcomes in the long run^{1, 2}. However, there are a number of enduring and substantive issues to consider when reframing methods and approaches to healthcare with these whānau.

In Particular whānau find access to effective healthcare more difficult than others. The Ministry of Social Development have used the term 'hard to reach' whānau, as a policy label term³. This is not a term whānau in this study use to describe themselves.

Māori leaders have been vocal in advocating for a whānau centered approach to healthcare, one that positions the obligation to remove barriers to care not with health services and government agencies not whānau. Therefore, hard to reach whānau may not be the correct way to categorize these whānau, some whānau would say it is the health services that are hard to reach, whereas some health services would say it is whānau who are hard to reach. For the purposes of this project, we have decided after taking advice from the Consultancy, Advocacy and Research Trust (CART), to refer to the whānau in this study as 'Ngā Whānau'. This supports the right to self-define according to the principles of Whānau Ora and Te Tiriti o Waitangi.

CART is a Māori organisation dealing with communities in the South Wellington region. Their clients formed the population group for our research and are defined by CART as: “people who seek whānau ora, gang members, prisoners and people who have been in prison, long-term unemployed, mentally ill, those on the margins of society, people alienated and alone and people who are struggling with drug addiction”⁴.

Ngā Mokai, meaning the ‘fatherless ones’, was a term coined by James K. Baxter in reference to this population group and is sometimes used by CART⁴. By forming a tribe of “Ngā Mokai”, Baxter “attempted to provide a family or community base for marginalised members of New Zealand society.”⁵

The barriers to whānau receiving healthcare continue to challenge both whānau and health professionals. Whānau Ora⁶ as a service model has whānau at the centre of the healthcare effort. Whānau Ora seeks to emphasise empowering factors, such as the value of having whānau engaged in health service design that meets their specific needs.

Whānau Ora approaches healthcare with an emphasis on whānau defining for themselves their requirements of health services, and is a further example of changing the assumptions that have been part of the way in which health services have delivered healthcare away from one that is more service centred to whānau centred. Whānau Ora is a strengths-based approach to health and wellbeing that seeks to allow whānau to “be able to freely negotiate with agencies to achieve the best results, consistent with their aspirations”⁶. As a health service model, Whānau Ora appeals to whānau⁷. It also supports more integrated and holistic approaches to healthcare⁸.

Although healthcare services are a key part of Whānau Ora, the model is about more than that – it is about the aspiration that “Māori families are supported to achieve the fullness of health and wellbeing within Te Ao Māori and New Zealand society as a whole”⁶. The Whānau Ora model underpins this research project, although there is still much that remains unknown about the long-term

effectiveness of Whānau Ora and the ways in which it can be interpreted and applied.

Hon Tariana Turia, Minister for Whānau Ora made the following statement:

*Whānau Ora is about whānau being empowered to develop a plan for our future; and to trust in our own solutions. It is about restoring to ourselves, our confidence in our own capacity to provide for our own... I believe that Whānau Ora represents a major transformation in the way services are designed and delivered.*⁸



Figure 1

Table 1:

There are 7 principles underpinning Whānau Ora, per the Whānau Ora Taskforce Report.

-Ngā Kaupapa Tuku Iho: the ways in which Māori values, beliefs, obligations and responsibilities are available to guide whānau in their day-to-day lives.

-Whānau Opportunity: all whānau will have chances in life that will enable them to reach new heights, do the best for their people, engage with their communities and foster a strong sense of whanaungatanga – connectedness.

-Best Whānau Outcomes: the success of Whānau Ora interventions is measured by increases in whānau capacities to undertake those functions that are necessary for healthy living, and shared contributions to the wellbeing of the whānau as a whole, as well as the wellbeing of whānau members.

-Coherent Service Delivery: recognises a unified type of intervention so that distinctions between services provided by health, welfare, education and housing, for example, are not allowed to overshadow wider whānau needs.

-Whānau Integrity: acknowledges whānau accountability, whānau innovation and whānau dignity. This principle assumes that a code of responsibility is present in all whānau, though it may sometimes be masked by events or circumstances that propel whānau into survival mode or trigger a defensive reaction.

-Effective Resourcing: underlines two important aspects of services to whānau. First, the level of resourcing should match the size of the task – whānau-centered approaches may initially be time intensive. Second, resourcing should be tied to results. Effective resourcing means allocating resources in order to attain the best results and an intervention plan should include a set of indicators that can measure successful outcomes.

-Competent and Innovative Provision: recognizes a need for skilled practitioners who are able to go beyond crisis intervention to build skills and strategies that will contribute to whānau empowerment and positive outcomes.

Table 2: Principles of Kaupapa Māori research ⁹

A Kaupapa Māori research framework involves upholding Māori views, solutions and ways of life, and aims to address issues of social justice.

Tino Rangatiratanga – The Principle of Self-determination

Tino Rangatiratanga relates to sovereignty, autonomy, control, self-determination and independence. The notion of Tino Rangatiratanga asserts and reinforces the goal of Kaupapa Māori initiatives: allowing Māori to control their own culture, aspirations and destiny.

Taonga Tuku Iho – The Principle of Cultural Aspiration

This principle asserts the centrality and legitimacy of Te Reo Māori, Tikanga and Mātauranga Māori. Within a Kaupapa Māori paradigm, these Māori ways of knowing, doing and understanding the world are considered valid in their own right. In acknowledging their validity and relevance it also allows spiritual and cultural awareness and other considerations to be taken into account.

Ako Māori – The Principle of Culturally Preferred Pedagogy

This principle acknowledges teaching and learning practices that are inherent and unique to Māori, as well as practices that may not be traditionally derived but are preferred by Māori.

Kia piki ake i ngā raruraru o te kainga – The Principle of Socio-Economic Mediation

This principle asserts the need to mediate and assist in the alleviation of negative pressures and disadvantages experienced by Māori communities. This principle asserts a need for Kaupapa Māori research to be of positive benefit to Māori communities. It also acknowledges the relevance and success that Māori derived initiatives have as intervention systems for addressing socio-economic issues that currently exist.

Whānau – The Principle of Extended Family Structure

The principle of Whānau sits at the core of Kaupapa Māori. It acknowledges the relationships that Māori have to one another and to the world around them. Whānau, and the process of whakawhanaungatanga are key elements of Māori society and culture. This principle acknowledges the responsibility and obligations of the researcher to nurture and care for these relationships and also the intrinsic connection between the researcher, the researched and the research.

Kaupapa - The Principle of Collective Philosophy

The 'Kaupapa' refers to the collective vision, aspiration and purpose of Māori communities. Larger than the topic of the research alone, the kaupapa refers to the aspirations of the community. The research topic or intervention systems therefore are considered to be an incremental and vital contribution to the overall 'kaupapa'.

Our study aims to incorporate Whānau Ora into a set of values, goals and processes that inform this research.

The research framework was also informed by the values of kaupapa Māori (Table 2) research which are compatible with Whānau Ora. However, the research methodology combined elements of kaupapa Māori research (those aspects of the research process led by CART) alongside Cunningham's research typology¹⁰. The two categories of research that best fit are described in the methodology section of this report and include research involving Māori and Māori-centered research. The values underpinning kaupapa Māori research which guided are included in Table 2. The research was conducted was in line with these principals. However, this project was not strictly kaupapa Māori research; rather it used a quality approach with overlaid kaupapa principals. The overall research question was "What are the barriers and enablers to access to healthcare for a group of marginalized whānau in south wellington?" These whānau are a group that are often studied and spoken about as a 'problem' - rather than a group of people that is spoken to or consulted with. In keeping with the Whānau Ora approach we consider the information gathered from the study whānau to be of the utmost importance, representing as it does the feelings and experiences of the people at the centre of the Whānau Ora model.

To this end we carried out a review of the literature and interviewed leaders in Māori health, health practitioners, policy analysts, researchers and most importantly whānau themselves in order to build a more complete picture of what the realities and issues are that prevent access. A qualitative analysis was then performed and solutions to the problems elucidated developed.

Literature Review

A review of the literature was performed to provide background information on what is already known in this area, to define terms and constructs, to set the parameters of the study and to inform the research design.

COLONISATION AND INSTITUTIONAL RACISM

Jackson¹¹ has applied an analytical model to examine issues in the relationships between Māori and Government publicly funded healthcare, based on the framing of ongoing challenges to Māori self-determination as a result of the conditions established during colonisation. Colonisation in a healthcare context has been identified as a particularly important determinant informing Māori health disparities, inequalities and inequities^{12, 13, 14}. The application of a colonisation analysis is obtuse for many researchers and healthcare practitioners because it calls for a re-examination and naming of the racism inherent in all colonising processes and an acknowledgement that many 'downstream' inequalities and discriminations have their roots in colonial acts, ideas and institutions¹⁵.

Racism is a recognised and significant health determinant affecting many minority groups^{16, 17}. Racism is a phenomenon of systematic prejudice and differential treatment on ethnic grounds that induces inequalities across ethnic groups and can be manifested through beliefs, stereotypes, and discrimination¹⁸.

The evidence confirms that those who experience racism more frequently have poorer health outcomes and poorer self-reported health status^{17, 19, 20}. Harris et al.²¹ found that experience of discrimination was "significantly associated with poor or fair self-rated health, lower physical functioning, lower mental health, smoking and cardiovascular disease". Priest et al.¹⁸ found that mental health issues (depression and anxiety) occurred frequently in those indigenous peoples who experienced racism.

Harris et al.¹⁹ stated “racism, both interpersonal and institutional, contributes to Māori health losses and leads to inequalities in health between Māori and Europeans in New Zealand.” Harris et al.²² also found that racial discrimination by a health professional correlated with lower rates of breast and cervical screening among Māori women.

In the international literature, Priest et al.¹⁷ found racism to be an important health determinant in young Aboriginal people in Australia. Over half of this population had experienced racism to some extent. Nearly 20% reported ‘quite a lot’ or ‘a lot’ of racism. Those who reported racism were twice as likely to be depressed and nearly four times as likely to have worries/poor mental health compared to those who had not reported experiences of racism. They were also two and a half times more likely to have poor/fair self-reported health. This is consistent with a cross-sectional study of Aboriginal children in remote regions of the Northern Territory. Composite child illness was found to be associated with carer and household reported racism¹⁸.

Racial discrimination is strongly associated with poorer youth mental health in remote indigenous communities¹⁸. 121 studies of indigenous young people aged 12-18 were examined in this systematic review. It was found that mental health outcomes (such as depression and anxiety) were frequently reported. These were associated with racial discrimination in 76% of the outcomes examined¹⁸. Behavioural problems (e.g. aggression and conduct problems), smoking, drug, and alcohol use were associated with reported racial discrimination. Poorer quality of life and negative pregnancy/birth outcomes were also more prevalent in those who were racially discriminated¹⁸.

A Ministry of Health report published in 2010, *Health in Justice*²³ highlighted the health of prisoners in New Zealand. It found that prisoners are frequently under financial and relationship stress. Compounding this, most have significantly high mental health needs. Over half of the New Zealand population has a psychotic mood or anxiety disorder, twenty percent were contemplating suicide, and nearly 60% had personality disorders of varying severity. A lifetime prevalence

of substance abuse was found in 89% of prisoners²⁴. Given that 51% of New Zealand's prison population are Māori²⁵ this is clearly a significant burden on Māori health.

Jones et al.¹⁶ demonstrated that socially assigned race could affect the health status of an individual. Those who were socially assigned as white had significantly better health status across all self-identified non-white races. This was particularly notable in Hispanics and American-Indians who were more 14 and 20 percent more likely to report better health than if their race was correctly socially assigned.¹⁶

Isolated or 'difficult to reach' communities such as new immigrants or refugees experience barriers to health care which has ramifications for health systems that provide for them. Whitley et al.²⁶ interviewed West Indian immigrants with symptomatic mental illness in Montreal to find barriers to access in mental health services. Immigrants found that doctors were over-zealous when prescribing a pharmaceutical intervention, lacked time and were dismissive towards them, and their beliefs in nonmedical interventions and traditional healers.²⁶

Practitioners commented on the high financial deprivation and different beliefs about health as major contributors.²⁷

EXPERIENCES OF HEALTH SERVICES

Māori experiences with the health system influence healthcare access. Attitudes of both healthcare providers and Māori play a significant role in healthcare pathways and outcomes.

Cram's qualitative study²⁸ of Māori attitudes to health found that "participants' experience and knowledge of Pākehā doctors was not overly positive". Participants found that rapport between doctor and patient, and acknowledgement of wairua and rongoā were especially important to their

interactions with the health system, consistent with the findings of Whitley et al.²⁶ Experiences of participants' whānau members were also important influences, with “suspicion and even fear of the health system... grounded in whānau experience”.²⁷

From the health practitioner's perspective, McCreanor found that Tauīwi practitioners often did not know whether their patients were Māori or not. General practitioners noted that their Māori patients exhibited significant non-compliance, poor health literacy, and a 'present-focused, laissez faire' view to their health.²⁹

Scant knowledge of Māori health models, such as Te Whare Tapa Whā³⁰ or Te Pae Mahutonga²⁹ and rongoā was noted amongst general practitioners^{29, 31}. However, it was acknowledged that Māori self-determination in health was necessary to achieve better health outcomes²⁹.

Practitioners have also commented on the high financial deprivation and different beliefs about health as major contributors.²⁷

Māori health providers were identified as important to Māori participants^{19, 21, 32, and 33} with participants frequently describing positive experiences. Some of this may be related to a more holistic approach by Māori providers, with one participant in Slater's qualitative study of Māori cancer patients describing the Māori providers' approach as “whanaungatanga and all that kind of stuff”.²¹ However positive experiences were also reported of Pākehā doctors who understood participants' use of rongoā.¹⁹

Resilience often underpins Māori primary health care approaches. The goal of this is to increase whānau resilience by supporting them to identify and access resources that sustain their wellbeing in culturally meaningful ways. It is this improved access to resources that contributes to whānau empowerment.³⁴

However it is hard to link the concept of resilience to whānau ora. ³⁴ A resilience approach is focused on adversity and hardship constructed from a position of scarcity and risk. In contrast, Whānau Ora is an aspirational strengths-based approach to health and well-being. ³⁴ The outcome sought is to maximise the potential of whānau and whānau collectives to reach goals for their own health and well-being.

Health literacy is also a recognized concern in Māori health. Poor health literacy contributes to poor health outcomes through a number of mechanisms, including reduced rates of preventative strategies, later presentation to health services and worse management of long-term conditions³⁵, and Māori have much lower levels of health literacy than non-Māori³⁶. Low levels of health literacy and linked to lack of self-determination and empowerment, and Whānau Ora aims to improve health literacy for these reasons. ³⁷

ECONOMIC BARRIERS

Cost was consistently identified as a major factor limiting Māori use of healthcare services. Ellison-Loschmann³⁸ and Marrone³⁹ both identified cost as a significant barrier to healthcare utilization by Māori and other indigenous groups. Crengle⁴⁰ specifically identified GP and prescription co-payments as modifiable barriers to Māori access to primary care, and suggested substantial reductions in these. This is supported by Jatrana's⁴¹ finding that Māori were more likely have deferred buying a prescription for reason of cost in a 12-month period.

Qualitative studies of Māori single mothers⁴² and Māori patients with gout⁴³ also identified cost as a major factor, with Lee stating “overwhelmingly, costs of healthcare were barriers to benefit-dependent participants in accessing health care”⁴².

*The Health of Prisoners' Families*⁴⁴ was a qualitative document produced by Wesley Community Action in 2009. It found that prisoners' family members

frequently worried about their wellbeing, having a lack of money, and about trying to maintain contact and a relationship with the prisoner. This often manifested as worsening of existing condition and symptoms, stress (such as high blood pressure), and increased alcohol use.

Working for families (WFF) is a government policy based on the 'reducing inequalities framework'. Families that met the criteria found that the additional income enabled them 'to "survive" and not have to "struggle" quite so much to make ends meet'.⁴⁵ Financial securities were seen as one necessary aspect but not sufficient to address the other range of factors that contribute to achieving whānau ora.

Similarly, transport has been cited as a barrier, with both travel costs and dedicating time to travel identified as barriers. Crengle⁴⁰ noted geographical/transport barriers as significant and suggested mobile or satellite clinics as an option to reduce time and monetary costs and improve access. In a qualitative study of a group of Māori cancer patients, participants described difficult experiences with travel, especially with greater geographic distance²¹. This group also identified time as an issue independent of travel – with participants describing having to be away all day even for a short appointment²¹. Lee's study⁴² of single mothers also found travel time and distance to be barriers.

CONCLUSION

We found that the major factors impacting Māori access to healthcare are due to institutional racism, negative personal or whānau experiences, and economic deprivation.

Structural and systemic barriers include racism and culturally inappropriate behavior by healthcare workers including covert attitudes, judgments and stereotyping impacting all levels of health service experienced by Māori and other indigenous and hard to reach whānau/families.

To unify these themes in indigenous peoples' health, Walters and Simoni⁴⁷ proposed an "indigenist" theory of how historical trauma, discrimination and traumatic life events are buffered by cultural identity, spiritual coping and traditional health practices to mediate health outcomes such as drug abuse/dependence and mental illness. Applying this model to the evidence here, in the New Zealand context, health inequity in Māori can be targeted by reducing traumatic events such as experience of racial discrimination, and by increasing the strength of cultural buffers – e.g. by accepting and promoting use of traditional health practices. This is compatible with the Whānau Ora model's goals of whānau empowerment, and this along with the Whānau Ora framework will inform our suggestions.

Methods

Research Team

The research team consisted of 18 fourth year medical students studying at the University of Otago, Wellington School of Medicine. Dr Keri Lawson-Te Aho (Lecturer, University of Otago, Department of Public Health), Anaru Waa (Lecturer, University of Otago, Department of Public Health) and Dr Richard Jaine (Senior Lecturer, University of Otago, Department of Public Health) supervised the project. The team was split into smaller groups, each with a specific role, including literature review, interviews, analysis, and discussion to complete the project. To facilitate the completion of the project there was discussion between groups. Hinewaiora McCleery and Isaac Tranter-Entwistle were appointed as the Project group leaders. Given the nature of the project, expertise in Kaupapa Māori needed to be included in the overall leadership of the project. That specialised input was provided by Māori staff from CART; our client and project partner and Dr Lawson-Te Aho.

Category B Ethics Approval was granted by University of Otago Ethics Committee prior to research commencement (Appendix One). The key ethics issues were safety of both the participating whānau and students through preservation of the anonymity of the empirical data while also being able to report the data while at the same time, preserving the anonymity of the research participants.

Māori Research Methodology

Cunningham's Framework¹⁰ for addressing Māori knowledge in research, science and technology contributed to informing the research methodology. Accordingly, the research was positioned between two research categories in the Cunningham Framework – 1. Research Involving Māori and 2. Māori-centered research. Additionally, elements of Kaupapa Māori methodology were applied through the leadership role of CART, a kaupapa Māori community based Whānau Ora service. The methodology was a significant challenge for this study as there

was no clear demarcation between mainstream applied research involving Māori, Māori centered research and research in which elements of kaupapa Māori featured.

Research involving Māori has the following characteristics relevant to this study:

1. Research where Māori are involved as participants or subjects
 - o The majority of the research participants were Māori. These included 11 members of 4 Whānau Interviews; 11 health practitioners, 4 CART staff members and 11 Māori health experts.
2. Research where Māori data is sought and analysed
 - o The data sought revolved around barriers and enablers to access healthcare by the study whānau
 - o Māori and non-Māori health practitioners
 - o Māori and non-Māori leaders, advocates and policy-writers
 - o While non-Māori were also interviewed, the majority of the interview data is from Māori respondents.

Māori centered research has the following characteristic of relevance to this study:

- o Research where Māori are significant participants and are typically senior members of the research team

Māori were significant participants in the study. CART, a Newtown based Whānau Ora provider was the client for this study and had a key leadership role that included participating in all aspects of the research process from design to administration to interpretation of whānau data and analysis. This aspect of the research methodology might be interpreted as inclusive of **elements of a Kaupapa Māori** approach to research in which the leadership of CART supported the research study and enabled access to the study whānau. However,

this study was not exclusively and fully kaupapa Māori in terms of the methods used.

Kaupapa Māori

Kaupapa Māori Research is defined by Smith as ‘a theory and an analysis of the context of research which involves Māori and of the approaches to research with, by and for Māori’⁴⁸.

Smith adds that Kaupapa Māori does not exclude the use of a wide range of methods but rather signals the interrogation of methods in relation to cultural sensitivity, cross-cultural reliability, useful outcomes for Māori, and other such measures. Finally, kaupapa Māori is about thinking critically, including developing a critique of Pākehā constructions and definitions of Māori and affirming the importance of Māori self-definitions and self-valuations.

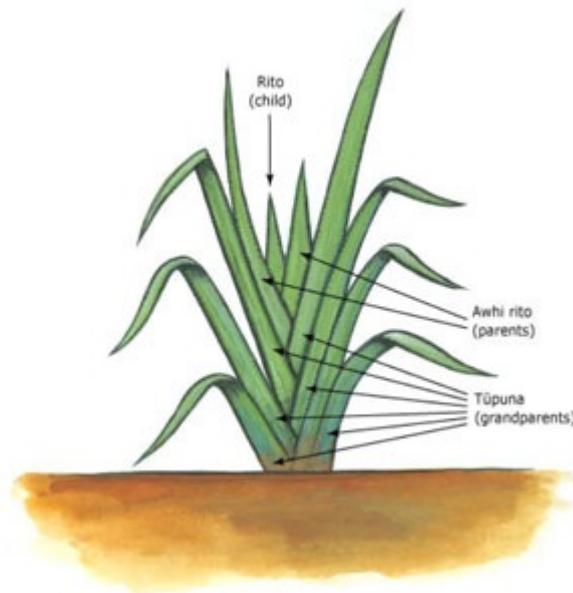
According to Royal⁴⁹

‘Kaupapa Māori’ is used popularly by Māori in a fairly broad way meaning any particular plan of action created by Māori, expressing Māori aspirations and expressing certain Māori values and principles. There might be a range of purposes for the action taking; however, it is generally held that the design of the proposed action is created by Māori reflecting Māori aspirations, ideals, values and perspectives. It also anticipates tikanga Māori, distinctive Māori ways of doing things, cultural behaviours and so on, through which kaupapa Māori are expressed and made tangible’

CART participated in the research design, development of the tools; identification of the whānau interview participants and analysis, providing ongoing advice and input into the research Kaupapa and Tikanga (protocols concerning conducting research with the whānau and working with these whānau. CART’s knowledge of local health networks and already well established relationships with whānau in the South Wellington region made the study possible, without which, access to the whānau at the heart of this study, would have been very difficult if not impossible.

Understanding and Conceptualising Whānau

The model informing the conceptualisation of whānau in this research was that of Te Pā Harakeke⁵⁰ which is a conceptual model in which the whānau are at the heart of the research process, with best outcomes for whānau sought as a result of the research process. The model of Te Pā Harakeke is depicted below:



This model depicts the generational model of whānau. In simple terms, Te Pā Harakeke represents a multi-generational, integrated system based on Māori cultural principles and values. The role of the older members of the whānau is to care for, nurture and protect the younger members (babies and children, grandchildren). Te Pā Harakeke is a Māori model of whanaungatanga, in which there is an inter-dependency that is generational. This model of whanaungatanga is based on kinship and bloodlines and is also referred to as whānau tūturu; or **whakapapa whānau**, that is whānau connected by kinship and common ancestry.

The whānau in this study were mainly whakapapa or tūturu whānau. However, there were also non-Māori whānau in this study who do not have Māori kinship and descent lines but they do have children who have kinship and descent lines.

This makes them an inherent part of this model and the model accommodates non-Māori whānau with Māori children or partners.

Kaupapa whānau refers to whānau who behave like whānau to achieve a common goal or purpose but kinship is not the organising principle. For example, a sports club may be a kaupapa whānau.

CART does not delineate between kaupapa or whakapapa whānau in terms of the provision of Whānau Ora services. However, the central and pivotal role of whānau in the promotion of Whānau Ora is recognised.

Research Tikanga

Tikanga Māori informed the way in which the research team interacted with CART and whānau during the interviews and the way in which the research team conducted themselves in relation to CART throughout the entire study.

Tikanga is described as protocols that represent Māori values and worldviews. Royal⁵¹ states

By way of a working definition, Rev. Māori Marsden defines kaupapa as 'first principles' I define tikanga as 'ethical behaviour'. The relationship between the two is based upon their mutually interacting and interdependent nature. That is, one is not able to determine whether an action or act is ethical or tika without recourse to a set of principles or values upon which to measure or assess the correctness of the act. Kaupapa and tikanga are interrelated as tikanga is the product of kaupapa, and through tikanga one comes to understand a kaupapa.

The **Tikanga** applied in this study occurred in stages with the first stage being the development of a relationship between CART and Otago University that began in 2012.

Relationships are critical in all research with Māori. Prior to CART attending the initial project briefing, where they met the students for the first time, the project supervisor, Dr Keri Lawson-Te Aho had been discussing the potential of a project over an 18 month timeframe. In February, 2014, the project started to take

shape. When the cohort of medical students began their Public Health run, taking on the Hauora Māori project, CART had developed an idea of what a project might look like. This was written up as a draft project brief and CART attended the initial briefing, introduced themselves and invited the medical students to visit CART premises. Dr Lawson-Te Aho then provided kai to manaaki/support the involvement of CART in this project.

At the second meeting between the medical students and CART, a **mihi whakatau** process happened in which CART staff welcomed the students to CART premises adopting Tikanga Māori which included a welcome in Te Reo Māori, karakia/prayer, waiata/song and kai/food. This was a critical first step in the relationship development process between the staff of CART and the 4th year medical students and set the tikanga for all subsequent hui/meetings between CART and the students which all featured, mihi/greetings, karakia/prayer and kai/food as fundamental protocol.

Whānau Interview Process

The Whānau Interviews were organised by CART and included:

Mihi whakatau/welcome to CART premises where all of the whānau interviews took place in which the student interviewers were introduced to the whānau; proceeded with the interview with CART staff sitting in on and supporting the free expression of whānau kōrero/talk. The process was concluded by the offering of a koha from the University of Otago via CART staff. The koha is an important part of Kaupapa Māori as it is a process of actively valuing the whānau and their kōrero/talk. In this case, the koha was a box of groceries. Then kai/food was shared and the process was concluded. This process was repeated for the four whānau interviews. The non-Māori solo mums interview was all in English, but a welcome was extended and a koha given on conclusion of the interview.

CART took the lead in setting the tikanga for the Whānau Interviews. In preparation for the interviews, the values of Kaupapa Māori research were discussed and advice given by Dr Lawson-Te Aho about the way the students were to conduct themselves.

Literature Review

A literature review was performed to frame the project in the context of current research. Pubmed and medline were accessed. Search terms included “Māori”, “Hard To Reach,” “Access,” “Whanau,” “Kaupapa,” “Treaty,” “Waitangi”, “Health,” “Models,” “Racism,” “Discrimination,” “Ora” and combined using Boolean operators. Relevant articles were reviewed and those relating to the subject matter were included.

Data Collection

Data collection occurred from the 29th of May to the 13th of June. Sessions consisted of whānau gathered by CART members. The interviews were facilitated by CART members to tautoko/support and āwhina/assist our medical students throughout the process ensuring a strong and appropriate tikanga and kaupapa Māori approach was achieved. To ensure consistency of the approach interview templates were developed for each group (Appendix Two). Four interviews with “hard-to-reach whānau” were organised by Consultancy Advocacy and Research Trust (CART) whom were our client and study partner within this process to assist our engagement with the whānau and to ensure the integrity of our desired strong kaupapa Māori approach. These were conducted on CART premises supported by CART staff to ensure student safety and to ensure the safety of the whānau we were interviewing; being in a familiar environment for the whānau, surrounded by Māori staff whom have a relationship with them encouraged their full engagement and subsided any feelings of whakamā/shyness. Purely due to the āwhina and guidance provided by the CART staff, we were able to break down some barriers and effectively communicate with these whānau in a neutral setting, allowing us the āhei/opportunity to listen and engage in some of their experiences they have encountered within the health care services in Aotearoa. As this was conducted in accordance to Māori tikanga, karakia/prayer initiated the session, and following the interview there was a koha given to each whānau, karakia mo te kai/prayer blessing the food and kai/food was shared to conclude the kōrero/talk.

A total of Māori key stake holder interviews were conducted. Key stake holders included CART staff, Health Practitioners and Māori Health Experts.

Interviews were organised by phone and email and were conducted kanohi ki te kanohi (face-to-face) where possible consistent with a Kaupapa Māori research methodology⁵². If kanohi ki te kanohi (face-to-face) was not possible interviews were conducted by phone.

Interviewers acquire informed consent at the start of each interview, all interviews were recorded. Due to time constraints interviews could not be transcribed. Interviewers listened to the recordings and highlighted themes that arose – using quotes to reinforce them, also integrating any comments or key issues detected by the CART staff that assisted in all of our whānau interviews. Dual write ups of the interviews (by the two medical students whom interviewed) were utilized to ensure consistency of interpretation. These along with the interview recordings were passed on to the analysis team.

Qualitative Analysis

Interpretive phenomenological analysis with an overlying Kaupapa Māori approach to research was used. Themes were elucidated and recommendations produced.

For results analysis, interviewees were allocated into four groups: whānau, CART staff, Health Practitioners and Māori Health Experts.

The whānau group consisted of four whānau group interviews with eleven individuals who were selected by CART from among whānau registered with the organisation.

The interviews with CART staff members were analysed as a separate group because of their mixed perspectives as whānau, service providers, and advocates for their community.

Māori Health Experts included leaders, advocates, academics, staff from relevant government agencies and Māori Health Development Group at the Capital and Coast DHB.

Health Practitioners included clinicians from the Emergency Department at Wellington Hospital, Ora Toa Health Services and Newtown Union Health Services.

Results

The results are presented according to the four informant groups: whānau, CART staff, health practitioners, and Māori health experts. The interview findings have been organised by topic areas that emerged from interview findings. Themes that emerged within each topic are discussed in the way they act as barriers or enablers to accessing effective health care, and solutions that were suggested by informants.

WHĀNAU

Whānau interviews provided some vivid illustrations of the impact of barriers on accessing effective health care.

A lot of our whānau treat themselves...one whānau suggested putting a vacuum cleaner into her (daughter's) nose to get the fluff or whatever it was (causing the infection) or using Māori medicine and 'sucking it (source of infection) out.'

I deal with little things (stab wounds), we use whatever we can, alcohol (as anesthetics) not the good stuff though...then I stitch up the stab wounds myself using a cotton and needle...when it gets infected, I have to go to the hospital. I tried to take my stitches out myself but they were fused to my skin.

1. Affordability

Whānau identified affordability of transport costs, consultation fees at GPs and after-hours services, and prescription charges as barriers to effective health care. They described their need to make trade-offs between health care expenditure and other living costs. This issue was vividly illustrated by one mother, who told the story of taking her child to ED after hours. She was informed that the waiting time was likely to be five hours, and was told that if she went to the After Hours Clinic and paid the \$75 fee, her daughter would be seen straight away. The

mother chose to pay the \$75 in order to get immediate medical care for her daughter as “she is my number one priority and you guys just took away my second priority to feed my kids”.

Several whānau interviewed are registered with Newtown Union Health and stated they “can’t afford going to another GP or health service.” This raised questions for whānau about whether they receive lower quality of services because they are less costly.

Does a free service mean less quality? It usually does.

Whānau mentioned that Well Health PHO used to offer subsidized medications, an initiative that worked well and meant whānau were getting their prescriptions. However, the funding ceased, “causing whānau to not access health services”.

Specific solutions suggested by whānau included reducing the cost of consultation fees and prescriptions, and providing

I wish all health care would be free for children up to eighteen.

2. Competing priorities

The time cost of health care was considered a barrier, with whānau identifying that waiting long hours in clinics and ED meant that sacrificing commitments such as work and school in order to receive treatment.

I’m willing to do it if it’s an hour to go in and see the doctor, but a whole day off work makes it seem more off putting.

3. Logistics

Whānau described the practical difficulties of accessing health services. At times, transport was discussed as a logistical challenge rather than a cost issue. Whānau also discussed issues such as parking and childcare, especially in emergency situations. In one example, a single mother had to leave children alone at home one night, “locked up in bed,” when bringing one child in due to an emergency. Although the children were old enough to be left at home, it was a distressing experience for her.

Although some PHOs offered support with transport, not all of these initiatives were considered effective by whānau.

The best they (GP Practice) could come up with was to give the social worker a snapper card...the social worker had to catch the bus over, then we had to load all the kids onto the bus and bus into the doctor.

Suggested solutions included dedicated transport services.

We almost need our own ambulance. Three kids, no car, up the hill – we need a small shuttle or van...something.

4. Health Literacy

During whānau interviews, there were a number of conversations and issues raised which fit within the theme of health literacy, including whānau knowledge about medical conditions, the way the health system works and their entitlements, and health-seeking behaviour.

Whānau narratives illustrated poor health literacy in many areas, and raised questions about the effectiveness of health literacy messages and explanation of treatment and medication by health practitioners.

One illustrative example was the understanding that arose among a community, during a health promotion initiative regarding flu vaccinations, that the vaccination involved “injection of the flu”. This led to parents refusing to vaccinate their children.

An additional example concerned the prescribing of large amounts of medication to children, with some whānau being suspicious that their children were being used experimentally.

The amount of medication they prescribe young ones...they're like little guinea pigs.

Some whānau displayed good health literacy, for example one mother who regularly visited the GP as a way of preventing ED incidents. In some cases, whānau had good levels of health literacy due to their multiple interactions with the health system. They provided examples of how knowledge about their children's medical conditions enabled them to access more effective services. For example, a mother who knew how her son's asthma attacks tended to progress requested that he remain in hospital despite being advised he could be discharged from ED. Within a short space of time, he deteriorated and needed more intensive intervention, and the health practitioner in charge thanked the mother for being firm about staying in hospital.

5. Whānau Perceptions

Negative perceptions of the health system and health practitioners were outlined in whānau group interviews. These perceptions included an overall mistrust of the health system. Whānau described how previous experiences of the health system led to these perceptions. In one example, misdiagnosis and/or poor communication about a diagnosis led to repeated admissions for a child from one whānau, whose experience led them to state that "she (daughter) suffered...obviously a trend in the background of medical professionals is 'trust us, we don't make mistakes'."

Other whānau described the negative impact of countless interactions with health practitioners; experiencing multiple admissions and still receiving the same treatment.

It gets predictable after a while so you stop engaging.

6. Discrimination

Experiences of racism and discrimination based on other factors are a significant barrier to effective health care, and a deterrent for whānau to engage with the health system. The basis of discriminatory treatment was wide ranging, from gang affiliation or perceived affiliation, to social situation and smoking status.

I'm used to be turned away but didn't expect it from the hospital – they should be impartial.

Whānau discussed these experiences in terms of feeling judged or treated differently; the term 'racism' was not used when describing incidents, and in one case whānau actively avoided using the term.

It might be a culture thing right? I don't even want to go down that card. It sounds like racism. Sometimes it's reality. I know its reality. I just want don't want to comment on that because I'm not racist but things just piss me off in that situation

A whānau described how they are questioned when they take their children to ED with bruises or broken bones, in one case being asked, "are you sure you didn't pull her arm when you were crossing the road or something?" This caused feelings of guilt and shame for the parents and discouraged them from engaging with health services in future.

7. Service Design and Focus

Whānau discussed a range of barriers and enablers related to the design and focus of health services. One of the most frequently mentioned barrier was waiting times in ED and GP practices, along with waiting times for GP appointments of up to three weeks.

When my kids are sick after five o'clock, I will not take them to the hospital. I won't take them there to sit six hours minimum before we're seen.

The location of health services was discussed, with whānau providing an example of community-based cervical screening at CART as an enabling approach, with whānau stating that “all screenings were done in two hours whereas none of us would have gone to the doctors to have that done and wait for hours.” This initiative and community-based services as a whole were seen as culturally appropriate, and able to mitigate the impact of logistical barriers, affordability, and waiting times.

Health promotions creates a sense of what health services are out there and not just for the community but for the services. They are looking for ways to engage the community; the in-between services make the connections between the community and health services.

Whānau suggested that more community outreach by health providers could be carried out as “when services are brought into the community, that is the time when the services are best utilized”. Whānau were of the view that such outreach allows health providers to build personal relationships with members of the whānau and vice-versa.

Health services are trying to remedy this by getting health services into community. CART are part of this rather than us having to go to their services which is not working.

Whānau discussed the practical difficulties that they’d experienced being with relatives who were patients in Wellington hospital, in terms of physical space and restrictions on visitor numbers. They had mixed opinions about the whānau rooms in Wellington hospital.

Mental health services were singled out as a particular concern by a number of whānau, with one woman having “nothing positive to say” about mental health services, stating that there were “lots of meeting, lots of planning, lots of talking but no action.”

Service coherency and integration was discussed, with whānau expressing frustration about dealing with multiple practitioners and services, and feeling that they are being shuffled around, seeing a couple of doctors and nurses before seeing the “actual doctor.”

We had four different doctors come in.... I got shitty.

Conversely, continuity of care was identified as an enabling factor, with a long term relationship with a GP having practical benefits such as being able to make alternative arrangements if whānau can't make an appointment.

Yeah he knows your history. Knows what works for me.

Having a Māori representative within a health care provider was considered an enabler. One whānau discussed a Māori health worker at Newtown Union Health who made sure everyone was seen, which resulted in whānau feeling like they had been prioritised by the service.

She would come out and be welcoming, bring a nurse out. It was an interaction that had whānau feeling good about coming to see the doctor.

8. Individual Quality of Care

Whānau frequently referred to the importance of the individual quality of care they received from health practitioners. The important components of this care included health practitioners' attitude towards whānau and their communication skills.

Some whānau have found doctors to be egotistical, not taking the time to listen to their problems properly.

One of them said to me – ‘we are busy you know.’

Some examples were provided of individual care that demonstrated an open, non-judgmental attitude, with whānau stating that it is “good to come across a doctor who will see you for who you are, not what you are.”

I went for a stabbing (sought help some days after being stabbed to avoid police action), the nurse looked into it, didn't call the police...there is an issue you have to report it to the authorities – there is wavy line – commitment to healing (of the patient) and an obligation to the safety of the community...I got to the point where I knew I had to go (see someone)... She was professional about it. She was just really real about it. 'Go home and hug your kids' (because you could have died)."

Several examples of poor communication by health practitioners were provided by whānau; situations which caused considerable distress and dissatisfaction with the health system.

There was no explanation, nothing, no information. This went on for two weeks and we don't want to hurt their feelings. It's our right as parents to get a second opinion but the line gets even further blurred for us...just wondering if John Key's kids get the same thing.

Some of these examples involved the delivery of bad news in culturally inappropriate and disempowering situations, with limited consideration of the level of knowledge that whānau might have about a particular condition.

When you are dealing with us, with whānau that don't have connections, try and be as open as possible. Build trust with us so we can stop not trusting.

However, whānau also identified excellent interactions with clinicians, nurses or receptionists as enabling factors, and provided examples of doctors who knew them well and understood what works for them, or who "go the extra mile" and think outside the square to solve problems.

She is for the people. She sincerely cares about you and says lovely things to make you feel good. She knows me and my family.

Whānau suggested that greater attention be paid to communication, including in the early stages of presentation in hospital so whānau can make plans accordingly.

Within the first half an hour, it would be nice to know exactly what's happening to you. So you can tell someone 'I'm going to be staying, need a pick up etc.'

Doctors need to be more honest with us...even if it's bad, as monotonous as it might be...if we don't know and you don't know...what happens to our kids? We just need to be told if you don't know. Be honest so we can work it out together.

CART STAFF

1. Whānau Perceptions

CART staff described a range of whānau perceptions that were described as “reactions to their bad experiences.” These included feeling fear, suspicion and impatience towards the health system, and acted as barriers to accessing effective health care.

Sometimes we feed our own assumptions and sometimes they're just made without us contributing to them at all and that can be a barrier for our whānau.

A perception that was described was that at some point in time, receiving healthcare was seen as a weakness for whānau, as if it was the equivalent to admitting defeat. For these whānau, who feel that they have no power or control over their lives, refusing treatment and healthcare was a way of regaining control.

Going to the doctor was seen as a sort of a bit of a weakness, bit of a Pākeha thing and a surrender of power...of the little power they had left.

2. Health Literacy

An important theme that was emphasised by CART was health literacy in the community. CART provide the community with rudimentary health teaching to crucial groups (e.g. young mothers, young men, ageing community) in order to improve their access to healthcare. The aim is to “develop a well-informed

community...who know how and why it is important to access that primary health care”.

CART acts as an enabler for these whānau by helping them to see healthcare as an entitlement rather than as a weakness. They help whānau to “see their entitlement to these health services, so now there’s a change in paradigm”.

3. Discrimination

CART staff was aware that whānau experience discrimination, at times in the form of racism, but often due to gang affiliation. CART described the entrenched discrimination that their community experiences, such as having security staff accompany them whenever they go to ED. They described the judgements made and labels added to those whānau who are associated with gangs (even if they are not necessarily members themselves). As described by CART members, these whānau were thought of as ‘troublesome’ or ‘difficult to deal with’ by health providers.

The hard to reach thing comes because of the labelling. So your father...was a gang member, so when the police recognise your name, they see you as being a gang member.

CART viewed discriminatory treatment as based on health workforce prejudices towards whānau, including beliefs that they are less deserving of healthcare than other people, difficult to work with, non-compliant and uninterested in their own health. Discrimination resulted in whānau being less likely to access healthcare because they have felt wrongly judged or accused in the past

Health professionals should just treat people regardless of who they are or where they’re from and what they wear.

4. Service Design and Focus

CART staff discussed the barriers presented by long waiting times for GP appointments and in primary health services waiting rooms. Waiting times of three to four weeks in the face of an immediate health need led to frustration and

lack of timely health care for whānau. Waiting times were mainly attributed to over-subscription of primary care services.

These issues are sometimes ameliorated for the whānau when CART are able to advocate and sometimes accompany their whānau to the primary health care services and improve their experiences. Sometimes CART will also accompany their clients to ED in order reduce 'bad behaviour' which helps to make ED staff more comfortable providing services for these whānau.

Often in mitigating the bad behaviour of some of our people who might be intoxicated or on some form of substance that made them...difficult to deal with.

CART provides a range of health promotion services to their clients and the community. By providing these services, they are not only promoting whānau fitness and health but also building a sense of community, which shows that they have a holistic approach towards health for their clients. Their programmes also aim to engage their tamariki which has, in turn, inspired their parents to make positive changes – “that’s a really good tool to engage the older whānau”.

CART had some suggestions to improve the services provided by health systems in terms of the delivery of care. One of the suggestions was to employ more Māori within the system. This was to ensure better treatment of whānau and increase the level of cultural competency.

Another suggestion was to improve general customer service within the health system, especially for the frontline staff within the system. An example of what type of improvements they would like to see would be better explanations of possible wait times etc.

It may just be lip service...you may just have to have a long wait so don't get upset'...they are more likely to stick around for the three hours.

CART staff suggested that health services need to recognise the importance of treating individuals as part of a whānau, and as a whole person, taking an holistic

approach to health rather than just focusing on disease, in order to improve health services for whānau.

At its root, what we're talking about is Whānau Ora, which assumes potential. So it's not treating people as a pathology...I see your potential for wellness, even though there may be things that you are doing at the moment that get in the road of that.

A suggestion made by a member of CART was to see whānau as consultants in their own right. It was identified that the power relationship needs to be changed from one where doctors are in a position of power to an equal relationship where both sides of the conversation are equally valuable.

The power relationship shifts from the doctor or medical professional to being more of a partnership...a tuakana-teina, older brother, older sister type of relationship...a respectful one.

HEALTH PRACTITIONERS

1. Affordability

Health practitioners identified affordability of transport, consultation fees or debts, and prescription charges as barriers for whānau. They recognised that whānau were forced to make tradeoffs between paying for health care and other living expenses.

Knowing that you won't be judged and that your doctor cares about you is great but it doesn't pay the bus fare or taxi fare.

Health practitioners outlined the impacts of whānau being unable to afford the costs of accessing health care as non-attendance at services, attending ED instead of primary care services, choosing less costly medical investigations or treatments, and not collecting prescription medication. They recognised the frustration and despondency that affordability issues caused whānau.

Practitioners gave examples of existing initiatives to mitigate the impact of affordability of transport. The Wellington Free Ambulance was seen as an enabler, although one practitioner commented that in some instances the ambulance would not attend callouts at homes affiliated with gang activity.

Transport assistance by primary care services was identified as an enabling factor, with initiatives including payment for taxis and the Red Cross shuttle

We also regularly pay for the taxi fare for several of our patients that we know who have highest health needs... and they probably wouldn't come if we didn't fund that transport.

Health practitioners suggested that policies to expand the provision of free primary health care were a solution to one aspect of affordability barriers, and further transport initiatives were needed.

2. Competing priorities

Health practitioners observed whānau making choices about their health in light of other priorities.

When you sit down and talk to them about what the pressures or priorities are for a person's life at the moment, [diabetes is] often number nine or ten ... debt, food, money, court fines, kids, troubles with the family, agencies and school and then there's diabetes.

3. Logistics

Health practitioners identified a few logistical barriers to accessing health care that were not tied to financial costs in particular, including transport and child care.

4. Health Literacy

Health literacy was identified as an important factor in access to health care, with many practitioners identifying a lack of understanding about health conditions, the health system, services and processes as barriers to access.

Poor self-management of health and poor health-seeking behaviour were identified as barriers particularly for men and those with mental health conditions.

ED does their best to help people, but there are times when they need to help themselves

Practitioners suggested that poor health literacy leads to a wariness of health services and a sense of whakamā when whānau interact with health practitioners.

Practitioners identified their role in “improving people’s health literacy and working out how the health system works”, and recommended whānau education to improve health literacy as a solution that would empower whānau to take control of their health.

One practitioner identified the effectiveness of health navigators in improving health literacy and health seeking behaviour.

... navigate (whānau) through the different things that happen when you see a doctor or a nurse. People are getting good healthcare, attending appointments and things are happening. This kind of promotes health seeking behaviours.

5. Whānau Perceptions

Health practitioners identified reluctance to seek or receive help as a barrier. This was ascribed to a range of reasons, including past experiences with health services, forced attendance by government departments, low health literacy, and perceptions of the health system as Pākehā. Some whānau were interpreted as “too proud to go down the Pākehā way”

6. Discrimination

Racist and prejudiced attitudes and discriminatory behaviour of health practitioners were identified as a barrier to appropriate health care. Racism and discrimination based on perceptions of the social status and gang affiliation of whānau were identified as negatively impacting the quality of care provided to whānau.

...treat them badly, 'cos of how they look or how they behave, or they are perceived to have been behaving.

With the health system a culturally foreign environment for whānau, any negative encounter, particularly early on in an admission or appointment is a barrier.

That first contact that people get is so important, because they're already coming into a foreign environment and already feeling unwell and if they get kind of knocked down again at the door, I think that's a huge barrier to access

Furthermore, practitioners identified the impact of discrimination on whānau morale (whakamā) and their perception of the health system, leading to reduced or reluctant utilisation of health services by whānau and their communities.

They pick up an inbuilt prejudice against them already, that they're like this, it's their fault and they're just going to be this self-fulfilling prophecy where you expect poorly of them then of course they will continue to do poorly.

Non-discriminatory, welcoming services were seen as an enabling factor, whether at an individual level of care, or at a service level.

It's about kind of being open to anything, even if you don't share that experience; like not judging.

7. Service Design and Focus

A number of aspects of health services design were identified as barriers to access for whānau.

I feel the health system is set up for people like me and you and not people who are 'hard to reach'.

Health practitioners identified ethnic differences between health practitioners and whānau as a barrier, related to but distinct from issues of cultural competency.

...60% of ED staff (clinical) are from overseas.

Māori health practitioners were viewed as better able to provide culturally appropriate care (manaaki tangata), and therefore enable access to health care. Health practitioners recommended an increase in the number of Māori health professionals, with the rationale that a 'by Māori for Māori' approach would improve access, cultural appropriateness and quality of care.

The location of services was discussed in terms of the impact it has the cultural safety of whānau, power dynamics between the provider and whānau, and on the ability of whānau members to participate in the care of their relatives. Health practitioners recommended that more health services should be provided in community facilities such as schools and churches, marae, or in the home, with the aim of creating a safe space for whānau to access services.

You're in need of health care, and we need to come to you... like Tamariki Ora

It's really nice as a doctor to see where people are living, what people are living in, how they live. I think it gives you a good perspective of what life's like for the patient as well.

Lengthy waiting times in ED and for GP appointments were viewed as a barrier to utilisation of services and receiving timely care, with short wait times at GP conversely seen as an enabler. One solution proposed was to alter the format of primary care services to make better use of clinicians' and patients' time, for

example having one doctor available for walk-ins each day to cater for immediate and urgent appointments.

Time constraints on consultations were identified as a barrier for health practitioners, restricting their ability to understand the social context of the whānau and address issues beyond the presenting complaints.

Having not enough time in the appointment or too much pressure with other patients waiting for me to be able to sit, look them in the eye, talk to them about what's really happening for them, rather than just the cold that their kid's got.

Health practitioners frequently referred to issues of coherent service delivery. Good communication between practitioners and integrated services were seen as enabling factors, with a recommendation to improve information sharing across the range of services. A significant barrier that was identified by ED clinicians was the when whānau were no GP, or over-subscription at local GP practices.

Health practitioners valued the role of social workers, Whānau Care and Pasifika services. They were seen as particularly effective in improving follow-up care, and addressing social determinants of health. Practitioners saw the limited after-hours availability of these services as a barrier, and recommended greater resourcing as a solution.

When social services are unavailable we sometimes have to admit patients with complex social issues to make sure they are cared for until we can get appropriate follow-up in place 20b

Continuity of care was an important factor, with a recognition that it's "better to be able to be seen by the person they want to be seen by, that they have a good relationship with, that they trust, that they feel like they're not going to be judged by."

Health practitioners identified the focus of health services as an important factor in access to appropriate care for whānau. ED was described as focusing on

immediate physical health needs, with limited concern for social or mental health issues. Conversely, the Whānau Ora approach was seen as a pragmatic and enabling factor.

Because a lot of the time it's a group effort to make the person who's unwell better.

Health practitioners recommended wider use of Whānau Ora as holistic and empowering framework, and practical steps to improve the cultural appropriateness of health care. Specific examples included strengthening whakawhanaungatanga, increased use of karakia and blessings, and facilitating whānau involvement with a relatives receiving health care by enhancing the whānau room concept and ensuring enough physical space for whānau to be present with the patient.

8. Individual Quality of Care

Health Practitioners identified the importance of the therapeutic relationship in contributing to whānau engagement, comfort, and ongoing use of health services.

A positive relationship, generally that is what will make that person come back

The important enabling aspects of individual care included facilitating whakawhanaungatanga, being non-judgmental, encouraging, catering to individual needs, and communicating effectively.

I find that particularly the Māori whānau, it's important to connect and they like to know my connections as well and I'm quite happy to talk about this stuff.

With someone just released from jail I'll always leave the door open to acknowledge that being confined in a room can be very threatening.

Cultural competency was raised as a key determinant of the relationship's quality, with lack of adherence to tikanga and kawa, a barrier to building rapport with whānau.

Health practitioners recommended cultural competency training would improve individual quality of care. It was noted that current training is not compulsory for CCDHB practitioners.

MĀORI HEALTH EXPERTS

1. Affordability

Māori health experts identified the financial costs of health care, including the cost of consultation fees, prescriptions, and transport as barriers for whānau. Experts discussed the decision-making issues that whānau face where trade-offs are made between utilising health care and paying for other living expenses like food. Experts explained there were times when whānau decide to not seek health care in order to pay for food. Māori health experts attributed the lack of affordability of health care to poverty and unemployment.

Debts may also play a role, where whānau would not go back to follow up appointments as they hadn't finished paying their bills or wouldn't pick up prescriptions as they had owed the pharmacy money.

Some Māori health experts identified existing services that make health care more affordable, such as “CART, being a free service with outreach programmes”.

To make health services more affordable for whānau, Māori health experts recommended that services receive more realistic funding and some free services should be provided for high needs people such as the whānau who are the focus of this study.

2. Health literacy

Māori health experts identified poor health literacy among these whānau as a barrier. There were issues surrounding jargon used in the hospitals and also a lack of understanding around when to access services, and which ones to use.

To address this barrier, they proposed outreach programs increasing community awareness “of what services are available and ... what they can access or what they need to access”.

A key aspect of capability building is health literacy. Health professionals are notoriously bad at communicating in words that make sense to whānau.

3. Discrimination

Māori health experts identified that racism and discrimination on the basis of other factors were observed within the health system. Racism was identified as occurring at many levels, at an interpersonal level as well as the structural level.

In terms of health care and access to care, racism is very complex and can operate at many levels and in many ways.

At the level of the service provider, Māori health experts stated that attitudes and stereotypes come into play, which can manifest unconsciously in a consultation setting.

Racism can also occur at an individual provider level, where due to provider bias, differential quality of care is seen. This is due to the various stereotypes about ethnic groups which providers may have, affecting the way they behave. This is usually very subtle and may not be a conscious decision.

In terms of possible solutions mentioned by Māori health experts to reduce discrimination, suggestions were made to encourage people to be aware that we live in a society where there is a need for interaction with people from different groups.

Anti-racism training aims to have providers be aware that if you grow up in NZ you will be exposed to messages about Māori and gang whānau and these may be negative, particularly if it comes from mainstream media, and that these may impact on us in some way, leading us to have biases or assumptions about Māori.

It's training is centered around delivering care where we don't invoke these stereotypes and assumptions that we are exposed to.

4. Service Design and Focus

Some Māori health experts saw the way the health system is designed and services currently delivered as a barrier.

Some of [the barriers] can be in and around the systems that we have in place, the hours that we're open, the services that we deliver.

The need to modify current service design was identified as an important factor in improving access to services.

So we need to broaden it to include what the system can do to make it easier for whānau to engage with healthcare... it's important to look at ways in which the system can change, rather than expecting the individuals to change.

A range of specific issues was identified. Māori health experts discussed service coherency and integration, identifying fragmentation of services as a barrier to access.

Whānau do not live in sectors. Until health and social services, including education, are synchronized whānau will be offered bits of a service that make little sense. That fragmented approach will reinforce the observation that many services are geared to meet sector and provider needs rather than to understand the whānau realities. They will continue to be hard to reach services.

Turning to the focus of health services, Māori health experts identified Whānau Ora as an enabling model of health care, and recommended that services need to have “whānau located at the centre” to improve their access to health care. They described Whānau Ora as prioritising whānau needs over the needs of the services and aiming to eliminate the attitudes of blame and condescension towards whānau.

The Whānau Ora model has attempted to address some of [the] shortcomings, mainly by emphasizing that whānau need to be at the centre of planning.

Services need to fit in with whānau perspectives, priorities, and opportunities. Further, the Whānau Ora approach recognizes that empowerment requires more than fixing up a problem. Unless fixing the problem is accompanied by serious efforts to build capability, then little will change for the next generation.

Māori health experts discussed the need to increase the number of Māori in the health workforce, strengthening their clinical leadership.

Evolve and develop the Māori community i.e. our Māori and Pacific children who already have a commitment to our community because they grew up in it and understanding and awareness of it...they provide a different sort of leadership because of their commitment to here, they can then juggle the competing priorities better in theory, because their commitment will always be to 'what does this mean for my community?'

Other solutions around system and policy included a Healthy Prison Framework/Strategy promoted by World Health Organisation (WHO). It was thought that spending time promoting healthy lifestyles and educating within the prison system can be effective because in this environment, the barriers that do exist outside the prison system (such as costs, transport, time) are no longer an issue so it was viewed as a good chance to set them into a healthy routine.

It's a manual or a guide really to what prisons can do in their administration, to develop you know a focus on health and that can include things like promoting recreation in prisons, providing for specialist treatment for people who are, you know, have secondary illnesses or mentally unwell or stuff like that...Might be more about promoting health awareness from how to manage diseases like diabetes, and so on.

In order to know whether changes to services were making a difference or not and to guide the service configuration for whānau, Māori health experts highlighted the importance of robust collection of ethnicity data.

Collection of ethnicity data is therefore really important so we can monitor how the service is doing in terms of providing care for particular groups and to check

that they're not actually contributing to those inequalities but trying to address them.

Māori health experts identified the presence of DHB Māori Health Plans as a positive step, and the development of a set of indicators means that Māori outcomes can be compared across DHBs.

Now, you can quite clearly see their commitment to Māori and what area they are trying to improve specifically (e.g. Māori health, Māori in the justice system, Māori welfare etc.).

5. Individual Quality of Care

At an individual level, Māori health experts focused on cultural competency. Some of the Māori health experts interviewed believed that healthcare providers who do not understand Māori culture will not, in turn, be able to provide appropriate care for whānau.

Lack of understanding [by the staff] of the culture, and perception of why patients and whānau think the way that they do.

Some viewed the issue as a failing within the education system where cultural competency is not taught along with professional training.

You cannot be clinically competent if you are not culturally competent – they're not two separate things.

There seemed to be a general agreement among Māori health experts that some form of cultural competency training needs to be implemented for health service providers. This would be in order to increase staff awareness about hard to reach whānau and the difficulties they face. It was suggested that programmes be implemented within the medical schools that promote relationship building and general cultural competence about Māori and also other ethnic groups.

On an individual level, cultural competency training is very important. By this I don't mean that providers need to know about other cultures, but have a deeper understanding of how their own culture can impact the way that they engage with particular people.

SUMMARY

Through inductive analysis of the interviews, eight themes emerged. It is important to note the complex and overlapping nature of these themes.

1. Affordability

The costs associated with health care were directly discussed as barriers by all informant groups except CART. Costs include transport, consultation fees at GP and after hours services, and prescription charges. These costs were unaffordable for many whānau, and examples were provided of whānau being forced to make trade-offs between spending money on health care or other living expenses.

Some examples of enabling factors in this area were low-cost GP services, free health promotion initiatives, and transport provision or payment by primary care providers. Suggested solutions revolved around reducing cost of health care provision through providing targeted funding, and increasing prescription subsidies. More broad-based suggestions focused on targeting social determinants of health.

2. Competing Priorities

Informants recognised that whānau have a lot of things going on in their lives, and sometimes health issues and seeking health care is not a top priority. Accessing health care can be a particular problem if it takes up a lot of time, meaning individuals miss work and school commitments.

3. Logistics

Aside from cost issues, whānau and health practitioners discussed the practical difficulties of accessing health care. These included arranging childcare, especially in emergencies, and coordinating transport for different whānau members, especially if whānau live far away from the service in question.

Some initiatives that acted as enablers within this theme were discussed, such as the ambulance service, the Red Cross shuttle, and transport paid for by service providers.

4. Health Literacy

Health literacy was identified as an important factor in determining health-seeking behaviour, and accessing effective care. This includes knowledge about medical conditions and medications, awareness of health service entitlements, and understanding of the way the health system works, including services and processes.

Predominantly, informants discussed the low health literacy of whānau as a barrier, and the need to increase whānau knowledge so they feel more in control of their health care.

Current enablers included navigators or support workers who facilitate improved whānau access to the health system.

A variety of solutions were proposed, including emphasising the obligation of doctors and other clinical staff to communicate effectively to improve literacy, and community-based education and awareness programmes.

5. Whānau perceptions

Throughout the interviews, informants referred to perceptions that influence the way whānau view health care and health practitioners as barriers to access. Some of these are caused by, or strongly linked to other themes, but in many cases the root cause of the perceptions were not elucidated.

A reluctance to seek or receive help, along with fear, suspicion, and strong sense of mistrust in health professionals and health services were commonly discussed. Overwhelmingly, such perceptions were ascribed to previous

negative experiences with the health system, or with government agencies more broadly. In some cases, perceptions appeared to be rooted in culture or subculture, such as a perception that seeking health care indicated weakness, or was seen as going down a Pākehā way.

6. Discrimination

Racism and discrimination on the basis of social situation and gang affiliation was widely discussed by all groups as a very important barrier. Racism and discrimination were identified as occurring at an institutional as well as interpersonal level, affecting the quality of care provided, whānau morale and perception of the health system, and their willingness to seek health care assistance.

Whānau largely discussed discrimination in terms of feeling judged by health practitioners and other staff in the health system. Stereotypes lead to assumptions about lifestyle issues, expectations that whānau will be troublesome and difficult to deal with, and a less deserving of health care than other people.

Solutions included anti-racism training, and a conscious switch in the power dynamics of the relationship between provider and patient, in order to see whānau as consultants in their own right.

7. Service Design/Focus

A range of health service design and focus issues were identified as important factors in accessing effective health care, effectively making health services 'hard to reach'.

All groups discussed lengthy waiting times for GP appointments and in waiting rooms, which were sometimes construed as discrimination. The location of services was raised in terms of the impact it has on whānau comfort levels, power dynamics, and the physical space available for whānau to support each

other. The existence of whānau rooms was discussed as a positive feature of the hospital layout, and suggestions were made to strengthen the whānau room concept.

The coherency of service delivery was an important aspect of this theme. Integration of medical and social services, coordination between primary and secondary care, follow up on discharge from ED, and the continuity of care received in primary care were common issues.

Most groups discussed workforce issues, and many informants considered that when health practitioners were not Māori, they were unable to deliver culturally appropriate care. The need to train and employ more Māori health practitioners was identified across the interviews.

The focus or philosophy of services was considered an important factor, and informants distinguished between patient-centered and whānau-centered care. The Whānau Ora approach was seen as an empowering and pragmatic way to improve health care for whānau.

Other suggestions within this theme focused on policies to improve health care in prisons, and ensuring ethnicity data is collected in order to improve the evidence base for targeted interventions and outcomes for whānau.

8. Individual quality of care

All groups discussed the relationship between whānau and individual doctors or other health practitioners. Whānau in particular emphasised the importance of this relationship, the quality of which impacts whānau engagement, comfort levels, and ongoing use of health services.

Whānau illustrated the many ways individual practitioners can present barriers to accessing effective health care, for example by not taking time to explain

things properly, assuming an egotistical attitude, poor cultural competency, or displaying poor communication skills.

Notable enabling factors in these relationships included effective communication, attention to whakawhanaungatanga, cultural competency, and a non-judgmental attitude. Whānau referred to a number of doctors who went the extra mile.

Solutions suggested included improved cultural competency training from medical schools through to work place training.

Discussion

1 Discussion of Themes

The analysis has revealed eight main themes. We will discuss these themes in relation to the topics outlined in the literature review, before addressing potential solutions. Our recommendations aim to apply a Treaty of Waitangi lens through the Whānau Ora model emphasising the need of partnership, protection and participation. Our potential solutions aim to reduce barriers to health care access identified through this study, taking into account the three key principles of the Treaty, Kawanatanga (governance), Tino Rangatiratanga (self-determination and control) and Ōritetanga (Equality).

1.1 Affordability

New Zealand has a mixed model of health care. Secondary (hospital level) health care is mostly funded by the state (with private care available on a user pays model) ⁵³. Importantly, emergency department care does not carry a cost. Primary (community level) health care is subsidised by the government, with some direct costs being met by the consumer on the day of consultation (“out of pocket costs”). These out of pocket costs have been identified as one of the major barriers to accessing effective health care, especially amongst indigenous groups in society³⁹⁻⁴².

The literature review, as well all groups interviewed all emphasised that consultation fees, prescriptions, after hours GP fees as well as transport costs can force whānau to prioritise living expenses over health care.

These out of pocket costs can also result in an inability of whānau to present for healthcare in a general practice setting³⁵. As a result, some healthcare conditions most appropriately dealt with in a general practice setting are inappropriately diverted to the emergency department and, additionally, health conditions

further progress as a result of a not obtaining initial treatment - to a point where they require secondary level care.

Māori health experts agree that free or further cost reduced services for high need, low resource whānau would be appropriate. This is supported by Jatrana's finding that Māori were more likely have deferred buying a prescription for reason of cost in a 12-month period⁴¹. Potential models are discussed in the solutions section.

1.2 Opportunity cost and competing priorities

The opportunity cost of lost income from missing work was identified as a barrier to accessing health care³⁵. This opportunity cost is exacerbated if there are long wait times when accessing health care.

Other competing priorities for patients have also been identified by whānau and health care practitioners such as dropping and retrieving children from school, paying for adequate food and providing adequate childcare. These competing interests have not currently been addressed in depth in the literature, however indications from whānau and healthcare practitioners suggest they are also important.

1.3 Logistics and travel

Logistics and travel were potential barriers acknowledged in the literature review^{21, 41, 43} that were further identified by whānau and health practitioners in our interviews and analysis. In addition, difficulty parking, transporting (large groups of) whānau to the hospital was also identified as barriers.

From the perspective of whānau, as well as many of the Māori health experts and health practitioners interviewed, it is the health system itself (rather than ngā whānau) that is 'hard to reach'. Māori health expert Dr O'Sullivan supported this in his interview stating "hard to reach whānau can be wrongly perceived as

hard-to reach. It could be that we are not trying hard enough to reach out". Long waiting times and expensive public transport are the kind of barriers to healthcare that require intervention not simply at an individual level but from within the health system and at a wider public policy level.

1.4 Health literacy

Health literacy is a complex issue, involving both patients' knowledge of health systems and the way in which health information is appropriately conveyed. It was noted in a study by McCreanor and Naim that Māori patients generally have poor health literacy²⁹.

Poor health literacy can be viewed in relation to other social determinants such as education, with low levels of knowledge and understanding of how and when to utilise health services identified as a barrier to effective health care by both healthcare practitioners and ngā whānau³⁵.

Several different perspectives can be drawn about health literacy, depending on whether health literacy is considered a barrier from the whānau or health system point of view. From our analysis, it was generally agreed that the health system is responsible for improving health literacy in the community, with suggestions such as increased outreach programmes and health promotion from various health organisations. A key concept of Whānau Ora is to increase self-determination and control of Māori over their own health³⁴, and this is not possible without a certain amount of knowledge of the healthcare system.

1.5 Whānau and community perceptions

Both whānau and Māori health experts interviewed in our study identified that community perceptions, a general mistrust of the system and its treatment of whānau was a significant factor in preventing access to healthcare²⁹. This mistrust is often a result of negative past experiences.

In terms of willingness to access the system, Māori health practitioners have been identified from our study as contributors to positive whānau experiences,

as have Pākehā practitioners who embrace use of rongoā and other tikanga Māori^{19, 21, 32, 33}.

It must also be acknowledged that there are multiple reasons underlying whānau perceptions aside from past experiences - many of which may be subconscious, and interlink with other the barriers discussed. Therefore, it is perhaps best to consider these perceptions in relation to barriers such as discrimination, poor health literacy, service design and focus, and individual quality of care.

1.6 Discrimination

Discrimination, particularly racial discrimination was one of the most common reasons found in the literature for why indigenous people (including Māori) are not accessing sufficient health care¹⁵⁻¹⁸.

Experience of racial discrimination is an important determinant in the inequities in health that Māori face in New Zealand¹⁹. Both interpersonal and institutional discrimination contributes to these inequities¹⁹.

Our interviews support interpersonal racism as a determinant of whānau accessing health care. Whānau, Māori health experts and healthcare workers in our study all identified discrimination against race or social situation (i.e. gang affiliation) as an important factor in preventing access to appropriate health care.

Feelings of whakamā (shame) were reported by the whānau when they were judged or discriminated against in the healthcare system, particularly in relation to suspicion of child abuse. One individual's comment of "I'm used to being turned away, but didn't expect it from the hospital – they should be impartial" illustrates the effect of discrimination on whānau.

The concept of institutional racism was illustrated at the PHO level. Historically, Māori PHOs were being audited much more often than other PHOs, resulting in decreased time to provide health care services.

On an individual level, both health practitioners and Māori health experts in our study were aware of a subtle and often subconscious level of stereotyping of patients based on race, socioeconomic status and gang affiliation. According to our study, one bad experience could be enough for whānau to stop accessing health care due to fear of embarrassment or stereotyping.

Discrimination in health care, based on race or any other social factors, is something that the Whānau Ora initiative aims to reduce through an emphasis on cultural competency, whānau empowerment and whānau-centred models of care⁶.

Whānau-centred services especially should address this issue, making Māori feel more accepted, valued and empowered when accessing health services. A suggestion that builds on this, raised by a Māori health expert, is that anti-racism, cultural competency training may make it easier for health practitioners to appreciate both the subconscious and conscious assumptions that they make about Māori and other minority cultures in New Zealand.

1.7 Service design and focus

Whānau, health care practitioners and Māori health experts that we interviewed all recognised that there needs to be more adaptation of service design to facilitate and work with whānau to improve healthcare outcomes. A specific area of service identified as needing remediation was that of communication between primary and secondary health care. Several interviewees identified fragmentation of communication between primary and secondary care, in conjunction with poor healthcare communication directly from practitioners to patients, as a barrier⁶⁻⁹.

Additionally, some whānau identified that not being able to access community health care after hours because of prohibitively expensive after hours general practitioner care.

Under the Whānau Ora model, “whānau need to be empowered as a whole which required multiple government agencies to work together with families rather than separately...”⁶. Whānau should have the choice to access health and social services practitioners who offer wrap around services tailored to their needs. Appropriately subsidised after hours care could be targeted to those high needs whānau as required.

It was also identified from our interviews with health practitioners that 60% of New Zealand healthcare practitioners are trained overseas. Accordingly, whānau identified that there was a general lack of understanding of Māori culture in the New Zealand healthcare workforce. Cultural training is not currently compulsory, service design as well as cultural competency checks have been identified as a way of promoting appropriate cultural communication between services providers and Māori².

1.8 Individual quality of care

Cultural competency, understanding and effective communication have been identified as key elements of providing effective individual quality health care^{2, 6, 7}.

A patient centred approach with increased communication and feedback with the relevant DHB has been suggested as an appropriate approach to effect this^{1, 6-9}.

A common theme found across all groups interviewed was that increasing cultural competency results in an increase in individual quality of care and Māori health experts believe it is linked to service design⁶. An inclusive, whānau ora view of medicine where cultural competence is inextricably linked to clinical competence is required^{7, 8}.

Health practitioners in our study identified that, when possible, delivery of services in the community (in conjunction with CART or with the Marae) could potentially facilitate engagement with culture and increase quality of care.

2 Whānau Ora Model and Recommendations

Whānau, Māori health experts and health practitioners have all highlighted the interwoven nature of these barriers, many of which have roots in the conditions created during colonisation leading to an enduring sense of historical injustice. Given this complexity, a holistic approach is needed to generate effective solutions¹⁹⁻²¹.

For this reason we have used the Whānau Ora Model to develop our recommendations. The Whānau Ora Model uses an evidence-based five part framework with a single overarching aim of producing best outcomes for whānau⁸. It recognises the position and role of Māori in New Zealand society as tangata whenua and uses the Treaty of Waitangi as its foundation to guide national development and integrated service delivery across the healthcare and social services spheres. Whānau Ora has 7 major principles: Best Whānau Outcomes; Ngā Kaupapa Tuko Iho; Coherent Service Delivery; Effective Resourcing; Competent and Innovative Provision; Whānau Opportunity; and Whānau Integrity. This model is illustrated in the introduction section of our report.

Some of these recommendations we have directed specifically to our client CART, due to their direct involvement with the whānau that were interviewed in this study.

The whānau-centred framework contains five domains of whānau impact^{6, 8}:

- a whānau aspirational aim
- principles
- whānau outcome goals
- whānau-centred services

- a Whānau Ora Trust

2.1 A community shuttle would help minimise transport and cost issues identified as logistical barriers to whānau accessing healthcare. During the interview process, it was mentioned several times that a significant logistical barrier was lack of transport to health services. This specifically addresses the need for services to be “designed and delivered in a way that places whānau at the centre of the service provision”^{6,8}. This shuttle would be a way of removing logistical barriers for whānau. It is known that CART has already applied for funding for this and it was denied but it is still worthwhile advocating for this service. An example of this would be a CART owned shuttle that picked up ngā whānau who wouldn’t have come in to receive care otherwise and then left Newtown at specified times to take them back home. It is specifically related to Whānau-Centered Design and Delivery of Services in which “services are designed and delivered in a way that places whānau at the centre of service provision”^{6,8}. The point is to build “whānau capability so that they are able to prevent crises, manage problems and invest in their future”^{6,8}.

2.2 Free or further subsidised GP services for those with limited resources (socio economic criteria) and high needs and reimbursement of prescription fees for whānau meeting certain socio economic criteria are public policy initiatives that could further address affordability barriers to healthcare¹³. Removing the cost barrier is the first step towards assessing the health system. This will enable more frequent visits to health services so the whānau-practitioner relationship is strengthened and the whānau can develop self-empowerment. This would hopefully create a flow on effect. Better health can lead to a better life outlook overall such as being able to work can lead to a higher socioeconomic status, which can lead to better housing which in turn leads to better health. Additionally with ngā whānau presenting to GP this decreases the burden on the emergency department. Health professionals, Māori health experts and non-government organisations such as CART can influence government policy

through active advocacy, by and on the behalf of whānau and by empowering whānau to advocate for themselves.

At a national level, resource allocation is a major factor influencing health system decisions and making healthy public policy. Under the Whānau Ora model, one of the key foundations of effective whānau centred service delivery is an active and responsive government^{6,8}. The government should be able to align their actions to whānau, hapu and iwi goals and this includes funding decisions aimed at addressing areas of greatest need and greatest inequity. Funding aimed at social determinants such as housing and education (e.g. subsidies for insulation) must not be forgotten as they have an important influence on health outcomes for underprivileged whānau as discussed above.

2.3 Community childcare, facilitated within ngā whānau community, potentially with input from CART is a recommendation that will enable whānau to access health care more readily, in part by reducing anxiety about leaving their children without supervision. Many of our interviews highlighted the importance that these whānau place on their tamariki, with one particular interviewee stating that “she is my number one priority”. By connecting parents in this area, they can act as a collective whānau, caring for one another’s children when the need arises.

2.4 Outreach programmes implemented by CART have already been welcomed in this community, and from our interviews we recommend that more of these outreach programmes, aimed particularly at health promotion and education, be implemented. By increasing health literacy in the community it empowers whānau to take control and ownership of their health. This is in accordance with the Whānau Ora philosophy of self-determination, rather than viewing lack of health literacy as a deficit among whānau. CART could also make health information easily available through pamphlets providing culturally appropriate education on common health conditions and healthy lifestyles.

Another way of improving health literacy among whānau and making whānau more comfortable accessing the healthcare system is to have 'health navigators' to guide them through the often confusing and threatening process of using a healthcare service. Pacific 'health navigators' have been highly successful in this area, so we recommend that similar Māori 'health navigators' are used to introduce whānau to using the health system. This would include explaining what the whānau can expect from the service provider, including normal wait times, explanation of protocols, and how they can expect to be treated by the health practitioner.

Financial literacy and budgeting is also a consideration, as problems with this can lead to trade-offs between health care and living expenses¹³. It is possible that education on basic money management skills could increase health care service access through removing the affordability barrier. Budgeting advice could be offered for free through a community trust in the South Wellington region.

2.5 Whānau Ora also stresses the importance of producing whānau centred services, and reducing stereotyping by doctors and medical students^{6, 8}. This is related to three of the seven principles of the Whānau Ora model, namely Coherent Service Delivery, Whānau Opportunity, and Competent and Innovative Provision of Services. Our recommendation is that the Otago Medical School (Wellington campus) addresses this issue by developing a health promotion workshop run by 4th or 5th year medical students during their GP or Public Health attachments. This would produce six workshops, with around 20 students, in the Newtown area every year, aiming to provide free health promotion, chronic illness (e.g. diabetes) management advice, health literacy development and other health checks in which medical students are competent. This reflects the Whānau Ora model as it highlights the need for "partnerships between whānau and providers"⁶, and this would hopefully build a relationship between whānau and medical students in the South Wellington region. This will allow whānau to communicate with and trust the people that will be treating

them, their children and grandchildren in the future. It will also provide medical students with invaluable learning opportunities that will produce cultural understanding, empathy, and competent and innovative provision of health care in the future, in accordance with Whānau Ora.

Continued research projects in conjunction with CART also allow for development of these partnerships between medical students and whānau, and should be encouraged in the future.

2.6 The principle of Whānau Integrity^{6,8} is something we feel is compromised by the label of 'hard to reach' - a term externally applied to whānau perceived as having suboptimal access to healthcare and social services. 'Hard to reach' is a universal term used across government sectors such as the Ministry of Health and Ministry of Social Development - meaning organisations such as CART are forced to use this term when advocating for whānau and applying for funding. Feedback from our interviews and discussions with CART however suggest that 'hard to reach' has negative and somewhat accusatory connotations. For example, it may imply that barriers arise purely from whānau themselves being difficult to engage with, or perhaps do not access health services out of their own lack of motivation. With this in mind, we propose challenging the use of 'hard to reach' at a government and health practitioner level - as it only serves to reinforce judgemental and negative perceptions. As stated by Dr Lance O'Sullivan: "We've gotta stop judging these people that we think are lazy and just not prepared to help themselves".

2.7 This study has highlighted the importance of the whānau centred approach to delivery of healthcare. One of the seven principles of Whānau Ora is Effective Resourcing, which talks about firstly matching resource allocation to the size or importance of the task and secondly making sure these resources deliver result⁵.
⁶. Effective resourcing encompasses a holistic view of health including primary prevention - with the aim of producing the best possible outcomes for whānau.

For this whānau centred approach to be implemented, the relationship between whānau and providers needs to be a collaborative one in which information and knowledge is exchanged. The service provided should be “geared towards building resiliency and enhancing whānau strengths, as well as addressing issues of concern”⁶.

One idea is to have an integrated and coherent health service coordinated by a single whānau contact person - perhaps a respected person from the community. This would involve all practitioners - a GP, nurse, physiotherapist, social worker and so on - all in one place. Reduced costs as well as increased communication and collaboration between providers could result - reducing fragmentation as well as allowing development of whānau-centred and holistic approach to health care⁶. This kind of integrated delivery recognises the fact that quite often the current sectoral and fragmented approaches to healthcare can fail to account for wider whānau dynamics and as a result can miss the underlying or fundamental issues.

2.8 Further training of medical students and registered doctors in New Zealand about reflective cultural practice is also important^{21, 22}. Encouraging reflective cultural practice for all health professionals, as well as specific training provided by the DHB can reduce the everyday stereotyping and biases that many healthcare professionals have, but are not aware of. Attesting to this is a recent article titled “Racism: Tolerated and Trivialised in New Zealand”⁵⁴

From the evidence collected in this study it has become clear that this discrimination needs to be minimised in the health profession, in order to produce the best health outcomes for the entire population of New Zealand. Dr O’Sullivan, illustrates this point “It pains me to think that just by virtue of the fact these kids are born brown indigenous kids they’re gonna get a second rate chance at life.”⁵⁵ In relation to the Whānau Ora Model, this will hopefully increase competent and innovative provision of healthcare, as well as improving Whānau Integrity, and Best Whānau Outcomes.

While the term cultural competency is used in the above analysis it is suggested that shifting away from 'cultural competency' as a phrase will be helpful as this implies that providers can reach a certain level of competency and then require no further training, but rather 'cultural collaboration' as an ongoing relationship with whānau should be considered.

While there is not currently any compulsory cultural competency (collaboration) training in the CCDHB setting, we understand there is currently a pilot program regarding its implementation. We suggest cultural training as part of a wider CCDHB initiative as well as a core part of the medical school curriculum to ensure that doctors in the New Zealand work-force are have a greater understanding of the cultural needs of whānau.

2.9 Our final recommendation is about empowering whānau to provide feedback to their health service and making them comfortable doing so. While there are systems in place to make complaints/give feedback about hospital experiences, evidence from our research suggests these are often not or under utilised. We need to recognise the role of whānau and empower them to take charge of their own health-care by providing mechanisms to effect positive change where current medicine does not meet the requirements of whānau , as Sir Mason Durie states "Whānau potential is high and ready to be unleashed; Whānau Ora provider networks are extensive, committed, innovative and ready to learn from each other; and Whānau Ora is already anchored on solid foundations that will bring fresh opportunities and gains for whānau in the decade ahead." ⁵⁶ By empowering whānau to provide appropriate feedback and making sure organisations such as CART have appropriate information and mechanisms to facilitate this, we establish a cooperative relationship with whānau, address any immediate health experience concerns and build a collaborative approach aimed at better overall whānau health care, by empowering whānau to take an active role in their own health.

3 Study Limitations

Given the short time we had to complete the project, we were limited to interviewing participants that were available over a period of a few weeks.

It ended up being unrealistic to transcribe the interviews, which would have ultimately made data analysis more comprehensive. We had one of the interviewers writing notes throughout the interview and pulling out quotes retrospectively by listening to the recording. The inclusion of key statements, themes and quotes was dependent on what individual interviewers deemed important. Inappropriate and inconsistent selection of data may have introduced interviewer bias and led to misinterpretation of the data. An analysis template was used to make data interpretation consistent across the board and minimise interviewer bias.

Some of the Māori health practitioner interviewees were from around the country and thus did not fit in with our research definition of limiting the study to South Wellington. However, we consider their viewpoints relevant given the barriers and enablers identified were consistent with the key themes that emerged from local providers. Their input also strengthens our recommendations that are applicable at a national level.

We had multiple people doing the interviews, which brought consistency into question. We attempted to overcome any major variations in information gathering by using a template to identify key questions and prompts. In addition, the interviews were performed in pairs and they were all recorded.

4 Study Strengths

A key strength of our research project was the use of Whānau Ora as a framework to base our study methodology around. We were consequently able to carry out data collection in a culturally appropriate manner and formulate recommendations that are in keeping with the Whānau Ora whānau centered initiatives. By using a Kaupapa Māori approach we aimed to empower study participants by valuing their cultural context. This also aided the communication between interviewers and interviewees as we used a kaupapa Māori approach and incorporated tikanga.

By performing a qualitative study to address barriers and enablers to accessing health care we were able to examine the recurring themes in greater depth and detail compared to a quantitative study design. We had flexibility around the framework and direction of the study, meaning that our approach to the study could be revised as new information emerged. During the interview and data collection process we were not limited by a strict set of questions and could explore certain topics in greater detail as they arose in real time. Our research draws upon human experiences and gives a voice to the people who are intended to benefit from the research. By incorporating uncensored quotes and real life experiences the data we obtained is more compelling compared to a quantitative study design. In terms of a Kaupapa Māori research approach, a qualitative study is also particularly well suited to the Māori worldview given it enables more equal conversation to take place.

A positive outcome from the research project was the relationship building that took place between CART and the medical school as well as medical students and whānau. CART maintained a strong presence throughout the duration of the study and they were integral in bridging the way between the research group and whānau. We were able to gain insights from whānau that we wouldn't have otherwise had access to. CART's involvement also provided a space for whānau to be empowered and feel safe to talk freely during the interviews.

We as a group had our own perceptions challenged and have ultimately become more informed about the limitations that exist within the health system. We have furthered our knowledge about actions that can be taken to improve access and provide culturally acceptable care. Our project also provided an opportunity for whānau to voice their opinions and have their experiences and views validated.

Conclusion

Our project looked at barriers and enablers to accessing health care for “hard to reach whānau”. Our study defined the term “hard to reach whānau” as gang affiliated whānau, prisoners/ ex-prisoners, solo mothers, long time unemployed and whānau with mental health conditions. Literature on this population group was scarce.

From the literature review the major themes concerning access of whānau to health care were:

- 1 Socioeconomic status
- 2 Cultural differences/ incompetence’s
- 3 Structural and systemic issues involving racism, stereotyping, attitudes and judgmental behaviour

The information gathered from interviews with whānau, Māori health experts, health practitioners and CART staff aligned with the literature in most areas with a few extra points becoming apparent.

The important themes were:

- 1 Affordability
- 2 Competing priorities
- 3 Logistics
- 4 Health literacy
- 5 Whānau and community perceptions
- 6 Discrimination
- 7 Service design
- 8 Individual quality of care

By applying the literature and information gathered from our research, we have developed recommendations we believe would increase whānau access to effective health care. These recommendations aim to address both system level issues and practical issues that CART can address and some suggestions for whānau.

Our recommendations are:

- 1 A shuttle to minimise the effect of transport and logistical barriers.
- 2 Free or further subsidized GP services and prescription prices for high users or those meeting with the limited resources/ socioeconomic criteria.
- 3 Volunteer community child care to decrease logistical barriers.
- 4 Outreach programs to increase whānau health literacy
- 5 Create more whānau centered services.
- 6 Alter the terminology “hard-to-reach”, which is used with regards to particular groups, as they create stereotypes and pre-conceived connotations.
- 7 Service design and focus alteration to a more whānau based approach.
- 8 Further training of medical students and registered doctors in reflective cultural practice.
- 9 Empower whānau to provide feedback to their health service

These recommendations, if implemented, will enable “hard-to-reach whānau” to access effective health care. For this to happen we need health providers, government and whānau attitudes to change. We need to be dissatisfied with the large health inequities that exist in New Zealand and dedicate resources to decreasing the gap between Māori and non-Māori.

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Appendices

Appendix One : Ethics



Form Updated: February 2011

HUMAN ETHICS APPLICATION: CATEGORY B (Departmental Approval)

1. University of Otago staff member responsible for project:

Lawson-Te Aho Keri Dr.

2. Department: Department of Public Health, University of Otago
Wellington Campus

3. Contact details of staff member responsible: email: keri-rose.lawson-teAho@otago.ac.nz

Phone: (04) 385541 ext: 6050

4. Title of project: **Ma te HuruHuru: Barriers and Enablers to
Healthcare for Hard to Reach Māori Whānau: A Case Study.**

**5. Indicate type of project and names of other investigators and
students:**

Staff Research **Names**

Student Research **Names**

Level of Study (e.g. PhD, Masters, Hons)

External Research/ **Names**

Collaboration

Institute/Company

Consultancy Advocacy and Research Trust (CART).

6. When will recruitment and data collection commence?

30th May

When will data collection be completed?

20th June

7. Brief description in lay terms of the aim of the project, and outline of research questions (approx. 200 words):

This project aims to qualitatively identify the barriers that hard to reach whānau, experience when accessing primary care and emergency department services. This project will be run in concordance with CART (Consultancy, Advocacy and Research Trust Newtown¹). Hard to Reach whānau include gang whānau, prisoners, ex-prisoners, mentally ill, long-term unemployed, those on the margins of society and people alienated or alone. The hard to reach whānau in this project are clients of CART.

Healthcare in the Emergency Department (ED) at Wellington Hospital and community based General Practice (GP) (Newtown Union and Ora Toa in the Newtown/South Wellington community) will be the setting for this project.

The study methods include:

1. Key Stakeholder Interviews

2. Whānau Narrative Inquiry using Whānau Focus Groups

Key Stakeholder interviews will include clinical and non-clinical staff from from one PHO (Wellhealth) and two Newtown based GP practices (Ora Toa ki Pōneke and Newtown Union Healthcare), clinical and non-clinical staff from the Emergency Department at Wellington Hospital/CCDHB; CART Māori health researchers and Māori leaders. The draft key stakeholder list is attached to this Ethics Application².

The whānau focus groups will include Nga Mokai/hard to reach whānau identified by CART. These questions form the basis of the whānau Focus Group Interviews

3. What information is given to whānau by healthcare practitioners?

4. Do they understand this information?

5. What information do they want?

¹ CART is an advocacy trust based in the South Wellington region and supports the Nga Mokai, their word for 'hard to reach whānau'. These whānau are described as a "minority within a minority" and include hard to reach and difficult to deal with community members. CART makes itself available to these whānau and aims to improve their quality of life with the collective outcome being that of "Whānau Ora". They help with work, accommodation and financial and social support for the unemployed and other socially disadvantaged whānau.

² The document is attached and titled Key stakeholder interview possibilities.

For hard to reach whānau

6. Do you use health services and if not then why?
7. How often do you use health services?
8. What is health service to you?
9. What is your experience with health services?
10. What is your experience with the Emergency Department?
11. Are you registered with a GP?
12. If you could change one thing about the health service, what would it be?

The questions for healthcare providers will follow the same format but relate to barriers and enablers to healthcare (for ngā mōkai) from the position of a service provider.

8. Brief description of the method. Please include a description of who the participants are, how the participants will be recruited, and what they will be asked to do:-

The participants are the Ngā Mōkai whānau (also referred to in this application as hard to reach whānau) who will be identified by the CART staff. CART will facilitate the process of students explaining the study to the whānau and obtaining whānau informed consent to take part in this project. In order to attain informed consent, the students will provide an information sheet to whānau, talk them through the project and answer any questions they have and then ask them to sign the informed consent sheet.

Focus group interviews will take place at the CART premises. The interviews will be performed by student researchers and facilitated by CART employees with the support of Dr Keri Lawson-Te Aho will be present. Student safety will be ensured by the presence of CART staff members at all interviews. The medical student counsellor is available to all participating students for the duration of the project; Dr Keri Lawson-Te Aho is also able to provide access to clinical psychological services if required by students. Following the completion of the research all students will take part in group debriefs.

There will be two sets of interviews conducted as described below:

- o Focus Group Interviews: will be with groups of the Nga Mokai whānau. They will be grouped into three-five separate whānau groups for the interviews. Methods are being refined at the moment but need to take into account the level of literacy of these whānau and willingness to ‘talk’ about their issues. Methods that have been shown to work effectively with Ngā Mōkai include a card sort process³ and the use of art as a means of communication⁴. The overall project methodology is Kaupapa Māori and within that, a combination of standard and Māori specific methods will be used. Kaupapa Māori requires a level of cultural competence and CART and Dr Lawson-Te Aho will take responsibility for ensuring that Tikanga Māori is correctly observed.
- o Key Stakeholder Interviews: will be with ED staff, primary care staff, Māori development individuals/leaders and Māori health researchers. These were selected by the research team on the advisement of their supervisors, for their knowledge of barriers and enablers to healthcare by these particular hard to reach whānau.

These interviews will be analysed using thematic analysis. Data will be stored and coded on NVivo or Dedoose IF this is achievable given the five week project timeframe. Data will be triangulated to allow insight into the key access issues that impact the health of the Nga Mokai whānau. Hypotheses regarding the relevance and generalizability of the research will be presented in the final report along with any recommendations to reduce any identified barriers and enhance any enabling factors. An iterative process will be used for the data analysis and CART staff will be included as partners in the research process which is consistent with a Kaupapa Māori research methodology. Any publications will acknowledge CART as a key research partner.

³ O’Reilly, D. (2010). Participative action research: consensus cardsort – whānau future narrative. MAI review. <http://www.review.mai.ac.nz/index.php/MR/article/view/396/550>

⁴ Pipi, K. (2010). The PATH planning tool and its potential for whānau research. MAI review. <http://www.review.mai.ac.nz/index.php/MR/article/view/377/555>

Data will be stored on a password protected computer file at the University of Otago, Wellington in the office of Dr Keri Lawson-Te Aho until such time that appropriate storage facilities are available at CART premises.

9. Please disclose and discuss any potential problems: (For example: medical/legal problems, issues with disclosure, conflict of interest, etc)

Focus group interviews will not cover any information of a sensitive nature, including but not limited to, legally compromising details, drug use, or intimate relationships.

Assurance will be given to all participants about anonymity, and no names or identifying details will be recorded.

Applicant's Signature:

*(Principal Applicant: as specified in Question 1, Must **not** be in the name of a student)*

Signature of *Head of Department:

Name of Signatory (please print):

Date:

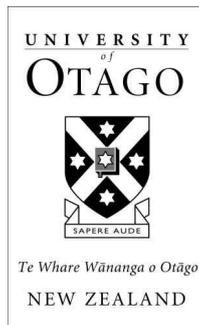
Departmental approval: *I have read this application and believe it to be scientifically and ethically sound. I approve the research design. The Research proposed in this application is compatible with the University of Otago policies and I give my consent for the application to be forwarded to the University of Otago Human Ethics Committee.*

**(In cases where the Head of Department is also the principal researcher then an appropriate senior staff member in the department must sign)*

INFORMATION SHEET

[Reference Number as allocated upon approval by the Ethics Committee]

[Date]



Critical analysis of access issues for hard to reach whānau from the South Wellington region.

A case study

WHĀNAU INFORMATION SHEET

PLEASE NOTE: CART staff will lead the process of explaining the study to the Nga Mokai whānau. These documents are guidelines from the student research team and can be used by CART staff as aids for explaining the project. Formal informed consent will be acquired by student interviewers

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether to take part. If you decide to take part, thank you. If you decide not to take part there will be no disadvantage to you and we thank you for thinking about taking part.

What is the Aim of the Project?

This project aims to identify barriers that you have experienced with the New Zealand healthcare system and your feelings and thoughts about health services you have been involved with. In this interview, you will be asked about your experiences with different health care services.

What Type of Participants are being sought?

Participants are whānau who have been selected by the CART team. You will receive a koha of groceries which has been put together by CART for being interviewed and kai during the interview. You may also be offered transport to and from the interview.

What will Participants be Asked to Do?

You will be asked some questions about your experiences with health services. There will be 2-3 students, Keri Lawson-Te Aho from the medical school and CART staff present in the interview.

What Data or Information will be Collected

You will be asked questions around barriers to care and your experiences of health services. Recordings will be stored safely by the project group. If it is ok with you we would like to record your korero so the project team can re-listen to the interviews. The answers you give will help the project to gain an idea of the barriers you experience and the thoughts you have about your healthcare. If you do not like the questions then you do not have to answer them and nothing more will happen.

The final answers will be presented in a report that brings together everyone's answers. The results of the project may be published but you will remain anonymous in any publications and will be able to get a copy of the results of the study from CART.

You will be anonymous, no names or identifying details will be recorded.

This proposal has been reviewed and approved by the Department of Public Health, University of Otago, Wellington Campus.

Can Participants Change their Mind and Withdraw from the Project?

You can withdraw from the study at any time without any cost to you.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Dr Keri Lawson-Te Aho

Department of Public Health, University of Otago, Wellington Campus.

University Telephone Number: 385541 ext:6050

Email Address keri-rose.lawson-Te Aho@otago.ac.nz

This study has been approved by the Department stated above. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Critical analysis of access issues for hard to reach whānau from the South Wellington region.

A case study

**INFORMATION SHEET FOR
[PARTICIPANTS or PARENTS]**

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether to take part. If you decide to take part thank you. If you decide not to take part there will be no disadvantage to you and we thank you for thinking about taking part.

What is the Aim of the Project?

This project aims to identify barriers that hard to reach whānau have experienced with the New Zealand healthcare system and their perception of the healthcare services. You will be asked about your experiences with hard to reach whānau groups, including those with gang affiliations and long term beneficiaries.

In this project we (4th Year Medical Students) want to know about barriers hard to reach whānau experience with healthcare. We are also interested in your thoughts about issues around access to healthcare for this group.

What Type of Participants are being sought?

Participants are key stake holders in hard to reach whānau health who have been selected by CART (Consultancy, Advocacy, Research Trust, a Newtown based service working with hard to reach whānau).

What will Participants be Asked to Do?

Key stake holders will be asked questions in a semi structured interview format. These questions will allow sharing of experiences and thoughts from the key stake holders. Student interviewers will be present.

What Data or Information will be Collected and What Use will be Made of it?

Your answers to the questions will be recorded with your consent. The questions will be open ended questions (allow discussions) and be based around the barriers and thoughts of service providers including clinicians, towards access by hard to reach whānau to healthcare. Recordings will be stored safely on an encrypted data file in a locked filing cabinet in Dr Lawson-Te Aho's office. The answers need to be recorded so the project team can re-listen to the interviews. The answers you give will help the project to create understanding of what you believe the access issues to be for these whānau. As someone involved in health care provision, your responses are absolutely vital. If you do not like the questions then you do not have to answer them and nothing more will happen.

The final answers will be presented in a report that brings together everyone's answers. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand).

You will be anonymous, no names or identifying details will be recorded.

This proposal has been reviewed and approved by the Department of Public Health, University of Otago, Wellington Campus.

Can Participants Change their Mind and Withdraw from the Project?

You can withdraw from at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Dr Keri Lawson-Te Aho

Department of Public Health, University of Otago, Wellington Campus.

University Telephone Number: 385541 ext:6050

Email Address keri-rose.lawson-teAho@otago.ac.nz

This study has been approved by the Department stated above. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Critical analysis of access issues for hard to reach whānau from the South Wellington region.

A case study

CONSENT FORM FOR

PARTICIPANTS

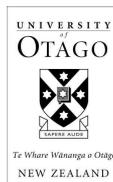
I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My participation in the project is entirely voluntary;
 2. I am free to withdraw from the project at any time without any disadvantage;
 3. Personal identifying information on audio-tapes that are part of the raw data on which the results of the project depend will be retained in secure storage for at least five years; these may also be used by CART for their own research.
 4. I agree to having this interview recorded - Yes / No
 5. This project involves an open-questioning technique. The general line of questioning includes barriers and perceptions of healthcare in New Zealand faced by the Nga Mokai whānau. The precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind."
 6. Whānau taking part in these interviews may have transport offered to get them to and from the interview. They will also be offered groceries to \$50 of value and food during the interview as giving back for the time they have given to this research.
- o The results of the project may be published and available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

.....
(Signature of participant)
(Date)



Notes concerning Category B Reporting Sheets

- o This form should **only be used** for proposals which are **Category B** as defined in the policy document "Policy on ethical practices in research and teaching involving human participants", and which may therefore be properly considered and approved at departmental level;
2. A proposal can only be classified as Category B if **NONE** of the following is involved:-
 - Personal information - any information about an individual who may be identifiable from the data once it has been recorded in some lasting and usable format, or from any completed research;
(Note: this does not include information such as names, addresses, telephone numbers, or other contact details needed for a limited time for practical purposes but which is unlinked to research data and destroyed once the details are no longer needed)
 - The taking or handling of any form of tissue or fluid sample from humans or cadavers;
 - Any form of physical or psychological stress;
 - Situations which might place the safety of participants or researchers at any risk;
 - The administration or restriction of food, fluid or a drug to a participant;
 - A potential conflict between the applicant's activities as a researcher, clinician or teacher and their interests as a professional or private individual;
 - The participation of minors or other vulnerable individuals;
 - Any form of deception which might threaten an individual's emotional or psychological well-being.
 - The research is being undertaken overseas by students.

[If any of the above is involved, then the proposal is Category A, and must be submitted in full to the University of Otago Human Ethics Committee using the standard Category A application form, and before the teaching or research commences];

3. Please ensure the Consent Form, Information Sheet and Advertisement have been carefully proofread; the institution as a whole is likely to be judged by them;
4. A Category B proposal may commence as soon as departmental approval has been obtained. No correspondence will be received back from the University of Otago Human Ethics Committee concerning this Reporting Sheet **unless the Committee has concerns**;
5. Please submit a Category B Reporting Sheet immediately after it has been signed by the Head of Department to the Human Ethics Committee:
**Manager,
Academic Committees
Academic Services
Room G23, Clocktower Building
University of Otago
gary.witte@otago.ac.nz**

Appendix Two

Keystake Holders: Maori Leaders

Key Stakeholders: Māori Leaders and Advocates

Moana Jackson; Kim Workman; Hone Harawira; Pahia Turia; Cath Love, Moe
Milne

Professor Sir Mason Durie, Dr Lance O'Sullivan

Aim: Factors impacting access by hard to reach whānau to healthcare – Māori
leadership and advocate perspectives

Definitions: Hard-to-reach whānau: gang whānau, prison whānau, long term
unemployed and long term mentally ill whānau, sole parent whānau

Interview structure:

Phone call, NB. email the project description and the questions through before
the interview; informed consent will not be required for these interviews as they
are key stakeholder interviews with identified leaders in Māori health and
justice issues

Interview Questions:

Name:

1. Can you define hard to reach whānau from your perspective?
2. Can you describe your work with hard to reach whānau?
3. Based on your experience, what are some of the key barriers for hard to reach whānau accessing healthcare?
 - a. In the hospital?
 - b. In primary care such as doctors clinics?
4. What are some of the larger systemic issues impacting hard to reach whānau access to healthcare?
5. Can you outline some of the solutions to the healthcare barriers you have identified?

Thank you for your time. Invitation to attend the presentation

Key Stake Holders: Maori Development Team

Key Stakeholders: Maori Health Development Group

Riki Niania and Cheryl Goodyer

Aim: Identify modifiable/non-modifiable structural barriers and enabling factors to effective healthcare for hard to reach whānau in the South Wellington region

Definitions:

Effective Healthcare: Healthcare that meets the needs of hard to reach whānau

Hard-to-reach whānau: Gang whānau, prison whānau, long term unemployed and long term mentally ill whānau, sole parent whānau.

Key Stakeholders: Individuals and groups that have influence to impact the access to health care of hard to reach whānau

Interview Structure

Introduction – identify yourselves, explain the purpose of the interview

If face to face, ask stakeholders how they want to commence the interview

If phone interviews explain the purpose of the interview and commence

Ask if it is ok to record interviews/voluntary (for face to face interviews)

Consent form (for face to face interviews)

Make sure you use the modified consent form for providers. NB no koha offered to providers

Thank participants for participating in the interview/invite them to the presentation and lunch

Interview Guide

1. How do you define hard to reach whānau

Probe: Does specific or programmes policy exist addressing the needs of hard to reach whānau

Probe: Can you identify some key issues that impact these whānau

2. What are some of the barriers to access for hard to reach whānau such as gangs etc

Prompt: How does the Māori health development group respond to these barriers

3. How do you ensure that there are no attitudinal or other barriers for hard to reach whānau?
4. How do you respond to cases where hard to reach whānau have encountered difficulties accessing services?
5. What are the structural issues for CCDHB staff working with hard to reach whānau?

Probe: What is being done to remove these structural barriers

6. What are your recommendations about how to respond to the needs to hard to reach whānau?

Probe: Are these currently, or like to be implement in the future?

7. How can we better respond to the needs of staff and hospital services?

Probe: How are hospital staff prepared to work with hard to reach whānau

Key Stake Holders: CART

Key Stakeholders: CART

John Bishara, Dennis O'Reilly, CART Team

Aim: Identify modifiable/non-modifiable structural barriers and enabling factors to effective healthcare for hard to reach whānau in the South Wellington region. CART supports and mediates some of the experiences through their case workers.

Definitions:

Effective Healthcare: Healthcare that meets the needs of hard to reach whānau

Hard-to-reach whānau: Gang whānau, prison whānau, long term unemployed and long term mentally ill whānau, sole parent whānau.

Key Stakeholders: Individuals and groups that have influence to impact the access to health care of hard to reach whānau

Interview Structure

Introduction – identify yourselves, explain the purpose of the interview

If face to face, ask stakeholders how they want to commence the interview

If phone interviews explain the purpose of the interview and commence

Ask if it is ok to record interviews/voluntary (for face to face interviews)

Consent form (for face to face interviews)

Make sure you use the modified consent form for providers. NB no koha offered to providers

Thank participants for participating in the interview/invite them to the presentation and lunch

8. What services does CART offer for hard to reach whānau

Probe: How do these services differ from other providers?

Probe: What gaps in services currently exist?

2. What are CARTs recommendations for health service providers?

3. What are the barriers to accessing health service for hard to reach whānau

Probe: What are the enablers?

4. Does CART have a role in advocating for hard to reach whānau

Probe: Does CART meet with hospital hierarchy to discuss some of the concerns these whānau have about the quality of care they receive?

5. How does CART propose to improve access to health care for hard to reach whānau groups?

Probe: Have whānau interviews highlighted issues that CART was unaware of, if so which issues?

6. Present scenario from previous interviews

Probe: What is your response to this?

Probe: How does CART respond to this?

Probe: How can CART work in conjunction with existing services to improve this situation?

7. What are the barriers to CART improving health outcomes for hard to reach whānau

Hard to Reach Whānau

Interview Template for Hard to Reach Whānau Groups

Aim: Identify barriers and enabling factors to effective healthcare among hard to reach Whānau based on their shared experiences and attitudes to health.

Specifically, looking at how hard to reach Whānau understand/navigate the healthcare system. Access barriers to services, and past negative/positive experiences.

Definitions:

Effective Healthcare: Healthcare that meets the needs of Māori by using Whānau ora to empower whānau as a whole rather than focusing separately on individual family members and their problems.

Hard-to-reach whānau: Whānau that are a minority amount of Māori that are consistently unable to access appropriate healthcare services. They may be subject to racism, social isolation and prejudice and are frequently associated with gangs and prisoners.

Interview Structure

1. Introduction
 - a. Mihimihi and karakia for the kaupapa as guided by CART services
 - b. Ask if it is ok to record interviews, highlight, that this is completely optional
2. Consent form
 - a. Interviewers to inform the whānau members regarding why we are asking them questions and to obtain informed consent
3. Thank participants, invite them to share their stories with us

Interview Guide:

1. How's your Whānau health been?
 - a. Prompt: Can you tell me some more. Is your Whānau registered with a GP
 - b. Probe: What does your Whānau normally do when you get sick?
 - c. Can you describe the last time that you or one of your whānau went to a health care centre to see a doctor or a nurse? **If possible, try to discuss a time that they went to GP AND a time they went to ED using this same process/list of prompts*
 - b. Prompt: Could you tell us a bit more about it? how easy to get apt, any cost related barriers, how found overall experience (for the individual and wider whanau)
 - c. Probe: what made experience good/bad/ok
 - d. Prompt: Is this similar to other experiences you whanau have had?
 - e. Probe: After your visit to the ED, the next time you visited your Doctor did they know about it.
2. Has your whānau ever thought you should go to the doctor or ED but didn't? Can you tell us more about it?
 - a. Prompt: how easy to get apt, any cost related barriers, how found overall experience (for the individual and wider whanau)
 - b. Probe: what made experience good/bad/ok
 - c. Prompt: Is this similar to other experiences you whānau have had?
3. Have you or one of your whānau ever had an experience at the GP or ED that you thought was good? Can you tell us more about them?
 - a. Prompt: how easy to get apt, any cost related barriers, how found overall experience (for the individual and wider whānau)
 - b. Probe: what made experience good/bad/ok
 - c. Prompt: Is this similar to other experiences you whānau have had?
4. Is there anything that would make going to the doctor better for you or one of your whānau?
 - a. Prompt: how easy to get apt, any cost related barriers, how found overall experience (for the individual and wider whānau)
 - b. Probe: what made experience good/bad/ok
 - c. Prompt: Is this similar to other experiences you whānau have had?