

**Northland District Health Board Research Report:  
Whānau experiences of the diagnosis and management of  
Acute Rheumatic Fever for tamariki in Te Tai Tokerau, Aotearoa.**

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Cover photo: Taken by Aneka Anderson at a Kōhanga Reo beach trip in Northland. All whānau in the photograph (and care givers of children in the image) consented to the use of the image for this report.

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## Table of Contents

<b>Acknowledgements</b> .....	<b>1</b>
<b>Research investigators</b> .....	<b>1</b>
<b>Abstract</b> .....	<b>3</b>
<b>Summary of recommendations</b> .....	<b>4</b>
<b>Background</b> .....	<b>5</b>
<b>Methodology</b> .....	<b>7</b>
Kaupapa Māori Research Approach .....	7
Participants.....	7
Participant observation.....	8
Whānau and individual semi-structured interviews.....	8
Data analysis .....	8
<b>Results</b> .....	<b>9</b>
Participants.....	9
Understanding of ARF/RHD .....	10
Accessing health care.....	11
Barriers to accessing health care.....	11
Facilitators of health care access.....	12
ARF/RHD diagnosis experiences .....	12
Barriers to diagnosis .....	12
Facilitators of diagnosis .....	13
Hospital experiences .....	13
Home care .....	14
Experiences of secondary prophylaxis.....	15
Barriers to secondary prophylaxis .....	15
Facilitators of secondary prophylaxis .....	16
ARF/RHD adult experiences of secondary prophylaxis.....	18
ARF/RHD information .....	18
Impacts of ARF/RHD on whānau.....	19
Coping with ARF/RHD .....	20
<b>Discussion and recommendations</b> .....	<b>22</b>
Structural barriers.....	22
Accessing health care.....	23
Racism.....	24
Sore throat management .....	25
ARF/RHD Health literacy.....	26
ARF/RHD support .....	27
Strengths and limitations.....	27
<b>Conclusion</b> .....	<b>28</b>
<b>References</b> .....	<b>29</b>

## Abstract

Rates of Acute Rheumatic Fever (ARF), a preventable disease which can develop into Rheumatic Heart Disease (RHD), are decreasing in most developed countries. In Aotearoa/New Zealand however, ARF remains a significant health problem with persistent ethnic, social and demographic inequities. Māori children between 5-15 years of age in Te Tai Tokerau (Northland) have some of the highest ARF rates nationally.

Our study explored whānau experiences of ARF, including pathways to and through ARF diagnosis and treatment and aimed to support more appropriate and relevant interventions for Māori living in Te Tai Tokerau. The study applied a qualitative Kaupapa Māori research design that included participant observations, whānau interviews, and individual, semi-structured interviews with 10 whānau groups (36 participants) who resided in Te Tai Tokerau at the time of the research.

ARF impacted on financial status, employment and education of whānau and resulted in whānau experiencing significant emotional, social and economic stressors. The principal pathways to reducing these stressors included the presence of whānau support, and good rapport, communication and continuity of care with healthcare professionals. Recent ARF health promotion campaigns, media coverage and discussions from health care professionals sometimes created cultural deficit explanations of ARF that were internalised by participants, eliciting additional anxiety and conflict for whānau. Within the primary care setting, inadequate throat swabbing and/or antibiotic prescribing in conjunction with experiences of health service-related discrimination and racism were barriers to improving ARF outcomes for whānau.

Based on our findings we suggest that health services need to employ an integrated support service for ARF prevention and care that promotes youth and whānau centered approaches. We recommend the implementation and regular evaluation of cultural safety training and greater emphasis on whakawhanaugatanga/rapport building between health practitioners, clients and their whānau across the health sector. To avoid further stereotyping and to improve ARF interventions, we suggest that health promotion campaigns target the underlying structural causes of ARF rather than focusing solely on ethnicity and behaviour. Finally, we recommend that a quality of improvement process is implemented for the management and utilisation of sore throat guidelines within Northland's primary health care services.

### **Summary of recommendations**

- Employ an integrated support services approach for ARF/RHD whānau that includes health, financial, employment, childcare and education assistance
- Promote child/youth and whānau centred approaches within health services and interventions
- Develop multi-pronged approaches to improve access to health care that address lack of transport, lack of childcare, lack of appointment availability and after hours care as well as cost
- Implement rapport building/whakawhanaungatanga training such as the hui process by Northland DHB and PHOs for health care professionals
- Facilitation of annual cultural safety training for GPs in accordance with their Maintenance of Professional Standards accreditation
- Develop a sore throat guideline implementation strategy
- Support current “rapid response” free at point of care access in Te Tai Tokerau
- Undertake feasibility research for self-swabbing practices
- Promote ARF/RHD information delivery via DVDs and other visual media rather than in written form
- Develop health promotion messages to target structural causes of ARF/RHD as well as the importance of sore throats and avoid using imagery and discourse that further stereotypes Māori and Pacific
- Implement a feasibility study for the development of a ARF/RHD internet support and information group

*“Kua tawhiti kē tō haerenga mai, kia kore e haere tonu.  
He tino nui rawa ōu mahi, kia kore e mahi nui tonu.”*

*‘We have come too far not to go further.  
We have done too much not to do more’*

Tā Hēmi Hēnare (Ngāti Hine 1989).

## **Background**

Acute rheumatic fever (ARF) is a preventable inflammatory disease which can develop after pharyngitis caused by group A streptococcus (GAS) bacteria. The most severe sequela is rheumatic heart disease (RHD) with mitral and/or atrial valve damage, which may require cardiac surgery and valve replacement (Milne et al., 2012). Prevention of ARF requires early effective treatment of GAS pharyngitis with an appropriate antibiotic. Once rheumatic fever has occurred, tamariki (children) and rangatahi (youth) are at risk of further heart damage from repeated strep infections. This is prevented by secondary prophylaxis with monthly intramuscular benzathine penicillin for a minimum of 10 years (The Cardiac Society of Australia and New Zealand, 2008). Both ARF and RHD remain significant causes of morbidity and mortality in Aotearoa/New Zealand (Jaine et al., 2008; Webb and Wilson, 2013). After decades of decline, ARF rates in Aotearoa began to increase in the 1980s and have since remained relatively constant. Large disparities exist in incidence rates of ARF, associated with age, ethnicity, socioeconomic status, and by geographic region.

Rates of ARF are highest in Māori and Pacific children between the ages of 5 to 14 years (Jaine et al., 2008; Webb and Wilson, 2013). Jaine et al. (2011) calculated incidence rates by ethnicity from 1996 to 2005 and reported rates of 8.0 per 100,000 for Māori, 16.6 for Pacific and 0.8 for New Zealand Europeans. Recent studies have also shown that these disparities are widening with increasing incidence of ARF among young (5 to 15 year old) Māori and Pacific people in Aotearoa (Webb and Wilson, 2013). Rates for these subgroups are comparable to some of the highest reported in the world (Jaine et al., 2008).

Socioeconomic deprivation and household crowding have been shown to be strongly associated with ARF in Aotearoa (Jaine et al., 2011; Webb and Wilson, 2013). Not surprisingly, the majority of ARF cases occur within the most deprived regions of Aotearoa. The highest rates of ARF are seen in Te Tai Tokerau (Northland), South Auckland, the Bay of Plenty and Tairāwhiti (Gisborne) (Webb and Wilson, 2013).

Te Tai Tokerau is one of the most economically deprived areas of Aotearoa (Ministry of Health, 2014a), and Māori are disproportionately located within the most deprived areas

of the region compared to non-Māori (Maré et al., 2001; Robson et al., 2007). Te Tai Tokerau communities also experience a high unemployment rate (9.9% compared to the national rate of 8.3%) (Ministry of Business, Innovation and Employment, 2014). According to the 2013 New Zealand Census, Northland has the lowest national median gross personal income (\$23, 400) and median household income (\$46, 500) (Statistics New Zealand, 2014a). Within the Northland region, as across Aotearoa, there are notable disparities in income evident between Māori and non-Māori. The median gross personal Māori income in Northland is \$19,100, compared to the total regional median income of \$23,400, and \$22, 500 for all Māori in Aotearoa (Statistics New Zealand, 2014a; Statistics New Zealand 2014b).

Along with income and employment, household crowding has been identified as a challenging issue. Te Tai Tokerau has one of the highest national crowding levels for children aged 0 - 14 years (Ministry of Health 2014a). Household crowding is often associated with deprivation (Lee, 2012), and crowding levels for Māori have been reported to be up to four times higher than for Pākehā in Aotearoa (Flynn et al., 2010). Overcrowded homes can increase the risk of disease transmission of infectious diseases, particularly for GAS, where the cross infection rate is between 15% to 50% within a household (Jaime et al., 2011; Lowe et al., 2011).

In terms of ARF incidence, Northland District Health Board (NDHB) reported in 2011 that 95% of ARF cases within the DHB were tamariki Māori (Māori children) (Northland District Health Board 2011). Rates of ARF among tamariki Māori in Te Tai Tokerau calculated from 2002-2011 are some of the highest in the country with rates of 78/100,000 per year in tamariki Māori between 5 - 15 years of age compared to 4.6/1000,000 per year in non-Māori (Robin et al., 2013).

Primary prevention programmes focus on preventing diseases such as GAS from occurring within populations (Webb and Bain, 2011). There have been few published evaluations to date of primary prevention programmes for ARF in New Zealand but international research supports application of targeted primary prevention within high-risk ARF areas such as Te Tai Tokerau (Kerdelmelidis et al., 2010). Since late 2011, the government has funded primary ARF prevention programmes in high-risk areas of New Zealand but secondary prevention programmes (i.e. those that focus on secondary antibiotic prophylaxis for known cases of ARF) remain “the backbone of disease control in New Zealand” (Webb and Wilson, 2013, p.4). Apart from published audits of secondary prevention registers (Grayson et al., 2006; Atatoa-Carr et al., 2008), there has been little research that seeks to understand the perspective or experience of the person with ARF (New Zealand Guidelines Group, 2011). Additionally, although access to health care has been cited as a probable cause for the disparities seen in rates of ARF in Aotearoa (Atatoa-Carr, 2008; Webb and Wilson, 2013), there has been no published research into this specifically.

Our research aimed to fill some of these gaps in current understanding of ARF/RHD, and explore peoples’ experiences of ARF, including their pathways to and through treatment. Our research also aimed to support more appropriate and relevant rheumatic fever prevention interventions targeted at Māori living in Te Tai Tokerau. To achieve these

aims we investigated underlying issues that enabled or prevented whānau with children with ARF and/or RHD from accessing health care services in Te Tai Tokerau. Further objectives of our research were:

- Understanding how whānau ‘made sense’ of and understood ARF
- Establishing how knowledge about the health system influenced ARF diagnosis and treatment pathways in Te Tai Tokerau
- Investigating how broader political, economic, social and cultural dimensions influenced experiences with ARF/RHD
- Exploring experiences of possible perceived discrimination within the health care system
- Describing the current and future impacts of ARF on the health of tamariki Māori and their whānau in Te Tai Tokerau.

## **Methodology**

Our study applied a qualitative Kaupapa Māori research design that included participant observations, whānau interviews and individual, semi-structured interviews with 10 whānau groups (36 participants) who resided in Te Tai Tokerau at the time of the research. Ethics approval was received from the University of Auckland Human Participants Ethics Committee in August 2013 (reference 9922).

### ***Kaupapa Māori Research Approach***

To ensure that the research was relevant and of benefit to Māori, a Kaupapa Māori research (KMR) approach was undertaken. KMR has been described as a framework that gives meaning to the life of Māori (Walker, 1996), that conceptualises and validates Māori knowledge and paradigms (Nepe, 1991), and a methodology that is owned and controlled by Māori to benefit Māori (Nepe, 1991, Smith 2000). KMR operates under a decolonising lens by simultaneously critiquing colonial structures of power and employing Māori epistemologies (Mahuika, 2008). These elements of KMR allow the methodology to operate as an empowering critical framework that prioritises Māori world views, places Māori at the centre of the study and rejects cultural deficit explanations (Barnes, 2000; Walker et al., 2006).

### ***Participants***

Participants included individual people who self-identified as Māori, who had ARF and/or RHD and who had received ARF/RHD treatment in Te Tai Tokerau. Participants also included consenting whānau<sup>1</sup> members of people with ARF/RHD. Participants were recruited with the support of NDHB Public Health Nurses (PHNs) from the NDHB Rheumatic Fever Prophylaxis Register.

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<sup>1</sup> Whānau in this research refers to nuclear and/or extended family as defined by the research participants themselves

### ***Participant observation***

Participant observation is a method that allows for firsthand accounts of people's lived experiences to be understood and recorded by researchers (Emerson et al., 1995). It involves researchers 'getting close' to people through observing and participating in their everyday lives. In our study, participant observations were undertaken with whānau members for up to three days, they occurred in their homes, at their workplaces and at social/community events. Participant observations were undertaken to understand how discourse and understandings of ARF/RHD were expressed and enacted, to gain firsthand knowledge of health seeking behaviours, to help contextualise the negotiation of health care access and gain firsthand accounts of political, economic and cultural influences on participants' lives within local environments. Data was collected in a field journal by the researcher then transcribed and analysed through the processes described below.

### ***Whānau and individual semi-structured interviews***

Semi-structured interviews involve open ended questions based around key research topics or themes to allow for fluid, in-depth narratives from participants (Angrosino, 2002). As in our study, semi-structured interviews are usually preceded by observational data collection to allow for a rich and in-depth understanding of the topic (Cohen and Crabtree, 2006).

Whānau interviews were focus group interviews with individuals with ARF/RHD and their whānau. Focus group interviews involve in-depth group interviews with participants from a specific/purposive population (Rabiee, 2004), in this case, experiences of ARF/RHD. Whānau interviews were used to elucidate collective understandings and experiences of ARF/RHD, treatment pathways and impacts of ARF/RHD on whānau. If individual participants were not able to be interviewed with their whānau (or chose not to be interviewed with their whānau) then individual interviews using the same interview schedules were undertaken with them.

Interviews were held in participants' homes, places of work, community centres or at NDHB. Interviews were audio recorded and aligned with Kaupapa Māori approaches to interactions, including for example: karakia (prayers) at the beginning and end of each interview and kai (food) and koha (gifts) provision for participants.

### ***Data analysis***

All data were transcribed and entered into a NVivo 10 software programme. Data was then thematically analysed using a general inductive approach. This approach enables the development of meaningful thematic categories from raw qualitative data that are determined by both the research objectives and repeated readings and interpretations of the data (Thomas, 2003). Independent coding was undertaken by three of the researchers then triangulated for consistency and entered into NVivo.

## Results

### *Participants*

There were 36 participants in our study from 10 different whānau groups (refer to table 1). Whānau groups ranged from one to eight members (there were also two infants in our study who were not included as participants). The majority (n = 8) of the whānau had moved homes within the last decade. For most this involved moving from outside of Te Tai Tokerau and two whānau moved from outside of Aotearoa. The most commonly cited reason for moving was due to financial pressure such as seeking employment or cheaper living conditions. The majority of whānau were either renting and/or living on whānau/hapū (sub-tribe) land; two whānau owned the homes they were living in. Chronic health conditions were common among whānau. These included: asthma, eczema, allergies, diabetes, cardiovascular related diseases, and for one whānau, Alzheimer's disease.

Eight 1-2 hour whānau interviews were undertaken in our study, whānau size ranged from two to eight people. Two 1 hour long individual, semi-structured interviews were undertaken with participants who did not want their whānau included in the research or whose whānau were unable to participate in the research.

Table 1: Research Participants

Whānau	Participant	Sex	Age	ARF/RHD status
1	1	Female	Adult (>18)	None
	2	Male	Youth (16-18)	ARF/RHD
	3	Female	Child (<16)	Suspected ARF
2	4	Female	Adult (>18)	RHD
3	5	Female	Adult (>18)	ARF
4	6	Female	Adult (>18)	None
	7	Male	Child (<16)	ARF
	8	Female	Adult (>18)	None
	9	Female	Child (<16)	None
	10	Male	Adult (>18)	None
5	11	Female	Adult (>18)	None
	12	Male	Child (<16)	ARF
	13	Male	Adult (>18)	None
	14	Female	Adult (>18)	None
6	15	Female	Adult (>18)	None
	16	Female	Child (<16)	ARF
	17	Female	Adult (>18)	None
	18	Male	Adult (>18)	None
	19	Female	Child (<16)	None
	20	Female	Child (<16)	None
	21	Female	Adult (>18)	None

	22	Female	Adult (>18)	None
7	23	Female	Adult (>18)	RHD
	24	Female	Child (<16)	ARF
8	25	Female	Adult (>18)	None
	26	Male	Child (<16)	ARF
	27	Female	Adult (>18)	None
	28	Female	Child (<16)	None
	29	Female	Child (<16)	None
	30	Female	Child (<16)	None
	31	Male	Child (<16)	None
9	32	Female	Adult (>18)	Childhood ARF
	33	Male	Adult (>18)	None
	34	Male	Child (<16)	ARF
10	35	Female	Adult (>18)	None
	36	Female	Child (<16)	ARF

### ***Understanding of ARF/RHD***

Other than whānau who had personally experienced ARF before their child’s diagnosis, most had no understanding of the illness when their children were first diagnosed. Almost all whānau described rheumatic fever as a “bug” caused from sore throats that could affect the heart. Some whānau described rheumatic fever as a cold, others as an illness that caused sore joints.

*“I was shocked at first only because I’ve heard it but I don’t know what it is. I sort of wanted to know what is rheumatic fever? My thoughts of rheumatic fever were the sore joints but goes away you know, that sort of stuff. I didn’t know it could affect your heart” (P6).*

Understandings of rheumatic fever were informed by experiences of having ARF/RHD or caring for their tamariki with ARF/RHD, health beliefs, information from health care professionals, and the media. When asked about causes of rheumatic fever many whānau cited “*strep A*” (group A streptococcus) as a causal factor of sore throats that lead to rheumatic fever and understood that Strep A could be cured through antibiotics. Rheumatic fever was also attributed to “*genetics*”, weather/seasonal conditions, sharing drink bottles, and immunisation.

Cultural explanations of health were also common among whānau. Participants explained how their engagement at tangihanga (funerals), marae noho (marae stays) and living with extended family was attributed to causing ARF due to crowding. These understandings derived from information given to them by health professionals about crowding and from the influence of mainstream media. These explanations created tension for whānau who described feeling conflicted between their cultural values and keeping their children safe.

*“There are some things that I suppose we need to accept, I suppose us being Māori, cause we’re Māori and we have big families... You associate some health issues with overcrowding. As it’s perceived today but we don’t see it as, ‘this is what you would classify in a three bedroom house with 80 square metres as overcrowding’, we would see it as ‘this is how we live, this is our culture’. So now you, you sort of have to get to a point where ‘this is my culture, these are serious health [issues], where do we get the balance between these?’ Because I’m not going to give up who I am and who my whānau is because this is who we are as Māori” (P1).*

### ***Accessing health care***

#### ***Barriers to accessing health care***

Not all whānau were able to access medical care for their tamariki. Barriers included not being able to get appointments with their doctors, working commitments, not having access to a car, not being able to afford petrol for their cars and living far away from health care facilities.

*“Yip not very often I could go out so yeah it wasn’t something that my mother could just take me to the doctors, cause my mother was working, my father was working, yeah so not very often I got to go to see a doctor” (P4).*

A common reason whānau cited for not taking their tamariki to see medical professionals when they were experiencing the initial symptoms of ARF was thinking that their child just had a virus or other minor ailments that they could take care of at home (such as “*growing pains*”). Other factors that influenced whānau not seeking health care were their lack of trust in GPs ability to provide care and adequate treatment, and prior negative experiences within primary care contexts.

Most whānau reported having negative experiences within primary care services where they were made to feel inferior. They felt their doctors did not look them in the eye, were more interested in typing on the computer than paying them attention, did not listen to them, and were dismissive of their experiences and questions.

*“I think it’s the brushing off like, ‘you’ve just got the flu’ you know? It’s like you’re made to feel you’re a bit bloody second class citizen, like that sort of sort attitude, like we don’t count....I would say to him[GP] questions like ‘ah doctor X do you think she needs to see a specialist?’ [He’ll reply] ‘who is the qualified doctor here?’ that sort of crap” (P1).*

Whānau also spoke of experiences of discrimination within primary care where they felt they were being judged by the geographic area in which they lived, their physical appearances and their behaviours.

*“And I’m sitting there going ‘how am I supposed to swallow this [a pill]?’ I can’t even swallow water properly and then, you tell me I have to have food with this! Yeah so goh, and then he [GP] said to me, ‘well it’s a not like you’re small, not like you’re going to suffer’ and it was just like ‘you arsehole’, what I wanted to say [was] ‘fuck you’, like you*

*know? You don't think I know I'm fat? I live with myself man. But anyways there was always this attitude kind of thing that happened" (P5).*

Although all whānau knew the importance of getting sore throats swabbed and being prescribed antibiotics, they commonly cited concerns about lack of throat swabbing and under prescription of antibiotics as barriers to primary health care. They described situations when they and other whānau members had presented with sore throats, asked for throat swabs and had not been given them. Whānau claimed that unless they had “*pushed*” or been “*aggressive*” they would not have had a throat swab taken.

*P2- Yeah [the doctor] just said I had the flu, sent me home on some different drugs  
P1- Paracetamol sent him home um, [GP said] 'see how it goes over a couple of days'.  
But he [doctor] never took a throat swab  
P2- Nah he just brushed it off.....*

*P1- And we're aggressive, we're really aggressive when we go into the doctors  
P2- We have to be aggressive with these fellas  
P1- But what happens if it's a whānau that isn't as experienced or aggressive as us?  
What happens to them? You know, and their kids go undiagnosed because they're taking  
what the doctors are saying as law, and it's terrible care.*

Some whānau chose to go directly to a hospital emergency department rather than seek primary care due to the cost, their belief that it was a quicker option, and that they would most likely be referred to hospital anyway.

*"I know if I go to the doctors they're going to send me up there [hospital] anyway so I may as well just go straight up there. So I just went straight up there and, and sat there for six hours waiting for his turn...yeah they were quite busy aye, there was a lot a sick people in there that day" (P25).*

#### Facilitators of health care access

Factors that facilitated primary health care experiences were good rapport, communication and trust with GPs and other primary health care staff members.

*"Doctor X is our GP now because he's done really well with our son, when we see him on the street 'how's P34?' You know? It's become like a personal relationship now, where he asks about him [P34] and he cares about him" (P32).*

#### ***ARF/RHD diagnosis experiences***

##### *Barriers to diagnosis*

The barriers to accessing health care described above all contributed to delays in diagnosis for participants. Diagnosis of ARF (from time first taken to a doctor) varied between an immediate diagnosis at primary care to a four month delay and eventual diagnosis in hospital. Two of the RHD participants explained that their past ARF went undiagnosed and it was not until they presented with RHD symptoms that they were aware that they had suffered from ARF in the past. For another two whānau, their

children were only diagnosed with ARF when they presented at the hospital with other illnesses (kidney infection and bronchiectasis).

Delays in diagnosis occurred even when whānau suspected their children had ARF and voiced their concerns to their GPs.

*“A good four years before that I had a fair idea that P36 had rheumatic fever and I had been into the clinic a couple of times and I had explained to them that I was sure it was rheumatics because of the symptoms he was getting but the doc, the nurses at the clinic were telling me he had rheumatism arthritis and I was adamant that it was rheumatics because I had dealt with the symptoms before with my eldest son but they kept putting it off and kept telling me it was rheumatism arthritis and then yeah, couple years later he’s diagnosed with rheumatics... I think about three times I had gone in there with him.....they kept telling me it was rheumatism arthritis” (P35).*

At least two whānau felt that delays in the ARF diagnosis of their children were due to lack of knowledge and awareness of ARF by secondary health care professionals.

*“Because they [hospital doctors] had never seen it [ARF] before, there was only one doctor that’s what I’m saying, there was only one doctor who knew his stuff. All the rest they were just practicing on me basically, well I was all right with it but they didn’t know what they were up to” (P2).*

#### Facilitators of diagnosis

Factors that facilitated diagnosis included being able to access GPs, trusting GPs to have an understanding of ARF and provide expected sore throat management.

*“They [doctors at primary care clinic] always take swabs every time, like even with my moko [grandchild], he’s two in March, even when I hear him cough, poor Dr X (laughs). I’m pretty sure he’s too young to get rheumatics but oh he’s off to the doctor to get swabbed, my poor moko you know? He, even [the] doctor goes ‘I’m pretty sure it’s not’ and I go ‘I don’t care, I want it swabbed’” (P35).*

#### **Hospital experiences**

Tamariki spent between four days to three months consecutively in hospital settings. Whānau liked the fact that they could stay in hospital with their children. However, due to employment obligations, long distance commuting, and having to look after other whānau members (particularly other young children), whānau often could not stay with their children which was a great stress for them (and their tamariki).

Most tamariki had some negative experiences during their hospital stays as they had to contend with time away from their whānau in a new environment. These experiences were compounded by coping with pain and fear associated with their illness and boredom at their confinement. Feeling “*scared*” and “*lonely*” were the two most common descriptions for hospital stays used by tamariki.

*“Oh it sucked, that was the worst time. Yeah, always felt longer than what it really was I guess (pause). I used to cry cause I was only a kid and no parents around sort of thing. In the hospital I didn’t feel safe” (P2).*

A few of the children, and their whānau spoke of their tamariki being harshly treated and spoken to by hospital staff.

*“There was one nurse she was shocking sometimes, the kids would get scared of her and even P36 did and one night I just got sick of it cause when I saw P36 acting like he was asleep because he was scared I just got sick of it and we ended up having an argument about it because I feel when the kids are sick and they’re in hospital the nurses and that are supposed to make them feel safe” (P35).*

Whānau experienced various forms of racism and other forms of discrimination within secondary health care contexts. Whānau spoke of being treated differently than non-Māori families and felt that hospitals lacked “*cultural sensitivity*”.

*“They’re not culturally sensitive anyway full stop. And they make that quite clear a bit of racism I believe, that’s how it comes across. That you’re stereotyped, you’re just stereotyped as Māori. You go in there they don’t know your background because of the way you look, like your colour, you got a sick child who has a heart condition, obviously you’re, you know, not a very good mum... However why I say it’s racist is because then there’s another family that comes into the hospital, [a] Pākehā family, oh they were getting good care, she [the nurse] was speaking to them her body language was really good, the tone in her voice really nice and pleasant but then when she came back to us it was sharp, very cold body language” (P1).*

Factors that facilitated hospital experiences for tamariki included having their whānau stay in the hospital rooms with them, having similar aged children in the ward with themselves, being engaged in “*fun*” activities, and having health care professionals who made an effort to form a rapport with them and their families.

### ***Home care***

Participants experienced extended periods of home care during early ARF treatment periods. Most of the young participants described feeling “*bored*” and “*cooped up*” during this time.

*“It was slow for me...I was always inside, so time did fly but it was really hard to go outside. It was a bit different for me. I used to like being outside... Being young and having a little sister around that just wants to play you know, it was hard” (P2).*

All young participants in our study preferred home-care over hospital care. Their preference was due to feeling safer at home, feeling cared for and loved, and being in a familiar environment where they could ask for personal requests such as being taken to the toilet and showered without feeling embarrassed.

Caring for tamariki at home, particularly when they were on strict bed rest was challenging for whānau, particularly mothers. Mothers were often trying to juggle looking after their sick child and their other children, as well as run a house and negotiate time off work and other commitments. Whānau also described this as an anxious period of waiting for their child to get better and for their life to return to normal.

*“We had to carry him to the toilet and set him up in the sitting room actually... Yeah, it was just really long, and I remember it just felt like forever sort of anxious really, I remember being really anxious, like ‘is today going to be the day when I find out what’s going on?’ You know, ‘can he go back to school yet?’ ‘Can he play sport again?’ Cause he wasn’t allowed to go to school” (P1).*

### ***Experiences of secondary prophylaxis***

Most whānau were aware that either injections or oral medicine could be taken for secondary prophylaxis (prevention of recurrent ARF due to further strep infections). Not all whānau were offered a choice of options. Those who were followed the advice of their health care professionals, opted for injections due to the convenience of having the long acting antibiotic injection once every 28 days compared to having to take pills twice a day every day for at least 10 years. In contrast to adult whānau, almost all young ARF participants stated that they would rather take pills daily than have injections.

*“The doctors they were talking to me about like injections later when P7 was confirmed with rheumatic fever or tablets, taking tablets daily but they sort of recommended the bicillin because it’s like a month of antibiotics that helps and it’ll help the swelling and the sore joints and stuff like that. So we sort of opted for that... Um the reason why we preferred it is because it’s only once a month that you know you get it, you don’t have to worry about it again and if you do, the time you forget the date the nurses are there to chase you, you know?” (P6).*

Although whānau were aware of their options they did not have a good understanding of the medication; many expressed they would like to know more about the pills. Whānau also did not understand why their child had to keep having injections or why they had to have them for such a long time. Their explanations ranged from believing the injections would stop their children from getting bacterial and viral infections to helping their bodies stay stronger to “fight off the rheumatics bug”.

### ***Barriers to secondary prophylaxis***

Most ARF participants experienced their first bicillin injections in hospital following their diagnosis. Participants (and their whānau) spoke of this experience as being “scary” and “painful”; many said it had made them cry. Tamariki were referred to the community nursing service for delivery of the bicillin by PHNs until they left school. When tamariki found out they would have to continue getting injections for at least 10 years their reactions were of shock and disappointment.

*“She [PHN] explained to P16 that injections were going to happen and that would be alternate sides and that would go on for every month till she was 21[years old] and P16*

*goes 'what if I don't want it? Can't I just take a pill or something? What if I don't want it?'* (P22).

Whānau and tamariki undertaking treatment also expressed concerns over the impact of treatment on their ability to leave home to study, work and travel.

ARF participants all described experiences when they had been given injections the “*wrong way*” by their PHN which involved the injections being delivered too fast and in the wrong place. They would describe how such injections would cause them muscle and hip pain that would last up to a week.

Other negative experiences related to PHNs not listening to their patients or not taking their experience or feelings into account. These accounts were generally from new, replacement or temporary PHNs working with the families. Whānau explained that they found it difficult to cope with changing PHNs and having to repeatedly built rapport and trust with new nurses.

*“Well our nurse that we have is just great and it's like once you build a relationship with a public health nurse though the problem is that you have that relationship with them so you trust them, you've shared things with them in the you know, half an hour they're sitting with you in your home, every month over several years so when it changes and you get a new nurse you've got to start from scratch you know? We accept that they have their own lives and that they may have a career change and all of that but (sigh) that's probably the hard stuff”* (P1).

Although most whānau valued the flexibility of whether their tamariki could receive their injections at school or at home, some tamariki described feeling embarrassed about having to have their injections at school because all their friends would know what was happening.

Most participants and their whānau were aware of when their injections were due. Whānau described behavioural changes in their tamariki when their injections were due. This was a huge concern for three whānau, they explained that their children would become “*irritable*”, “*grumpy*”, and “*moody*” around a week before their injection time.

#### *Facilitators of secondary prophylaxis*

Over the treatment period, participants, regardless of their age, became ‘lay’ experts in regards to their injections. They could all explain the “*best way*” to give the injections in terms of causing the least amount of pain. Their explanations included injections being delivered slowly and “*hitting the right spot*”. Some patients also spoke of having a preference for placement of injections (even though they are given in alternative buttocks each month).

*“It helps to go a bit slow cause it goes into your muscle and it has to make a little, its own little like pocket for the blood to take it away throughout the month, yeah and that's why they do it slow to kind of ease the pain of the muscle getting ripped into two pieces*

*for a pocket to sit sort of thing.....oh I'm a bit of a pro at it, if I could give myself an injection I would" (P2).*

All participants liked numbing cream to be used by their PHNs when getting their injections and other techniques such as freezer buzzy bees and massage.

*"It's a, it's a gadget that you could take the wings off, this buzzy bee thing you put them in the freezer and it sort of makes it ice cold and then once you have the injection it's a buzzing thing so it vibrates on their muscles and it helps. Yeah and the cooling pads just help cool the area down" (P6).*

Other factors that facilitated the injection experiences included incentives being provided to participants after injections, and having experienced nurses give the injection who took on board and listened to children and their whānau.

*"I was just happy to get it [injection] over and done with. I just want it um, that my treat was um McDonald's if I get it done I get McDonald's" (P2).*

In general, whānau spoke positively about their PHNs. The two most favourable attributes of PHNs for whānau were their rapport with the family and their skill in administering bicillin injections. Getting to know whānau, finding common ground, and building up relationships of trust were highly valued traits of PHNs held by all whānau. Other characteristics of PHNs that were valued was their ability to listen to their clients and take their experiences and feelings into consideration, their ability to answer questions in a basic, easy to understand manner, their sense of humour and being able to work appropriately with children.

*"She's [PHN] so cool, just like the way she talks to me and she explains things more properly, I like her, she's cool, mum likes her too. She explains things more easier" (P24).*

Whānau liked having the flexibility of choosing where their tamariki could have their injections. However, they had mixed reactions to the PHNs coming to their homes to give injections. Most perceived this as a great advantage because they did not have to worry about remembering injection times or organising travel to a clinic.

*"Oh having the public health nurse come and give him injections, blinkin great. And actually them making contact cause we don't remember when the four weeks, next four weeks or 28 days or you know, when you can, when you get a nurse, I forget" (P1).*

In contrast, two whānau described having PHNs deliver treatment as a stressor as they worried that they needed to remember the day to "keep on top of the nurses" to make sure they did not forget their appointment.

A strategy used by three whānau to help their tamariki cope with ARF was to encourage their children to be responsible for their own medication. This was often influenced by the realisation that their children would be receiving treatment until their early 20s.

*“You know, responsibility is a big part of that, he needs to be responsible to himself if he wants to get better, if he wants to get off the injection say at the age of 22, well he needs to comply by the rules that the nurses put for him, not so much that we put for him, it’s them, they’re the ones that’s got the injections, it’s them that’s got to waste the phone call to make sure you’re going to be in the place, it’s them that’s going to use their gas to come to him to make sure, so you know, a lots on them and we don’t want to be wasting people’s time or wasting gas or wasting money or wasting anything not allowed, he maumau [a waste]” (P6).*

#### ARF/RHD adult experiences of secondary prophylaxis

Experiences for adult participants with ARF and RHD were different to those of younger participants. Unlike children, adults with ARF not enrolled at school were not eligible to receive treatment from PHNs in their homes or workplaces; instead they had to travel to health centres for treatment. The process relied on consistent rapport between the patient and health provider, and was described as being disruptive to work and life events for participants.

*“I’m always busy and so I forget, you know, jab day or something comes up and I can’t do it and another thing that I get annoyed with is like waiting around. Cause I can make an appointment for 9 o’clock and then I get there and I’m there for 45 minutes, just to get my jab and I tried to do the ‘can I like go back to work and can you just call me when my time, my space is up? Cause I can’t be sitting here for 45 minutes” (P4).*

RHD participants spoke of the trauma of undergoing heart surgery and the difficulties they experienced with delays and cancellations they experienced in getting their surgery. Some RHD participants described the difficulty they had with having to keep their warfarin levels monitored and having to remember to take their medication. One RHD participant also spoke of suffering from depression and confusion as a side effect of heart medication and the impact of this on their whānau, job and self-confidence.

#### **ARF/RHD information**

After diagnosis of themselves or a whānau member, participants obtained information about ARF/RHD from a variety of sources including the internet, libraries, health care professionals, and talking with friends and whānau who had previous experience with ARF/RHD.

*“I’d never heard about it before so I just hopped on google and searched it up and read about it, and this was a wow! I ended up talking to a kaimahi [employee] at Kōhanga [Reo][Māori language emersion pre-school] about it and her brother has got it as well” (P8).*

When provided with verbal and/or written descriptions of ARF/RHD by health care professionals, whānau reported that they were left without a great sense of understanding of ARF/RHD and commonly reported feeling “*overwhelmed*” by all the material.

*“When you’re hearing this for the first time you just think ‘what the heck, I have never heard this stuff before’ but here’s all the information to read and see, we get quite overwhelmed with that information, you can’t truly comprehend it because you don’t really know what the hell it is” (P1).*

Unlike verbal and written descriptions of ARF/RHD, whānau found that DVD/video clips that were shown to them in hospital made ARF/RHD easier to understand.

*“When they explained I had it [rheumatic fever], it was sort of hard for me to try and understand but then they showed us this video and it was sort of like of pac man<sup>2</sup>, the pac man game you know? ... Well it showed us that the pac man is the bug you know? Going around eating all these little things in the throat, it starts off with a bug in the throat and when we watched the video on it, it sort of was easier to understand” (P35).*

### ***Impacts of ARF/RHD on whānau***

ARF/RHD resulted in whānau experiencing significant emotional, social and economic stressors. Whānau experienced a variety of emotions during the diagnosis and secondary prevention of their or their children’s ARF/RHD including: worry, stress, sadness, anger, guilt and confusion.

ARF/RHD impacted on financial status, employment, and education of whānau. Family members, particularly mothers, had to leave paid employment to accommodate treatment and care of their children for periods of up to a year, while often still caring for other children and running a household. Some fathers also reduced their working hours to allocate more time for whānau support during diagnosis and treatment periods.

*“I gave up what I was doing to be with my son, so we needed at least one of us to bring an income in, to keep the household going so I gave up what I was doing and my husband carried on what he was doing. And we just kept doing that but it was really hard on us” (P1).*

Guilt was an emotion experienced by most whānau in our study. Mothers and grandmothers were more likely to discuss feeling guilty and felt they had “*failed as a mother*” because of their children’s illness. Whānau blamed themselves for not realising how sick their children were, not understanding what ARF was, and not pushing hard enough for medical treatment of their children.

*“I was like ‘oh my God’ that was my fault because I knew that it [ARF] comes from a sore throat. They [medical professionals] said, ‘well you just didn’t pick it up that they had a sore throat’ and I was like ‘Oh my God’ .... you feel like a terrible parent cause you just missed all this stuff” (P15).*

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<sup>2</sup> Pac man is an animated character from a childrens’ arcade game

Another impact of ARF/RHD was that children (including those with ARF/RHD and their siblings) were often not able to attend school for periods of up to six months. Parents found it hard to visit and care for sick children in hospital (or on home-based bed rest) and look after their other children, resulting in educational absenteeism.

*“She [sibling of child hospitalised with ARF] should have been at school but we didn’t send her to school through that whole time, we kept her with us, because it was just too hard to send her to school and then one of us has to be back by three which would have been me, and then pick her up, and then go back to the hospital. It was just easier just to have her with us” (P1).*

One young participant with Sydenham chorea<sup>3</sup> was too embarrassed to go to school due to fear of being made fun of.

*“He was jerking, couple of months, yeah his left hand side cause he writes with his left, his left hand right down to his leg would go like that [demonstrates movement]. Cause he was too embarrassed to go to school and his mouth, he couldn’t talk properly, his mouth, his speech was going off too, yeah” (P25).*

Other impacts on education included youth not being able to concentrate in the class room, and not being able to hold pens/pencils or use iPads/computers to do their school work. For Kura Kaupapa students having to be taught in English at hospital schools was especially challenging.

Whānau expressed anxiety and fear over the long term impacts of ARF/RHD for their tamariki in regards to not being able to undertake certain career paths, always having to be conscious of their body weight, and the fear of long term heart failure and shortened life expectancy.

*“They say to me ‘oh you know, he’s never going to get better from this, he’s always going to have a heart murmur’. ‘Okay so what are our options for the future for him, if he gets sick again?’ And the doctor then says to me ‘two options: heart transplant or he’s dead’. Now how do you feel when you’re told that as a parent, you have two options for your child? If they get sick again either they going to die or you’ve got to find a heart? Where the hell am I going to find a heart from?” (P1).*

### ***Coping with ARF/RHD***

Having close, supportive whānau and social networks such as marae, schools, and work places (particularly workplaces with flexible hours for parents with sick children), was the most commonly reported facilitator in coping with ARF/RHD experiences for participants. The inverse was also true where whānau with limited family/social support cited this as a key barrier to coping with their ARF/RHD experience.

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<sup>3</sup> Sydenham’s chorea or rheumatic chorea is a neurological manifestation of rheumatic fever that is characterised by jerky, uncontrollable movements, loss of motor control, muscle weakness and disturbances of speech (Kotby et al., 1998).

*“I had my family, like my mum and dad you know, they took a lot of stress off me. They took P24, like how when I was diagnosed [with RHD] they took the responsibility of bringing the girls up, like I would, and even after surgery because it took me like another month to heal” (P23).*

Whānau spoke about the need for additional support and information in coping with ARF/RHD. Two whānau recommended implementing some form of online internet support forum to help them gain information and cope with the experience.

Whānau stated that having a long-term health care plan for their children (particularly those with RHD) in relation to heart surgery and heart transplants would also ease their worry.

External health promotion programmes (such as health camps, diet and exercise programmes) that were undertaken in partnership/referral from health providers were seen as positive and helpful for whānau. Maintaining a healthy weight was seen as integral to coping with ARF/RHD. However, the emphasis on healthy eating to ensure healthy outcomes for participants with AFR/RHD was a double edged sword. Whānau understood the importance of healthy food but some could not afford to buy fresh food and vegetables and/or had difficulty accessing healthy food.

*“I was like ‘yes’ you know, ‘I can do this, I can do my exercises and go for walks and stuff’. Well that lasted for two weeks by myself and then I was like ‘oh I really can’t afford to eat like this all the time’ because it’s expensive you know? I didn’t have a car so I couldn’t go shopping and I couldn’t afford to maintain that healthy eating buzz. It was just me and I had to pay bills and you know, buy groceries and then I could only go to these shops which was very limited and they don’t even have all that stuff and so I couldn’t really keep up with it” (p5).*

Food preference of children was also a barrier encountered for whānau. They explained that their tamariki did not like the taste of ‘recommended’ healthy food types and they felt guilty for not providing tasty food to them and denying them “*treat food*” when they were unwell.

*“Yeah so they had him on this really strict diet and as a mother again you’re feeling sorry because now he’s really like ‘oh this is yuck’. You’re a parent and if you’re a loving parent, you’re going to make sure that you do everything in your power to make them better but at the same time you want to make them happy cause what they’re going through is absolutely horrible. So when they’re saying, ‘give your son a healthy diet, don’t give him any junk food’ and then dad’s coming home with McDonald’s cause he feels sorry for you so ‘I brought you this big Mac son’ or ‘this big 10 piece pack of KFC to make you feel better’ that doesn’t help the situation” (P1).*

Many ARF/RHD participants cited engagement in sports as an enjoyable way to stay fit and have fun. However, participation in sports and exercise was also a key area of conflict and confusion for participants. Whānau were aware that exercise was good for

health and weight maintenance but many were concerned that too much physical exertion would place stress on their children's hearts.

*“So it's something that he's always wanted to do [join the gym] but I've sort of been holding him back cause I don't know what stimulates the heart too much you know? I want him to do exercise but first find the heart out first and then do it sort of thing you know?” (P6).*

A coping strategy commonly used by whānau was to keep life as normal as possible for themselves and their tamariki with ARF/RHD. This included encouraging their tamariki to engage in regular school, work and social routines, and not making a big deal out of hospital visits and bicillin injections.

*“I think it's about trying to keep life normal as well you know? Be normal, just be aware, be conscious of it [ARF/RHD] but just try and keep life the same sort of thing, don't have to make big changes in your life because of that you need to make that fit around your lifestyle...Normally a Monday your injections coming up so sort of keep everything normal. Still go to school, still have your injection, still go to class, you know?” (P6).*

## **Discussion and recommendations**

Our research demonstrates the significant emotional, educational and financial impacts that ARF/RHD has on whānau in Te Tai Tokerau. The effects of having or caring for a family member with ARF/RHD are complex and multifaceted, influenced by broad historical, social and political processes as well as current practices within the health system.

### ***Structural barriers***

To prevent ARF in Te Tai Tokerau, interventions need to address the underlying structural causes by addressing racism, employment, income and housing. Interventions also need an integrated inter-sectoral approach that includes health, housing, financial, employment, childcare and educational assistance. Given the age group (5 - 14 years) of those most at risk of contracting GAS infections (Baker et al., 2008; Lowe et al., 2011; O'Sullivan, 2011), a youth and whānau centred approach (Powers and Tiffany, 2006) should also be implemented within any ARF intervention. NDHB is an active partner in “Healthy Homes Tai Tokerau”, the local home insulation programme, and also in “Manawa Ora” a new Ministry of Health-funded housing assessment intervention targeted at children at high risk of rheumatic fever (Northland District Health Board 2013). If these are implemented equitably, along with advocacy and referrals to integrated support services (such as Whānau Ora collectives), they could be of benefit in addressing structural issues that influence health outcomes. However the poor quality of housing stock in Te Tai Tokerau, complex land ownership issues and fuel poverty are not able to be addressed by these programmes. In addition, median incomes have stagnated for Māori in Te Tai Tokerau in the last decade, and they remain disproportionately represented in unemployment statistics (Ministry of Business Innovation and

Employment, 2014). Therefore, multi or inter-sectoral interventions would be the only effective means of addressing these current inequities.

### ***Accessing health care***

As well as highlighting the impact of structural determinants of health on ARF/RHD experiences, our study identified key barriers whānau faced to accessing health care services in Te Tai Tokerau. Barriers were geographical barriers, inability to get appointments to see health care providers, cost of services, lack of trust and rapport with health care professionals, and previous experiences of discrimination and racism in the health sector. The barriers to health care identified in our study are consistent with current health literature in Aotearoa (Anderson, 2008; Hayman et al., 2009; Kerr et al., 2010; Lee, 2012; Mincham et al., 2000) indicating that these are persistent issues not yet addressed through health policy or systematic change in Aotearoa.

The cost of health care services and prescription fees, and difficulty getting appointments to see health care professionals are well recognised access barriers for Māori in Aotearoa, and can create delays in diagnosis and treatment of ARF/RHD (Jatrana and Crampton, 2009; Kerr, 2010; Lee, 2012). In a recent 2015 health survey, NDHB found that 36% of Māori respondents were more likely to have unmet need for primary health care than non-Māori participants (24%) and substantially more Māori (20%) reported cost as a barrier to seeking health care than non-Māori (8%) (Rumball-Smith, 2015). The report also revealed significant ethnic inequalities between Māori (9%) and non-Māori citing lack of transport as a contributor to unmet need for GP care. Almost 20% of the whole Northland sample was unable to obtain an appointment at their usual medical provider within 24 hours, which is a statistically significantly higher proportion than the national sample (16%).

Not being able to obtain timely GP appointments is an increasingly common barrier to accessing health care in Aotearoa (Anderson, 2008; Ludeke et al., 2012; Slater et al., 2013). Various initiatives such as walk in clinic appointment systems and flexible operational hours (Ludeke et al., 2012; Slater et al., 2013) have been proposed to help counter this issue. However, there are structural barriers in implementing innovative services and widening the scope of the primary care workforce. This is predominately due to the funding mechanism of general practice and its essentially private enterprise model in Aotearoa (Finlayson et al 2012). Given the health impact and complexity of this issue, further research is needed to explore the influence of existing primary care service models impact on health, and to investigate the possibility of alternative models of care.

As noted above, cost of health services and cost of prescription fees are well recognised barriers to health care in Aotearoa. Standard GP consultations with children under six years of age have been free of costs since January 2009 in Aotearoa. In July 2012, free GP consultation for children under the age of six was also extended to after-hours consultations (Ministry of Health, 2014b). This initiative was further extended in Te Tai Tokerau where from October 2014, doctor visits and prescription medicines were free for patients under 13 years of age. Despite the free health care for under 13 initiative in Te

Tai Tokerau, there are still notable inequities in primary healthcare access between Māori and non-Māori (Rumball-Smith, 2015). Visits to GPs have increased for all groups but the difference in rates of utilisation between non-Māori and Māori and Pacific has increased (*Personal communication*, August 2015). These inequities demonstrate the complexity of issues that influence access to health care. Rather than relying on a single intervention to target a sole barrier such as cost, a multi-pronged approach that can address multiple identified barriers including lack of transport, lack of childcare and lack of confidence in medical professionals could be a more effective strategy.

One of the greatest facilitators of positive experiences within Northland's health care system identified in this study was establishing a good rapport (or *whakawhanaungatanga*) between health care providers and *whānau*. The impact of good rapport, communication and trust between health care professionals and their clients' experiences with healthcare services in Aotearoa has been well established, with greater perceived rapport promoting greater patient satisfaction (Jansen and Smith, 2006; Kerr et al., 2010). Given the importance of such relationships, NDHB and Northland's Primary Health Organisations (PHOs) need to place more emphasis on continuity of care between *whānau* and PHNs (and other treatment providers). Training and evaluation specifically targeted to rapport building/*whakawhanaungatanga* should be established for health professionals throughout the health sector. The "hui process" (Lacey et al., 2011) is a health education framework that could be implemented to support this. This framework was developed by the University of Otago to improve doctor-patient relationships and communication within a culturally congruent process and is currently used in training of medical students at both the University of Otago and University of Auckland.

### ***Racism***

Racism was experienced by *whānau* at institutional and interpersonal levels within primary and secondary health care contexts. Experiences of racism were perceived by *whānau* as a key barrier to accessing health services. Recent New Zealand-based research has revealed that racism is emerging as a key determinant of health and is associated with lower self-reported health outcomes for Māori, Pacific and Asian populations in Aotearoa (Harris et al., 2006; Harris et al., 2012). Cultural competency is a common tool used in health care contexts to help health care professionals understand and work effectively with patients from cultures different from their own (De Souza, 2008). However, the practice of cultural competency has been criticised for its role in perpetuating discrimination within health services by strengthening western practices and values and rendering the impacts of historical and structural causes of racism invisible (Kumagai and Lyson, 2009; Came and da Silva, 2011). In contrast to cultural competency, cultural safety has been proposed as an anti-racist intervention to address the current systemic racial inequities between Māori and non-Māori (Came and da Silva, 2011). Cultural safety is a process of critical self-reflection with a focus on the perceptions, behaviour and biases of the health practitioners themselves rather than their patients (De Souza, 2008). To help mitigate the disadvantageous effects of racism within primary care contexts, we recommend that Northland's PHOs facilitate annual cultural safety training for GPs for their Maintenance of Professional Standards accreditation. Currently cultural competency (in contrast to cultural safety) is espoused by the Royal New Zealand

College of General Practitioners (RNZCGP) for Maintenance of Professional Standards (Royal New Zealand College of General Practitioners, 2013). Therefore, a move towards cultural safety would require changes to RNZCGP and their continuing professional development programme. Harris et al. (2006) have argued that in addition to health sector interventions, a range of different policy approaches need to be applied at a societal level to address issues of racism within New Zealand.

### ***Sore throat management***

Other key barriers to accessing health care and contributors to delays in diagnosis of ARF identified in our study were lack of throat swabbing and inappropriate prescription of antibiotics within primary care contexts. Many whānau were not given throat swabs or prescriptions for antibiotics even when presenting to their GPs with sore throats, requesting throat swabs and disclosing personal or whānau histories of rheumatic fever. These experiences indicate negative perceptions by whānau of GPs within Te Tai Tokerau and additionally influenced whānau decisions to bypass primary care services in favour of secondary care.

Best practice guidelines for sore throat management in Aotearoa (Lennon et al., 2014) recommend that throat swabs are undertaken and patients are started on appropriate antibiotic treatment<sup>4</sup> if the patient is deemed at 'high risk' of developing rheumatic fever. High risk in this context is defined if the patient has a "personal, family or household history of rheumatic fever or have 2 or more of the following criteria: Māori or Pacific, aged 3-35 years, living in crowded circumstances or lower socioeconomic area" (Lennon et al., 2014, p. 13). All whānau members who presented to GPs with sore throats in our study would have met at least two of these high risk criteria demonstrating that sore throat guidelines are not currently being followed by all GPs within Te Tai Tokerau. The findings from our research are supported by a recent study undertaken by Shetty et al. (2014) that assessed adherence of school-based sore throat programmes and GPs in Te Tai Tokerau to national guidelines for the management of laboratory proven GAS pharyngitis. The study found that one in five children presenting to general practices with positive throats swabs did not receive treatment regimens recommended by the national guidelines.

A number of reviews have shown that guidelines often have only moderate effectiveness in improving clinical outcomes or changing process of care (Lugtenberg et al., 2009; Grimshaw and Russell, 1993; Grimshaw et al., 1995). However an effective implementation strategy can overcome health provider barriers (Grimshaw et al 1995). Given the experiences of whānau in our study, we recommended that a sore throat guideline implementation strategy be developed. This strategy should address identified barriers. General practitioner-mediated barriers are likely to include a lack of awareness with guidelines, lack of agreement with recommendations, lack of outcome expectancy and lack of motivation (Lugtenberg et al 2009).

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<sup>4</sup> Recommended antibiotic treatment is either 10 days of empiric penicillin or amoxicillin or a single dose of IM benzathine penicillin (Lennon et al. 2014, p.13).

Our research findings also would support other ways of increasing access for whānau to high quality sore throat management, including the “rapid response” free at point of care access currently being implemented for children and youth at high risk in Te Tai Tokerau (Northland District Health Board, 2013, p.3). Recently published research also suggests that self-swabbing or swabbing by parents/caregivers is non-inferior to swabbing by health professionals for the detection of Group A Streptococcus (Murray, 2015). Self-swabbing may overcome some of the barriers that whānau experience in accessing primary care. The feasibility of implementing self-swabbing requires further research and policy development in the New Zealand context.

### ***ARF/RHD Health literacy***

Health literacy can be defined as obtaining, understanding and using health information appropriately (Zarcadoolas et al., 2009). The findings from our study suggest that providing multiple written forms of information about ARF/RHD to whānau after their diagnosis and during treatment was not an effective nor efficient form of delivery. Whānau felt “*overwhelmed*” by the content and amount of information provided to them and, as a result, were not able to process the material. Verbal information was received in a similar manner with whānau saying they were often feeling too anxious and confused to understand spoken medical descriptions, instructions and advice. These issues were compounded for the young Kura Kaupapa students who found reading documents written in English challenging as English is often not introduced as a taught subject in Kura Kaupapa until year 9. In contrast to written and oral forms of information regarding ARF/RHD, DVD and video resources were found to be an effective information medium for participants regardless of their age or English language competency. Participants found basic images in these visual clips easy to understand and relate to. A review of health literacy studies suggests that visual images such as cartoons, pictograms and multimedia presentations are more effective health literacy interventions than oral or written communication (Bau et al., 2010). Given the effectiveness of DVD/videos in conveying ARF/RHD information to whānau we recommend more resources should be allocated to this form of delivery.

The recent “sore throats matter” campaigns have been successful in portraying the importance of sore throats as a pathway to getting ARF/RHD and reinforced the importance of getting sore throats treated. However, broader causal factors and management of ARF/RHD were not well understood by whānau. An issue of particular concern in regards to health literacy of ARF/RHD was the cultural deficit understandings of ARF/RHD that were informed by media coverage, health promotion campaigns and discussions with health care professionals. Cultural deficit discourses attribute poor outcomes such as high rates of ARF/RHD to particular cultures and groups of people (Valencia, 1997), in this context attributing ARF/RHD as a disease of Māori and Pacific. Currently, sore throats matter campaigns are targeted at Māori and Pacific groups, and almost exclusively feature images of ARF/RHD with Māori and Pacific people and contexts. In addition to these images, many whānau in our study were informed by their health care providers that aspects of their culture such as staying on marae, engagement at tangihanga and living with extended whānau were reasons for their tamariki getting rheumatic fever. Brough et al. (2004, p. 216) caution such approaches, particularly within

indigenous health contexts, stating “health promotion needs to be aware of its own potential to utilise the culture concept superficially, 'explaining' unhealthy behaviours in reference to a series of stereotypical cultural traits drawn from the popular culture”. Associating ARF/RHD solely as a Māori and Pacific disease disregards the underlying risk factors for this disease, such as poor housing, unemployment and economic inequities that stem from historical colonial processes and racial discourses (Bond, 2005; Borell et al., 2009; Moewaka Barnes et al., 2014; Reid and Robson, 2007). In addition, such discourse can be embodied by those it is targeted at, producing internalised racism, stress and ultimately increasing negative health outcomes for those who are already marginalised within society (Krieger, 2011; Moewaka Barnes et al., 2014). As well as promoting awareness of the importance of sore throats, ARF/RHD health promotion messages need to target structural factors such as poverty and poor housing standards and avoid utilising material that can further stereotype and stigmatise ethnic groups and their culture. Such an approach would increase health literacy of ARF/RHD in a non-victim blaming manner.

### ***ARF/RHD support***

Another area identified in our study where health literacy could be promoted in regards to information about and support for ARF/RHD are internet-based support groups. As highlighted in our research, guilt was an emotion commonly experienced by whānau, particularly for mothers and grandmothers who had children (and grandchildren) with ARF/RHD. Two participants in our study (both mothers) expressed the need for a support group where they could network with other whānau coping with similar issues and could talk about and share their experiences. One of the mothers suggested that an interactive internet site would be a good ARF/RHD support resource. Given the geographic distances between whānau who experience ARF/RHD in Te Tai Tokerau (and nationally), an internet site could counter physical barriers of accessibility for such a support group.

Sharing health related experiences, seeking health information and advice from the internet is becoming increasingly popular (Griffiths et al., 2012). In the United States it has been reported that over 28% of internet users have visited an online support group at least once (Griffiths et al., 2009, p. 1). Although there has been little published evaluation of the effectiveness of internet support groups (ISGs), a randomised control trial undertaken by Griffiths et al. (2012) for ISGs for depression found that such resources were effective in reducing depressive symptoms of ISGs members. Developing an ISG for ARF/RHD could potentially provide social support for whānau and act as an information source. The ISG could be developed as part of a national programme or as a local Northland initiative. Additional research would have to be undertaken to determine the need, accessibility and feasibility of developing such an ISG for ARF/RHD.

### ***Strengths and limitations***

Our study has been able to provide a qualitative context to research on ARF/RHD in Aotearoa, demonstrating how the experiences and narratives of those who suffer from the disease are important. As noted by Associate Professor Papaarangi Reid at the 2008 New Zealand Primary Health Care Symposium (University of Auckland 2008), it is important

to remember that “behind every number is a person” (*personal communication*). Although there are a number of reports and publications of the epidemiological trends of ARF/RHD in Te Tai Tokerau and nationally, this is the first research to look at the personal stories and experiences behind these numbers. In addition, the study emphasised the value of presenting patient and whānau voices within health contexts, an approach that has previously not been utilised within ARF/RHD literature.

Our study included a relatively small sample size, therefore it may not represent the diversity of whānau experiences in Te Tai Tokerau. In addition to sample size, selection bias may have occurred during the recruitment process. ARF/RHD patients and their whānau who did not have access to a PHN, who did not want to speak about their experiences or for other reasons that influenced their non-participation may potentially have had quite different experiences from those participants who did consent to participate in this research.

A further limitation of our study was the non-inclusion of health care professionals. Including the perspectives of both whānau and health care professionals in health-related research can lead to a more comprehensive understanding of utilisation of health care services (Anderson, 2008). Future research should be undertaken with healthcare professions associated with ARF/RHD diagnosis and treatment to provide a broader understanding.

Despite these potential weaknesses, our research provides a beginning point to inform high rates of ARF/RHD in Te Tai Tokerau from a qualitative research approach. This framework can be applied to future research looking at experiences of ARF/RHD in Aotearoa to provide a fuller understanding of these challenging issues.

## **Conclusion**

Our applied a qualitative Kaupapa Māori research design that included participant observations, whānau interviews and individual, semi-structured interviews with 10 whānau groups living in Te Tai Tokerau at the time of the research. We were able to illustrate the broad impacts that AFR/RHD experiences have on whānau and elucidated barriers and enablers of pathways to health care for ARF/RHD. A number of actions were recommended to facilitate experiences of ARF/RHD for whānau and improve access to health care, diagnosis and treatment of ARF/RHD in Te Tai Tokerau (refer to page 4 for a summary of recommendations). The next phase of research and service delivery will be to consider the implementation of these recommendations and evaluate future interventions.

## References

- Anderson A. 2008. Understanding migrants' primary health care utilisation in New Zealand through an ethnographic approach. *Diversity in Health and Social Care* 5 (4): 291-301.
- Angrosino M V. 2002. *Doing Cultural Anthropology: Projects for Ethnographic Data Collection*. Illinois: Waveland Press Inc.
- Atatoa-Carr P, Bell A, Lennon D R. 2008. Acute rheumatic fever in the Waikato District Health Board region of New Zealand: 1998–2004. *New Zealand Medical Journal* 121(1285):96.
- Baker M, Jaine R, Venugopal K. 2008. Epidemiology of acute rheumatic fever in New Zealand 1996-2005. *Journal of Paediatrics and Child Health* 44 (10): 564-571.
- Barnes H M. 2000. Kaupapa Māori: Explaining the ordinary. *Pacific Dialog* 7(1):13-16.
- Bau A, Brinson D, Ali W, Smartt W. 2010. Interventions to mitigate the effects of low health literacy: A systematic review of the literature. *HSAC Report* 3(21).
- Bond C. 2005. A culture of ill health: Public health or Aboriginality? *Medical Journal of Australia* 183(1):39-41.
- Borell B A E, Gregory S A S, McCreanor T N, Jensen V G L, Moewaka Barnes H E. 2009. It's hard at the top but it's a whole lot easier than being at the bottom": The role of privilege in understanding disparities in Aotearoa/New Zealand. *Race/Ethnicity: Multidisciplinary Global Contexts* 3(1):29-50.
- Brough M, Bond C, Hunt J. 2004. Strong in the City: Towards a strength-based approach in Indigenous health promotion. *Health Promotion Journal of Australia* 15(3):215-220.
- Came H A, da Silva S. 2011. Building political competencies for the transformation of racism in Aotearoa. *Kōtuitui: New Zealand Journal of Social Sciences Online* 6 (1-2):113-123.
- Cohen D, Crabtree B. 2006. *Qualitative Research Guidelines Project*. Princeton NJ: Robert Wood Jonson Foundation.
- De Souza R. 2008. Wellness for all: The possibilities of cultural safety and cultural competence in New Zealand. *Journal of Research in Nursing* 13(2):125-135.
- Emerson R M, Fretz R I, Shaw L L. 1995. *Writing Ethnographic Fieldnotes*. Chicago: The University of Chicago Press.

Finlayson M P, Sheridan, N F, Cumming J M, Fowler S. 2012. The impact of funding changes on the implementation of primary health care policy. *Primary Health Care Research & Development* 13(2): 120-9.

Flynn M, Carne S, Soa-Lafoa'i M. 2010. *Māori Housing Trends 2010*. Wellington: Housing New Zealand Corporation. Cited February 2015, available from: <http://www.hnzc.co.nz/our-publications/maori-housing-trends/2010-maori-housing-trends-report/2010-maori-housing-trends-report.pdf>.

Grayson S, Horsburgh M, Lennon D. 2006. An Auckland regional audit of the nurse-led rheumatic fever secondary prophylaxis programme. *Journal of the New Zealand Medical Association* 119 (No. 1243): 51-57.

Griffiths K M, MacKinnon A J, Crisp D A, Christensen H, Bennett K, Farrer L. 2012. The effectiveness of an online support group for members of the community with depression: a randomised controlled trial. *PLoS One* 7 (12) e53244. DOI 10.1371/journal.pone.0053244.

Griffiths K M, Calear A L, Banfield M. 2009. Systematic review on internet support groups (ISGs) and depression (1): Do ISGs reduce depressive symptoms? *Journal of Medical Internet Research* 11 (3): e40. DOI 10.2196/JMIR.1270.

Grimshaw J M, Freemantle N, Wallace S, Russell I, Hurwitz B, Watt I, Sheldon T. 1995. Developing and implementing clinical practice guidelines. *Quality in Health Care* 4: 55-64.

Grimshaw J M, Russell I T. 1993. Effect of clinical guidelines on medical practice: A systematic review of rigorous evaluations. *The Lancet*. 342(8883): 1317-1322.

Harris R, Cormack D, Tobias M, Yeh L, Talamaivao N, Minster J, Timutimu R. 2012. The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science and Medicine* 74:408-415.

Harris R, Tobias M, Jeffreys M, Waldegrave K, Karlsen S, Nazroo J. 2006. Racism and health: The relationship between experience of racial discrimination and health in New Zealand. *Social Science and Medicine* 63: 1428-1441.

Hayman N, White N, Spurling G. 2009. Improving Indigenous patients' access to mainstream health services: the Inala experience. *The Medical Journal of Australia* 190 (10): 604-606

Jaine R, Baker M, Venugopal K. 2008. Epidemiology of acute rheumatic fever in New Zealand 1996-2005. *Journal of Pediatric Child Health* 44(10):564-71.

- Jaine R, Baker M, Venugopal K. 2011. Acute Rheumatic Fever associated with household crowding in a developed country. *The Pediatric Infectious Disease Journal*, 30(4):315-319.
- Jansen P, Smith K. 2006. Maori experiences of primary health care: Breaking down the barriers. *New Zealand Family Physician* 33 (5):289-300.
- Jatrana S, Crampton P. 2009. Primary health care in New Zealand who has access? *Health Policy* 93 (2009) 1-10.
- Kermedelidis M, Lennon D R, Arroll B, Peat B, Jarman J. 2010. The primary prevention of rheumatic fever. *Journal of Pediatric Child Health* 46:534-48.
- Kerr S, Penney L, Moewaka Barnes H, McCreanor T. 2010. Kaupapa Maori Action Research to improve heart disease services in Aotearoa, New Zealand. *Ethnicity & Health* 15(1), 15-31.
- Kotby A A, Badawy N E L, Sokkay E L, Moawad H, Shawarby M E L. 1998. Antineuronal antibodies in rheumatic chorea. *Clinical and Diagnostic Laboratory Immunology*. 5(6): 836-839.
- Krieger N. 2011. *Epidemiology and the Peoples' Health*. New York: Oxford University Press.
- Kumagai A, Lypton M. 2009. Beyond cultural competence: Critical consciousness, social justice and multicultural education. *Academic Medicine* 84(6): 782-787.
- Lacey C, Huria T, Becket L, Gilles M, Pitama S. The hui process: A framework to enhance the doctor-patient relationship with Maori. *New Zealand Medical Journal* 124(134):72-78.
- Lee R. 2012. Maori Solo Mothers' Healthcare Access: Experiences, Barriers and Complexities of Access. Unpublished master's thesis for master's degree, University of Auckland, Auckland, New Zealand.
- Lennon D, Peat B, Kermedelidis M, Sharpe N, Liddel R. 2014. *New Zealand Guidelines for Rheumatic Fever Group A Streptococcal Sore Throat Management Guideline: 2014 Update*. Auckland, Heart Foundation New Zealand. Cited January 2015, available from: <http://www.ttphs.govt.nz/vdb/document/1056>.
- Lowe L, Miller J, Sharpe N. 2011. Rheumatic Fever in Māori: What Can We Do Better? *Best Practice Journal* 37: 22-31.
- Ludeke M, Puni R, Cook L, Pasene M, Abel G, Sopoaga F. 2012. Access to general practice for Pacific peoples: a place for cultural competency. *Journal of Primary Health Care* 4(2): 123-130.

Lugtenberg M, Burgers J S, Westert G P. 2009. Effects of evidence-based clinical practice guidelines on quality of care: A systematic review. *Quality & Safety in Health Care* 18(5): 385-92.

Mahuika R. 2008. Kaupapa Māori Theory is critical and anti-colonial. *MAI Review* 3(4):1-16.

Maré D C, Mawson P, Timmins J. 2001. *Deprivation in New Zealand: Regional Patterns and Changes. Treasury Working paper 01/09*. Wellington: The New Zealand Treasury. Cited February 2015, available from: <http://www.treasury.govt.nz/publications/research-policy/wp/2001/01-09/twp01-09.pdf>.

Milne R J, Lennon D R, Stewart J M, Vander Hoorn S, Scuffham P A . 2012. Incidence of acute rheumatic fever in New Zealand children and youth. *Journal of paediatrics and Child Health* 48 (8): 685-691.

Mincham, C, Toussaint S, Mak D, Plant A. 2003. Patient views on the management of Rheumatic Fever and rheumatic heart disease in the Kimberley: A qualitative study. *Australian Journal of Rural Health* 11: 260–265.

Ministry of Business Innovation and Employment. 2014. *Quarterly Regional Labour Market Update for March 2013: Northland*. Wellington: Ministry of Business, Innovation and Employment. Cited February 2015, available from: <http://www.dol.govt.nz/publications/lmr/reports/regional-mar-13/regional-mar13-nth.pdf>.

Ministry of Health. 2014a. *Analysis of Household Crowding based on Census 2013 data*. Wellington: Ministry of Health.

Ministry of Health. 2014b. *Zero Fees for Under 6s*. Wellington: Ministry of Health. Cited February 2015, available from: <http://www.health.govt.nz/our-work/primary-health-care/primary-health-care-subsidies-and-services/zero-fees-under-6s>.

Moewaka Barnes H, Borell B, McCreanor T. 2014. Theorising the structural dynamics of ethnic privilege in Aotearoa: Unpacking “this breeze at my back” (Kimmell and Ferber 2003). *International Journal of Critical Indigenous Studies* 7(1): A341.

Murray M A, Schulz L A, Furst J W, Homme J H, Jenkins S M, Uh J R, Pritt B S. 2015. Equal performance of self-collected and health care worker-collected pharyngeal swabs for group a streptococcus testing by PCR. *Journal of Clinical Microbiology* 53(2): 573-8.

Nepe T M. 1991. *Te Toi huarewa tipuna. Kaupapa Māori an educational intervention system*. Unpublished master’s thesis, The University of Auckland, Auckland, New Zealand.

New Zealand Guidelines Group. 2011. *RapidE: rheumatic fever. A systematic review of the literature on health literacy, overcrowding and rheumatic fever*. Wellington: Ministry of Health. Cited February 2015, available from:

<http://www.health.govt.nz/system/files/documents/publications/rf20systematic20review20w20nz20case20studies20included.pdf>

Northland District Health Board. 2011. *Eliminating rheumatic fever in Te Tai Tokerau by 2020*. Whangarei: Northland District Health Board.

Northland District Health Board. 2013. *Rheumatic Fever Prevention Plan 2013-2017*. Whangarei: Northland District Health Board.

Cited January 2014, available from:

<http://www.northlanddnhb.org.nz/Portals/0/Communications/Publications/NDHB%20Rheumatic%20Fever%20Prevention%20Plan%20V1%200.pdf>.

O'Sullivan L. 2011. Pounamu: e Runanga o Te Rarawa Rheumatic Fever Reduction Programme – Kaitiaki. *Journal of Primary Health Care*. 3(4): 325-326.

Powers J L, Tiffany J S. 2006. Engaging youth in participatory research and evaluation. *Journal of Public Health Management & Practice*. 12 (Suppl. 6): S79–S87.

Rabiee F. 2004. Focus-group interview and data analysis. *Proceedings of the Nutrition Society*, 63 (4):655-660.

Reid P, Robson B. 2007. Understanding Health Inequities. In Robson B and R Harris (eds) *Hauora Māori Standards of Health IV. A Study of the Years 2000-2005*. Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare.

Robin A, Mills C, Lennon D, Tuck R. 2013. The Epidemiology of Rheumatic fever in Northland, 2002-2011. *New Zealand Medical Journal*, 126 (1373):46-52.

Robson B, Cormack D, Cram F. 2007. Social and economic indicators. In Robson B and R Harris (eds) *Hauora Māori Standards of Health IV. A study of the years 2000-2005*. Wellington: Te Rōpū Rangahau a Eru Pōmare.

Rumball-Smith J. 2015. *NZ Health Survey 2011-2014, Te Tai Tokerau*. Whangarei: Northland District Health Board.

Shetty A, Mills C, Eggleton K. 2014. Primary care management of group A streptococcal pharyngitis in Northland. *Journal of Primary Health Care* 6 (3):189-194.

Slater T, Matheson A, Davies C, Tavite H, Ruhe T, Holdaway M, Ellison-Loshmann L. 2013. 'It's whanaungatanga and all that kind of stuff'. Maori cancer patients' experiences of health services. *Journal of Primary Health Care* 5(4): 308-314.

Smith G H. 2000. Protecting and respecting indigenous knowledge. In Battiste M (Ed.). *Reclaiming Indigenous voice and vision*. Canada: UBC Press.

Statistics New Zealand. 2014a. 2013 Census QuickStats about a place: Northland Region. Wellington: Statistics New Zealand. Cited February 2015, available from: [http://www.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-a-place.aspx?request\\_value=13068&tabname=Income](http://www.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-a-place.aspx?request_value=13068&tabname=Income)

Statistics New Zealand. 2014b. Ethnic employment and unemployment rate comparisons. Wellington: Statistics New Zealand. Cited February 2015, available from: [http://www.stats.govt.nz/browse\\_for\\_stats/income-and-work/employment\\_and\\_unemployment/ethnic-labour-force-stats-by-age.aspx#agestructurecomparisons](http://www.stats.govt.nz/browse_for_stats/income-and-work/employment_and_unemployment/ethnic-labour-force-stats-by-age.aspx#agestructurecomparisons)

The Cardiac Society of Australia and New Zealand. 2008. *A Summary of the New Zealand Guidelines for Rheumatic Fever*. Auckland: New Zealand Heart Foundation. Cited January 2015, available from: <http://www.ttophs.govt.nz/vdb/document/369>

The Royal New Zealand College of General Practitioners. 2013. Continuing professional development programme 2014-2017. Wellington, The Royal New Zealand College of General Practitioners.

Thomas D. 2003. A general inductive approach for qualitative analysis. Auckland: School of Population Health, University of Auckland. Cited December 2013, available from: <http://www.fmhs.auckland.ac.nz/soph/centres/hrmas/docs/Inductive2003.pdf>

Valencia R R. 1997. *The Evolution of Deficit Thinking: Educational Thought and Practice*. Oxon, RoutledgeFalmer.

Walker S, Eketone A, Gibbs A. 2006. An exploration of Kaupapa Maori research, its principles, processes and applications. *International Journal of Social Research Methodology*. 9(4):331-344.

Walker S. 1996. *Kia tau te Rangimarie: Kaupapa Māori theory as a resistance against the construction of Māori as the 'Other'*. Unpublished master's thesis, The University of Auckland.

Webb P, Bain C. 2011. *Essential Epidemiology: An Introduction for Students and Health Professionals*. United Kingdom: Cambridge University Press.

Webb R, Wilson N. 2013. Rheumatic fever in New Zealand. *Journal of Paediatrics and Child Health*. 49(3): 179-184.

Zarcadoolas C, A Pleasant, D S Greer. 2009. *Advancing Health Literacy: A Framework for Understanding and Action*. San Francisco: Jossey-Bass A Wiley Imprint.