



**“Feel the pain, get on the plane”:** Cook Islanders’  
experiences of seeking health across a transnational  
field

Report of transnational health research in the Cook Islands and New  
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## List of Figures

<b>Figure 1: Mural of mobility on the wall of the library in Avarua.....</b>	<b>1</b>
<b>Figure 2: Signage for the Rarotonga Hospital located on Sanatorium Road.....</b>	<b>14</b>
<b>Figure 3: Health checks at a mother and child clinic in Inave, Rarotonga.....</b>	<b>17</b>
<b>Figure 4: Scooters provide economical transport for people to get around Rarotonga.....</b>	<b>18</b>
<b>Figure 5: Small handout provides information on Maki Maro (TB) in Cook Islands Maori on the wall in the reception at the Aitutaki Hospital.....</b>	<b>21</b>
<b>Figure 6: Mother and child clinic operating outside a hall in Amuri, Aitutaki.....</b>	<b>23</b>
<b>Figure 7: Cannon's Creche Porirua.....</b>	<b>30</b>
<b>Figure 8: A home dialysis unit.....</b>	<b>32</b>

## Introduction

The connections that surround the contemporary lives of Cook Islanders are situated within a complex weaving of historical, political, cultural and familial processes. Cook Islanders have connections with people and lands both distant and near. The patterns of these connections can be framed within the theory of transnationalism (Alexeyeff 2010). Transnationalism theory places the lives of Cook Islanders and other highly mobile people across an active field of movement, where behaviours, goods, ideas, culture and people all move. These movements feed back into the transnational field thereby sustaining its force and exerting influence on the connected nation states (Levitt and Glick Schiller 2004).



**Figure 1: Mural of mobility on the wall of the library in Avarua**

The establishment of the Cook Islands transnational social field began with pre-colonial voyaging by Cook Islanders. Since this time, the sagas of colonisation, annexation and more recently, Free Association has aligned the lives of Cook Islanders with New Zealand. The Cook Islands and New Zealand share a currency, citizenship and many adopted state systems. The many relationships that have emerged between New Zealand and Cook Islands are visible in both countries. Although the national borders between the Cook Islands and New Zealand remain significant, increasingly, Cook Islanders have become proactive in leveraging the

connections with New Zealand, whether for employment, family reconnection, sojourning, or as in the case of this research, the search for health. The more frequent engagements between Cook Islanders and the transnational field are predominantly perceived as exerting a positive influence on the lives of Cook Islanders. Indeed, it allows for remittances to flow (Loomis 1990; Marsters et al 2006), economies to be broadened (Lewis 1998) and people to be mobile (Underhill-Sem 2000). The transnational field may be seen as part of an overall survival mechanism, a way to connect resources and people who have limited opportunities.

Transnationalism considers the sustainability of culture, language and traditions across time and space (see Nakhid 2009). As transnationalism theory has developed, researchers have begun to turn towards the less visible and more problematic symptoms of transnational relationships (Dunsford et al 2012; Yuval Davis 2003). Below the seemingly rose-coloured transnational world, where happy but resource-poor people connect with each other via means of advanced technology, are the difficult realities, where gender inequalities exist (Alexeyeff 2008) and where people experience health conditions which can be explicitly or implicitly linked to their transnational activities.

The lives of Cook Islanders are situated within the complex and confusing reality of transnationalism. To capture a clearer picture of what this means for the daily life of Cook Islanders, the transnational field must be interrogated from multiple points and, for this project, a range of ethnographic data was gathered in the hope that I could paint a clearer picture of what the Cook Islands transnational field looks and feels like, and how this influences people's health. I wanted to sort through the dense pile of *rito* [a fibre used for weaving], to select key strands to begin this story and to ultimately include enough strands that I could create something of use, like a fine Manihiki hat which protects the wearer from the sun.

The complexities of Cook Islanders' lives are presented in this report within a framework which considered the interwoven and interacting forces at play on a person's physical body. Syndemic frameworks provided the *vaka* to explore, consider and analyse the seemingly

inseparable connections that contribute to Cook Islanders' experiences of Type 2 Diabetes and Tuberculosis (see Singer and Clair 2003). This form of analysis is not compromised by the expectation that the data would have to be ultimately clearly bounded and reduced; instead, the connections, the overlaps, and the gaps are emphasised. What follows is an ethnographic account of my field research. The intention is to illustrate the trials and tribulations of transnational research and to also highlight some of the themes and patterns which emerged during my field research.

The format of my research reads like a multi-sited ethnography, as I stepped in and out of discrete places within a set amount of time. Whilst in organisation my research was indeed a multi-sited ethnography, I was heavily influenced by the idea of a Cook Islands transnational field and used tactics to demonstrate my commitment to the people who participated, even when I was not there. Field research was conducted with Cook Islanders who have experiences of TB and Type 2 Diabetes in Auckland, Porirua, Rarotonga and Aitutaki. The limited time available at each site meant that I had to rely on many of the same mechanisms that Cook Islanders use when circulating between New Zealand and the Cook Islands. The key tactic was to establish strong connections with those I interviewed by way of multiple interviews. Over the course of two years, phone calls, Christmas cards and emails served to maintain connections with many of my participants. During my field research phase from July 2010 – July 2012 the research experience was somewhat punctuated with coming and going from various places. I found that efforts placed on ensuring that I also had strong relationships with people in the health landscape of each site helped ensure continuity. At the end of these two years, I felt comfortable that I was part (albeit a minor one) of the social fabric of the Cook Islands health community.

## **1.0 Tracing the edges of the transnational social field**

The Auckland region is the largest provider of health services to Cook Islanders. More Cook Islanders reside in Auckland than anywhere else in Cook Islands and New Zealand. The health

of Cook Islanders who are in Auckland either permanently, transitionally or momentarily to access health services are served by three of the largest District Health Boards in New Zealand. Before embarking on the collection of experiential accounts I began the process of tracing an outline of the health services available to Cook Islanders with TB. The decision to begin with TB as the predominant enquiry rests upon the wider remit of the “Transnational Health in the Pacific through the Lens of TB” project. This research informs this project and preparatory reading on the subject signalled that TB provides a lens into the peculiar experiences of this disease but also the accompanying health conditions of poverty, overcrowding, smoking, vitamin D deficiency, malnutrition and Type 2 Diabetes (see Littleton and Park 2009). Interviews and informal conversations were held with key stakeholders in the area of tuberculosis diagnosis, treatment, surveillance and strategic management planning. This included the Auckland Regional Public Health Nurses (PHN), the Auckland Regional Public Health Services Chief Medical Officer, Pacific Liaison for the Auckland Regional Public Health Service and the Counties Manukau District Health Board and Biomedical Technicians at LabPlus. A lengthy discussion was also held with the Counties Manukau District Health Board in regards to the Memorandum of Understanding between them and the Cook Islands Ministry of Health.

Given that Cook Islanders are more likely to live in or visit Auckland than anywhere else in New Zealand, over time advocacy and leadership organisations have been established to promote health and well-being amongst Cook Islanders living in New Zealand. The hub of these groups is typically based in central or south Auckland. The Cook Islands Health Network Association (CIHNA), established in 2004, is an important networking and advocacy group. The role of this charitable organisation is to connect people of Cook Islands heritage within the health sector in New Zealand and to promote an increase in the health work force capacity of Cook Islanders. I attended two meetings at CIHNA headquarters, held in a back room of the Mt Roskill Family Medical Centre in Mount Roskill. Papa Joe Williams, founding and active member of the organisation and a well known GP to many of the Cook Islanders in Auckland, lends this room for the monthly meetings. At my first meeting with CIHNA, Metua Bates, whom I

interviewed previously, introduced me to the group and allowed me the space to introduce my research project and my community aspirations. I found that support for my research was enthusiastically forthcoming, and that the 'fresh face' on the Cook Islands health scene in New Zealand was warmly welcomed. The key strengths of this organisation are the readily available historical commentary on the health of Cook Islanders both in New Zealand and the Cook Islands as well as access to successful Cook Islands clinicians. The group also provides a nuanced understanding of the transnational orientation of Cook Islanders' lives. This understanding arises from both personal experience and events such as the annual conference which connects Cook Islanders both in New Zealand and in the home islands. The CIHNA is a critical part of the social fabric that surrounds the health of Cook Islanders. In a culture which prefers the use of committees and organisations to action change, CIHNA represented a group of people that could strongly influence the success of my research.

I was aware that over the course of my research, people were likely to ask me questions about whether I had been in touch with CIHNA about my project. These questions are part of Cook Islanders' interest in placing one's movements within their community. As such, I was also aware that attempts needed to be made to meet with Nuku Rapana, a figurehead in the Cook Islands community and manager of the Pukapuka Community Centre. The Pukapuka Community Centre in Mangere is very active in providing a range of services to the Pukapukans in Auckland. They provide an early childhood centre, car seat rental, business advice, Information Communications and Technology (ICT) training and a run a small commercial kitchen. I visited with Nuku twice and spent some time observing the range of activities in the centre. At the time of the research, the Pukapuka community centre was already heavily involved in a Gout research project being directed from the University of Otago by Professor Tony Merriman. The involvement included regular blood screening of participants in Auckland and also expected travel to Pukapuka to repeat the exercise. I was keenly interested in this research because of the intention to perform a transnational investigation, even if it was of a

more clinical foundation. Because of possible research overload and conflict of interests however, a decision was made not to recruit participants from this organisation.

My travels to New Zealand health services and the Cook Islands community provided an overview of the connectors within the health realm of not only TB but Cook Islanders more generally. Key people's names would constantly be repeated, not just in their official capacity, but also because of the services they were providing at a community level. During this process I was able to isolate key nodes of significance in terms of TB screening/diagnosis, contact tracing and treatment. Exploring these places also highlighted that what binds the multiple elements of TB as a disease was the Public Health Nurses. These people both deliver Directly Observed Therapy (DOTs) and *connect* the dots that surround people's experiences of TB. Given the significance of this group of people, before interviewing could begin, the assistance of the Public Health Nurses was critical. I introduced my research topic to the Auckland Regional Public Health Service meeting in February 2010. I later approached the PHNs to see if they would mind signalling my interest in conducting research with Cook Islanders who they were treating/had treated. If an interest to participate was identified, with the potential participants permission, I was then given access to their clients' contact details. Place is a determining factor in the treatment of TB, with each PHN being designated to cover a particular geographic area. Accordingly, this means that PHNs have differential expertise on the TB experiences of groups of people most vulnerable to TB given that they tend to cluster in certain areas. Because of the higher number of Cook Islands residents in the suburbs of Glen Innes, Avondale and Otara, three PHNs working in these areas connected me with the Cook Islanders who would become my participants. Over the course of two years I formed a particularly strong working relationship with the PHN who works in Glenn Innes. She allowed me to observe her working life in her office, her car and in the homes of some of her clients. When my field research had ended, she also helped to validate my data. The access and information granted by this PHN was reciprocated by my developing an understanding of the challenges of the job of a PHN and a

deep appreciation for the wider service these people provide to families. I believe that the PHNs enjoyed being able to allow someone to walk in their shoes, if only for a very short time.

### **1.1 Moving across the transnational field in search of participants**

Health research is problematic because participants are usually identified and recruited because they are experiencing some form of physical difficulty. The desire for personal privacy, experiences of shame and lengthy treatments make the process of participant recruitment all the more difficult. Often my searches would lead to dead ends, and at times the waiting seemed tiresome; however, with each failed attempt it became clearer that the stigma of having TB is real, and that given that it is a disease of poverty in New Zealand, the stresses and symptoms of surviving on limited resources become a key obstacle (see Lawrence 2007). A researcher in this environment must tread very lightly, slowly reassuring people that one's motives are good, and that all precautions to limit possible harm will be taken. Beyond the necessary precautions when dealing with those with serious health conditions, I was mindful of the social and cultural constructions of Cook Islanders' experiences with disease (Mila-Schaaf 2009).

Frequent contact with the PHNs was needed to remind them to think of this research despite their hectic schedules. This contact was also an opportunity to reassure them that I would treat their clients with respect. PHNs delivering DOTS into people's homes become protective of these people as they form a daily relationship with them over long periods of time. The difficulty I faced in the recruitment of people with TB provided the impetus for me to elevate my understanding of research ethics beyond the stock standard university guidelines. Reading more widely on ethics provided me with similar concerns researchers have with protecting their participants and indeed themselves in areas of sensitive research. I came to understand that nurturing a small selection of participants enabled me to care, protect and value the stories they shared with me.

A significant personal event also occurred for me during the research period. I became pregnant with my second child in April 2010. Cook Islanders are very family orientated, and my pregnancy was always met with congratulations and questions about my growing family. My pregnancy diminished some of the barriers I had previously experienced when conducting research with Cook Islanders. Being a parent provided me with an important common dominator with my participants.

In-depth interviewing was my primary method of research throughout the two years of my field research. The decision to rely heavily on the information gathered during these interviews rested with my intention to use the accounts to construct a realistic portrayal of living in a transnational social field. From the outset, I imagined that only through interviewing would I also be able to get a sense of the interacting factors contributing to person's experience of disease. For a syndemic framework to be applied, careful attention needed to be placed on both hearing and observing the multiple forces at play which impact a person's health. My earlier research in the Cook Islands also demonstrated that although questionnaire-based research is useful for some forms of information, Cook Islanders are more comfortable relating their life story in the form of conversations which frequently include stories of family histories, personal relationships and the local politics (see Marsters 2003). The accounts shared in this report, whilst significant in their own right, also speak broadly to the experiences of other participants. Although the case studies below were commonly located in suburbs familiar to many Cook Islanders in Auckland, such sentiments were repeated to me in other places. The narratives arising from these accounts as well as others also feature later in the thematic section of the report.

### **1.3 Auckland: The largest provider of health services to Cook Islanders**

My first in-depth interview was in the suburb of Otara. I had been put in contact with Anabelle<sup>1</sup> via a Public Health Nurse. This elderly woman who had TB shared her health related

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<sup>1</sup> pseudonym

stories with me over the course of 5 interviews in 2 years. Anabelle spent most of her time alone at home while her granddaughter attended university during the day. She enjoyed the company that the interviews provided and was very open from the beginning. Together we talked about a range of physical, social and emotional associations she had with her TB. Fear of the hospital and staff dominated these conversations, but social isolation, misunderstanding the diagnosis and the physical unease she was experiencing also surfaced. Over time, the conversation also drifted to her relationships with other members of the family and the difficulty she faced supporting herself and her granddaughter on her pension. The background to these conversations was her circular movements between Mauke and Rarotonga. Never far out of earshot was also Anabelle's relationship with Type 2 Diabetes. Anabelle had spent her entire life in Mauke up until 11 years ago, when her now deceased husband's health condition brought them both to Auckland. This seminal interview touched upon many of the elements that would later form the sharpened focus of my research. Quietly in the background of this participant's stories I heard of the health related mechanisms which facilitated or obstructed her movement to and from the Cook Islands.

From the outset of my in-depth interviewing I would dedicate considerable time to writing notes that captured the surge of information I gathered in these settings. Often my hour drive home provided me with the opportunity to talk through these notes in my own mind, solidifying the memories to ensure not much was lost between the interview and the time I got to my computer. This hour long drive also served as a sort of transitional period, between entering the field and returning to my own family. It was a good opportunity to contextualise my experience.

Many Cook Islanders live in Glen Innes and there is a visible Pacific community. Glen Innes is positioned just downhill from one of Auckland's wealthier suburbs of Remuera. In Glen Innes I met Teina<sup>2</sup> and Ingaro<sup>3</sup> and their six children. TB had touched this family's life from multiple

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<sup>2</sup> pseudonym

directions over the last ten years. There was both past and present TB history for this couple and some of their children had become very sick with this disease. This family was explicitly connected by TB with another family in Auckland, and implicitly with another family in Rarotonga. I would learn how movement to and from Rarotonga had clearly changed the TB status to active TB of at least one person. Again, this relationship was fostered over a series of interviews. At times both Teina and Ingaro were present, but mostly I talked with Ingaro. Type 2 Diabetes and associated TB had led his mother to die on Christmas Eve in 2009, an event that was entangled with many movements directly related to this woman's health and subsequent death. The whisper of the connection between Type 2 Diabetes, TB and population mobility was starting to increase in volume and provide the validation that my research problem was appropriately framed.

My interviews in Glen Innes occurred during the winter months of 2011. In this couple's home I could see the additional strain that winter had put on this family's health, financial restraints and mood. The children's health complaints of flu, asthma and gastroenteritis were frequently talked about. Most striking was the disconnect between these complaints and the way in which the family lived. Basic hygiene was low, children were not well dressed for the cold and nutrition was often cheap and filling starch. Over time, I sensed that the disconnections in their understanding of how to live a healthy life were the result of chaos and disorganisation of a family of this size with limited economic resources and a form of medical pluralism involving misinformed health advice from family and friends. On my last interview I asked Ingaro if he felt prepared to come to New Zealand when he left Rarotonga. He admitted that the steepest learning curve was the different economy in New Zealand, and how dealing with the cash and credit based society had caught his family up in a cycle of debt. What came to light in this conversation was that Ingaro felt that they were not equipped fiscally, culturally or educationally to come to Auckland. Heartbreakingly, Cook Islanders are too often assumed to be fluent in New Zealand society just because they are New Zealand citizens. The absence of

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<sup>3</sup> pseudonym

'migration' support coupled with some bad advice from friends meant that this family's life in New Zealand had started from the back foot and their health had subsequently suffered. Although obviously engaged in some forms of transnational activities, the connections were not strong enough to allow a seamless, healthy movement between the two countries.

In March 2012 I met with another participant in Glen Innes. Prior to meeting Taoro<sup>4</sup> my participants had all been over 50 years of age. Taoro, however, was a young man in his early twenties who had been diagnosed with TB in October 2011. His story was distinctly different to my other participants in that his mobility history had been within New Zealand and Australia as he spent many transitional periods in and out of foster homes and moving between his birth mother and feeding mother<sup>5</sup>. Although a lively and friendly young man, I could tell that there had been personal emotional pain in his past. Aside from being younger than my other participants, Taoro also self-reported as being an otherwise healthy non-smoking young man before he was diagnosed with TB. The diagnosis was missed on several occasions by his GP and was misdiagnosed at Auckland Hospital, where he was thought to have pneumonia. Taoro had spent three weeks in a general ward diagnosed with pneumonia before he was eventually placed in an isolation unit and commenced TB treatment.

Taoro shared a similar lack of knowledge about how to access health care in New Zealand to that of Ingaro. Even though he had spent the majority of his life in New Zealand, his transitory childhood had in part contributed to him being unaware that hospitals were free. Until being taken to the hospital by his girlfriend, Taoro had never been to a hospital, not even to visit a friend or relative. This led me to consider the isolation that Cook Islanders resident in New Zealand may encounter and how this impacts upon health related decisions. In the case of Taoro, his decision to not attend the hospital could be attributed to his disintegrated social and familial networks which were the result of his highly mobile childhood. This participant had experienced being on the periphery from TB and his upbringing. In different circumstances,

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<sup>4</sup> pseudonym

<sup>5</sup> Akin to Whangai adoption in New Zealand

visits to the hospitals to visit family members would most likely have been a part of his life, and health related knowledge acquired during these visits would inform decisions made later in life.

I was very thankful to a PHN who put me in contact with John Lindsay<sup>6</sup>, a prominent Cook Islands musician who had recent experience with TB and was also a dialysis patient. I first met John in November 2011 in his house in Avondale. John, like the other participants in Auckland, lived in a state house. His three bedroom house was part of an estate of ten other similar houses positioned around a small cul-de-sac. On top of the usual nerves approaching the interviewing, the cul-de-sac environment also added to my anxiety. A group of people in their early twenties were talking on the driveways of the houses and my presence was immediately recognised. For my interviews I always made a point to dress in a smart manner, but not so smart that I could be confused with a social worker, police officer or housing person. I also never wore jewellery or carried anything that would denote my relative privilege. On this day, these surface attempts were fruitless, because even though my purpose for entering the estate was unidentifiable, my very presence was met with antagonistic glares. I decided to be the first to speak, and asked which house was John's. Some of the glares faded and I was pointed in the direction of the house. I purposefully employed this strategy, because I knew John was of an age that would command some respect in this estate. This uncomfortable moment didn't last long, and when I met John I was pleased to be greeted warmly and invited into his home.

John is in his 50s and continues to work as a part-time musician. In 2003 John was diagnosed with Type 2 Diabetes and a year later his kidneys failed. He now has three sessions of dialysis a week at either the Carrington Road facility or the Auckland hospital facility. The first time I met with John in 2011 he was coming to the end of his 6 months of TB treatment. The presence of both of these diseases in another of my participants was hugely interesting; so too were John's accounts of his mobility before and after his diagnosis with these diseases.

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<sup>6</sup> This participant has requested that his real name be used in all publications. He hopes that his story will be an inspiration to other Cook Islanders.

After our first meeting I also attended one of John's dialysis treatments at the Carrington Road Facility. John was dozing on a lazy boy chair when I arrived, his mechanical kidney gently pumping away to the left of him. He looked relaxed and comfortable, as did all of the patients. Visitors clearly were not common in this place, as there was no procedure of signing in or out, leading me to believe that visitors were very rare. John and I chatted for an hour or so. The presences of the dialysis machine lead the conversation down a biological route on this occasion. I could tell John was proud of his level of medical knowledge and his own autonomy in managing the machine each time he uses it. John's ability to talk clearly about what he felt and his fears for the future meant that John's interviews also became a source of validation for me. A lot of what John spoke about had emerged in my other interviews and together we were able to talk about the possible themes in the research.

#### **1.4 Rarotonga: the home island?**

The four cases above signal the emergence of several themes which began to surface whilst I was researching in Auckland. Importantly, these themes also emerged in other places on my research journey. For ease of readership I have collated accounts together based on my research location. We now move onto to Rarotonga, where all attempts were made to mirror the research process carried out in Auckland. Rarotonga is a significant place in the health of Cook Islanders. Rarotonga is the capital of the Cook Islands and has the majority of wage employment opportunities throughout the Cook Islands. The international airport in Rarotonga, which opened in 1975, facilitates the movement of people and goods between the Cook Islands and elsewhere. Rarotonga is also the location of specialised and secondary health services and today the Rarotonga hospital is the main liason point for Cook Islanders from all islands who receive referrals for health services in New Zealand. In 2010 I travelled with three other members<sup>7</sup> of "the Transnational Pacific Health through the Lens of TB" research project team to Rarotonga to begin tracing the outline of the health landscape of this island, and the Cook Islands nation. Julie Park, a Principal Investigator for the project, had arrived earlier to the

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<sup>7</sup> Dr Yvonne Underhill-Sem, Associate Professor Julie Park and Ms Debi Futter-Puati

Cook Islands, and before her two-week trip to Atiu she was able to prearrange meetings with key stakeholders for the project. During our five days in Rarotonga we were able to meet with the Minister of Health, Tupou Faireka, then Secretary to the Ministry of Health; Dr Rangi Faireu, Director of Public Health; Nuks Pokura, TB Project Coordinator; Karen Tairi, Nutritionist in Public Health; Heather Aitu Webber, then manager of the Rarotonga Hospital; and Wilkie Rasmussen, then Secretary to the Culture Department. Overall, my main purpose for this visit was to begin to establish relationships with people in the Cook Islands who would later play an important role in assisting elements of my research. The meetings also served as an opportunity for Julie Park to update these stakeholders on the achievements of the larger project to date. During this brief visit I was also able to participate and observe at a Diabetes clinic in Tupapa and familiarise myself with some of the nurses and doctors. The trip was an excellent signifier that there was a lot to achieve during my longer research period and that my limited time would need to be used very wisely.



**Figure 2: Signage for the Rarotonga Hospital located on Sanatorium Road**

In August 2010 I arrived in Rarotonga for 8 weeks of field research accompanied by my 3-year-old son and my mother. To make childcare easier, each member of my family, including my husband, had decided to join us at different moments during the trip. We arrived in Rarotonga on the weekend and spent our time settling into our house in Matavera where we would stay for four weeks. My first week of research was dedicated to recruitment of participants. At the advice of my Aunty, who was a registered nurse at the hospital at the time, Tupou Faireka was approached for local approval from the Ministry of Health for my research. Tupou provided a 'blessing' on my research information form which proved to be invaluable throughout my time in the Cook Islands. The consent form process, which in Auckland had worked without any tension, needed some form of local contextualisation for Cook Islanders in the Cook Islands to be included in the study. It is important to note that contextualised approval in the form of a blessing was used alongside the research approval that had already been sought from the Government of the Cook Islands Prime Minister's Office and National Ethics Committee of New Zealand<sup>8</sup>.

My previous week in Rarotonga had indicated that finding people with a history of TB would be difficult due to both low case numbers and the stigma attached to the disease. The willingness of Karen, the nutritionist, to put me in contact with people with Type 2 Diabetes led me to explore the reality of people with Type 2 diabetes as well. I reintroduced myself to key officials and also visited people at the National Council of Women and the Red Cross. I reminded them to think of me if anybody they knew might be willing to talk to me about their experiences of TB. I was not deterred by people often saying "no, no one has TB anymore". My New Zealand upbringing and distance from my Cook Islands family had meant that my language skills were limited. Therefore I decided to attend the Cook Islands Maori Language course being held weekly at the University of the South Pacific. During my Masters research in the

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<sup>8</sup> MEC 08/07/076

Cook Islands I had gained some basic skills and was able to understand some of what people were saying; however, my confidence to converse was limited.

The most striking example of an individual whose health history had affected his life in Rarotonga was with Ta'i<sup>9</sup>. Ta'i defied my own misconceptions of how Cook Islanders with Type 2 Diabetes typically appear. Ta'i had never been, and even now in his 50s was not an overweight man; in fact, he was quite lean. Ta'i had discovered he had Type 2 Diabetes after an injury on his finger had not healed. Looking back, he remembered feeling tired and needing to use the toilet more frequently than usual. Finding out that he had this condition was a considerable shock for Ta'i, as it was not something he imagined would happen to an otherwise fit person like himself. Ta'i used to drink alcohol socially and enjoyed the occasional chocolate bar, but aside from this, his past behaviour could not have been interpreted as contributing to serious risk factors for Type 2 Diabetes. Ta'i held a professional job and his education allowed him to understand his condition and to conduct research for himself. Ta'i was also able to offer a critique of the services provided to him after his diagnosis. He relayed to me a frightening story about how he had his finger amputated in the hall of the Rarotonga hospital because the surgery was busy. He was only given local anaesthetic. Ta'i's accounts also highlighted how powerful the stigma experienced by people with Type 2 Diabetes is, even when physical disability from obesity is not present.

Because of the success I had had with PHNs in Auckland in helping to recruit participants, I decided to make a considerable effort to form relationships with the PHNs in Rarotonga. Unlike in Auckland, where I had been well received, I found it difficult to establish trusting relationships with the local nurses. Later I would learn from one of the nurses that the PHNs are weary of research because of possible scrutiny. Eventually I formed a good relationship with one nurse, Moka<sup>10</sup>, who had had some responsibilities with TB contact tracing in the past. I had previously met Moka in Auckland while she was on a TB contact tracing course. The PHNs in

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<sup>9</sup> pseudonym  
<sup>10</sup> Pseudonym

Rarotonga are more casual than those in Auckland, which worked in my favour, as Moka would allow me to spend entire mornings with her while she attended clinics in the villages and preschools. Like in Auckland, Moka was responsible for the public health of a designated geographical area, which in the case of the Cook Islands is a village. During our time together, I was able to gain a greater understanding regarding the health of people in her remit, Arorangi. The women and babies would gather at the designated clinics to have their babies weighed and checked over by Moka. It was during these times that Moka would enquire about people in the village, constantly adding to her log of information regarding the health of people under her care.



**Figure 3: Health checks at a mother and child clinic in Inave, Rarotonga**

After a week in Rarotonga I reached a point where I was able to interview at least one person a day. I gained the contact details of these participants through the PHN Moka, people at the Ministry of Health, the National Council of Women and the hospital. Others who were identified during my previous research trip in July were also contacted. These interviews may have been a person in an official capacity or a person with health and mobility stories. Interviews were organised over the phone and I travelled to meet people by car. Often the interviews were performed at work. When an interview occurred in a person's home, it allowed for additional participant observation to be carried out. Petrol shortages were in place during this time, so travel and interviews were designed to dovetail into each other.



**Figure 4: Scooters provide economical transport for people to get around Rarotonga**

The petrol shortages served as an important reminder that in the Cook Islands, supply and demand do not have a symmetrical relationship. This event made me consider the vulnerability of the Cook Islands in regards to supply of and demand for medical professionals, medical equipment, diagnostics and pharmaceuticals. Labour and goods are crucial strands of the

transnational field and like the petrol, how these strands are connected depends largely on the functioning of multiple governments, aid agencies and shipping companies. With this in mind, an image of the Cook Islands health system as a fragile ecosystem began to emerge.

During my time in Rarotonga I encountered a considerable breadth of research participants. Unlike in Auckland, where it was easy to go back and forward for multiple interviews, interviews in Rarotonga were individual and ran for approximately an hour. In Rarotonga, I was unable to interview anyone with a current history of TB, although there were interviews with people who assisted in the care of family members with historical TB. The majority of my participants had Type 2 Diabetes. One participant had recently returned to Rarotonga after a lung transplant operation in Melbourne. The data gathered during this period of field research was of a significantly different character than the data I had collected in Auckland. Whereas in New Zealand, rich case studies could be formed, in Rarotonga, the data lent itself towards thematic analysis which will be discussed in the next section.

## **1.5 Aitutaki post Cyclone Pat**

After four weeks in Rarotonga I travelled to Aitutaki with my husband and my son. I had prearranged to meet with Maria<sup>11</sup>, a PHN I had met in Auckland while she was performing some TB contact tracing training. Maria had responded to my emails and was happy to assist my week-long research stay in Aitutaki. My first stark impression of Aitutaki was that the structural wounds from cyclone Pat in February 2010 were still very evident. There were half-finished concrete dwellings alongside flimsy white tents where people still lived. The island, which is usually abundant with fresh fruit and vegetables, was experiencing shortages of both. In most places the orange-brown topsoil was still bare.

Aitutaki is renowned for its lagoon beauty; however, I found it hard to take in this beauty of the lagoon when I saw the expensive resorts juxtaposed with the locals living in extremely vulnerable conditions. Such vulnerable conditions were a motivating factor for me to travel to

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<sup>11</sup> pseudonym

Aitutaki for research. Natural disasters have implications for mobility, displacement and health. Aitutaki had not experienced the combined misfortune of high incidences of infectious disease that often accompany recovery from natural disasters in developing countries, yet I sensed that the stress of demolished houses and loss of livelihoods would have had an impact on people's health. Before meeting with Maria I spent some time with the Island secretary and enjoyed a morning tea with the rest of his staff. I also interviewed the Island Mayor who was able to share many interesting details on the barriers to recovery that Aitutaki was experiencing. Ta'i Herman, the Mayor and a local advocate for the disaster relief and rebuild, retold many accounts of the obstacles Aitutaki was facing in terms of supply. Basic household commodities were becoming expensive for people as demand for imported goods had grown with the agricultural disruption. Materials had also arrived from Australia and New Zealand to provide shelter for some of the families; however, there was a shortage of both tools and labour to get these completed.

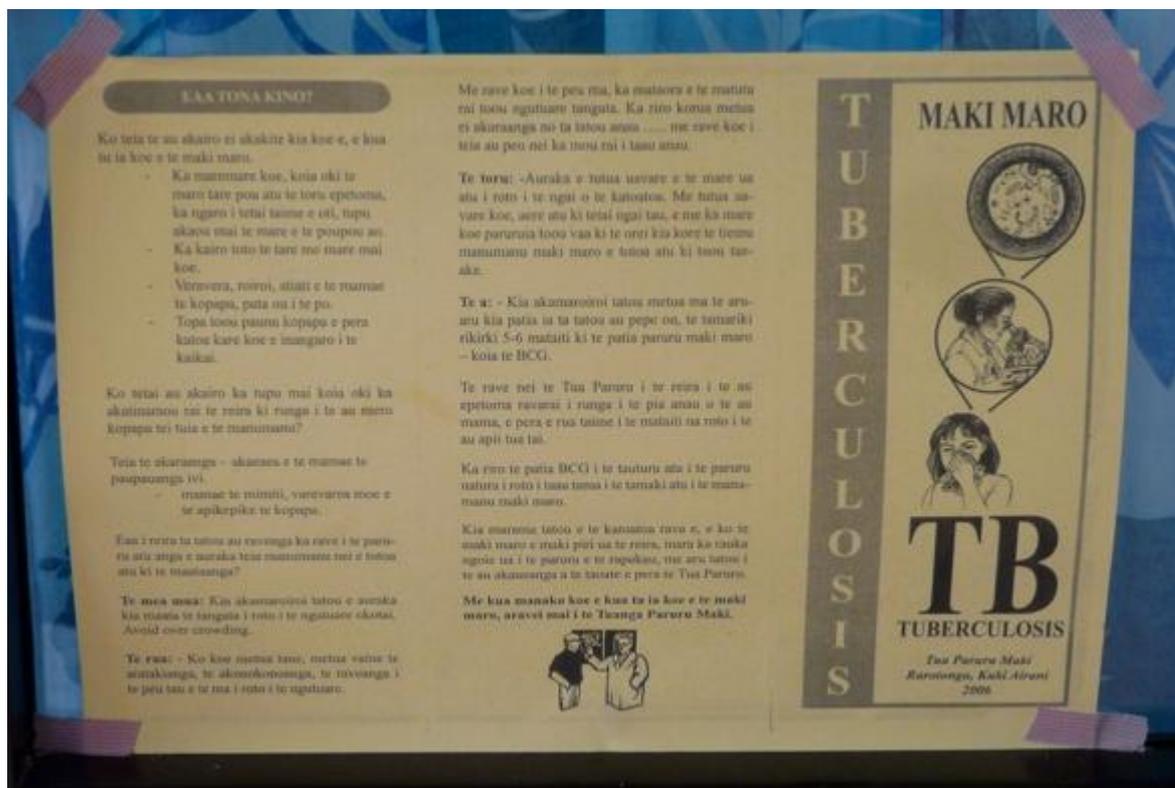
On my first day accompanying Maria on her work schedule I was given a tour of the hospital, which consists of a 22 bed ward, one surgery and one maternity delivery suite. Mama Ki'i<sup>12</sup>, a nurse in the hospital, shared many memories of the TB epidemic with me during this visit. Maria was also able to connect me with two participants, one historical and one recent case of TB. Both participants also had Type 2 Diabetes.

In Aitutaki I experienced some difficulties with language. Maori is the main language spoken, and although I had become familiar in Rarotonga with using simple words to translate medical jargon, in this context, I had to rely heavily on Maria to act as a translator between myself and the participants. Maria, in her capacity as a PHN, had experience in transcending different languages to elicit information relating to a person's health. I learnt many new phrases from her. When asking about 'Stigma and TB', I learnt to ask if 'You are shy of *Maki Maro*' [Cook Islands Maori for TB]. Language was not the only defining characteristic of my time in Aitutaki. I

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<sup>12</sup> pseudonym

also experienced a different openness to talking with me. In Rarotonga people had appeared hesitating and needed time to warm up, while in Aitutaki, there was a genuine openness to talk. I asked Maria about this, and she informed me that Aitutakians are known for being cheeky and open. Aside from a cultural disposition I also associated this openness with the slower pace of life on the island. The distance between Rarotonga and Aitutaki is small in comparison to the other dispersed outer islands; nevertheless, the differences between the two cultures in Rarotonga and Aitutaki were apparent.



**Figure 5: Small handout provides information on Maki Maro (TB) in Cook Islands Maori on the wall in the reception at the Aitutaki Hospital**

Maria also introduced me to Mana, who had recently had TB on the island. We approached Mana casually without making an appointment and he agreed to an interview with me. Mana had lived in the village of Amuri for most of his life and had been on treatment for his Type 2 Diabetes for some time. In 2009 he was diagnosed with TB in Rarotonga hospital. Mana’s case study outlines the processes navigated between a small atoll and larger hospital in search of health.

Mana attended the small hospital in Aitutaki because of his persistent coughing. Mana was known to have a long history of heavy smoking, which led the clinicians to a diagnosis of lung cancer. During this time he was in a general ward and not suspected to be infectious. A sputum sample was routinely collected by Maria at the hospital and sent to Rarotonga for testing. Mana's condition deteriorated rapidly, and so without results from the tests, Mana was transferred to Rarotonga on the passenger plane. His rapid deterioration led Maria to suspect that TB might be the cause of the coughing but given that no test results had arrived, the normal protocol of wearing a mask was not followed.

When Mana arrived in Rarotonga, the ambulance transferred him to the hospital. Although not a confirmed case of Tuberculosis, the doctor was alarmed to see that he was not wearing a mask. Mana was confirmed as having Active Tuberculosis Disease, and was treated for six months in Rarotonga. After his initial treatment in Rarotonga he also received DOTS back in Aitutaki. The family contact tracing was performed by the nurses in Aitutaki. No positive cases were identified.

After spending time in the Mother and Child clinics in Rarotonga I knew that much knowledge could be gained by listening to the women discussing the family life of the people living in their villages. Conversations were not solely about health, but also included the movements of people, upcoming social events, sports and island politics. The progress with the cyclone recovery was also discussed. Stories of stressful living situations because of lack of housing, partners having to leave the island in search of employment and a lack of fresh fruit and vegetables were common topics. Unlike in Rarotonga, where these clinics were held in purpose-built dwellings, the clinics in Aitutaki were held outside the village halls. Maria had mentioned that inside the halls people were not cleaning up after Bingo or other social events, so it was often cleaner to have the meetings outside. Mothers and grandmothers would arrive with their children by scooter or on foot. Maria would weigh and record the children's weight and any other health issues that had occurred since they were last seen. These records were

kept in the New Zealand Well Child Books, another visual representation of the overlapping health initiatives between the Cook Islands and New Zealand. Women appeared very organised to have these on them and proudly showed me the details they would add when an infant had cut a new tooth. It was a relaxed and enjoyable atmosphere. Some of the mothers appeared very young. At both clinics fundraising for a Christmas BBQ for the village children was discussed. I thought this was a lovely idea and decided to donate a small *koha* towards these events.



**Figure 6: Mother and child clinic operating outside a hall in Amuri, Aitutaki**

Maria and I spent many hours talking about the reliance the residents place on the hospital and hospital staff for all health requirements. Even the most basic services, such as applying a bandaid, take place in the hospital as household basic first aid kits are rare. Because of this heavy reliance on the hospital Maria carries basic first aid and blood sugar level (BSL) and blood pressure (BP) monitoring equipment with her at all times, so she can treat people while on other duties to try and relieve some of the pressure on the hospital. She had also recently given the three primary schools and one secondary school first aid kits to stop children arriving during lesson times for basic ice packs and band aids. After this conversation I began to reflect on dependency debates regarding small island economies (see Bertram 1999). A few days prior, the Mayor and I discussed the multiple dependencies which were at play during the recovery process of Aitutaki, most of which Aitutakians had not played a key role in planning. To then hear about the collective dependency of the people on the hospital for even the most basic forms of health care led me to question how powerless these people must feel. The empowerment of the most basic level of health literacy is lacking at the population level. In Aitutaki the hospital system is also vulnerable to the mobility of medical staff. Whilst I was there, one out the two usual resident doctors had been seconded to Rarotonga, so the staff had been bolstered with two volunteer trainee doctors from New Zealand.

For five straight days it rained heavily, so exploring on foot or on the lagoon was limited. In between interviews and participant observation my family and I would take drives around the island and enjoy the island's beauty. I could see that once recovered from the cyclone, the rich topsoil would create abundant fruit and vegetables. The persistent rain, while only a nuisance to me, served as a reminder of how difficult living conditions must be for the families still living in the white tents.

## **1.6 Aitutaki – Rarotonga – Auckland: small islands to large cities**

With air travel, Cook Islanders can cross considerable space in short periods of time journeying from small atolls to large cities in a matter of a few days. I began my homeward journey to Auckland with a week stopover in Rarotonga. I returned to Rarotonga committed to performing some more interviews and presenting some preliminary findings at the National Council of Women conference and to a small group of key officials at the Ministry of Health. The National Council of Women conference was a highlight. Over two days, women from all over the Cook Islands gathered to talk about a range of topics, share their arts and enjoy each other's company. There was a full day dedicated to health. Aside from my presentation on TB and Type 2 Diabetes, there were sessions on diet and exercise, mental illness, and sexually transmitted diseases. During this day, I witnessed an interesting scenario, which anecdotally talks to the issue of behavioural change. Karen Tairi was conducting an interactive workshop where the Mamas were to choose from a range of options how much sugar was in a variety of foods. The Mamas all appeared to be keenly engaged, laughing, joking and celebrating when they got the correct answer. Group discussions on perceptions of barriers and solutions to healthy eating were also conducted. While this was in session a young child around 4 years old approached one of the Mamas. While engaging in this activity which used sugar carbonated drinks as an example of high sugar density and a risk factor for Type 2 Diabetes, she reached down and passed the child a 1.5 litre bottle of Fanta. This example typifies the sentiment that was often expressed to me by those working in public health: that people could easily relate public health information word for word, yet their behaviours remained exactly the same.

I also spent some time with the pharmacist at the Cook Islands Trading Company (CITC) pharmacy to get a better sense of the pharmacy laws in the Cook Islands and the synergies and tensions between the private pharmacies and government pharmacy. Shannon had been the pharmacist there for about a year, and found it difficult when other dispensaries on the island freely administered medications without consulting with the clients. The pharmacist also spoke of supply issues; at times the private pharmacy is called upon to boost supplies in the public

pharmacy when supplies have run low. At the time of my field research the Ministry of Health was in the process of employing a new pharmacist, so I was unable to gain the public health perspective. I did, however, visit the pharmacy on one occasion. The pharmacy appeared much smaller than that in the CITC main shop in Avarua. It was a small but well organised dispensary where the technician worked behind a closed window which slid open when a person approached for their medication. No money changed hands at this site. For local people, the price of their medication is included in the \$5 they pay for their consultation and medication at the clinic. For me, a Non-Cook Island Permanent Resident, the cost of a consultation and the medication would have been \$20.

Last on my list of things to do in my final week in Rarotonga was to chase up promised reports, policies and datasets from people I had previously interviewed. These pieces of secondary data would provide background and context for my thesis. Participants would mention reports or statistics during our interviews and would assure me that they would be emailed through shortly. Even after follow up phone calls I discovered a far better method was to visit the offices of the participants, tell them that I was leaving in a few days and present my USB stick for the file to be put onto. I feared that once I was 'off island', while the intention to get the report or data to me might be there, the lack of urgency would mean that it would no longer be on their list of priorities.

After over two months in Rarotonga I began to feel I had transcended the boundary of being an unknown researcher to being a known Cook Islander. I could greet many people on the streets by their first name, wave at people on their scooters and have long conversations about local politics with interested people. I could also see the many layers of culture and society in Rarotonga, a view that the tourists for week long visits could not get a sense of. Although only in the Cook Islands for a short time, I believe I positioned myself at the edges of the social fabric of Rarotonga and had a more nuanced appreciation for life on a small island such as Aitutaki.

## **1.7 Cook Islanders in the capital**

Pacific peoples including Cook Islanders reside not only in Auckland but in other parts of New Zealand as well. I was curious about how the transnational social field stretched to and operated in places outside of Auckland. Following this curiosity, I travelled to Wellington and Porirua in September 2011. CIHNA had put me in contact with a Cook Islands social worker who worked out of the Fanau Centre in Cannons Creek, Porirua. Kitiona had been welcoming over email discussions and believed that she would be able to help introduce me to people with health and mobility stories. There was also an opportunity for me to meet with representatives of the Ministry of Health in Wellington, the New Zealand Aid Programme (formerly NZAID) and the Pacific Paramedical Training Organisation. These people and organisations had been identified as important dimensions to Cook Islanders' health during my early mapping exercise. Kitiona proved to be quite difficult to contact, and rising research anxiety over lack of interviews led to me to ask her if it would be appropriate to arrange a morning tea at her facility for Cook Islanders interested in participating in the study. I used this strategy as way to meet prospective participants and to begin the process of gaining trust, hopefully securing their permission to contact them directly to be part of the study at a later date. This was scheduled for later on in the week, giving me a few days to spend on meetings in Wellington. It is important to note that this week in Wellington was designed to provide an entry into this field, not the entire component of the field research. Like my week in Rarotonga, this period provided me with a chance to get closer to the reality of people's lives and to allow me to design my future research based on increasing my background knowledge of the transnational Cook Islands community and their health-related experiences.

I first met with Caroline Briasco in the offices of International Development Group, a section of the New Zealand Aid Programme. As a senior health advisor she had been responsible for the relationships between the Cook Islands and New Zealand and specific programmes that fell under the realm of health aid to the Cook Islands. We talked at length about the programme of "health specialists' visits" and the recent research that had been undertaken on the feasibility of

a dialysis unit in Rarotonga. Issues of the sustainability of the health specialists' visits surfaced, with the majority of the specialists offering their services heading towards retirement. The feasibility study on a dialysis unit in Rarotonga was very much an econometric study, with the bottom line being that it was cheaper for Cook Islanders to access services in New Zealand. Water quality was also cited as a key reason why dialysis for Cook Islanders should continue to be provided for by the New Zealand services. Cook Islanders, like other Polynesians with a moderate degree of chronic renal failure, are more likely to progress to end stage renal failure (Moore and Lunt 2000). Given that the mobility to New Zealand by Cook Islanders is circulatory in nature and many Cook Islanders wish to retire in their home islands, the need for dialysis treatment demonstrates that for some, dialysis is the end of mobility to and from the islands.

What was really interesting about this interview was that Caroline, a middle aged Pakeha New Zealander, was currently undergoing treatment for Latent TB. It was thought to have been contracted during her time as a nurse in Cambodia, and because she was leaving the International Development Group for a nursing position overseas, a Mantoux<sup>13</sup> test had recently been performed. Caroline talked about how difficult it is to navigate receiving treatment for TB. Because the treatment for TB is aligned with specific groups identified as at risk due to higher rates of TB, she had found it difficult to get a clear idea of where to go for treatment. Even her GP did not know. The New Zealand health system operates in discrete areas and obstacles in the system are obviously present, not just for Pacific peoples and other migrants, but for all New Zealand residents.

The Pacific Paramedical Training Centre provides opportunities for people from Pacific Island nations to be trained as lab technicians. Cook Islanders use this service to train and further up-skill their lab technicians, and also to send through microbiological samples and reports for evaluation. Their small offices were at the back of Wellington Hospital and I got the feeling that not many people ever came to visit them. We spoke of their role in the Cook Islands

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<sup>13</sup> Mantoux test is the most common form of testing for TB.

and held a discussion about the wider issues of laboratory constraints in the Pacific region. According to one microbiologist, the Cook Islands has one of the most organised and efficient laboratories in the Pacific. This success he attributed to the linkages Cook Islands has with New Zealand.

After the meeting at the Pacific Paramedical Training Centre, I drove to Cannons Creek, where Kitiona had arranged for several people to meet with me. I was nervous about what I would arrive to. Would there be five or 15 people? What had they heard of the project? What would they expect in return for their time? I decided to approach the meeting casually and friendly; after all, if nothing else, it would give me a chance to meet with some of the residents of Cannons Creek. When I arrived Kitiona informed me that five people had come to meet with me. They were waiting in an internal meeting room of the Fanua centre. When I greeted the five people (two couples, one man and Kitiona) they all appeared to know each other well. I later learnt that the two couples attended the Apostolic Church with Kitiona and that the other participant was a fellow social worker student with Kitiona. They sat in a u-shape around the meeting table, with a spare chair for me opposite them. I was grateful for Kitiona to start the meeting by introducing me and asking me to introduce myself in terms of research interests and family lineages. After nearly two years I had become quite proficient in this protocol. I was, however, aware that a group setting required me to reframe my research methods. Initially I positioned the opportunity as a forum to introduce my research and to gauge the interests of the attendees in participating in an in-depth interview at a later stage. I sought consent to record the conversation, because I sensed that those present wanted the opportunity to talk today as well. What followed was not what I had imagined. Instead, it was a rich focus group session which delved into the many dimensions of living with Type 2 Diabetes. At the end of the focus group there was a sense of relief among the attendees. They discovered through the session that although their experiences were individually expressed, there was a sense of collective understanding of the struggles of living with, and caring for, a person with Type 2 Diabetes. I walked away from the focus group aware of a genuine interest in my research and

the trust that I had gained in a relatively short space of time. Later I would travel back to Cannon's Creek to interview those present in more depth.



**Figure 7: Cannon's Creek, Porirua**

I revisited Wellington in December 2011 to conduct two in-depth interviews. I had prearranged three interviews from Auckland using the contact details provided on the consent forms signed at the focus group session. Unfortunately only two of planned interviews occurred. Looking back, I probably organised these meetings too far in advance (four days prior) and needed to follow up with a reminder phone call a day before as one the participants had forgotten. The two interviews that I did have were in the homes of Solomon and Tu. The first interview was with Solomon<sup>14</sup>, a middle aged man with Type 2 Diabetes. Solomon lived in a State-owned house in Porirua where he had raised his 6 children. This house now served as the hub for the family that had grown with a whole new generation of numerous grandchildren.

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<sup>14</sup> pseudonym

The house was simply furnished and clean, but bitterly cold without any heating. Even in early December I could understand why Solomon referred to this house as a ‘morgue’ during winter.

We talked about his daily life with Diabetes and his mobility history at the kitchen table while Solomon drank a large cup of tea out of a litre jug. At times his wife, who was also present at the focus group, would join us, dramatically changing the tone and content of the conversation. Solomon would become more censored in terms of his own experiences and focus more on the impact Type 2 Diabetes had had on the family. For Solomon, he had both an individual and relational story to share about his life with diabetes. Sadly, in this conversation, death surfaced many times both in relation to his own mortality and also the significance of recent deaths in the family. One could easily refer to Solomon as a ‘jolly’ man, but in between his jokes and giggles, stories of death and references to his own mortality would frequently appear.

The second interview was with Tu<sup>15</sup>, a participant who had both Type 2 Diabetes and end-stage renal failure. At the time of the interview, Tu had just finished his home dialysis which he did overnight on the couch in the lounge. Again, his wife was at times present during the interview and at these times the conversation would be censored a little. In this situation, I felt that Tu was protecting his wife, by avoiding sharing some of his concerns with her. Tu had an interesting health and mobility history, where his life and the health of other members of his family had intertwined and led to their current residency in Cannons Creek. Tu has originally held an important post in the Cook Islands government but had moved to New Zealand to seek cancer treatment for his pre-school aged son. 23 years later, Tu is still in New Zealand, and aside from short periods of employment has been either off work because of health, or unemployed. Tu’s story alerted me to the fact that health related mobility can be disruptive to social mobility. Because of Tu’s dialysis, his mobility is now limited to potential but very costly short stays in Rarotonga.

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<sup>15</sup> pseudonym



**Figure 8: A home dialysis unit**

During my interview with Tu, Kitona called to say that Mama Mi'i, wife of the current Cook Islands High Commissioner, would like to meet with me, and given her experience as an ex-nurse she would be well-positioned to inform my research. At the end of my interview with Tu, his wife dropped me at the home of Mama Mi'i's sister and there I was greeted by three sisters. Mama Mi'i was wearing an *ei katu* and was smartly dressed for the occasion. I was able to record the conversation which flowed between these three sisters. Mama Mi'i had a keen interest to talk about wider community health concerns. One of the other sisters had Type 2 Diabetes and was able to share her experiences. The other sister spoke mostly of her older brother's experience with health conditions associated with Type 2 Diabetes and kidney failure. I witnessed an interesting hierarchy between the Mama and her two sisters. Mama Ki'i dominated the conversation and positioned herself as both the expert on matter concerning Cook Islanders health, and the experiences of the wider family. I was later invited to an impromptu lunch with them: a meal of fried chicken and chips, which the granddaughter of one of sisters hurriedly went out to purchase. This meal of fried chicken could have been

interpreted as in stark contrast to our conversation about healthy eating, but in reality, the Mama of the house had been caught in a moment when there was no food in the house and with a genuine desire to share food with me, so a solution was found at very short notice. I felt for this mama, because aside from not having enough food in the house her kettle also blew up in the process of making me a cup of tea. Nevertheless, a pot performed the simple task of boiling the water and we sat down to lunch together. I had a small *koha* [gift] left over from the interview that did not occur earlier in the day. I felt reassured that I had been able to contribute at in least in part to our shared lunch.

Before departing for Wellington and then Auckland I met with Kitiona and updated her on my research. I mentioned that it was my intention to return to Cannons Creek one more time to speak to Tu. By June 2012 I had had time to digest the transcriptions of our previous interviews and wanted to validate his mobility story. Within the narratives there existed powerful emotions around not being able to freely move back and forth between the Cook Islands and New Zealand. When I arrived for this second visit, I felt like an old friend. Both Tu and his wife were lying on the mattresses on the floor in the lounge. They didn't get up to answer the door when I knocked; instead they called out to me and asked me to join them. This time the conversation arrived at a place where I felt that I could elicit some of Tu's more personal, emotional experiences. Tu was able to clearly articulate the emotional strain and financial hardship that his dialysis treatment placed on his family. Dialysis treatment constrains people in many ways. Tu relayed many emotional sentiments related to his body's inability to function like other people's, his inability to work full time and the barriers that prohibit him from retiring in the Cook Islands.

## **1.8 Summary**

The first section of this report was intended to introduce some of the places, the people and the research experiences encountered during my PhD research. Over the course of two years, as I entered and retreated several times from people's homes and places of work and observed

Cook Islanders in many different settings, certain themes began to emerge which did not sit in isolation, but instead related to and interacted with each other. The themes began to flow into and over each other, leading me to realise that my field research periods were not distinct, but rather a continuation of exploring the diversity of Cook Islanders' experiences within a transnational field. The weaving of common threads in regards to the experiences of Cook Islanders is of course reassuringly consistent with ideas around the characteristics of highly mobile people. These themes are discussed in more detail in the following section.

## **2.0 Emerging Themes**

Several interrelated themes emerged during the field research which can be loosely categorised into the physical, emotional, political and cultural experiences of living with Tuberculosis and Type 2 Diabetes. The voices of the participants feature heavily in this section, with the intention to highlight personal constructions of living with a serious health condition. An enormous volume of narratives were recorded, so the decision of which pieces of dialogue to use was difficult. The narratives used in this section poignantly echo the experiences felt by other participants.

### **2.1 Bodily experiences of TB and Type 2 Diabetes**

Evelyn: So how have you been? You all good? Healthy?  
Solomon: Healthy? What's that (laughs)?

The bodily relationship a participant had with TB and/or Type 2 Diabetes was often the entry point of the interviews. A person's construction of their own health and that of their family is subject to emotional, cultural and political experiences; however, it seemed appropriate to begin with the kinds of physical and bodily manifestations of disease a person had experienced. Starting from this position was familiar to all participants given that it is part of the medical model of diagnosis. But, as the above quote depicts, our own understanding of health always rests upon a set of subjective and experiential ideas.

It became clear through my research that people's physical experiences of TB and/or Type 2 Diabetes began with diagnosis. Previously, participants reported not feeling well and could accurately list a range of symptoms that would connect their bodily experiences with either or both of these diseases. In the case of Type 2 Diabetes, men were often diagnosed after they had attended a clinic for an injury from work, gardening or sport. The health services in the Cook Islands have responded to the delay in accessing medical services, which is common for Cook Islands men, by carrying out routine checks of blood pressure, blood sugar levels and weight measurement during treatments for more spontaneous injuries. The scenarios depicted below explain the process two participants went through before being diagnosed.

Ta'i: I didn't realize I had this until I was about fifty-something.

Evelyn: Did they think you had it for some time when they diagnosed it?

Ta'i: Yes, but it was an accident that I had, I hurt my finger because I was weeding and a splint got stuck into it and my whole hand swelled up so I didn't realize what it was until I went to the doctor. The doctor said I'd got diabetes... I remember, as I said I didn't know I had it, there was sore legs all the time and I was weak, wanting sweet stuff all the time and drinking practically morning, noon and night, not water or anything like that, I was thirsty most of the time. So after that I felt a bit better and I couldn't do a lot of work around the home without getting too tired and then I could sleep properly.

Tupou: That's when I found out that it started off like, ah I had a, cut on my foot, but it was taking a long time to heal.

Evelyn: Right.

Tupou: It took a long time to get healed and then ah I hate this, its awkward, so I went up to the hospital, I think it was doctor [name], was the doctor at that time, he said oh, I need to do some checks on you, and they took me through the tests and then, they diagnosed me and my diabetic was increasing. Yeah it was that, that incident made me, that time I was in hospital, I'm , I'm a diabetic.

Evelyn: Did you have any symptoms before that? Just the cut on the foot?

Tupou: It was the cut on the foot. It took a long time to get healed. And, apart from other symptoms like headache and that I had some flu symptom or whatever. But it was this cut on the foot that made me think again because it took a long time...

Tupou: It was at that time he took me through they ah for ah, the for ah for the diabetic, the blood test and all that, ok, so it was through that, that I am diabetic....

Within the account above, the participant reveals the jolting reality that he is now "a diabetic". For both of these participants, they arrived expecting a topical treatment for a surface

injury, but what followed was a diagnosis of something systemic. Hindsight had provided both of these participants with an opportunity to think about the other physical signals their bodies were displaying which may have indicated the need to seek medical care more promptly. Ignoring these symptoms may well have been a conscious health-related decision. The vivid moment in which participants could convey their diagnosis and the significant weight attributed to becoming a diabetic suggests that one of reasons could be fear of this particular diagnosis itself.

All of my participants expressed a difference in their connection with their bodies post-diagnosis. After diagnosis, the participants began to embed different meanings to the disease beyond the physical realm. What struck me repeatedly with the participants that had either or both Tuberculosis and Type 2 Diabetes was that although their lives had changed dramatically as a result of their diagnosis, they still had little clarity about the physical causality of the diseases/conditions. For example, although participants expressed some adverse stigma associated with TB, each one asked me for lengthy explanations of their disease/condition, treatments and at times medications. Overall, my participants expressed not knowing, or not understanding, the changes that had occurred with their bodies. Furthermore, although usually compliant, the treatments they were on and the medications used were also poorly understood. In the beginning I thought that this could be mostly attributed to a lack of health education; however, the more this appeared the more I began to think about the type of interactions these people have had with medical services. In the Cook Islands, medical doctors are well respected and have a high status in society. Exchanges with medical service providers for Cook Islanders begin from an unequal power position, which I believe stymies some of the participants' ability to ask questions. Participants would not want to convey their ignorance to a person of such cultural stature.

Outside of the medical services, the participants who had Type 2 Diabetes related evidence of monitoring and adjusting their life to manage the physical effects of the disease. I came to

think of this as 'listening to their bodies'. Ta'i and Tupou's quotes highlight that listening to one's body was present pre-diagnosis. Post-diagnosis, participants felt a sense of empowerment by being able to monitor, report and in some cases reactively treat some of the symptoms of diabetes. This may appear to be at odds with the above observation regarding Cook Islanders' hesitancy in asking doctors for medical information. To me, it signaled that post-diagnosis, education regarding the maintenance of their condition was successfully reaching most of the participants. The people performing this important function are the nurses and the public health advocates.

Cathy: I had high potassium count. I had high blood pressure and high cholesterol. My blood pressure had dropped, my cholesterol dropped but everything else is still there. My blood count is actually dropped, its sitting at like a 6 or 8 and when its high its 11 and that's not actually high. At one point I remember I was actually sitting at 27. But in me now I think my body is starting to work together in terms of like, if my blood pressure or my blood sugar count is up high my body tells me, mate your sugar levels have gone up.

Anabelle: When I am dizzy then you know, I take my... you know

Evelyn: Your blood sugar?

Anabelle: Yeah my blood sugar, I take it, it is 5, too low, so I take a cup of water and make it very, very sweet, you know this is like a miracle, Evelyn. You know my head to get, no more dizzy...sometime when it's 17 and 19 that is not a good one no, those times sometimes I will get 4 and that, so it needs to be in the middle.

Ta'i: I was able to control my needs and so really it doesn't worry me because I can feel when I am either too high or too low, I can adjust that with my food. But I am very careful about my food intakes.

While some participants took great pride in their ability to control their Type 2 Diabetes, two participants expressed a very strong connection with the bodily experiences of the disease, to the point where great risks were taken to challenge their own physical responses to the disease.

Unfortunately for one participant, the severity of his Type 2 diabetes led to renal failure and his physical experience of disease is now both bodily and mechanical.

Tu: I refused to take my injections and my tablets... (later on) I've got my injection... for my energy cells in my body. I do not have enough red blood cells in my body. I need to inject myself 3 times a week with that otherwise... from here to there I'd be out of air. I'll be puffing and sweating and that's what I use. I thought I'd bring it in and of course, this is only for decoration. I never use it...I never use it. Only when I feel so tired then I use it just to check my blood and then inject myself.

Tu: (Pointing the dialysis machine in his home) Right now, that's my kidney, see all those wires coming out? If you put the solution in and it's cold you feel cold. If it's warm and it should be warm if you put it on top of the machine then you don't feel it...I haven't been *mimi* [urine] because the machine is actually taking my *mimi*.

Another participant challenged his physicality shortly after being diagnosed with Type 2 Diabetes. This participant connected missing his medications for up to several months at a time because he "couldn't be bothered" and "being stubborn" to the early onset of his renal failure. Even after this, the participant tells three stories about his taking risks with his body function. In the first story the participant relays the turn of events that caused him to get an infection while back in Rarotonga on holiday. The second story highlights this participant's desire to control his body and to test its limitations after receiving treatment for his renal failure. His comment regarding setting up his own dialysis inside the clinic setting illustrates his need to retain some autonomy over his body. In a completely different and historical setting, this participant again conveys his risk taking tendencies.

John: You don't want to go through that, it was really bad, like someone operating on you, you know without you know, anesthetic and all this you know really painful. And of course I was supposed to dialyse in an enclosed area but I was doing it outside on our veranda you know. Not really taking um, um, you know it was funny I was dialysing one day and was outside on our veranda and the dog sitting beside me. (laughs) That didn't help, yeah. Because I was told to dialyse in an enclosed area but I was dialysing while having to eat with my dog you know.

John: Even I used to dialyse at home, do my own dialyse. And um, I got to one stage and I think I was playing with my own life. I wanted to find out how long I was going to survive without dialysing. So I tried, I was supposed to dialyse three times a week. So I cut it down to two. And I cut it down to three (two?) and one week I didn't even dialyse and that's when I started to feel ooo you know I was starting to really get sick. And um, I ended up in the hospital.

Evelyn: Why do you think you did that?

John: Ooo, just a dare I suppose.

Evelyn: A risk?

John: A risk yeah. A lot of, I heard people were saying you can only survive two or three days without dialysing. Ok, I'll give it a go. (laughs). Most stupid thing I ever have done. (still laughing). So yeah I did survive the whole week I think I went up to eight days without dialysing. But ar, that was dangerous. And then,

Evelyn: What did they say in the hospital?

John: I got a good growling from the doctor. And they took my machine away from me and they said no, you are going to the hospital to dialyse now. So that's why I am back in the hospital, but no, I am glad. But I still do all my own set-up, I do all my own needles and all that. But um, I am glad that I am back at the hospital.

John: It's funny, I dared myself to eat those fish. (laughs). Me and my mate, parrot fish and all that we got on the reef. Because of fish poisoning you know there is fish everywhere they don't go on the reef anymore, so we caught a couple of parrot fish. Took it back, cooked it, looked at it and said what do you think? Ah, let's eat it. We ate it and then we waited an hour. Because they had been saying that after a couple of hours of eating it. Few hours, nothing happened. There you go mate, there you go. And the funny thing, a few days after that we caught a small koma. We caught it and fried it. Eat it. After a couple of hours, just the tiny fish, we got hit by it. Some only two days we were vomiting and all this scratching and itching and all this. But after that it was gone. There's a lot of people got hit by it bad. By the fish poisoning.

Evelyn: Yes, I am very careful.

John: I know one family that the dog died and I think the husband died.

The Cook Islanders in this study expressed the physical experiences of disease in an individualized and medical manner. Whilst talking about the physical effects they experienced, the accounts were very personal and did not often refer to how these bodily experiences related to those around them. The participants revealed an ability to explain the physical experiences of their body to me, and how diagnosis with a specific disease alters the way in which people listen to their bodies and monitor their own baseline of health. While the male participants overwhelmingly delayed seeking medical advice about a range of symptoms felt inside of their body until such time that an injury on the outside of their body occurred, Cook Island women generally came into contact with medical advice sooner. After diagnosis, a different relationship with their bodies was described. The information provided by the medical profession created a new awareness of the way their body works. There was a large range of awareness among the participants. For two participants, there was a strong reaction to challenge not only the advice they had been given, but also their own bodies. Ignoring medical advice became a strategy of coping with the reality of having to independently manage their health condition amidst many obstacles.

Solomon: I'm going to die you know... I'm kind of the silly boys that say I would rather die happy.

Tu: I will fight this myself. At least I've reached to my 50s.

## **2.2 Stigma and being 'healthy'**

John: ...and that was the beginning of my nightmare.

Beyond the bodily experiences, conversations with all of my participants quickly moved on to how TB and Type 2 Diabetes had flowed outwards to change relationships in their lives. When I began my field research I expected to hear about the isolation and fear associated with the stigma attributed to those with Tuberculosis. To my surprise, what emerged was a significant amount of material associated with the stigma and corresponding emotions that Cook Islanders living with Type 2 Diabetes experience. Emotional responses to disease(s) for my participants included shock, fear, worry, hardship, confusion, hopelessness and victimisation. These emotions were responses to experiences in relation to certain situations or a lack of engagement from other people. It is important to mention that emotive stories were more frequent with those with Type 2 Diabetes than those with TB. For participants with both, the emotional experiences of living with Type 2 Diabetes surpassed the experiences of living with Tuberculosis. Repeatedly, those living with TB found reassurance in the concept of 'being cured'. Because of the timing of my interviews being either after or towards the end of their treatment, all participants were experiencing some sense of relief from the disease and treatment. If I had spoken to the participants at the time of diagnosis I would expect to have uncovered a range of different emotional responses.

### **2.2.1 Fear**

Anabelle: I was frightened you know and I was surprised too. I never expect that I got TB because I'm old. And I said, "how come this sickness come on the old people?"

Fear became a repeated emotion for my participants. Fear was very present for Anabelle, who had lived her entire life in Mauke until she was aged 60. This history explains some of her uncertainty around TB and her diagnosis and also explains her fear, given that in her lifetime, TB was more common during her childhood but not something that would have been common

more recently. The history of the participants reminds us that people's emotional responses to disease need to be contextualised. The account below highlights this participant's fear of the hospital and her longing to be home. A male nurse features as a key catalyst for this fear. Male nurses would be unusual to an elderly Cook Island woman; however, I believe that for this participant, it was the size of the male nurse and her isolation that compounded this fear. For another elderly participant with TB, his experiences in hospital were referred to as being in a "gaol".

Anabelle: It's good to come home, yeah, I you know, I never don't like again to go to the hospital, go to the Auckland hospital.

Evelyn: Why?

Anabelle: You know, scared of the things over there and the boarding over there, and I don't like to eat their food...

Evelyn: Fair enough

Anabelle: You know I wasn't going to be er transferred home that time but on the other night when I was in my room, you know the first time I saw that nurse is coming in my room, it's not, it's a man male nurse. It's a guy, after midnight, my light was on, on at the you know the toilet and then he came in the room I open my eyes it's a balding male head he said to me I was at the light he told me "will you get off the light?" Now this is the first time he came in my room that nurse male nurse. I said "no I want the light to be on", I said and I moved to the, I bring my phone to me and I ring and I ring the phone for the nurse to come in, for the other nurse and then he ask me, "who are you ringing?" I said, "I'm ringing the nurse" and then not a long time the nurse came in my room and then when the nurse came in he just take out, took out go out. And then I ask the nurse, "Who's that man?" the nurse said, "it's a male nurse" I said, "what's, well tomorrow I'm telling you I will tell the doctor about him he's told me "to off the light and whom I'm ringing", yeah, you understand me? Evelyn: Yeah I do.

Anabelle: He just take out. Now in the morning, in the morning the doctor came and visit all the sick er TB and I told him the doctor. And the doctor said, "You are right. Today you can go home". You know that man I'm scared of him.

Evelyn: Really?

Anabelle: Yeah, he's big and er he got a bald head, and the other lady said that he was a male nurse working over there. I said, "no, this is the first time I saw him in my room". He never came and visit me all the time only different nurses. But this, tonight, that night, he was the nurse after midnight came and say "off the light" and "who are you ringing?" "I am ringing the nurse". So I'm frightened. Who asks a question like that? Make me scared.

Evelyn: Were you in the room by yourself?

Anabelle:.. Yes. I was,

Evelyn: No other patients?

Anabelle: No other patients, because, because of different rooms. Lucky I woke up. He didn't, I think he didn't knock the door. He just open my door and he came in right when I look at him he's a nurse he got a uniform like a nurse but he's a male nurse and I'm scared of him that night.

Evelyn: Was it a *papa'a* [person of English heritage]?

Anabelle: Not really a *papa'a*, he's big he was a big er nurse working in the TB. But the first time I saw him. I told the doctor about him.

E: Was the doctor, was the doctor a woman or a man?

Anabelle: The doctor?

Evelyn: Yeah was the doctor a woman or a man?

Anabelle: Ah, a man, I have two of them, one man and one woman, they came and visit me all the sick patients and I told to them.

Evelyn: But you weren't scared of the male doctor? He was, he didn't scare you?

Anabelle: No, he is good but, the nurse er the male, the male nurse he's big you know, huge and bald head.

Evelyn: So because of that you're quite scared to go back

Anabelle: Yeah, I don't want to go back and to no good to go back I don't want. I'm better having my treatment at home instead of being in the hospital.

I heard this story on three separate occasions. When I accompanied Anabelle to a chest clinic appointment she clutched tightly to my hand as we approached the doctor's office. The Sanatorium which is now the hospital in Rarotonga holds many 'scary' memories for some of my participants. Fear and being scared was also common among the participants with Type 2 Diabetes. For Anabelle, Tuberculosis was scary in itself; however for the participant below, the fear was initially of the disease itself and then extended into his relationship with wider society.

Evelyn: How did you feel when you found out that you had diabetes?

Ta'i: Well, at that time there was no shock, there was nothing, but after that being able to access information and then I sort of thought oh just as well I had got to the doctor early otherwise I would have lost an arm and then you read about other people, suffering from things, so it was scary. I think there is still a bit of stigma involved in that you are scared to tell people that you are diabetics because, probably because they were scared of people telling you in public, don't do that, don't eat that, and there's no confidentiality sometimes. I mean some people, I mean I don't care now what people say if you are diabetics, that's their problem, but a lot of people still sit back and I want to eat what I want to eat and I don't want people telling me what to eat, who cares if I am a diabetic.

Being scared to tell someone that you are diabetic was a frequently relayed emotional response. The fear of how others will treat you, particularly at social gatherings where food is involved, is so pervasive that one participant did not realise his own father was a diabetic until after he died. Ta'i knew of other people in the family with diabetes, but not his own father. In a culture where food is central to family and social life, participants found themselves having to redesign their relationship with not only food, but also their social world upon finding out they had Type 2 Diabetes. In this social world, the responsibility to independently manage one's

diabetes is still strongly asserted by both the medical systems and wider society. As Type 2 Diabetes reaches epidemic levels in some developing countries, strategies to encourage collective responsibility of these populations struggling with this health condition will need to be designed.

The case study of Solomon earlier in this report identified his frequent references to mortality. In the narrative below, it is clear that food is so central to his life, that changing his relationship to food has been more difficult than both an alcohol and tobacco addiction. Without the freedom to eat the portions and types of food that Solomon enjoys, this participant felt that his life was over. The only respite Solomon would get from his Type 2 Diabetes was in heaven.

Solomon: “Oh you need to lose that, lose the drinking and then oh, you are a smoker, you need to lose the smoking”, and then I lose the smoke. And then they say you need a palm-size chop for eating. I said, “God, you told me to lose my drinking, I lost my drinking, you told me to lose my smoking, I lost my smoking. And now you tell me to have only one piece of chop, God, I might as well go and die.” I said that to the doctor, I might as well go and die. God, gees, I don’t know whether you are trying to help or trying to kill me. I mean that’s what I thought. ... Gee, I’ve got rid of my drinking, I’ve got rid of my smoking, but the eating part. That is always the part that I always say to my dietician, Yeah, it wasn’t hard for me after a while of giving up drinking and smoking, but the eating, God! I don’t know why? Yeah, that was the hardest part...I know one thing, there’s no diabetics up there (pointing skywards towards heaven).

For another participant, he felt like a ‘victim’ of Type 2 Diabetes, given that his food was now restricted. The repeated concept of being a ‘victim’ conjures ideas of being assaulted by the disease and by other people. I was retold a story of overhearing doctors and nurses yelling at Type 2 Diabetes patients. The same participant cited this as a reason why some people did not seek care for fear of diagnosis and why some patients did not attend clinics to get new supplies of medications for fear of being demoralised. Solomon relayed a story of meeting with a dietician who scolded him for the way he had been eating and his response was immediately defensive. Another dietician’s method of providing affirming suggestions for his diet was so starkly different to the others that he had encountered that his first reaction was of disbelief. This approach is discussed in more depth in the following section.

Solomon: Well, that's why I mentioned to you about those dieticians, exactly the same thing, as far as I thought, they were just pushing, pushing me to the limit. "Don't do that, don't do that, do that", I mean, hey, who the hell are you to tell me, you know, I mean, excuse the language and then the last one which was Sam was like "Do that, do that", and I was like "Are you crazy?"

Negative impacts on their social lives were expressed by four participants with Type 2 Diabetes. Being active was retold as a key strategy for managing Type 2 Diabetes by three participants; however, active for Cook Islanders means not just physical exercise but also being active in community and church events. The stigma and fear of judgment is so powerful for some of my participants that it has further reduced both forms of activity and compounds their social isolation. Often they would refuse invitations to social gatherings and if they do go, they eat before going because they don't want to be judged for what food they decide to eat when they attend. Overwhelmingly, participants' changing relationship with food was the key emotional story told to me.

Ta'i: Because you will find here that sometimes the doctors and nurses would rather than be sympathetic towards you will say well I told you not to bloody well do that thing before. I've seen it in the hospital, accidents come in and here's the nurse screaming at the poor guy suffering, you know that sort of attitude, rather than be sympathetic and be pleasant. For example, if I am at the doctor and the doctor turn around and said I bloody well told you not to eat that sort of stuff, I've bloody well told you before. That's enough – here you are suffering you face the doctors or the nurses screaming at you, whereas the overseas doctors seem to understand how to handle the situation.

Evelyn: OK, do you think because of that some people might avoid seeking hospital care?

Ta'i: Exactly. Some of them don't want to go and stay in the hospital.

Evelyn: Because they will get told off?

Ta'i: Yes, because of that sort of attitude

Tupou: Well, that's another issue because, the missus knows about it too ah, she's aware of diabetic and what to and what not to do but she's coming on "stop it, don't eat this". I say eh, none of this none of this. I said it's not going to be a big change in my lifestyle, it's like going to be taking like bits like bits (changing habits slowly).

Solomon: Well you know, it's been a problem, I still have a problem with my eating. That's been the greatest problem in my diabetic life. But I suppose, all my life really. I love eating... Before I was really active, going out and into sports and everything. Now I just don't go out to birthdays and weddings, I just don't feel like going out. I just stay home, I send my kids, "go on, go".

Tu: Yeah, I mean, to me I actually control what I eat and one of the best ways that I found is avoid any invitations. That's why you guys don't see me at a lot of Cook Islands' *kaikai*. I don't wanna be there. If I do come there, I'll end up eating pork. I

stay away. I stay home. I send my daughter. Even when I came to a wedding, one of my nephews, I just stood there and watched everybody getting their plateful and they couldn't understand what the hell I was you doing. And then one of my nieces said, "Uncle, are you going up?", and I said, "Yeah, I'll go". I waited until everyone had finished, I was hoping by the time I get to the table, nothing left.

Evelyn: And do you still enjoy going to birthday parties and things?

Wife of Joshua: Oh, he doesn't want to sit beside me because I always tell him off especially touching the pork because I don't want him to. If I called out for him to come and sit beside me, no, he ignored me (much laughter) and go sit somewhere. But to be honest sometimes if I see him touching the pork, I go straight and tell him off. I don't care if people watched me, (another lady's approval mmm at the background). I said, "Don't touch that." I mean, (pause) you don't want to lose your partner, to be honest, that's the main reason why I'm trying my best to encourage him to listen to me not to.

The complex nature of Type 2 Diabetes as a disease combined with the necessary lifestyle changes caused the majority of my participants' confusion. Medical practitioners and public health messages place the onus and accountability for their health on the individual. While medication can help manage this condition, the reality of the changing relationship with their own bodies and their social world was a new experience for all of them. Previously for all participants, issues they had with their physical body were short-lived and with the help of medical intervention 'cured' or 'fixed'. Despite this, the complicated biology of the TB bacteria also caused my participants much confusion, and in some instances 'worry' about the future, as if TB was lurking somewhere in the background. For the participants with Type 2 Diabetes, the future for them was uncertain and with diagnosis begins a recalibration of their relationship with their own body and their relationships with their family, social world and, overwhelmingly for my participants, food. Keeping in mind the importance of food in Cook Islands culture, this reorganisation of their lives is extremely difficult. What makes this experience all more difficult is receiving inconsistent and often conflicting advice.

Tupou: Yeah, but the only concern that I have is with the doctors. Each doctor has a different opinion, of what is this disease and it makes a big question mark to me ah you, are you doing ah, are you using it as a testing ground? Or what is it, or what? 'Cause one doctor said like I need to come down to five and one doctor said I need to come down below ten, so which is which? And the doctor that told me that I need to go down to five, if you can't come down to five then we are going to change my ah, medicine, and they going to put me on ah, injection, I said, forget it, no way, but I didn't even ask the question how come your diagnosis are one is saying this and one is saying this?"

Participants also reported misunderstanding what foods they were 'allowed' to eat and why sometimes they needed extra sugar and sometimes they weren't 'allowed' any. The experience of having many doctors and nurses involved in their diabetes management was relayed as the key reason behind this misunderstanding. In the Cook Islands, where committees are established to raise and find solutions to a range of issues, it seemed like the logical solution to some Cook Islanders living with Type 2 Diabetes in the Cook Islands to form a committee to provide fellowship and to create a forum and place for delivering consistent advice. It also demonstrates a desire from Cook Islanders for Type 2 Diabetes management and treatment to be facilitated in more collective ways. This brings us to the next section, where Cook Islanders living with disease(s) relate to their world in different political ways.

### **2.3 Cook Islanders' Political relationships with their disease(s)**

Once a Cook Islander has been diagnosed with TB and/or Type 2 Diabetes it changes not only their body, their emotions and personal relationships but it also affects their lives in distinctly political ways and many began to engage with political systems or frameworks in new ways. In some instances, participants were able to critique the medical systems. For other participants, their health placed them in new relationships with other social organisations to do with housing.

Cook Islanders' lives often include participation in range of committees which serve various functions, from church organisations, school fundraising, political party support and public health. For two participants living with Type 2 Diabetes in Rarotonga, they felt there was a weakness in the ability of the health system to provide support for those living with Type 2 Diabetes. The emphasis, they believed, rested too strongly with prevention, while those living with both the physical and emotional manifestations of this disease felt they had no 'place' in the health system.

Ta'i: Well actually we tried to form a society which is still on-going, a diabetic society here, and I am one of the founding members, but it's a dead sort of thing because the presidency is really not active so the society has really been dead for

the last five years or so since it was formed.

Evelyn: What was its purpose when it was being formed?

Ta'i: It was to encourage diabetics to get together and talk about this and Karen was one of the main instigators of the whole thing but as I say when they were shifted around I think she wasn't able to continuously but that was the idea, to get the diabetics together.

Evelyn: And did it provide support do you think when it was running, was it a good thing?

Ta'i: Well it only ran for a couple of months I think...as I say, if there was a clinic, if the society has actually come to this and you could go to the clinic, you could go there and get the information and a proper, I think a proper person, a proper doctor who knows about diabetes who is not involved in any other things and sit down and talk to us people because sometimes the doctors are multiple, there's nobody really, I mean they are trained in that, there's not enough, like previously an older doctor who was diabetic but you would go there every day and he would repeat himself and then you didn't want to listen to him. He would pass on all the information to you – this is what I do, I wake up at six o'clock in the morning – that's not really what you wanted to listen to. And a lot of the awareness programmes, like I say it's in the media, not many people listen to the radio, not many people read the papers, that's why I say you need a clinic where we could go there and actually listen to each other and sort out our problems with our diabetes and how we are managing it – I think in that way you would get the message across to each other.

Evelyn: Do you think that outsiders are in a position to do that?

Ta'i: Yes, sometimes it's better because we will listen. If it's our own people they say what do you know about diabetes? You know, that sort of reaction. Oh who cares what you say...we tend to listen to other people more. I don't know what it is, maybe because of the closer relationship here, "oh go away, we don't want you".

Interestingly, the above participant repeats three times the need for a 'proper' person. Later on in the same conversation, this participant starts to talk about the different perceptions local people have of foreign doctors. They are perceived as being more knowledgeable, professional and efficient. Because of the relative distance between their patients and the community compared to local doctors, foreign doctors are also perceived to be more confidential. Another participant expressed her interest in establishing a TB committee. For her, this committee would allow people who cared for a person with TB or those who have had TB to come together and share experiences. For Cook Islanders, there is a desire to mobilise, educate and support people with experiences of disease through the form of committees. For these participants being heard and having a place within the health system is a priority.

In Auckland, two participants had new and positive relationships emerge out of being diagnosed with TB. Both these participants had been 'off the radar' in terms of the unsuitable

housing that had been supplied for them by Housing New Zealand. With the advocacy of Public Health Nurses, one elderly woman's flat was re-carpeted and fitted with a ramp and disabled shower and another family was found a four bedroom house of their own for their 8 person family. Before the children were diagnosed with Tuberculosis they had been living in a two bedroom flat.

Another participant in Porirua undergoing dialysis treatment at home was able to receive a heat pump for his house. This heat pump was placed in the lounge where he sleeps while he dialyses. This conversation raised another issue for this participant, the inability for him to pay for the cost of using the heat pump while on his benefit. Housing issues are not confined to physical space, but also being able to afford the utilities.

Evelyn: The heat pump is affordable to run, or?

Tu: Well, August this year was very very cold for us, the average temperature was about 7 and our power bill was \$480. I needed to keep warm, I've got oil heaters in the room for the kids. We all ended up bringing all the mattress down inside there (points to lounge) 'cause that's where the heat pump is sleeping inside there.

Evelyn: That's a lot of money isn't it?

Tu: That's a lot of money especially when you are not working. 'Cause all I get is the invalid benefit and our rent is \$231 and that comes out of my invalid benefit by the time my other deduction is taken out I am left with \$24 a week. So my wife pays for our power bill and our food and my son is working and my daughter is also working to help out.

The relationship one participant had with a particular dietician was also very interesting. To him, she was the only person who could actually help him change his eating. She emphasised small changes, focused on portion size instead of cutting out certain foods. When she was moved to another area, his relationship with this aspect of his Diabetes management ended.

Solomon: You know, I can tell you, a lot of these people tried to help me. Until Sam eh? Sam was one of the dieticians. Oh I miss her, you know out of all the dieticians they put me on. I think Sam was the best one for me.

Evelyn: Was that the Canadian woman?

Solomon: Yeah

Evelyn: Yeah you told me about her.

Solomon: I would always go and see her every month, for our weigh-ins and everything. Because I truly believe, I truly believe it was her tactic it worked for me. She kind of made me eat eat eat eat eat. It's just getting used to making the

sandwiches eh? Like I used to only have one feed. At first she said, make the sandwiches, I said but I am going to eat the whole lot. She said, I don't care, make the sandwiches. So when I got used to make the sandwiches every morning, next month she said, how about splitting it in two. As long as you take it first smoko you have, split it into two. I split it in two and I came back the next month and I said, I've split it in four. She said yeah? I said yeah, you know, and then it started to happen, I was losing weight. And then when she phoned to say she was moving on, I said ARH no no no!

Evelyn: And the new dietician? Is that a new man or a woman that you go and see? Or you just stopped?

Solomon: I stopped, after Sam I stopped. The doctors and nurses say do you want to see a new dietician, I said no.

When this dietician left, Solomon began to put back on the weight he had lost. He admitted to understanding the method of this dietician but obviously the relationship with the person was what motivated Solomon the most. The method failed without her guidance. This illustrates that Cook Islanders with diseases, who value close and ongoing relationships with one person, are vulnerable to changes in organisations. At the moment, this participant sms messages in his results to a Public Health Nurse weekly and if everything remains at the status quo he can go months without seeing a doctor or a nurse. But for someone who obviously needs to make a personal connection to help his Diabetes management, it demonstrates that organisational efficiency is not in the best interest of some patients.

For Taoro, seeing the same General Practitioner three times resulted in three instances of misdiagnosis. This participant was very ill for three months with flu-like symptoms, fluid on the lung and dramatic weight loss. His local General Practitioner prescribed him antibiotics and told him to rest. Eventually his girlfriend took him to Auckland Hospital, where he was again misdiagnosed for three weeks with pneumonia. Eventually it was discovered that he had Tuberculosis.

Evelyn: Do you remember what the GP said?

Taoro: Oh yeah, I forgot about that, the GP just said that there is nothing wrong with you, just take these pills and you will be alright. See this is the fluid in my lung and what he thought was that if the pills get in there that they will take all that fluid away. But all the pills were doing was just hitting that wall, it wasn't really doing anything.

Evelyn: So even when you went back again?

Taoro: He just kept giving me the same pills as last time.  
Evelyn: Which GP was that?  
Taoro: Glen Innes  
Mele<sup>16</sup>: [name]Health Care. But I wasn't actually with him for those days. He kept going and coming back with the same results. So I was like, I'm going to take you to the hospital. Because he'd never been to the hospital before he didn't know it was free so he was kind of scared. Oh, I'll take you. I've been to the hospital heaps of times.  
Taoro: Yeah that was my first time.  
Evelyn: You didn't think it was free?  
Taoro: I just didn't know anything, 'cause that was my first time ever been in the hospital.  
Evelyn: Really? Even to visit someone?  
Taoro: Nah, maybe, I don't know.

The reason behind this participant's misdiagnosis is uncertain. It highlights that even in areas of Auckland where TB is more prevalent than others, General Practitioners are not thinking about the possibility of Tuberculosis infections. His inability to recall any knowledge of how the hospital system operates even in the throes of being so ill is an example demonstrating that for some people in New Zealand, basic information about health care has not reached them or is not taken up.

For the participants on dialysis treatment, their conditions mean that they regularly rely on the availability of treatment and associated materials, equipment and expertise. This heavy dependency on the health system in New Zealand has changed their ordinary experiences of travelling back to the Cook Islands. The Cook Islands does not have the facilities for dialysis. Poor water quality, lack of equipment and technical and medical expertise mean that it is more feasible for these patients to remain in New Zealand. However, two participants have responded to this by finding flexibility within the health system. Tu decided to have a peritoneal<sup>17</sup> fitted so that he could, when financially possible, arrange for all his equipment and fluid to be transported to the Cook Islands. The peritoneal fitting allows Tu to administer his own dialysis treatment at home and to take his equipment and fluid with him if he decides to

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<sup>16</sup> Pseudonym

<sup>17</sup> Dialysis fluid is introduced via a permanent tube in the abdomen and flushed out either over night while the person sleeps or regularly through the day.

travel away from home. Similarly, John goes to Rarotonga for three days at a time between treatments and is also working on a fundraising initiative to help raise awareness about renal failure and is working towards a future solution for a dialysis treatment facility located in Rarotonga. For both John and Tu, the ideal they are working towards is to live in Rarotonga permanently. At this stage, the only solution for this is a kidney transplant.

John: Not long ago because I was talking about my idea of fundraising to get some machines. And um, he [friend who is involved in government in the Cook Islands] said, the government had been researching that too, and it is very expensive for home. And not only that, but because at home we have problems with our water. Because the machine uses a lot of water and because back home we always have problems with our water tank and all that. And not only that, but getting people to go over and train there's a lot of cost and money involved in it. So they were pushed on it on tank water. So they will never when they heard, but anyways I had a chat with a lot of my friends in entertainment and all that and they are willing to help. But at the moment, things are on hold. Because of that problem that we have. I had a chat with one the nurses over here because I was asking about Samoa's one and she said that the Samoan units were sponsored China or someone there. And because they have the money to do all this and besides in Samoa they do not have problems with water. But back in the islands we do have that. So everything at the moment, it is on hold.

Overall, a common theme was that for people with TB and/or Type 2 Diabetes their experiences with their bodies became politicized in new ways. Navigating both health services and general society is different for people living with, or having had experiences of, diseases. On a small island, the size of the medical system can potentially work favourably for people with TB and/or Type 2 Diabetes. Primary health in these places takes advantage of being able to access medical and family history easily with such a small population. However, the scale of the place may also increase the possible stigma experienced, testing and treatment may have to occur away from home, or in the case of those receiving dialysis treatment, some people may never be able to live on a small atoll again.

In a big city, the complex and often disparate sections of the medical services are perceived as daunting. Despite this, Cook Islanders attribute the New Zealand medical system with a level of expertise not able to be accessed in the Cook Islands. The connections between the two medical systems and the movement of Cook Islanders have altered people's expectations of

health services and movement between the two countries for medical services is now a common practice. The mobility of foreign doctors to Rarotonga and the outer islands provides Cook Islanders resident in the Cook Islands with a standard of care that they have come to expect. For those with the available means, if a New Zealand doctor is not resident in the Cook Islands, travelling to New Zealand is for them a logical decision to make.

## **2.4 Summary**

The long history of Cook Islanders within the New Zealand health system has altered health-related decisions to a point where travelling between islands or between countries has become a commonplace practice in search of health services. For some Cook Islanders, whilst travel may not be the preferred option, it is the only option if the services cannot be provided for in their place of residence. At times, travel for health services may be independent; however, among the participants of this research, it is not only the person seeking health services who moves, but also their partners and whole families. For others, travel for health services is a preferred option, because expectations of services have been raised from previous engagements with the health services, confidentiality is important, or family members to assist with recovery reside in other places. Population mobility as part of health-related decisions is part of living in places which are remote from secondary and tertiary services. What is distinctive in the Cook Islands case is that this occurs across national boundaries, and the fabric which weaves together all the functions of a successful health system stretches across a vast geographical space. This space is active, with flows of medical practitioners, health promotional activities, medical equipment, diagnostic facilities, people and whole families. Movement across this field is not seamless, and this research throws light on the systematic gaps, the existing silos in the medical systems and the variable expectations and experiences that Cook Islanders have of their own health. This report captures both the movement of people seeking health, whether it be for their own or other people, and the experiences of people whose health can be analysed as part of the wider social forces at play.

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