



Māori and Pacific Whānau Experiences of Recurrent Rheumatic Fever and Unexpected Rheumatic Heart Disease in New Zealand

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**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)

Executive summary

Background

Rates of rheumatic fever (RF) are decreasing in most developed countries. However, in Aotearoa, RF remains a significant health problem with persistent ethnic, social and demographic inequities. Nationally, Māori and Pacific people have the highest rates of RF, recurrences of RF, and incidences of rheumatic heart disease (RHD). Despite these notable disparities, little is known about the lived experiences or the persistence of these inequities for Māori and Pacific people. This research aimed to address these knowledge gaps to inform health-service improvements.

Methods

The primary aim of the research was to explore Māori and Pacific whānau experiences and understandings of RF and RHD. The research applied a qualitative kaupapa Māori research framework in addition to talanga and kakala Pacific research methodologies. Data were collected using whānau interviews with 38 Māori and Pacific whānau (n = 80), six focus-group interviews with 24 secondary prophylaxis providers and nine semi-structured interviews with other health care providers (HCPs) who worked in RF/RHD contexts. In total, 113 people participated in the study. The research was undertaken in seven North Island District Health Board (DHB) areas of Aotearoa: Northland, Waitematā, Auckland, Counties Manukau, Waikato, Hutt Valley, and Capital and Coast.

Results

When reviewing whānau experiences of their pathways through health care, from the onset of symptoms until their eventual diagnoses, systemic failures became apparent within Aotearoa's health system, including the inability of health care services to meet the complex living contexts of whānau, which contributed to the development of recurrent RF (RRF), recurrent hospitalisations for RF (RHRF) and RHD. Protective factors that reduced the risk of recurrence of RF and RHD included whānau advocacy and support, good rapport and communication between whānau and health care professionals and good communication and referral pathways between HCPs both within and between DHBs.

Conclusions

This research describes the broad impacts that RF, RRF and RHD experiences have on Māori and Pacific whānau. Key barriers and facilitators of pathways to health care and to the management of RRF and RHD are described. This report outlines recommendations for improving RF, RRF and RHD health systems and services, for improving the management and prevention of RF, RRF and RHD and for increasing RF and RHD understanding and health literacy.

Summary of recommendations

Health systems: Reducing recurrent RF and unexpected RHD

- Health services should implement a coordinated national patient-management system across all DHBs to enable seamless tracking, transfer and referral of patients within and between DHBs.
- Health services need to acknowledge the complexities of life for many whānau and to develop flexible service-delivery models designed to meet the needs of whānau, as opposed to the needs of the services.
- Health services must undertake audits of sore-throat management and utilise sore-throat guidelines.
- Health services should make diagnoses and undertake management of RF resources available for upskilling HCPs, particularly in primary care contexts.
- The Ministry of Health and DHBs need to undertake a rigorous evaluation of cultural safety training for HCPs regarding short-to-long-term outcomes at institutional and individual HCP levels.
- RF/RHD services should seek their clients' insights as to whether their services are offered in a manner that health consumers determine to be 'culturally safe' to mitigate the disadvantageous effects of racism within RF/RRF/RHD-care contexts.
- The Ministry of Health and tertiary educational institutions must continue to promote, support and reinforce initiatives for Māori and Pacific health workforce development.

Improving Management/Treatment/Secondary Prevention

- The supply and quality of affordable housing in both urban and rural areas of Aotearoa must be improved to reduce overcrowding and the burden of infectious diseases, including RF.
- A community-based nursing model supported by kaimahi/culturally appropriate community health workers for the management of RF/RRF should be implemented within DHB regions with high rates of RF.
- Stronger links need to be established between RF/RHD HCPs and cross-agency and Whānau Ora providers to provide coordinated support for housing, finance, employment, childcare and health.
- RHD and RF must be recognised as requiring long-term prophylaxis as chronic conditions in adolescence.
- Age-appropriate resources and services need to be developed for RF/RHD, including training for HCPs.
- 'Return' strategies for exercise, education and employment for people with RF/RHD should be implemented.
- Concomitant administration of lignocaine and the use of counter stimulation via the *Buzzy® vibrating device, incorporating a cold pack, should be offered to all patients receiving intramuscular benzathine penicillin to reduce side effects—including fear—and to enhance adherence.
- It must be ensured that Pharmac delivers an uninterrupted supply of benzathine penicillin and that an alternative preparation is available for those with penicillin-allergic reactions to the standard supply.
- Further research needs to be undertaken to determine the most appropriate manner of providing patient and whānau support and advocacy, including exploring the need for and the accessibility and feasibility of developing an internet support group for RF/RHD information and support.

RF/RHD understanding and health literacy

- Current health-promotion messages must be reviewed to ensure that future messages avoid utilising material that further stereotypes and stigmatises ethnic groups, their cultures and behaviours, to avoid maintaining RF/RHD-associated stigma.
- More attention and resources should be directed towards improving health literacy concerning secondary prevention for people with RF and RHD.
- Funding must be made available for the development of further visual RF/RHD information sources for patient and whānau education that utilise jargon-free language in English, Māori and Pacific languages.

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Abbreviations

ARF	Acute Rheumatic Fever
AWHI	Auckland Wide Healthy Housing Initiative
DHB	District Health Board
GAS	Group A Streptococcus
GP	General Practitioner
HCPs	Health Care Providers
ISG	Internet-based Support Group
MOH	Ministry of Health
NMDS	National Minimum Dataset
RF	Rheumatic Fever
RHD	Rheumatic Heart Disease
RHRF	Recurrent Hospitalisations for Rheumatic Fever
RRF	Recurrent Rheumatic Fever
SUDI	Sudden Unexplained Infant Death Syndrome

Background

Acute rheumatic fever (ARF) is an autoimmune response to an untreated group A streptococcus (GAS) infection, usually in the throat (MacDonald et al., 2004). In susceptible individuals, it causes an acute generalised inflammatory response and an illness that affects the heart, joints, brain and/or skin (Marijon, Mirabel, Celermajer, & Jouven, 2012; Milne, Lennon, Stewart, Vander Hoorn, & Scuffham, 2012). Joint involvement is common and individuals with ARF usually are unwell, are in pain and require hospitalisation. While most symptoms and signs resolve without long-term effects, the major concern is the inflammation of the heart (carditis). Children and young adults with acute carditis typically develop inflammation of the mitral and/or aortic valves with associated valvular incompetence (leakage) of varying severity, potentially requiring medication or surgery.

Over 60% of people with RF will have some degree of long-term cardiac damage, or chronic RHD (Reményi et al., 2012; Webb & Wilson, 2013; Wilson, 2010). Chronic valve disease may require further medical or surgical intervention (Reményi et al., 2012; Webb & Wilson, 2013; Wilson, 2010). The long-term consequences of RHD include stroke, infected endocarditis, heart failure and early death. Every year, 160 people die from RF or RHD. On average, RF reduces life expectancy by 15 years (Milne et al., 2012).

There are significant personal, community and societal costs associated with RF and RHD. These result from repeated and prolonged hospitalisations, lack of resources required for medical prophylaxis and treatment, surgical intervention, negative physical and psychological experiences, loss of employment and income, disruption of the lives of patients and their families and premature death (Anderson et al., 2015; Burgess, 2016). Hospital costs are more than NZ\$12 million each year, largely because of cardiac surgery for people affected with RHD (Milne et al., 2012).

RF has largely disappeared from developed countries but remains endemic to Aotearoa/New Zealand. While rates in New Zealand European children are similar to those for children in other parts of the developed world, rates among Māori and Pacific children between 5 and 14 years of age are disproportionately high (Milne et al., 2012). Pacific children are over 50 times and Māori children over 30 times more likely to get ARF than New Zealand European children (Milne et al., 2012; Sharpe, 2012; Webb & Wilson, 2013). From 1996 to 2005, RF rates significantly decreased among New Zealand European children, but significantly increased for Māori and Pacific children (Ministry of Health, 2011). Between 2005 and 2010, the rate of RF doubled from 1.9 reported cases per 100,000 to 3.8 per 100,000 (Milne et al., 2012). The majority of cases occur in low socioeconomic communities in the northern and central North Island and in pockets around the Wellington region.

There is no evidence to support Māori and Pacific people having an increased genetic susceptibility to RF. Therefore, the increased burden reflects social, political and economic influences that result in socioeconomic deprivation, overcrowded conditions, an increased incidence of GAS infection and differing opportunities for appropriate and effective health care (Bryant, Robins-Browne, Carapetis, & Curtis, 2009; Jaine, Baker, & Venugopal, 2011). Patients who have had RF require antibiotic injections every 28 days for at least 10 years to prevent further episodes of RF and the progression of RHD (Spinetto, Lennon, & Horsburgh, 2011). Without this secondary prophylaxis, the risk of recurrent rheumatic fever (RRF) is as high as 75% among patients who develop another streptococcal throat infection (Spinetto et al., 2011). Each episode of RRF increases the incidence and severity of RHD, increases the requirement for valve surgery, and ultimately increases the risk of premature death.

Successful prevention of RRF and RHD requires appropriate clinical guidelines and quality health services with a frontline service-delivery model that provides regular prophylaxis in an accessible and acceptable manner and supports health literacy for patients. Appropriate access to cardiology, oral health, physicians and other health services is essential (Heart Foundation of New Zealand, 2006; Ministry of Health, 2014a).

Current literature has focused on the first diagnosis of RF or on the spectrum of RHD requiring hospitalisation. Worsening statistics and increasing inequities have led RF to become a Government Better Public Services target. While the focus was initially on the prevention of ARF, it has expanded to include other presentations of RF and broader disease management. The Ministry of Health (MOH) plays a role in this process, monitoring disease incidences and supporting the health sector to optimise secondary prevention services.

In addition to the 120 to 170 patients admitted to hospital with a new diagnosis of RF each year, a further 50 patients are hospitalised with recurrences of ARF and another 50 are admitted with an unexpected diagnosis of RHD (MOH, 2014b). 'Unexpected' hospitalisations for RHD occur when a young person or adult is admitted to hospital with a first diagnosis of RHD, having had no previous hospitalisation for RF, RHD or valvular heart disease (MOH, 2014b).

Despite the importance of RF as a significant public health concern in Aotearoa, there has, to date, been no published research that examines patient and whānau perspectives of RF, the secondary prevention pathway, the factors leading to the recurrence of RF or the events leading up to a new diagnosis of RHD. A recent qualitative, kaupapa Māori research project on whānau experiences of pathways through care for Māori children with ARF in Northland identified key areas for health system improvement, as well as suggestions to aid health literacy (Anderson et al., 2015). Another kaupapa Māori research project in South Auckland explored whānau experiences of RRF and found that current health care systems are not meeting the needs of the complex lives experienced by many whānau

(Burgess, 2016). The author provided a number of clear and pragmatic recommendations for improving health services and living conditions for whānau (Burgess, 2016). An Auckland study investigated Pacific peoples' understanding and knowledge of sore throats and RF (Naea et al., 2016). The findings from this research revealed low levels of understanding about the significance of sore throats and little awareness that RF was preventable (Naea et al., 2016). An unpublished Waikato DHB survey of 22 mainly Māori children with RF found that the children's understandings of why they needed to have injections was limited; the information provided to them was at too high a level and they felt confused; the children felt that they were 'not part of what was happening to them'; and they had a fear of dying and of not being cured (Liddle, 2011).

This research project was commissioned by the MOH to build on the findings of these studies from a national perspective and, specifically, to develop an understanding of the concerns and perceptions of children, young people and their whānau living with RRF, recurrent hospitalisations for RF and unexpected RHD.

Aims

The specific aim of this research was to investigate the lived experiences of Māori and Pacific people living with recurrences of RF and unexpected RHD and to use this information to improve health services and practices, thereby producing better health outcomes, for Māori and Pacific people in Aotearoa. To achieve this aim, the project specifically explored:

- how patients and their whānau understand RF/RHD and their perceptions of the consequences for their health and wellbeing
- their relationships, experiences and contact with the health services involved with RF/RHD care as well as what HCPs have communicated about the disease, their conditions and how appropriate health care can best be provided
- RF literacy among patients, their whānau and their HCPs
- whether health services have been responsive to the cultural needs of patients and whānau
- the events leading up to a diagnosis of RRF, recurrent hospitalisation or unexpected RHD
- how health services can be improved to better support patients who have had RF and require ongoing management and secondary prevention
- the identification of resources and approaches that could be used by the health sector to improve health literacy among RF patients and their whānau.

Methodology and research design

As our research was focused on Māori and Pacific whānau we undertook an innovative, collaborative qualitative research approach that applied a kaupapa Māori methodology along with talanga and kakala Pacific research methodologies.

Kaupapa Māori research

A kaupapa Māori methodological approach was undertaken to ensure that the research was relevant and of benefit to Māori. Kaupapa Māori methodologies prioritise Māori world views and place Māori at the centre of the research (Jones, 2012; Walker, Eketone, & Gibbs, 2006). As kaupapa Māori operates under a decolonising lens by simultaneously critiquing colonial structures of power and employing Māori epistemologies (Mahuika, 2008), it allows the research to operate within an empowering critical framework that avoids cultural deficit explanations (Smith, 1999). Kaupapa Māori research therefore acknowledges the validity and legitimacy of Māori, including the importance of Māori language and culture, of being connected to Māori philosophy and principles, of recognising the unique journey of each individual and of whānau, iwi and hapū. A kaupapa Māori approach is concerned with the struggle for Māori autonomy over Māori cultural wellbeing (Smith, 1999).

Pacific methodologies

Two complementary Pacific approaches were employed to engage with, effectively obtain interview narratives from and analyse data from Pacific peoples. The first approach used was talanga, an effective research method used when gathering Pacific people, sometimes in focus groups, to talk to each other. The method has been found to be particularly effective when identifying issues concerning people's health and wellbeing (Ofanoa, Percival, Huggard, & Buetow, 2015; Ofanoa & Raeburn, 2014). Talanga is a Tongan word for 'interactive talking with a purpose'. It incorporates talanga fakamatapule (talking together with respect), talanga feveitokai'aki (reciprocal/reciprocity—bringing stories and wisdom to share) and talanga mafana (inspiration—talking together to inspire one another) (Ofanoa et al., 2015; Vaioleti, 2016).

The second Pacific approach applied was kakala. This method uses the three stages of making a kakala (or Tongan garland) to show the different processes of undertaking research. This includes toli (data collection), tui (analysis) and luva (dissemination of the results). Kakala is useful for engaging Pacific peoples in research as it uses symbolic language to explain what is happening (Thaman, 1997). It respects Tongan and other Pacific cultures as its symbolism aligns with their world views and experiences.

Combining kaupapa Māori research methodologies with talanga and kakala methodologies therefore created the opportunity for Māori and Pacific participants and researchers to

engage with, theorise and produce knowledge that was meaningful to them and that centralised their world views.

To ensure that the influences of broader, non-Māori and non-Pacific contextual factors were also taken into consideration within this research project, the theoretical framework of political ecology was also employed. Political ecology combines historical and political economy and world-systems theory to analyse the production of inequalities in local contexts (Baer, 1996). The application of these theoretical frameworks ensured a guided, systematic and critical approach to data collection and analysis that was able to locate whānau experiences of illness and health care within broader social, economic, geographic and political contexts.

Consultation

A kaitiaki rōpū (cultural advisory group) was established early in the research development and consulted for advice about community engagement, recruitment processes, interview appropriateness, analysis and dissemination. The group comprised five kaumātua (Māori) and Pacific leaders. The research also received approval from the Tōmaiora research group, Te Kupenga Hauora Māori, at the University of Auckland. Community and/or stakeholder consultation hui (meetings) were held with DHBs involved in the research process. As recommended by Pihama (2012) for kaupapa Māori research, the study applied a kanohi ki te kanohi (face-to-face) approach when establishing networks and interacting and engaging with individuals and organisations.

Research sites

Data collection took place over seven DHB regions within the North Island of Aotearoa: Northland, Auckland, Waitematā, Counties Manukau, Waikato, Hutt Valley, and Capital and Coast. These DHB regions were selected by the MOH as they had high incidences of RF, provided a good rural/urban contrast and offered a range of health services.

Study population

The study population comprised children and adults under the age of 40 years who had been hospitalised in the study DHBs during the period spanning 2010 to 2014 with presumed:

- diagnoses of RRF
- clinical histories of recurrent hospitalisations (over a period of more than six months) for RF
- diagnoses of unexpected RHD.

Whānau¹ of these participants were also included in the study.

Participants were identified from the National Minimum Dataset (NMDS) by the MOH using the international classification of diseases (ICD) codes:

ICD-9

- ARF: 390, 391, 392
- RHD: 393, 394, 395, 396, 397, 398
- Valvular heart disease: 4240, 4241, 4242, 4243, 42490, 42491.

Or:

ICD-10

- ARF: I00, I01, I02
- RHD: I05, I06, I07, I08, I09
- Valvular heart disease: I34, I35, I36, I37, I38, I39.

Cases transferred to another hospital were included only once. There is no specific ICD code for recurrent RF or for unexpected RHD.

NMDS data were provided by the MOH to two clinical reviewers. Access to identifiable patient data, other than contact details, was limited to the clinical reviewers. At no stage did the researchers who were contacting and interviewing the patients have access to the patients' clinical information. The clinical researchers reviewed the clinical notes to identify cases of RRF and unexpected RHD. During this process, there was a significant number of cases in which a person had been readmitted to hospital and received a diagnosis of RF, but was not admitted with a recurrence. These were classified as recurrent hospitalisations with RF (RHRF). Reasons identified were subsequent hospitalisations for dental procedures or unrelated conditions and repeat admissions for assessment in the resolving phase of ARF. More information will be available from the audit commissioned by the MOH. As a significant number of the admissions thought to be RRF were in fact RHD, this group was added to the participant list. There were also many cases coded as RHD without prior RF, which, on clinical review, were new cases of ARF presenting with significant RHD. These issues arose as there were no ICD codes for RRF or for unexpected RHD and there were variations in coding across the DHBs.

The clinicians therefore divided the total list of hospitalisations into confirmed RRF, RHRF and unexpected RHD, and then subdivided each according to Māori and Pacific ethnicity,

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

age groups and different prophylaxis providers to ensure sampling across a range of affected children and young people.

Participants

Two main groups of people were identified to gain an understanding of the impact of Rf, RRF and RHD, their implications and the health system response:

- 1) Patients who self-identified as Māori and/or Pacific (including children, young people and adults) with RRF—or who had experienced RHRF and/or unexpected RHD from 2010 to 2014—and their whānau.
- 2) Health professionals involved in the care of patients with RRF and unexpected RHD.

Participant recruitment

After reviewing the hospital discharge data, the clinical reviewers contacted the study's recruiting research assistant (an experienced health community worker or kaiwhina) who contacted the patient and/or their whānau, provided them with information about the study and asked whether they would be interested in participating² (Stage 1 consent). If the individual was under 16 years of age, a legal guardian was contacted.

The researchers then contacted patients/whānau, discussed the project with them, provided them with participant information sheets and then, if patients/whānau chose to be included in the research, they were provided with consent forms to sign (Stage 2 consent).

Health care professional participants were identified using purposeful sampling from existing contacts in the health system (such as community nursing teams, clinical teams within the hospital and primary care teams). Health care professional participants were informed of the research via email and/or written letters and were invited to participate by contacting the principal investigators (Stage 1 consent). The principal investigators then contacted the health care professionals, provided them with participant information sheets and consent forms to sign (Stage 2 consent).

Data collection

Data were collected using kaupapa Māori and Pacific methodologies. All interviews (whānau, focus group and individual) were semi-structured and collected in-depth narrative accounts based around the following five themes:

² Two DHBs in the research project chose to use their secondary prophylaxis providers to undertake Stage 1 information provision rather than the nominated recruitment research assistant. The DHBs felt that their providers had a good rapport with the patients and that this would result in a better uptake of participants.

- 1) How patients and their whānau felt about their RRF/unexpected RHD and their perceptions of the consequences for their health and wellbeing.
- 2) The relationships, experiences and contact of patients and whānau with the health services involved with their care; whether these health services had been responsive to their cultural needs; and what the HCPs had communicated about the disease, the condition of the patients and how it could best be managed.
- 3) How health services could be improved to better support patients with RF who required ongoing management and secondary prevention.
- 4) Identification of information and approaches that could be used by the health sector to improve health literacy among RF patients and their whānau.
- 5) How broader political, economic, social and cultural dimensions influenced experiences, understandings and perceptions of RRF and unexpected RHD.

Interviews were facilitated by Māori and Pacific researchers. The interviews were audio recorded and observational; hand-written notes were also taken. To ensure that interviews were consistent with Māori and Pacific tikanga (customs/obligations), karakia (prayers) were offered before and after the interview and kai (food) and koha (food vouchers) were provided to participants.

Whānau interviews

Thirty-eight whānau interviews were undertaken with a total of 80 whānau members. The whānau interviews were guided by talanga, kakala and the key principles of the 'whānau tuatahi' research framework (Jones, 2010), including whakawhānaungatanga (rapport building), whakamana (empowerment), ngāwari (flexibility), utu (reciprocity) and hurihuringa (reflexivity). The interviews were purposive using a homogeneous sample (Ritchie & Lewis, 2003) in the sense that the research aimed to gain a detailed perspective of patients (and whānau) who had shared experiences of RRF and unexpected RHD.

For the whānau interviews, adults with RF or unexpected RHD (or the legal guardians of children under the age of 16) were able to select who was present at the interview and had the option of being interviewed alone if preferred (where individual interviews took place). Participants also chose where and when the interviews took place. Whānau interviews were usually between one and two hours in length and participants were given the choice of being interviewed in their first language.

Health care professional interviews

Interviews with HCPs were undertaken to collect in-depth narrative accounts of their perceptions and experiences of the diagnosis and treatment of RRF/unexpected RHD, their

relationships with patients and the factors influencing health care delivery, particularly secondary prophylaxis.

Nine one-on-one interviews were undertaken with HCPs who worked with children, young people or adults with RRF and/or unexpected RHD. These interviews took approximately 30 to 45 minutes and were conducted by phone or in person at venues of the participants' choice.

Six focus-group interviews were also undertaken with a total of 24 secondary prophylaxis providers (public health nurses/district nurses). Focus-group interviews involve in-depth group interviews with participants from a specific/purposive population (Rabiee, 2004)—in this case, those with experiences of providing secondary prophylaxis to patients with RF/RHD. The focus-group interviews took approximately one hour and were undertaken within DHB and clinical settings.

Data analysis

All qualitative data were transcribed verbatim and entered into an NVivo 10 software program. Data were thematically analysed using a general inductive approach (Thomas, 2003). This approach is used to develop meaningful thematic categories from raw qualitative data that are determined by both the research objectives and the repeated readings and interpretations of the data, and thus it has both deductive and inductive aspects (Thomas, 2003). This method of analysis is advantageous because it establishes 'clear links between the research objectives and the summary findings derived from the raw data and ensures these links are both transparent (able to demonstrate to others) and defensible (justifiable given the objectives of the research)' (Thomas, 2003, p. 2). Independent coding and coding consistency checks were undertaken by four Māori and Pacific researchers to ensure the trustworthiness of the analysis. Emerging themes identified from these coding sessions were also discussed with the rōpū kaitiaki to ensure robust cultural interpretations of the narratives as well as alignment with kaupapa Māori and Pacific methodologies.

Ethics and locality approvals

Ethics approval was received from the Health and Disability Ethics Committee in November 2015 (15/NTB/185). Locality approvals were also received from each of the seven district health boards involved in the research and the required Māori review approvals were sought from Northland DHB, Counties Manukau Health, Auckland DHB, Waitematā DHB and Capital and Coast DHB.

Dissemination

Key findings and recommendations from the research were disseminated back to whānau participants, the community and HCP stakeholders through oral community presentations



in each DHB. In addition, summary documents in English (Appendix A), Tongan (Appendix B) and Samoan (Appendix C) were provided to whānau participants.

Results

Participants

There was a total of 113 participants in the study (see Table 1). Pseudonyms have been used for all participants in this report. Any potentially identifying features such as home towns, schools and—for non-HCPs—occupations have also been changed or omitted to ensure the confidentiality of participants.

Table 1. Research participants by DHB area

DHB	Māori	Pacific	Health Care Professionals	Total
Northland	8	0	17	25
Waitematā	1	1	0	2
Auckland	2	15	0	17
Counties Manukau	17	22	8	47
Waikato	7	0	5	12
Capital & Coast	5	1	3	9
Hutt Valley	1	0	0	1
Total	41	39	33	113

Whānau participants

Whānau interviews ranged from one to eight whānau members and included 57 women and 23 men (see Table 2). Thirty-eight of the participants self-identified their ethnicity as ‘Pacific’ including: Cook Island Māori, Fijian, Samoan and Tongan. Forty participants identified their ethnicity as Māori.³ There were no Pacific participants included from Northland, Waikato or Hutt Valley DHB regions as a result of non-consent and lower numbers of Pacific people with RRF, RHD or RHRF in these regions.

Of the participants with RRF, RHRF and RHD, 20 had RRF, four had RHRF, and 16 had unexpected RHD. The ages of the participants with RRF ranged from 11 to 40 years and from 7 to 40 years for those with unexpected RHD.

³ Seven participants identified themselves as both Māori and Pacific. The ethnicity of these participants was recorded as ‘Māori’, as a prioritised output for ethnicity data collection (Ministry of Health, 2004) was utilised for this study.

Table 2. Whānau participants

DHB	Whānau	Pseudonym*	Sex	Ethnicity	Age**	RF status***
Northland	1	Mataī	M	Māori	Youth	RRF
		Aohanga	F	Māori	Adult	
	2	Tāpoto	F	Māori	Youth	RHRF
		Waihīrere	F	Māori	Adult	
		Paretaniwha	F	Māori	Adult	
		Pōtaka	F	Māori	Adult	
		Whakaari	F	Māori	Adult	
Tōtara	M	Māori	Adult			
Waitematā	3	Kakala	F	Tongan	Youth	RHD
	4	Rimu	M	Māori	Child	RRF
Auckland	5	Losa	F	Samoan	Adult	RRF
		Futu	F	Samoan	Adult	
	6	Mamala	F	Samoan	Child	RRF
	7	Ruawai	F	Māori	Adult	RHD
	8	Dovedove	F	Fijian	Child	RHRF
		Senimakosoi	F	Fijian	Adult	
		Doinisau	M	Fijian	Adult	
	9	Tiare	F	Cook Island	Adult	RHRF
	10	‘O’a	M	Samoan	Child	RHD
		Ateate	F	Samoan	Adult	
		Aoa	M	Samoan	Adult	
	11	Si	M	Tongan	Child	RHD
		Heilala	F	Tongan	Adult	
	12	Rangiwaho	F	Māori	Youth	RHD
13	Siale	F	Tongan	Child	RHD	
	Pua	F	Tongan	Adult		
14	Fetau	M	Samoan	Adult	RHD	
Counties Manukau	15	Langakali	F	Tongan	Youth	RRF
		Paini	M	Tongan	Adult	
		Fā	F	Tongan	Adult	
		Niu	M	Tongan	Adult	RRF
		Pipi	F	Tongan	Adult	
		Tava	M	Tongan	Youth	
		Pako	F	Tongan	Adult	
	Maile	F	Tongan	Adult		
	16	Miare	F	Cook Island	Adult	RRF
		Ngatae	F	Cook Island	Adult	
	17	Miro	M	Māori	Adult	RRF
		Taeore	F	Māori	Adult	
		Kauri	M	Māori	Adult	

DHB	Whānau	Pseudonym*	Sex	Ethnicity	Age**	RF status***	
	18	Fau	F	Samoan	Adult	RRF	
	19	Toatoa	M	Māori	Adult	RRF	
		Wharariki	F	Māori	Adult		
		Tānekaha	M	Māori	Adult		
		Akerautangi	M	Māori	Adult		
	20	Maire	M	Māori	Youth	RRF	
	21	Aloalo	F	Samoan	Child	RHD	
		Niu	M	Samoan	Adult		
		Teuila	F	Samoan	Adult		
	22	Pua Fiti	F	Samoan	Youth	RHD	
		Aloe	F	Samoan	Adult		
	23	Lole	F	Tongan	Child	RHD	
		Lose	F	Tongan	Adult		
		Fekika	F	Tongan	Adult		
	24	Sune	F	Samoan	Adult	RHD	
	25	Kahikatea	M	Māori	Child	RHD	
		Te Tātua	F	Māori	Adult		
	26	Wharawhara	F	Māori	Adult	RHD	
		Wharariki	F	Māori	Adult		
	27	Lau Ki	F	Samoan	Adult	RHD	
	28	Nikau	M	Māori	Child	RRF	
	29	Tiale	F	Samoan	Child	RHRF	
	30	Hūhiroa	F	Māori	Adult	RRF	
		Kōrari	F	Māori	Adult	RRF	
	31	Mamaku	M	Māori	Adult	RRF	
		Kawakawa	F	Māori	Adult		
	Waikato	32	Horokaka	F	Māori	Adult	RHD
			Kiekie	F	Māori	Adult	
			Akakura	F	Māori	Adult	
		33	Raupo	F	Māori	Youth	RRF
		34	Pōhuehue	F	Māori	Adult	RRF
Pingao			F	Māori	Adult		
Patē	F		Māori	Adult			
Capital & Coast	35	Toetoe	M	Māori	Adult	RRF	
	36	A'atasi	F	Samoan	Youth	RRF	
	37	Panakenake	F	Māori	Child	RHD	
		Hangehange	F	Māori	Adult		
		Kanuka	M	Māori	Adult		
	kōhia	F	Māori	Adult			
Hutt Valley	38	Akatea	F	Māori	Adult	RRF	

*Pseudonyms were employed for all participants. Māori and Pacific participants were given pseudonyms of flowers (for women) and trees (for men). HCPs were allocated names randomly by researchers.



***Age was aggregated into three groups: child: 0–14 years of age; young adult: 16–18 years of age; adult: > 19 years of age.*

****RRF = recurrent rheumatic fever; RHRF = recurrent hospitalisation for rheumatic fever; RHD = rheumatic heart disease.*

Many of the whānau in this study experienced complex lives that included living in relatively deprived environments, being highly mobile and remaining exposed to unstable and unhealthy housing conditions. These living contexts significantly influenced their experiences of pathways through health care, from the onset of symptoms to the diagnoses and management of their health conditions. The following sections will provide descriptions of the key thematic findings presented under the subheadings: ‘Experiences of diagnoses and the treatment and management of RRF/RHD’; ‘Health care services’; ‘The effectiveness of information, communication and education’; ‘Understandings of RRF and RHD’; and ‘Impacts of RRF and unexpected RHD’.

Health care participants

Nine individual interviews and six focus-group interviews were undertaken with 33 health care professionals, including three general practitioners (GPs), one paediatrician, three cardiologists, one practice nurse manager, one midwife and 24 secondary prophylaxis providers (public health nurses and district nurses). There were no HCP participants included from the Waitematā, Auckland or Hutt Valley DHB regions as a consequence of non-consent.

Experiences of diagnoses and the treatment and management of RRF/RHD

The whānau had varied experiences of the diagnoses, treatment and management of their ARF/RRF/RHD. Twelve patients in this study experienced missed or delayed diagnoses of their GAS infections or ARF symptoms. They explained that their symptoms were attributed to viral (throat and chest) infections, pneumonia, asthma, myalgia, dermatological conditions, fractured bones, strained muscles and rheumatoid arthritis. Difficulties in the diagnosis of ARF resulting in recurrent hospitalisations were particularly common for patients with Sydenham chorea. Participants reported that misdiagnosis occurred even when they (and whānau members) suspected they had ARF and informed their GPs of their concerns. For example, Akatea, a Māori woman in her thirties, sought medical attention from her GP when she suspected she was suffering from a recurrent episode of RF but was informed that this was unlikely given that she was ‘white’ and ‘an adult’.

Another participant, Aohanga, took her son Mataī to a primary care clinic three different times when she suspected he had ARF. Both Aohanga and her eldest son had suffered from ARF, so she was familiar with the symptoms. However, as she explains below, her youngest son, Mataī, was misdiagnosed with rheumatoid arthritis at each primary care visit:

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, 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 his brother 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 [RRF].

Diagnoses of initial ARF and RRF were often made in secondary care contexts when patients were referred to hospital for their symptoms. Previously unrecognised RHD was suspected when heart murmurs were detected at antenatal checks or when patients were admitted to hospital for other illnesses (such as kidney infections).

Lack of awareness of RF by family doctors and non-adherence to sore-throat guidelines were commonly cited by both whānau and HCP participants as key factors leading to misdiagnosis and to the development of ARF from GAS infections. Lachlan, a GP stated:

If you're not aware [of RF] then you don't think about that and obviously miss it ... I think it's particularly a problem for doctors from Europe where they see sore throats; sore throats are seen as a minor problem. And there's a big move away from treating them at all and run[ning] a swab, which is, um, completely different from what we do.

Limited knowledge of RF and poor utilisation of sore-throat guidelines were compounded by the difficulty health care professionals faced in maintaining vigilance for RF, which is a relatively rare occurrence for GPs, even in regions with proportionally high rates. It is even more problematic in regions where the prevalence of ARF is lower.

Mismatch between health services and whānau contexts

Many of the difficulties participants described in relation to the management of their RRF/RHD resulted from a mismatch between health services and whānau in terms of age, ethnicity, complexity of life, values and needs. It was evident from whānau narratives that even cost-free services that provided treatment to patients at their homes or at their places of employment were based on assumptions that whānau had stable home and employment contexts. Yet, as seen with the whānau in this research, this assumption was not a reality for many participants who moved homes often or for those who were homeless. The following narrative by Ateate illustrates these difficulties and highlights that for whānau facing such complexities, health is often not as important a priority as finding shelter and being able to *'function as a parent'*:

Families who are living in cars are getting looked down on because of that; that is why: because you do not get the help ... You have all these other issues going on that make you barely able to function as a parent or a person ... I was like 'dude, I just had a baby and he's only six weeks old, my oldest son has just come out of surgery and is still really sick with rheumatic fever and I've got two toddlers and a partner but we haven't had enough time to find a house, you try finding one ... who can find a house in Auckland to rent'?

Accessibility of health care for participants with RRF/RHD and their whānau was often reliant on the flexibility available within their health services. Whānau discussed employment commitments, childcare, family and social obligations, and availability of transport as factors that prevented them from accessing clinic-based health care appointments during working hours. In contrast, services that allowed flexibility in the timing and location of treatment were often able to counter such access barriers for whānau, as explained by Kendall, a secondary prophylaxis provider:

I had a school leaver who's a contractor for an outside occupation company. He can start at 6.00 [o'clock] in the morning and get home at 9.00 [o'clock] at night, and so we're [public health nurses] very innovative about when and how we can get his bicillin done. And often it's at 7.00 [o'clock] in the morning. He'll come in his work gears before he starts his work or, um, we have to, um, if he happens to be at home in the weekend, so I will do him there ... Because the fact of finding him in the middle of rural Aotearoa in between the hours of 8.00 and 4.30 are absolutely non-existent.

Racism

In addition to structural aspects of health systems, whānau described how personally mediated racism and a lack of cultural safety were factors that negatively influenced their treatment and clinical experiences. Racist encounters, particularly within hospital contexts, were experienced by many whānau in the study. Participants were subjected to verbal racism—such as being called 'coconuts'—and to being treated differently by HCPs because of their socially assigned ethnicity, as described by Miro:

Miro: because I was brown and she [hospital nurse] was like white, from day one when I just went in there and met her, I could just feel that she had problems with me, just from looking at me ... I just think they don't care about us, that's all I think, just, they don't care about Māoris [sic], because when I see them with Pākehā they're all right.

Researcher: They're all right?

Miro: [the health professionals would] have a laugh [with the Pākehā patients], but as soon as they come back to me, but as soon as they come back to me, their faces change and everything, so I just put it down to racism, they don't like Māoris, they don't like brown people.

Racism directed towards Māori and Pacific whānau was also acknowledged and discussed by HCPs in the research, as is evident in the following narrative by Caden, a hospital-based paediatrician:

Caden: ... the institutionalised racism that is served up in many health care services in and around New Zealand still.

Researcher: And is that something you've witnessed yourself or you've experienced yourself, within the system?

Caden: Oh, look, I think you have to be deaf, daft and blind not to spot it on a regular basis in our particular hospitals. It's all around us I'm afraid; it's rather endemic, that's very sad.

In addition to racism, whānau described how the lack of cultural safety of some HCPs created negative health care experiences. Examples provided by participants included nurses touching the heads of Māori patients without their permission⁴ and male doctors asking young Pacific girls to expose their bare chests for medical examinations. Participants explained how such experiences left them feeling scared, vulnerable and disrespected in the sense that their social values and sense of security had been compromised. Lack of cultural safety was also experienced by whānau during home-based RRF management. Losa, an adult Samoan woman, spoke of her discomfort when she had to receive her bicillin injections from a male nurse:

It was in the beginning, it was really uncomfortable because, being Samoan, you have that culture thing of you know, shame and stuff. Like, I will only be comfortable if my husband is there or with me [when receiving the injections]. Or if it's a lady nurse that's doing it. But recently, I've had a male nurse do it and with my husband not here, it's, it's ... In the beginning, he came with a lady nurse, so I was like 'oh nah that's [okay]'. But recently he came by himself, and it's like, it's, I don't, it's getting to be more uncomfortable because they should inform you first: 'Losa we've got, um, a male nurse coming'. And you should have the option of saying 'no, I'm not comfortable with that'. Like any doctor visits, it has clearly, it states clearly you know, if you're not comfortable with, um, if you want someone in, a support person when you're getting checked you know please say so, but in this case, I was not informed, I was not given the choice if it's a male or a female. But yeah, culture wise, it's funny because you know Samoan, and I'm sure Tongans [sic] is the same, yeah, it's, um, it's disrespectful.

Additional adverse experiences of care reported by whānau included feeling dehumanised and receiving rough handling, as Siale stated:

⁴ Heads are deemed to be tapu or sacred for Māori and should not be touched or examined without appropriate tikanga (custom/protocol) (Mauri Ora Associates for the Medical Council of New Zealand, 2008).

I think they [health care professionals] become desensitised and they forget that we're human and we're not just a heart for you to fix, we've actually got feelings and we know aye.

Whānau also reported being subjected to rough and inappropriate care from their health care professionals that often left them feeling bruised and in pain, as described by Miro:

Instead of asking where it's sore, you know, they just poke around and squeeze things, and obviously if they see it's swollen, why would you go and squeeze?

Whānau explained that, while in hospital, they often received 'rough treatment' during their check-ups, when being washed or showered and when being given quick, painful bicillin injections or, as Langakali described, 'jab and go' injections. Taeore, a caregiver of Miro, was particularly concerned that bicillin was being delivered into Miro's buttock while he was asleep:

Miro: Yeah, they used to do [it] a lot [deliver bicillin injections] in my sleep. Yeah, while I'm sleeping. Whack around—well, if I move, does that mean it's sore? Instead of waking me up ... they used to do it while I was sleeping.

Taeore: Just so he wouldn't wake up and be, so every time they'd touch him, he'd be asleep.

As with Taeore, other whānau described how difficult it was to witness mistreatment of their children. Kōrari stated, 'In the shower, oh my goodness. If you know the child is sore and in pain, you don't be rough for them'. Kōrari was so concerned about the rough treatment that her daughter Hūhira was experiencing that she decided to stay in the hospital with Hūhira and tend to her care and personal hygiene herself to avoid further mistreatment.

Working with adolescents

The delivery of RRF and RHD treatment and management also highlighted problems with the provision of appropriate care for adolescents and young adults.

Both the whānau and HCPs recognised a gap in age-appropriate care in the current health models and services. Whānau discussed the difficulties they experienced in trying to support their teenagers through the mood swings, 'bitchiness' and social pressures associated with adolescence, as well as having to cope with their serious health conditions. These narratives were mirrored by young RRF/RHD patients who described how difficult this stage of life was for them and how it influenced their attitudes towards their health conditions and treatment. Langakali explained that she stopped taking her bicillin regularly and then went on to develop RRF; she attributed her non-adherence to 'that phase' of adolescence:

Yeah I had a relapse a few years ago. Ummmm, that wasn't so good. I couldn't walk. I didn't know why. Ummmm, but yeah, it was because I wasn't taking my injections and stuff. I was just being silly. They [the district nurses] will all give me a call and be like, 'okay you're finishing school this year, what's the plan for next year in the future?' And I was like, 'I don't know, I don't know what I'm going to do'. I'm thinking about the school ball and you're calling me now! I just started thinking silly and didn't care about my condition ... I think it was because at that time I was struggling with my parents you know, when you go through that phase where you think you know everything? That was me. I was like, 'I know my shit'.

One of the key themes to emerge from this research was the challenges that HCPs experienced when working with teenage and young adult patients. Health care professionals discussed the difficulties they experienced with engagement and rapport building with youth as well as trying to convey RF/RRF/RHD health literacy to their young clients. Many of the secondary prophylaxis providers found that while their patients were still at school their RRF/RHD was easier to manage as they were a 'captive audience'. The exceptions were clients who were not always at school (or clients who would run away if they knew they were due for their bicillin injections). However, generally, HCPs mostly struggled with young adults, whom they sought to empower to take care of their own health, but whom they often still had to treat like children to ensure that they were receiving regular bicillin injections—as described by Carly, a secondary prophylaxis provider:

They're [young adult patients] not that compliant as adults either. So, they're reliant on us to chase them around, track them down, practically tackle them on the spot. You know and that sometimes you can sit there and go 'nah, come on, you are an adult'.

Many of the HCPs attributed such difficulties in the treatment and management of RRF/RHD of youth to their senses of invincibility or 'bravado', as explained by Michael, a cardiologist:

I think rapport with, ah, late teenagers is always a challenge. It can be very difficult and trying, and even into late adult life, twenties and thirties. I think rapport is not so bad when you get into their teenage years, once you get them there. I think it's the difficulty in getting them to understand they need to be seen more. It's that sense of bravado that there's nothing wrong with me. That I'm going to be fine and that there's no need to have those heart check-ups.

Many of the HCPs, particularly secondary prophylaxis providers, felt that having specific, youth-targeted training and resources would help them with the treatment and

management of their adolescent and young adult patients, as stated by Hinenui, a secondary prophylaxis provider:

I think one of the biggest things we need is better resources; we should get good patient resources. It's so hard to get good patient resources and teenage ones, you know ones for teenagers to relate to, um, just on such, I mean, you know, health care; the Heart Foundation has the resources but they're not actually aimed so much for, um, teenage [sic], you know?

Pain of injections

Whānau reported that embarrassment and the physical pain of having bicillin injections were other barriers to the management of RRF/RHD. Almost every RRF/RHD participant in the study found the physical pain of the injections difficult to cope with, not only at the time of delivery, but also in terms of the muscle pain that lasted up to a week following the injection. Participants described how the painful injections elicited feelings of fear and dread about having to continue having them; as described by Miare: *'we have to get monthly injections and those are really, really sore. Like, is there any way we can make it not so sore and scary'*? Pua Fiti also described how the pain of the injections proved to be a key barrier to her adherence: *'I always dreaded injections; I'd be like, "Nah, NAH!"'*

Three secondary prophylaxis providers in the study discussed how they believed that an alternative delivery of bicillin would be beneficial for reducing their patients' exposures to the pain and embarrassment of current injections. Their suggestions included developing a slow-release, long-acting secondary prophylaxis source that operated in a similar way to Depo-Provera or nicotine patches.

Whānau also described how the delivery technique of injections influenced their pain. Most RRF/RHD participants preferred their injections to be delivered slowly and into a specific area of their buttock. Lau Ki, an adult woman with RHD, chose to self-deliver her injections to ensure that they *'hit the right spot'* and were delivered slowly. Another participant, Miare, got her husband to deliver her injections for the same reasons. Almost all of the participants who were offered numbing agents such as lignocaine⁵ found it to be helpful in reducing the pain of the injections. Others, such as Langakali, found the use of buzzy bee vibrating ice packs to be key facilitators of their bicillin injections:

Langakali: the hardest thing for me was getting my injections. I HATED them. They had to give me numbing cream, but ...

Researcher: Did that help?

⁵ Not all secondary prophylaxis providers or DHBs offered lignocaine to their patients.

Langakali: Nope! I don't know what, but that did not help. So my first experience with the injections that was the worst experience; I got it in my thigh, and I just screamed the ward down, oh it was so bad, so I dreaded the next month ... and then it started getting okay because we tried different spots, so, yep, so I found out that the buttock, like, above here [points to spot on buttock], like, that was less painful, but nowadays they have the buzzy bee. And they, I LOVE that, I'm going, like, I'm 30 years old and I still ask for that.

Whānau support

Many RRF/RHD participants described how their whānau facilitated their RRF/RHD experiences through the provision of emotional support and encouragement in persisting with their treatment and coping with their illnesses. Whānau also assisted with material resources, such as transport, costs of living and childcare, as Fetau stated:

I think it was me and my wife that ... really stand[ing] strong together, and supporting one another and that was actually the main thing that kept us, and [a] positive attitude and courage to face and cope with it, with the health issue.

Whānau support and advocacy was also instrumental in helping to buffer the difficulties that RF/RRF/RHD patients experienced during hospital stays. Several mothers and other whānau members chose to stay in hospital with their children to ensure that they were well cared for (as described by Kōrari above on page 17). These mothers often became advocates, not only for their own children, but also for other children staying in the hospital. They would offer other whānau advice about their children's ARF/RRF/RHD, and about aid with feeding and caring for the children and would actively deter negative treatment of the children, as described by Aohanga:

I think I was about the only parent that was in our room all the time with our kids [her son Mataī and the other children staying on the ward] and, yeah, there was one nurse, she was shocking sometimes, the kids would get scared of her and even Mataī did, and one night I just got sick of it 'cause when I saw Mataī acting like he was asleep because he was scared, I got, you know, I just got sick of it and we ended up having an argument about it because I feel, you know, when the kids are sick and they're in hospital the nurses and that are supposed to make them feel safe.

Rapport with health care professionals

From whānau narratives, it was evident that the relationships between whānau and their HCPs were pivotal to their experiences of RRF/RHD and had significant influences on the diagnosis, treatment and management of RRF/RHD. Whānau described how having a good rapport with HCPs promoted an understanding of RRF/RHD, fostered communication, trust and respect, and facilitated adherence to the treatment and management of RRF/RHD.

Whānau valued HCPs who were non-judgemental and friendly and who were able to ‘have a laugh’ with them. When HCPs formed relationships with the whānau of patients rather than just with the patients themselves, the whānau found that they were able to become more involved and supportive of the management of the RRF/RHD of their family members. Patients also expressed that they felt more comfortable when they were treated as part of a whānau and found that they were better able to establish connections and an understanding with their HCPs. Some whānau described their HCPs as ‘part of the family’. Fau explained that the ‘genuine’ connection between her secondary prophylaxis provider and her whānau facilitated her RRF experience:

My mother and my nurse had some kind of connection, whatever ... My nurse was nice, yeah, she helped out our family. She did her job, but, I don’t know, just something about her. It just felt meaningful ... It was out of love, yeah. It’s just genuine. It’s not like fake, in and out, done. She was cool.

Ethnic concordance between whānau and their HCPs was also perceived by participants to develop better rapport, empathy, trust and communication as a result of shared cultural understandings and language, as expressed by Kakala:

If I had a Pacific doctor, I would feel more comfortable talking to a Poly [sic] doctor than to other doctors [of an] other nationality ... if I was [to] talk to a Pacific Islander I would be more likely to express how I feel, I guess. I wouldn’t be scared.

As well as facilitating communication and understanding, cultural concordance countered the racism experienced by whānau in the health sector, as illustrated by Fā’s narrative:

Fā: They [the hospital health care providers] show us the [RF] paper, the pamphlet, how the disease—and one of the doctor[s], Doctor X, the Tongan doctor came and he told us in Tongan ‘that’s mofi hui (rheumatic fever)’ ... He was came to [see] another person and he just came, [he] walk[ed] pas[t me], he saw the name, [my] Tongan name, and he just came to the room and he asked me why we [were] there and I tell him, explain what’s happen[ed] and he explain [ed it] to me in Tongan.

Researcher: So it was more understandable for you when Doctor X came?

Fā: yeah, I can understand a little bit, but when he came and told me in Tonga[n] it [was] more understanding about the disease ... They [the hospital health care professionals] are being racist sometimes to be honest when you go to the doctor. If the doctor [is a] Tongan doctor, he look at us Tongan [people], we come first, but I go there [to see] a Palangi (Pākehā) doctor, he look down at me, I’m a brown people, he look at the Palangi man before me, I think they [are] racist sometime[s].

Health care services

Access

Financial pressures associated with the complex living contexts of many whānau created barriers to accessing both primary and secondary health care services for their RRF and RHD. Common barriers were securing transport and meeting the costs of health care and medical prescription fees, as described by Miro:

I have no car half the time, so I have to wait for somebody to come along and drop me off at the hospital, and the buses, there's a bus station over here, but on certain days, I had no money to get over there, but I had food.

Other barriers to accessing health care included limited appointment availability, lack of trust in HCPs, whānau and work commitments and geographic barriers to health services. Barriers to accessing primary health care resulted in delayed diagnoses of initial ARF episodes and recurrences of RF. Barriers to health care also occurred for RRF/RHD patients who received secondary prophylaxis from busy, urban RF clinics and GP services who provided secondary prophylaxis. Urban RF clinic patients described often experiencing long waiting times for secondary care RF or cardiology clinics. Difficulties resulting from waiting times and the large numbers of patients within the clinics were also discussed by HCPs, as Maude and Lisa, two secondary prophylaxis providers, explained:

Lisa: I think one of the really big things is not going to clinic appointments as well ... on whether that's due to transport or things like that, but they [patients] don't realise that when they miss out on the clinic appointments, that they're not going to get another one for three to four months as well. That's why we like tend to look up on the system to see when their next one is, so we can keep talking to them about it and things, but, yeah.

Researcher: So if they miss that clinic, are they followed up after that or is there a lag before the next?

Maude: There is a lag, yeah 'cause it's such a waiting list for it, you know, and especially things for, like, the echoes on their heart, and it's only the rheumatic fever kids who have that. It's a big waiting list.

Monitoring and patient management

Current secondary prophylaxis monitoring and recall systems (or lack of systems) contributed to RRF for whānau in this study in several ways. They caused delays in receiving bicillin and resulted in patients being lost in the system. These difficulties were described by Malakai, a GP who worked in a primary care clinic that provided secondary prophylaxis for patients: *'That is the problem with the Med-Tech [the patient-management system used*

by the primary care clinic] or any network ... you know, in the end they [the patients] become lost and people get missed [for bicillin injections]’.

It was evident from the whānau and HCP participants in this study that DHB primary community services that deliver secondary prophylaxis also experienced difficulties with their patient-management systems. These difficulties at times resulted in missed bicillin injections for patients. Three different whānau in this study discussed times when their secondary prophylaxis providers had missed or ‘*forgotten*’ to come and give their family members bicillin injections when they were required, as Fetau stated:

I don’t know why she [the district nurse] couldn’t call me: ‘Fetau can we reschedule because, um, I forgot; I knew I was coming to do your injection, but I don’t have the injection on me’. I was, like, okay, here I am, I’m trying to be on top of my injection, and here you are saying you forget.

Some of the secondary prophylaxis providers explained how they still had to rely on ‘*paper notes*’ to monitor their patients’ health and maintenance of regular bicillin injections. Paddy, Waitarehu and Charlene, three secondary prophylaxis providers, described how their patient-management systems affected their ability to manage their patients with RF/RRF/RHD:

Paddy: And the other thing in our DHB is that we still got silos of notes, you know, we still have paper notes, it’s, it’s just a nightmare. With all the technology in the world there are silos of notes, and I counted up, one of my patients actually had seven lots of separate notes within the same organisation. And yeah and one of the, that’s just the bane of my life ...

Waitarehu: It’s just horrendous.

Paddy: ... the fact that we’re not electronic and that, and that ... and the reality is it’s really, it is a huge barrier if a client, if a client goes to, say, another clinic (to receive their bicillin), there’s ... no way that they can pull up their notes to know what work has been done with that client.

Charlene: And that’s a big gap, a huge gap.

Difficulties tracking patients who travelled within and between DHB areas led to recurrences of RF. High levels of mobility were common for whānau who tended to travel and move homes often because of social and family arrangements, seeking employment and education opportunities, as a consequence of economic insecurity and to meet housing needs. Whānau moved within and between the DHB regions in Aotearoa and, Pacific participants, in particular, moved to and from the Pacific islands. Two participants in the study had been homeless for extended periods of time after being diagnosed with ARF. Their whānau described how their unstable housing contexts and moving between

DHB regions created barriers for them when seeking to access health services and led to disruptions in the treatment, monitoring and management of their conditions, as was evident from Toatoa's narrative: *'I wasn't taking [bicillin], because I was like in and out, I was in foster homes and stuff. So I wasn't really stable ... And then, once I got back into a stable place, then I went back onto it'*.

The following narrative from Losa also highlights that barriers to health care, a lack of established transition processes between secondary prophylaxis providers and a lack of information from HCPs promoted missed bicillin injections. These barriers occurred even though Losa had a history of treatment adherence and actively sought help from her HCPs:

I had, um, my injections regularly, every month; I don't want to miss it, until 2014, when I started missing them because we moved out this way. I was getting my home visits when we were in this urban suburb, so the district nurse would come and do my injections at home, but, because we moved out here, I didn't know where to go. Um, I'll go to my GP but they said I would have to go to another place to get them done. So I didn't know any information on how I can ... transfer it here to get the home visits. And that was a huge thing, because we have the one car and I had, I couldn't get to my appointments.

Like Toatoa and Losa, many of the whānau in the study spoke of missing or discontinuing their bicillin injections when they moved from their homes or travelled. These narratives were mirrored by both secondary prophylaxis providers and GPs, who found it difficult at times to manage secondary prophylaxis provision to patients who moved from their clinics/services/DHBs. Prophylaxis providers explained that, if they were made aware of their patients moving from their service and were able to establish contacts and a good relationship with the providers in the area to which the patients had moved, then transfers could be managed well. However, when providers were not aware that their patients had moved and/or they did not have any contacts with prophylaxis providers in their patients' new locations, some patients were lost to follow-up care. Such a scenario was described by Ameila, a secondary prophylaxis provider:

But some of the DHBs, like down in, I think Christchurch and, is it, Taupo? Somewhere down there, they have to have it [bicillin injections] at their GP, so that's a big problem because we don't know what GP they're at. So ... if they [the patients] don't let us know, we can't transfer all the information down there.

Difficulties in managing secondary prophylaxis provision also occurred for patients when they transferred from paediatric-to-adult services in some DHBs. Whānau spoke about the difficulties they experienced when they left school and their secondary prophylaxis providers no longer came to their homes (or schools) to give them their medication. The key concerns whānau experienced were discontinuity of care with providers with whom

they had built up rapport and access barriers, such as transport and cost difficulties, as explained by Langakali: *'When they [the district nurses] stopped coming around and I had to go to the medical centre it [the bicillin injection] costs \$15 dollars so I had to stop [having the bicillin]'*. Secondary prophylaxis providers also identified paediatric-to-adult service transfers as problematic, as stated by Mata, a secondary prophylaxis provider: *'the transition from being under paediatric care to under adult care can be very fraught, I think'*. HCPs described how young patients had been lost to follow-up and were at risk of developing recurrences of RF through the lack of youth-appropriate transition services.

Almost all the HCPs interviewed in this study felt that a national secondary prophylaxis-management system for RF patients would help to prevent patients being lost to follow-up and progressing to RRF as a consequence of poor recall systems and transferences. As discussed by Amanda, a clinical nurse manager:

having a national [RF] register I think is a really important tool to mitigate a non-risk of recurrences amongst transferring patients to lower risk. We think we are doing really well, we [have] got really good relationships with two regional DHBs, which are the key areas in which our patients transfer. But even in those best-case scenarios, from time to time we do miss patients and they do miss a dose, if not more, if we are not checking and that is under really intense follow-up, and we know that there are a lot of patients throughout the country that don't have these kinds of systems and processes that a national register would just completely cut through and make easier and better and reduce the risk of recurrence for rheumatic fever.

Benzathine penicillin delivery

Secondary prophylaxis was via long-acting penicillin (bicillin) injections every 28 days for most participants and via daily oral medication for two participants (with allergies to penicillin). Unavailability, discontinuation and allergic reactions to benzathine penicillin were also factors that led to RRF for participants in the study.

Past interruptions in the supply of benzathine penicillin led to RRF for Toetoe, a participant in the study, as he explained: *'back then, they [the secondary prophylaxis providers] were trying a new injection or something [because of the unavailability of benzathine penicillin] and ... it didn't work and that's why I had a relapse'*.

Two participants in the study experienced recurrent episodes of RF, despite having completed 10 years of secondary prophylaxis. Both participants were adult women and experienced their RRF episodes approximately five and seven years respectively after completing their initial 10-year course of bicillin. One of these women had young children who had experienced sore throats. The other participant was often in contact with young children before her recurrence.

One participant, Futu⁶, suspected that the timing of her daughter Mamala's injections caused her daughter's RRF:

I think about a year after she [Mamala] had the surgery she relapsed and they found out [that] the medicine dosage, by the time she had gone onto the next injection, the medicine had already worn off her. Yeah, so that's what we found out, she had relapsed ... they realised for Mamala it's not gonna work having the monthly [28 day] injections because once the month comes it [the bicillin] has already worn off her body.

Interactions between health services

Whānau and HCPs described RRF/RHD services as 'fragmented' as a consequence of siloed services and poor communication between services. However, considerable variation within and between services was described by participants. For example, in some RF clinics, HCPs described good communication and information sharing as occurring between RF clinicians and secondary prophylaxis providers, but not cardiologists. In contrast, most GPs and community-based secondary prophylaxis providers found that there was very little information sharing between their services. Similarly, Caden, a paediatrician, described gaps in communication between paediatricians, adult cardiology services, and DHB community secondary prophylaxis providers:

When you're maybe looking at guys in their early twenties, they may have seen a cardiologist and they may be due to have a repeat echocardiogram to monitor the heart valve. So, I might not be quite sure how well that gets followed up. I know, I see sometimes it's a problem in the prison, where my guys have not been attending follow-up appointments. Um, the other key [group of] people is the public health nurses who obviously administer the prophylactic antibiotics in the community. So those are key people and, although I don't liaise with them a lot, I understand they are passionate that their young people get their antibiotics on time with their injections ... But I can't say I have a lot of direct contact myself with the public health nurses.

Health care professionals were also aware of how the gaps in the current RRF/RHD services and a lack of clear communication between the services could affect the care that was provided to whānau as expressed by Lleuarn, a GP:

⁶ Clinical note: The above clinical scenario for Mamala is unusual: The majority of recurrences occur as a result of missed doses on the 28-day regime of bicillin. A small number of people require bicillin every 21 days as they metabolise bicillin faster than usual (as in Mamala's case).

So there's a lot of places where things can be overlooked. How much interaction do you have with other recurrent providers? Oh, look, very, very little. And, once more, when they [RF patients] change over from nurse to GP or GP to nurse, I'm not quite sure which way, I'm always sent this huge form to fill in, it's like 10 pages. It's very long ... it's very off putting. So the, it's not a smooth transition, I think it's smooth from hospitals to nurses when they're children? Where the GPs fit and how they get in or get out of the relationship is a bit messy.

As described previously (refer to pages 24–25), the majority of HCPs interviewed felt strongly that having a national RF register would help to reduce the loss of patients to follow-up care because of difficulties transferring RF patients between health care services. Where continuity of RF care was maintained between child and adult services, the secondary prophylaxis experiences were facilitated for whānau, which also helped to prevent patients from being lost to follow-up. Another key facilitator of positive RF experiences for whānau was having community rather than clinic-based care. The whānau described how having nurses who came to their homes, schools or places of work was helpful in creating rāpports and prevented many of the access barriers they had experienced with clinic-based health care. Aohanga, the mother of Mataī, explained how the rāpport developed between her whānau and their community-based secondary prophylaxis provider allowed for clear communication and for the transferal of RF care for her son:

Nurse X [a secondary prophylaxis provider who works with the whānau], um, she's so primo as, and, yeah, she comes to us and even, like, in the holidays if Mataī [her son with RF] has gone to the city, which he usually does, goes down by my whānau in the city in the holidays; she still keeps, you know, gets in touch with the nurses down there to go over to my whānau to do his injections to keep him up to date and [the] same when Mataī comes up here 'cause he's still on the injections; she comes out if she knows he's up here in the holidays; she comes out to do his injections ... so the nurses are primo as.

Secondary prophylaxis providers who worked within community-based care models found that their knowledge of their local communities and engagement with whānau were essential elements of their roles, as Paddy, Waitarehu and Charlene explained:

Paddy: we really rely on that on networking, so, um, we have a good engagement with the whānau and I, for the small rural town it's easy for me because, like I said, you know, I'm up there and I know the majority of people so I know who to connect up with.

Charlene: it's about not only the relationship, the whanaungatanga [process of establishing relationships], but it's also about knowing ... the iwi they come from and, yeah, 'cause if you get it wrong, then you won't be in the house again

... Yes, so whakawhanaungatanga is really important. It's important to them as much as it is for us. I think they like to know they can connect with, or may know somebody who may know somebody who actually knows you ...

Waitarehu: Also, I think in a rural community, um, you're engaged with a community as a mother, as a nurse, as the netball team, you play squash, wind surfer of the harbour, you know, you have your kids at school, um, I could just say, um, that one of my children is a long-term, immediate health [concern] and that's well known in the community, so that has opened doors for me that might have been a bit more closed than usual.

The complex lives of whānau and the mismatch with RRF/RHD services meant that often secondary prophylaxis providers and community health workers were having to 'fill the gaps' of whānau needs by undertaking non-health services, such as driving their patients to supermarkets or health appointments and advocating for their patients within health services and for social support services, such as Work and Income New Zealand (WINZ) and housing, as described by the secondary prophylaxis providers below:

Kendall: that day we'd gone to the, I think we'd taken her to the doctors, taken her to budgeting and we'd gone to the food bank, taken this lady to the food bank to get some food because she had no food.

Minnie: ... take them shopping ... to the supermarket and then pick them up afterwards and take them back home or take them to the doctors or [to get] food parcels or for budgeting or all those sort of things. I always know when I go to my lady who's 45 that I may as well wipe out the morning because I know she will want me to take her there ...

Carly: ... [patient] dreading the dentist ... 'I just can't, I just can't do it right now and I actually don't like them, I don't like the way they treat me' [patient] ... how about: I will pick you up, I will take you, I will take you, walk you straight through, I will be in there with you. I will sit in there with you. Just friggin' get your teeth done (Laughter).

Minnie: ... getting them to a doctor to get all their medication and stuff ...

Kendall: Or it might be they just wanna go to town and they haven't got a ride or they want a ride so you give them a ride on your way back to work, yeah, and drop them off to WINZ, yeah, like that, bend over backwards, yeah, or sometimes it could be that you give them their injection at home at eight o'clock in the morning and drive them to school.

Minnie: ... I'm their bus and transport and that works.

It was evident from the whānau and health care provider narratives that these non-clinical aspects of care greatly facilitated whānau experiences of RF/RHD treatment and management. However, HCPs noted that these were often unacknowledged aspects of the secondary prophylaxis providers' roles. According to HCP participants, having community health workers or kaiāwhina also helped to bridge the same difficulties for whānau and take some of the pressure off secondary prophylaxis providers.

The effectiveness of information, communication and education

The whānau perceived that there was inadequate provision of effective RF/RHD information and communication. This had significant impacts on their experiences of RRF/RHD. There were several whānau who reported that they were not provided with any information about ARF/RRF/RHD following their diagnosis or about their RHD surgery. The whānau explained that this lack of communication often left them feeling anxious and confused, as illustrated by Pingao, the mother of Pōhuehue: *'They [the doctors] didn't really explain anything. They just took her [her daughter, Pōhuehue] in. Remember when they were trying to give you needles in your backside? In your leg? They didn't really explain anything'*.

Verbal and visual information and communication

A major theme that arose from participants' narratives was the dichotomy between HCP and whānau perceptions of best practice for effective communication. HCPs tended to promote one-on-one, face-to-face discussions with whānau and some endorsed the use of charts and diagrams to aid communication. This was illustrated by comments from Michael, a cardiologist: *'I think, generally, face-to-face, verbal [is the best form of communication with patients]. I would often find myself drawing things, hearts or sketching out hearts and what they look like. But it's more verbal than anything else ...'*

In contrast, whānau found that when HCPs used direct verbal communication with them, they often felt confused. Whānau described their difficulties trying to understand the spoken technical jargon or *'big words'* used by their HCPs, as Mamala explained:

The main thing was all of these medical terms, we just didn't understand, we were just like 'yup, yup', we couldn't understand those long, big words. I think for awareness, for families or people who have or [are] about to be diagnosed with rheumatic fever, I think if they [the health care professionals] can just make it simple and easy for families to understand ...

Whānau also described how the medical terminology used by HCPs elicited feelings of embarrassment for them because of their lack of understanding, as Fau stated: *'they'll say it's a heart condition, blah, blah. They'll start going [in]to detail and start speaking doctor. Then I feel like [a] dumb shit and tell them "that's enough"'*.

Despite difficulties in communication between whānau and HCPs, there was a common concern expressed by most HCPs that they had to continually reinforce health literacy information to whānau regarding RRF/RHD, as Lisa, a secondary prophylaxis provider stated: *‘Usually mum and dads have had a lot of education from the hospital about [RF] but it’s just going over it and reinforcing it again I think’.*

Many whānau described how effective they had found the use of diagrams and visual pamphlets for communicating understandings of RRF/RHD. For youth with RRF/RHD, such as Langakali, visual imagery broke down the barriers of reading and being familiar with different languages:

Because the nurses and doctors would tell you about it [RF], come and talk to you about it, but, um, you hear it totally different, when they’re talking ... so I was just hearing the same repeat. So when they actually gave me the pamphlets and the pictures of what happened, and what was happening with me, that helped me. Yeah, it was the pictures really. Because even reading it was, but when I was looking at the pictures I was, like, ‘ohhh wow, oh, it’s attacking my throat’, like, ‘oh it’s attacking this and that’.

Deficit framing of RF

Another strong theme that emerged from the whānau interviews was their awareness of the deficit-based explanations and the stereotypical framing of Māori and Pacific peoples within medical explanations and the health promotion of RF. Whānau felt that they were being portrayed as *‘the problem’* and were being stereotyped as irresponsible, unhygienic and uneducated, as poor parents and as living in poverty and overcrowding. The stereotype that only *‘brown’* Māori and Pacific whānau get RF/RHD was illustrated by Akatea, a Māori patient with RRF who experienced delays in her diagnosis of RRF because she was not socially assigned as Māori by HCPs, as she explains, *‘they were boggled why I had it [RRF], being an adult and white, because I remember a doctor saying to me, “you’re white, you’re an adult, and you can’t have rheumatic fever”’.*

Whānau expressed how upset and angry they felt as a result of the deficit-based explanations and stereotypes. Some whānau experienced internalised racism and made this explicit during their interviews by indicating that they felt they were to blame for their children becoming sick because of their home living environments. Toatoa, an adult male with RRF, expressed his *‘upset’* at the severity of blame that disproportionately affects Māori and Pacific peoples:

Yeah, well just from what I have seen, probably really more the TV adverts that I have seen, and because my children are Māori/Pacific Island, we get sort of upset. Like, even the assumption that my child, I mean he does come from a big family, but the assumption that it’s something to do with poverty,

overcrowding, poor housing, etcetera ... Do you know what I mean? That assumption that like, it's a Māori Polynesian problem, and poor people get it, you know. And almost sort of poor parenting, poor care of kids.

Whānau felt that stereotyping Māori and Pacific families and pinpointing the way they live as a key causal factor of ARF/RRF/RHD ignored the real underlying causal factors, such as poor housing and cold temperatures, as stated by Siale: *'And the fact they [the media] always say its Māori and Pacific Islands, you know? I mean its rheumatic fever "hello, you people", "Māoris [sic] and Pacifica you know you live badly, you all sleep together when it's cold", yeah because it's bloody cold'.*

Discourses of blame, particularly around parental behaviour and attitudes, were also evident from some HCP narratives. The impact that these had on whānau, particularly in eliciting feelings of parental guilt, were also acknowledged by HCPs, such as Maude and Lisa, two secondary prophylaxis providers:

Maude: you know, whatever the [parental] knowledge, um, sometimes very good but sometimes very poor. If they haven't been interactive with their kids through their journey, aye, [they're a] bad parent.

Lisa: A lot of the parents feel really guilty and in coming to terms with the fact that their child has to have injections for the next 10 years.

It was apparent from the whānau and HCPs interviews that deficit framings of RF have created a stigma about the disease that has negatively influenced whānau experiences of the illness and their interactions with HCPs. Secondary prophylaxis providers described the stigma associated with RF as creating *'defensiveness'*, *'denial'* and *'embarrassment'* for their patients and their whānau. RF stigma also led to internalised blame and guilt in the whānau, as explained by Kendall, a secondary prophylaxis provider:

We [the secondary prophylaxis providers] work really hard of not putting [sic] that stigma on them [RF patients]. I've got a little girl [with RF] ... and because of where she lives—and her parents are fine, they're good, kind, caring parents. However, they live in a very old home that's not very well insulated and it borders on being overcrowded so they've said that this little girl has to stay on it [bicillin] for at least another year and then they'll review again ... it's been explained to them that because of where they live, unfortunately, they have to continue with the injections ... so the stigma sits there again, even though I haven't put it [the blame] on [her] Mum and Dad. You know her mum said to me the other day 'it's cause of our house, aye, it's cause of where we live, because we live in this area of Aotearoa?'

Whānau and community-based communication

Whānau in the study described actively seeking information about ARF/RRF/RHD from sources other than their HCPs. The internet was the most common place where whānau sought and obtained information about ARF/RRF/RHD, although some whānau also gained information from books. Many whānau stated that they had to independently seek out information because they had not received adequate or meaningful information from their HCPs or because they did not trust the advice and care of their HCPs, as described by Horokaka, an adult woman with RHD:

As soon as she [the doctor] confirmed I had the mitral valve stenosis and then she told us and [we] didn't even know what it meant. That's when we 'Doctor Googled' it. Doctor Google ... if the doctors try and put me on a medicine and I'm not sure of it, [I] check online because it'll tell me if it's going interact with the medicines he's [the other doctor] put me on. Because they sometimes do that with antibiotics, put you on the wrong antibiotics. Especially if I'm not seeing my normal doctor.

Some whānau also sought information from other whānau/community members, such as other parents whose children had ARF/RRF/RHD, as Akatea explained:

My daughter's friend at school, he got rheumatic fever, and his mother rang me up saying 'can you explain it to me'? While she's sitting in an A&E [Accident and Emergency Department of the hospital]. And no one had kind of explained it to her, but [the health care professionals] just said 'he's got rheumatic fever'. She rings me: 'what the heck is it?' And I'm, like, 'wow, that's really sad, I'll tell you what I know about it'.

Several Pacific families described how information about RF/RHD had been presented to them at their local churches and that they had found this to be an effective way of conveying information as it reduced language barriers for them and was delivered in a fun and performative manner, as described by Fau: '*... my other friends at the church, it was a competition between five churches to see who comes up with the best dance or skit for rheumatic fever*'.

Understandings of RRF and RHD

Whānau had varied understandings of RRF and RHD. Most whānau understood that ARF and RHD were initially caused from sore throats, as stated by Toatoa: '*it's [ARF] caused by a sore throat. And if you don't get it checked out, your heart gets damaged*'. As described above, these understandings were largely informed by recent media campaigns, from sharing information with whānau who had also experienced ARF/RHD and from information provided by HCPs. However, even with recent media promotion of ARF there

were still some whānau who had relatively limited understandings of RF, as explained by Toatoa:

I think it has been this last year or so since there's been this big public awareness of it [ARF] and, you know, promotion on TV and stuff like that, that's, um, you know, people are a lot more aware of it but, as I say, I was totally ignorant about it, I thought it was an old fashioned you know [disease], sort of like TB [tuberculosis] or something like that, something that is generations or so ago, that was a problem but it wasn't really a problem now.

Common explanations and beliefs held by whānau relating to causes of ARF included contagion (via people and saliva shared from drink bottles and smoking), genetics (as a hereditary disease and a disease of Māori and Pacific people), poor hygiene, household overcrowding and cold and damp housing conditions.

In contrast to ARF, whānau had relatively poorer understandings of RHD with very few whānau able to explain what was wrong with their hearts and what caused their heart damage. Some participants, such as Lau Ki, were able to offer basic understandings but were not confident in their knowledge:

There is some bacteria or something, it can go into the blood system and then it can go on to hurt your heart and that's how I have the heart valves problem because I guess it just spread to my heart or something like that? I kind of got an idea of it but I can't remember how they [the health care professionals] explain[ed] it. I just remember something about the sore throat, the bacteria and that, something like the blood and then it goes to my heart and the longer I leave it, the more it affects my heart.

Whānau also described having limited understandings of secondary prophylaxis and its role in preventing GAS infections and recurrences of RF. Most whānau were aware that they (or their family members) had to 'have injections every month' but they did not understand why the injections were monthly, what sort of medicine was in the injections, how the injections prevented GAS or why they had to keep having injections for such a long time. These were questions that whānau commonly asked researchers during the interviews. It was also evident from the whānau narratives that limited understandings of secondary prophylaxis contributed to missed bicillin injections for some participants, as Fau stated:

I just know that I have to get injections every month. But I don't know what happens inside. Yeah, I had a [RF] relapse a few years ago. Um, that wasn't so good. I couldn't walk. I didn't know why [I had the relapse]. Um, but, yeah, it was because I wasn't taking my injections and stuff.

Impacts of RRF and unexpected RHD

RRF/RHD resulted in whānau experiencing significant emotional, social and economic stressors. Whānau reported experiencing a variety of emotions during the diagnosis, management and treatment of their ARF/RRF/RHD including worry, stress, sadness, anger, guilt and confusion.

Whānau explained that having ARF/RRF/RHD (or whānau members with ARF/RRF/RHD) tended to create significant disruptions for them and often compound the difficulties they already faced within the complexity of their daily lives. ARF/RRF/RHD impacted on the financial status, employment and education of the whānau.

Many family members of ARF/RRF/RHD patients stated that they had to their leave paid employment to accommodate the treatment and care of their whānau members, while often still caring for other children, as Ateate, the mother of O'a described:

The carry-on effect of what it [RF] does to your family and how it actually impacts on everything. We had to stop work, he [Ateate's husband] had to stop work, you know, like, we had to re-evaluate EVERYTHING. You know, somebody had to be at home with the kids, somebody had to be up with O'a [Ateate's son] in Starship and, for a long time after he came out of Starship, he was in a wheelchair because ... his rheumatic fever was still so hot, so we had to do things, like; you never knew when he was on monthly clinic appointments, and we never knew if, up at Starship, whether they would say 'no, he's got to stay' or 'yes, he can come home'. So, he'd pack his bag and we'd would go up there ... Sometimes it would be 'Yeah, sorry, tonight you're gonna have to stay O'a and it's all right we got our bag packed' or 'nah, O'a, it's all right you can go home'. But all of this stuff happened because of that.⁷

Parents and caregivers of youth with ARF/RRF/RHD explained how difficult they found visiting and caring for their sick children in hospital (or on home-based bed rest) and looking after their other children. These situations led to educational absenteeism and resulted in huge disruptions to the daily lives of Whānau, as Futu's narrative highlights:

Definitely the hardest bit is not knowing, because you have a child that's sick, and I just had a new-born, so it was really hard because we had Losa [the daughter with RRF] and then her, the second child. She was only about maybe five [years old] at the time and then we had her little sister. So she was just born

⁷ Clinical note: Hospital staff will discharge children with resolving RF earlier in the recovery phase to reduce the family disruption of having a child in hospital for prolonged periods (sometimes weeks to months). However, this approach requires frequent repeat assessments in hospital to monitor the recovery and, if the disease does not settle as expected, unanticipated admissions for further management.

and that was really hard to try and balance, to try and stay in hospital for her, but caring for the youngest, she [was] just a couple months, and then trying to maintain a relationship with Losa's dad and him going to work. It was always a constant on the toes kind of thing, and sort out who she's with and how [we] were gonna do this. And then Losa [was], the main focus at the time. Yeah it was really hard.

Another impact of the ARF/RRF/RHD experienced by school-aged youth was that they were often not able to attend school for long periods of time. Participants and their whānau explained how these periods of absenteeism influenced the educational outcomes for young participants and their mental health, as Langakali explained:

I was off school for about four, five months. And then I got home schooled. And then that made me, after that experience, I felt a bit depressed for the next few years, I felt a bit depressed because I had to repeat fifth form. Moved back to Auckland and then I had to repeat. And I felt like I missed out A LOT.

Whānau reported that having access to social services, a good rapport with health services and access to whānau and community support helped buffer the negative impacts of RRF/RHD, as Fā, the mother of Langakali explained:

That's a hard time for us, with the food, with our rent, but lucky that, uh, when we went there [to hospital] we got different help. We got help from the heart department, we got help from the social worker, they give us a voucher for petrol every week and even, uh, the social worker give us a shopping [voucher] from the hospital and also the work and income pay for our arrears—it's about nine-, almost 1000 dollar[s] [in] arrears in our house because he [her husband] stay[ed] home with the kids and [was] off work, yeah. We [to] start with [found it] hard but with all the help and even, like, my family because my brother, he was the most help out for my, for us and also my family and most of the church people, help from everywhere.

In addition to the immense stress that coping with RRF/RHD placed on whānau, many parents and caregivers also described experiencing anxiety and guilt as they felt they were at fault for their child's illnesses. Whānau blamed themselves for not realising how sick their children were, for not seeking medical attention soon enough for their children and for not pushing HCPs and services 'hard enough' for the medical treatment of their children. Such a discourse of self-blame was expressed by Waihīrere, the mother of Tāpotō:

I was like, 'oh my God', that was my fault because I knew that it [ARF] comes from a sore throat, they [the doctors] said, um, 'well you just didn't pick it up that they had a sore throat' and I was like, 'Oh my God'. You feel like you're, ah, (pause) ... you feel like a terrible parent 'cause you just missed all this stuff.

Participants also described how having RRF/RHD could result in social exclusion from recreational activities, sports, attending social functions, schooling, travelling and ‘being normal’. Key drivers for social exclusion experienced by participants were the restrictions placed on physical activities, dietary restrictions, being too ill to participate and the embarrassment and stigma associated with RF/RHD. Siale’s narrative below conveys the emotional impacts of social exclusion on her life as a consequence of RHD:

I was not coping very well, you know, I did not like it [the scar from RHD surgery]; I will never like it, you know, it’s never something I’ll accept or anything ... I mean the scar [un]til this day, I don’t like it, you know? People, ‘cause I don’t see people my age with one, you know? I go out, go to clubs, [I have a] nice top and I don’t like wearing it just because, oh my God, people stare at it ... I was told, you know, you’re gonna have a mechanical valve and be on warfarin for the rest of your life, um, you’ll never have children, you’ll never play sports again, you’ll never do this, you’ll never really be able to leave the country. Like, I’m trying to go on holiday to Australia and [to get] insurance. Um, now because I’m high risk, you know, they tell me that and, honestly, it just broke my heart. You know you take the one thing away from me that made my life so good, my sports.

The embarrassment of the physical impacts of ARF/RRF/RHD such as scars and involuntary body movements from Sydenham chorea were so significant for some youth that they went to great lengths to try and hide their symptoms from their family and friends. Tiare, a woman who had Sydenham chorea explained:

Basically, I lost control of my left hand. Like, I couldn’t, it was just flying anywhere and I would drop things without noticing. I couldn’t control it myself so, basically, I had to hold it down, like, whenever I go somewhere. I was so embarrassed about that, I didn’t tell my mum. I ended up staying home for nearly the whole term. I took a term off school.

Undertaking bicillin injections was also a source of embarrassment for many RF/RHD participants. Some youth who received their bicillin injections at school said they found it easier to cope with the stigma of RF through the camaraderie they formed with other students receiving the injections at the same school. Another intervention that helped counter the embarrassment of having bicillin injections was the action of the secondary prophylaxis provider, as Fau described:

My whole family used to mock me, they’ll be like, ‘where did you get your injection at? Oh, down there’. I’m like, ‘shut up’. Yeah, so, Nurse X she always used to put a plaster sticker over here (points to her arm). Just a fake one. It’s the little things that she does that just made my life easier. And I was like, ‘nah, look it’s [the injection] in the arm now, look’. And they’re [her family] like ‘oh,

it's in the arm now'. They used to mock me and be like, 'oh, it's because you broke your ass now right?' And I'm like, 'noooo!' Especially in the holidays when everyone will be in the house, like cousins and they're sleeping over ... So, yeah, me and Nurse X will go in my room and she'll be like, 'we'll put a sticker on your arm, don't worry I got you girl' (laughs). So, then she'll walk out, 'okay, no pressure on your arm'. And I'm like, yeah. And my family's like, 'but everyone does it down there', but I tell them it's because I'm special.

Weight management was another impact of RRF/RHD that whānau expressed concerns about. Whānau understood the importance of maintaining a healthy weight to manage their RRF/RHD but they explained how they often struggled with this because of the economic and access barriers to purchasing healthy food, the restrictions on the physical activities with which they could engage and, for parents and caregivers, the attempt to cater for their children's food preferences and their inability to see their children go hungry, as Aohanga explained:

When we were first diagnosed with the rheumatic fever with Mataī [her son], the paediatrician that we work with is always going on to Mataī about [eating] healthy and getting a dietician and that and, because he is a big boy, he was bigger than he is now, um, and, yes, that's my fault 'cause I don't like to see my kids hungry, so I always make sure we've got a lot of kai (food). But I found with the rheumatic fever, when Mataī was first diagnosed (pause), with all the bed rest he, um, didn't, wasn't, didn't become lazy, but just [it was] too long, the bed rest and, you know, when you get young males like Mataī and all they've got to do is bed rest? Well 'cause I found he was going to get unhealthy if that's what they want to call it. 'Cause I think the paediatrician at one part was kept going on to me about his weight and that and I kept trying to say to her, 'well, it's hard because, you know, he's not allowed to do anything'.

The extent to which participants with RRF/RHD could engage in physical activities was another area in which whānau expressed concern. Many RRF/RHD patients discussed their engagement in sports and exercise before being diagnosed with ARF/RRF/RHD as an enjoyable way to stay fit and have fun. Whānau explained that they were often told by their HCPs and/or whānau members that they could not continue with these physical activities and that this commonly led to disappointment and frustration, as described by Miro: *'They [the health care professionals] said I had rheumatic heart fever and that I had to have an operation ... So it ruined everything I used to do, sports and all that. I wasn't allowed to [do] all that ... I wasn't allowed to play sports, or do anything physical'.*

Health care professionals were also aware of the impact that not being able to engage in physical activity had on RRF/RHD patients and of their questions around participating in sports and exercise, as evident from Michael, a cardiologist's narrative:

Um, I guess the commonest question [from RHD patients] is ‘can we still play sports?’ I guess, ‘what’s the impact in terms of exercise?’ ‘What things can or can’t people do who actually have rheumatic fever?’ That’s the common question ... I guess the initial questions revolve around exercise or activity levels. And it’s a real issue for people who’ve had a documented episode of rheumatic fever. They may have well been on bed rest for a period of time and they might have got accustomed to that degree of activity, I mean it might be a little bit more difficult to get back into regime or an active lifestyle [than] beforehand.

Discussion and recommendations

Health services, treatment and management of RF

The mismatch between health services and complex whānau lives

The findings clearly demonstrate the mismatch between the complex living situations of Māori and Pacific whānau and the RF/RHD health services. Many current RF/RHD services are not flexible or agile enough to reduce access barriers and/or to manage the challenging contexts in which Māori and Pacific young people and their whānau live, in timely, effective or meaningful ways. To improve RF/RHD services in Aotearoa, interventions need to address the underlying structural causes by addressing housing, racism, employment, income and youth-friendly health care.

Recommendation: This report recommends that health services develop flexible, holistic service-delivery models designed to meet the complex needs of whānau.

Housing

Housing was reported as a significant concern for whānau. Many participants in this study experienced cold and overcrowded housing conditions that they felt were responsible for the poor health of their families. Poor housing conditions, such as mould, dampness and overcrowding, have established associations with transmissions of GAS infections and associated RF (Engel, Stander, Vogel, Adeyemo, & Mayosi, 2011; Jaine et al., 2011; Rauh, Landrigan, & Claudio, 2008). An Australian prospective, family-based cohort study by Danchin et al. (2007) found that 41% of siblings of children with GAS pharyngitis also developed streptococcal infections and attributed this to overcrowding. Given the current housing shortage experienced in Auckland and in other urban centres of Aotearoa as well as the increasing rental prices of homes (Parker, 2015), this issue is of serious concern for RF and other communicable diseases. Despite the implementation of housing initiatives, such as the Auckland Wide Healthy Housing Initiative (AWHI), to address such housing issues, many Māori and Pacific whānau are not able to access healthy homes. From June 2014 to June 2015, AWHI received approximately 1,160 eligible referrals. In this 12-month period, only 65 of these families were successfully re-housed (Tesese et al., 2015).

Recommendation: This report recommends that urgent steps be taken to improve the supply and quality of affordable housing in both urban and rural areas of Aotearoa to reduce overcrowding and the burden of infectious diseases, including RF, among Māori and Pacific peoples in Aotearoa.

Racism

Racism was experienced by whānau at institutional, interpersonal and embodied levels within primary and secondary health care contexts. Whānau described being referred to

as ‘coconuts’ and being treated differently than Pākehā patients by the HCPs. Many RRF/RHD patients and their whānau expressed their concerns over rough handling by HCPs and described hospitals as ‘unsafe’ places. These forms of racism created barriers to accessing health services and negative experiences of the treatment and management of RRF/RHD. Racism is a well-recognised, key determinant of health and is associated with lower self-reported health outcomes for Māori, Pacific and Asian populations in Aotearoa (Harris et al., 2012a; Harris et al., 2006) as well as with more negative health care experiences (Harris et al., 2012b).

Cultural competency is a common tool used in health care contexts to help HCPs 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 (Came & da Silva, 2011; Kumagai & Lyson, 2009). In contrast to cultural competency, cultural safety or kawa whakaruruhau has been proposed as an anti-racist intervention to address health inequities (Came & da Silva, 2011; Nursing Council of New Zealand, 2011; Papps & Ramsden, 1996). Cultural safety extends beyond understanding the cultural values of ethnic groups; it is a transformative process that involves applying critical self-reflection to identify and understand the personal biases, values and assumptions of health practitioners, rather than their patients (de Souza, 2008; Papps & Ramsden, 1996). Cultural safety can address health inequities by identifying power relationships between HCPs and patients, improving communication between patients and HCPs, facilitating access to health services and empowering people who use health services (Nursing Council of New Zealand, 2011; Papps & Ramsden, 1996). However, the evaluation and measurement of the effectiveness of cultural safety can be ambiguous (Walker et al., 2010), often fails to address the structurally institutionalised racism in health services and is commonly determined by HCP peers, rather than by more objective assessments of patient and whānau experiences.

Recommendation: This report recommends that the MOH and DHBs undertake rigorous evaluation of cultural safety training for HCPs regarding short- to long-term outcomes at structural, institutional levels, as well as individually based evaluations. Further, to help mitigate the disadvantageous effects of racism within RF/RRF/RHD-care contexts, we recommend that RF/RHD services seek their clients’ insights to inform whether their services are offered in a manner that the health consumers determine to be ‘culturally safe’. Services should commit to implementing change as result of whānau feedback. To avoid the coercion of whānau and the mistrust that may potentially bias responses, these evaluations should be undertaken by community health workers/kaimahi or someone in a similar role whom clients’ trust and with whom they have a good rapport.

Ethnic concordance

The ethnic concordance of HCPs with Māori and Pacific whānau tended to create a positive rapport, trust and an understanding of RRF/RHD for them. Ethnic concordance helped to buffer the racism experienced by whānau within health settings. Positive associations between ethnic concordance and health-service experiences, delivery and outcomes have been identified from national (Harris et al., 2012b) and international health research (Cooper, Roter, Johnson, & Ford, 2003; Saha, Komaromy, Koepsell, & Bindman, 1999). Curtis, Reid and Jones (2014) undertook research within the Faculty of Medical and Health Sciences at the University of Auckland, reviewing Indigenous student recruitment and education. Their research emphasised the importance of Māori and Pacific health workforce development and of cultural safety training within the health sector to reduce current health inequities.

Recommendation: This report recommends that the MOH and tertiary educational institutions continue to promote, support and reinforce initiatives for Māori and Pacific health workforce development, such as the Pacific Health Workforce Service (MOH, 2013), Te Uru Kahikatea (MOH, 2007) and the University of Auckland’s Vision 20:20 programme (Curtis & Reid, 2013).

Age-appropriate care

Patients, whānau and HCPs all reported difficulties associated with the provision of and engagement with prophylaxis and care for RF/RHD during adolescence, which in some cases led to the loss of adherence to prophylaxis and recurrent disease.

Even children and young people with little or no heart involvement, but who require regular prophylaxis, are in need of medical care over and above that which is usual for their age and should be considered as having a chronic medical condition (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). There are no studies that have considered RF/RHD in the context of chronic disease in adolescence.

Denny et al. (2014) used van der Lee et al.’s (2007) framework in their analysis of the prevalence of chronic health conditions reported by high school students in the Youth2007 study in high schools in Aotearoa. Emotional wellbeing was affected where students reported that their chronic health condition affected their activities (28%) or their ability to socialise (8%). High levels of depressive symptoms were found in those whose activities (18%) and socialisation (40%) were affected by chronic conditions (Denny et al., 2014). Many of our participants spoke passionately about the profound effect of the loss of sporting participation. Of significance to our young people with RF/RHD, students with chronic health conditions living in families in Aotearoa experiencing the highest levels of socioeconomic deprivation reported the greatest impact on their activities and socialisation (Denny et al., 2014).

Seven categories of self-reported barriers to medication adherence among adolescents across a broad spectrum of chronic medical conditions have been reported (see Table 3), all of which have relevance to adolescents and young adults with RF/RHD (Hanghøj & Boisen, 2014).

Table 3. Seven self-reported barriers to treatment adherence in adolescence (Hanghøj & Boisen, 2014)

1. Relations (peers , parents, health professionals)
2. Adolescent development (strive for normality , freedom vs control)
3. Health and illness (physical wellbeing , mental wellbeing, treatment perceptions and worries)
4. Forgetfulness (forgetting because of activities, forgetting by coincidence)
5. Organisation
6. Medicine complexity
7. Financial costs

Note: 'Top 5' categories are indicated in bold.

Relationships with peers are critical, but are a double-edged sword. Some of our young participants found having bicillin prophylaxis at school and receiving support from others also receiving prophylaxis to be helpful, others felt embarrassed about having injections at school and having to tell their peers.

Relationships with parents are also multi-faceted. Parental involvement has been shown to contribute to better control for adolescent type-1 diabetics (Duncan, Jekel, O’Connell, Sancı, & Sawyer, 2014). Whānau often provided emotional support and encouragement to adhere to treatment but struggled at times with the moods and behaviour of their adolescents. Some young participants also reported struggling with their parents and families.

Relationships with HCPs were both helpful—where HCPs provided support and acted as advocates—and unhelpful. Unhelpful aspects, also mirrored by Hanghøj and Boisen (2014), included poor communication from doctors, insufficient or unintelligible information and the lack of provision of age-appropriate information.

Some of the participants in this study struggled with having their injections at school, worrying about being perceived as different. Some participants rebelled against family, their HCPs and the unremitting necessity to adhere to 28 day injections. Adolescents express a desire to be seen as normal and a desire for freedom (Hanghøj & Boisen, 2014). They begin to establish an independent life, increasingly distinct from their parents and may hide their condition or become less adherent to fit in with their social group and avoid rejection (Duncan et al., 2014; Hanghøj & Boisen, 2014). However, Māori identity and engagement and family connectedness exert a protective influence on Māori adolescents (Stuart & Jose, 2014).

Patient and whānau complaints of pain as a side effect of bicillin and their consequent fear, potentially influencing adherence, were described. Once the acute effects of an episode of RF had resolved, participants mostly returned to feeling well and struggled to recall or understand why they needed to continue with painful, intrusive treatment that demonstrated no immediate benefit. Similar experiences of adolescents with a range of chronic conditions where a reduction in symptoms was perceived as a reduction in the need for medication and, therefore, for adherence are reported in Hanghøj and Boisen (2014).

Patients in this study also complained of the change in body image after surgery, with scars affecting their perceptions of themselves, the ways that they dressed and their capacities for social interaction. Weight gain associated with physical activity restrictions and whānau expressions of aroha (love) by means of food also resulted in changes in body image and social interactions. Patients also described physical activity restrictions and being forbidden to play sports as inhibiting their social interaction, stifling the areas of their life in which they had pride and achievement and, for some, removing their essence of self—each of which influence emotional wellbeing (Denny et al., 2014). Adolescents living with a range of chronic conditions reported that they were unsure whether the treatment was useful or necessary and that missing a few doses *'doesn't hurt'*. Some adolescents worried that they might die early, while others pretended that nothing was wrong with them to be more like their peers. Some adolescents believed taking medication was a sign of weakness (Hanghøj & Boisen, 2014). Among participants in this study, a range of these feelings was expressed in relation to treatment adherence and resulted in recurrences.

Loss of adherence may be the result of forgetting, including when treatment and treatment decisions obstruct activities important to the young person, such as the school ball mentioned by Langakali. Adolescents with chronic conditions struggle with organisational aspects related to treatment adherence, including inconvenient time requirements for treatment and appointments and the *'hassle'* of going to the school nurse for treatment, frustrations also reflected by participants in this study (Hanghøj & Boisen, 2014). Further barriers to adherence included not understanding the purpose of either the treatment or the clinic appointments, as we have illustrated.

The cost of adherence became an increasing barrier as participants in the studies reviewed became older, particularly in relation to work and to caring for families of their own, as related by O'a. Only one whānau reported receiving social-worker support and access to additional funding from WINZ to cover the increased costs of transport and health care associated with their child's condition. No whānau reported receiving support or assistance from patient support and advocacy organisations, such as Heart Kids.

Health care professionals also reported that they were frequently ill equipped to cope with young people who themselves were struggling with the life changes and demands of adolescence. Patients very often brought their complex psycho-social challenges to their

prophylaxis HCP. HCPs reported that they were not trained and confident in communicating with and responding well to these young people and believed that training would enhance their abilities to understand the perspectives of their young patients, to assist in increasing adherence and to provide more holistic care to a group of young people who, in contrast to their peers, had regular access to a HCP who might act as a potential health navigator in spheres outside RF prophylaxis (Ambresin, Bennett, Patton, Sanci, & Sawyer, 2013; Denny et al., 2014; Denny et al., 2013; Hanghøj & Boisen, 2014; Hassan et al., 2013; Teevale, Denny, Percival, & Fleming, 2013).

Recommendation: This report recommends that RHD and RF requiring long-term prophylaxis be recognised as chronic conditions in adolescence and that age-appropriate resources and services be developed, including training for HCPs to improve their abilities and confidence in communicating with and providing holistic care to adolescents and young adults, taking into account the cultural and psycho-social implications of living with a chronic condition and the positive benefits of maintaining connectedness with whānau.

This recommendation sits well with the MOH's own identified System Level Measures to be implemented during the 2017/2018 financial year: *Youth access to and utilisation of youth-appropriate health services* (MOH, 2016).

Sore-throat management

Despite national evidence-based guidelines for the assessment and management of sore throats (Heart Foundation New Zealand, 2006; Lennon, Peat, Kerdemelidis, Sharpe, & Liddel, 2014), many children and whānau in this study reported receiving health care that was contrary to best practice. This occurred for the initial episodes of RF as well as prior to recurrences for those with recognised RF and/or established RHD. This was reported to be a significant issue when whānau saw HCPs with no prior experience of RF, such as locums from overseas, from areas where RF was rare or from areas with small numbers of Māori or Pacific people.

Participants varied in their awareness of the importance of sore throats as a necessary precursor for RF and some reported trying to persuade HCPs to swab and/or treat. The recent health-promotion activities had increased awareness for some participants; however, on the whole, this was for young adults and whānau rather than GPs.

Recommendation: These results suggest that there need to be specific activities for HCPs including audits of sore-throat management and the utilisation of the sore-throat guidelines (particularly in primary care contexts).

Diagnosis of RF

Delays in recognition and diagnosis of RF/RRF/RHD were reported by both whānau and HCPs. On occasions, this occurred despite the whānau suggesting RF was the diagnosis, as

was evident for Aohanga, when she suspected her son had RF and sought help on three different occasions from her local GP, who *'kept putting it off and telling me it was rheumatism arthritis'*. Delay was particularly an issue for children and young people presenting with chorea as their manifestation of RF.

Recommendation: This report recommends that resources be made available to upskill HCPs in the diagnosis and management of RF, particularly in primary care contexts.

Chronic care disease management

RF and RHD are chronic health conditions with significant associated health, educational, social, financial and psycho-social consequences for the individual and whānau. RRF/RHD resulted in whānau experiencing significant emotional, social and economic stressors, as Ateate stated: RF *'actually impacts on everything'*. Whānau reported experiencing a variety of emotions during the diagnosis, management and treatment of their ARF/RRF/RHD, including worry, stress, sadness, anger, guilt and confusion. There was also significant concern about weight management and physical activity with many whānau feeling uncertain as to how to deal with the competing priorities. Of particular concern is the number of participants who reported missing extended periods of schooling.

Recommendation: This report recommends that RF and RHD be managed under a chronic-disease framework and that 'return' strategies for exercise, education and employment be implemented. This would include working with other disciplines to provide support and active guidance about rehabilitation, graded exercise, weight management, guilt, self-care and financial stressors.

Secondary prophylaxis provision and management

Poor secondary prophylaxis monitoring and recall systems in primary and secondary care may contribute to recurrences because of the potential for patients to be lost and by causing delays in receiving prophylaxis. Patients, whānau and HCPs all identified problems with the provision of secondary prophylaxis resulting from differing models of care in different DHBs and from problems with communication both within and between DHBs. Within DHBs, provision of prophylaxis was most reliably facilitated by a uniform model of care across age groups. The potential for the losses of rapport, engagement and continuity of care occurred at points of transition.

In some DHBs, different nursing services were responsible for delivering prophylaxis to children and to young adults. In some DHBs, patients no longer eligible for the provision of paediatric services were referred back to primary care providers who were unfamiliar with the provision of secondary prophylaxis, lacked sufficiently robust recall systems or charged patients for the provision and administration of prophylaxis. Even where prophylaxis was delivered by the same nursing service, leaving school, the associated changes in young

people's lives and the change in the model of delivery had the potential to disrupt regular prophylaxis.

Patients, whānau and HCPs identified significant difficulties where patients moved from one district to another, either within a DHB or between DHBs. Where services were wholly dependent on paper records, patients self-presenting to a clinic within the same DHB where records were not on hand were unable to receive prophylaxis. Where patients made HCPs aware of moves, the providers relied heavily on close relationships and provider initiative and effort to ensure the transfer of care between DHBs with which they had close relationships, but were concerned that, despite this, patients were lost and prophylaxis delayed at the time of the inter-DHB transfer. Where networks were not well established, the risk of a failure of transfer was perceived as much higher because no formal, fail-safe method of transfer exists. HCPs expressed difficulty in tracking patients who travelled within and between DHBs and to and from Australia and the Pacific.

Recommendation: This report recommends that a coordinated national patient-management system be implemented across all DHBs to enable the seamless tracking, transfer and referral of patients within and between DHBs. To be effective, such a system would need to be fully integrated with systems used by all primary and secondary providers so that its information was automatically transferred and further silo-ing and fragmentation was not created by a standalone system sitting outside other patient-management systems. This report also notes that the provision of prophylaxis was most reliably facilitated by a uniform model of care across age groups.

Pain as a barrier to adherence

Patients, whānau and HCPs reported the pain associated with intramuscular benzathine penicillin injections as being a barrier to adherence. Pain was reduced by the site of injection, the injection technique and the experience of the health care provider. The most effective mitigating strategies for the reduction of pain associated with injectable prophylaxis are the concomitant administration of lignocaine and the use of counter stimulation—the *Buzzy® vibrating device—incorporating a cold pack (Heart Foundation of New Zealand, 2014). Advice for the use of these mitigating strategies is published nationally (Heart Foundation of New Zealand, 2014), but has not been adopted by all prophylaxis providers. Two participants interviewed self-administered their bicillin under observation to reduce the pain. HCPs raised the possibility of developing a transdermal or longer-duration subcutaneous depot preparation to encourage adherence by reducing the frequency of injections and the associated pain.

Recommendation: This report strongly recommends that the concomitant administration of lignocaine and the use of counter stimulation—the *Buzzy® vibrating device—incorporating a cold pack, be offered to all patients receiving intramuscular benzathine penicillin to reduce side effects—including fear—and to enhance adherence. The

possibility of the supervised self-administration of prophylaxis by some patients and initiatives to develop less intrusive forms of prophylaxis, such as transdermal or longer-duration subcutaneous depot preparations, should be considered.

Availability of benzathine penicillin

Patients and whānau reported a lack of availability of benzathine penicillin, including an interruption of the supply and the lack of an alternative for patients with allergic reactions to the standard supply, as contributing to recurrences. The security of a supply of long-acting benzathine penicillin is essential at both a local and national level.

For those patients who are penicillin allergic, the only current alternative is oral prophylaxis. Despite not requiring regular, injectable prophylaxis, these patients need to remain under the care of the secondary prophylaxis services, as adherence with long-term oral prophylaxis is only at around 60% and the risk of recurrence is commensurately greater (Heart Foundation of New Zealand, 2014).

Recommendations: This report recommends that Pharmac ensures an uninterrupted supply of benzathine penicillin and that an alternative preparation to the standard supply be available for those with non-penicillin-allergic reactions. This report further recommends that patients receiving oral prophylaxis continue to be monitored and supported by their regional prophylaxis providers.

Community and whānau-based models of care

Whānau narratives in this report described many barriers that participants experienced when seeking to access hospital and clinic-based health care for their RRF and RHD. In contrast to clinic-based services, whānau valued the flexibility of community-based care where HCPs came to them to deliver their secondary prophylaxis. Participants such as Mataī and Fau explained how having community-based care reduced access barriers and also created '*meaningful*', '*genuine*' connections between their whānau and HCPs. Evaluations of RF prophylaxis programmes have also found that the delivery of secondary prophylaxis by community nurses with the support of local community workers or kaiāwhina promotes successful bicillin delivery and high adherence rates (Grayson, Horsburgh, & Lennon, 2006; Hooker, 2010; Spinetto et al., 2011). Evidence from international literature further supports these findings and demonstrates that the utilisation of community-based health care models for secondary prophylaxis providers is advantageous for patient engagement, treatment, management and health literacy (Brownstein et al., 2005; Freeman, 2006; Hadi, Alldred, Briggs, Marczewski, & Closs, 2016; Joo & Huber, 2015; van Ryn et al., 2011).

Another important role of community nurses and community health workers identified in this research was their role in bridging the gaps between health services and the complex lives of whānau. Community nurses and community health workers described driving

whānau to supermarkets and assisting them with health appointments, budgeting and WINZ appointments. Given the complexity of whānau lives, for RF health care to be effective, health services and interventions need an integrated inter-sectoral or cross-agency approach, addressing health, housing, finance, employment, childcare and educational assistance. Whānau Ora collectives show great promise in addressing such structural issues that influence health outcomes. A report undertaken by Te Puni Kōkiri (2013) on the service-delivery capability and outcomes of 27 Whānau Ora providers and collectives found the services to be effective in establishing whānau engagement and addressing whānau achievement and aspirations and provided a whānau-centred service delivery that facilitated collaboration with inter-agency community networks. The approach enabled whānau to access a broader range of services by linking social, health and education services to achieve whānau wellbeing. Another successful whānau-based, inter-agency initiative is Mana Kidz. Mana Kidz is a school-based RF prevention programme in Counties Manukau, where registered nurses and whānau support workers provide the daily assessments and treatment of sore throats and skin infections for children and the health assessment of wider whānau (Anderson et al., 2016). Mana Kidz has been effective in providing increased access to social support and health services for children and their whānau and has established positive, trusting relationships with the whānau who access their services (Anderson et al., 2016).

Recommendation: This report recommends that a community-based nursing model supported by kaimahi/culturally appropriate community health workers be implemented for the management of RF/RRF within DHB regions with high rates of RF.

Relevant, strong linkages between these RF/RHD services and providers, such as Whānau Ora, need to be established to address the complex needs of whānau in a coordinated way.

RF/RHD health literacy

Health literacy can be defined as obtaining, understanding and using health information appropriately (Zarcadoolas, Pleasant, & Greer, 2009). The understandings of RF/RHD by the whānau in our study were informed by media coverage, information from the internet, health-promotion campaigns and interactions with HCPs. From whānau experiences with RF/RHD health information, we suggest that the provision of multiple forms of written information about RF/RHD was neither an effective nor an efficient form of delivery. The whānau expressed feelings of being overwhelmed by the content and amount of information given to them. Participants such as Mamala and Fau also reported that they could not understand the spoken medical descriptions of their health conditions because of their jargon-laden content. Whānau reported that these forms of communication left them feeling '*dumb*', '*confused*' and too embarrassed to share their lack of understanding with their HCPs. These issues were made more difficult for whānau for whom English was a second language.

In contrast to written and oral forms of information regarding RF/RRF/RHD, visual resources including DVD and video were found to be effective information mediums for participants, regardless of their age or English-language competency. Participants reported that the basic images in these visual clips were easy to understand and to relate to. This finding is supported by findings from a systematic review of 132 health literacy interventions by Houkamau and Clarke (2016), who found that visual images such as cartoons, pictograms and multimedia presentations were more effective health literacy interventions than oral or written communication.

Recommendation: This report recommends that funding be made available for the development of further visual RF/RHD information sources for patient and whānau education that utilise jargon-free language in the English, Māori and Pacific languages.

Secondary prophylaxis health literacy

It was evident from participants' narratives that, while there are significant problems with the manner in which the message has been delivered, as discussed below, the recent 'Sore Throats Matter' media campaigns have been successful in portraying the importance of sore throats as a pathway to contracting RF and RHD and have reinforced the importance of getting sore throats treated. In contrast to the awareness around GAS infections, this research found a gap in health literacy pertaining to secondary prophylaxis. A lack of understanding of secondary prophylaxis, along with structural and health-service factors, affected patients' adherence to bicillin injections and ensured recurrent episodes of RF.

Recommendation: This report recommends that more attention and resources be directed towards improving health literacy concerning secondary prevention for people with RF and RHD.

Deficit framing and RF stigma

The deficit framing of RF/RHD in current health promotion, health literacy and media campaigns is creating a stigma associated with RF. Whānau expressed their anger and upset over RF being portrayed as '*a Māori Polynesian problem*'. Although genetic susceptibility does play a minor role in the pathogenesis of ARF—with current research suggesting that 3% to 6% of people exposed to untreated GAS infection will develop ARF (Bryant et al., 2009; Carapetis et al., 2000; Engel et al., 2011)—this predisposition is similar across populations 'regardless of geography or ethnicity' (Bryant et al., 2009, p. 1). Socioeconomic disadvantages, differences in GAS exposure and variation in access to and quality of health care have been reported to have much greater effects on the variances of RF than genetic susceptibility (Carapetis et al., 2000). Therefore, current RF health-promotion campaigns need to ensure that they do not promote cultural deficit explanations and need to target the disadvantageous environments and health care services that most influence RF, as well as providing messages that facilitate awareness.

Cultural deficit discourses attribute poor outcomes, such as high rates of RF/RHD, to particular cultures and groups of people (Valencia, 1997), in this context, attributing RF/RHD to Māori and Pacific peoples. Currently, sore-throat campaigns are targeted at Māori and Pacific groups and almost exclusively feature images of people with Māori and Pacific socially assigned ethnicities. These images largely convey children bearing scars on their chests from heart surgery and distressed mothers expressing their guilt over not seeking health care for their children or taking their sore throat seriously. By focusing the cause of RF/RHD on the behaviour of Māori and Pacific parents, these advertisements not only frame Māori and Pacific behaviour as problematic but also render invisible the broader structural determinants of health that ultimately cause GAS transmissions and RF/RHD, such as poor housing, lack of employment and economic inequities that stem from historical, colonial processes and racial discourses (Bond, 2005; Borell, Gregory, McCreanor, Jensen, & Moewaka Barnes, 2009; Bryant et al., 2009; Jaine et al., 2011; Kerdemedlidis, Lennon, Arroll, Peat, & Jarman, 2010; Moewaka Barnes, Borell, & McCreanor, 2014; Reid & Robson, 2007).

Houkamau and Clarke (2016) have found a similar deficit effect applied to Sudden Unexplained Death in Infancy (SUDI) health-promotion programmes for Māori, where framing of causation and ‘at risk’ discourses has impeded Māori service engagement and ignored the role of socioeconomic determinants in health. Likewise, Brough, Bond and Hunt (2004) caution against such cultural approaches, particularly within Indigenous health contexts, stating that ‘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’ (p. 216).

Deficit discourses can be embodied by those who are targeted as ‘the problem’, producing internalised racism, stress, stigma and ultimately increasing negative health outcomes for those who are already marginalised within society (Fife & Wright, 2000; Krieger, 2011; Moewaka Barnes, Borell, & McCreanor, 2014). The effect of the deficit discourse surrounding RF was evident in this study. As well as feeling blamed for being responsible for RF, whānau reported feeling stereotyped as irresponsible parents, unhygienic, uneducated and poor. The whānau and HCP narratives revealed how these stereotypes produced a stigma around RF, so that whānau expressed denial, defensiveness and embarrassment towards RF. Disease-based stigma has also been found to create barriers to seeking health care and to maintaining treatment for diseases such as tuberculosis, HIV/AIDS and sexually transmitted infections (Fife & Wright, 2000; MOH, 2014a; Morris et al., 2014) and is an area that should be explored further within RF/RHD contexts.

Recommendations: This report recommends that current health-promotion messages be reviewed and that future messages avoid utilising material that further stereotypes and stigmatises ethnic groups, their cultures and behaviour to avoid maintaining RF/RHD associated stigma. Such an approach would increase the health literacy of RF/RHD in a non-

victim-blaming manner. As well as promoting awareness of the importance of sore throats, RF/RHD promotion should also include secondary prevention and primordial interventions to address the structural determinants of health.

Further research is needed to elucidate RF-related stigma and its impacts on whānau.

RF/RHD support

Māori and Pacific whānau in this study identified social exclusion, emotional stress and guilt as issues of concern in the control and management of ARF/RRF/RHD. There is a huge need to address these stressors for whānau to improve their RF/RHD experiences and their general wellbeing. As discussed above, re-framing the health literacy and health promotion associated with RF/RHD can help in reducing the parental guilt associated with RF/RHD. No whānau in the study reported involvement in traditional patient and family support and advocacy groups.

Sharing health-related experiences and seeking health information and advice from the internet is becoming increasingly popular (Griffiths et al., 2012). Given that some whānau in this study used the internet as a key source of information for their RF/RHD, an internet-based support network for patients and whānau with RF/RHD may merit further investigation. Such a support network could overcome the geographic barrier of distance between whānau who experience RF/RHD in Aotearoa. 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., 2012, p. 1). Although there has been little published evaluation of the effectiveness of internet support groups (ISGs), a randomised control trial of ISGs for depression undertaken by Griffiths et al. (2012) found that such resources were effective in reducing the depressive symptoms of ISG members. However, a critical discourse analysis by Strong and Gilmour (2009) of ISGs for heart failure found that most ISGs utilise biomedical discourse, which can be confusing for some patients. Rowsell et al. (2015) also highlighted that for ISGs to be effective they should include simple language, audio and audio-visual information and must structure their content to patient needs.

Recommendation: This report recommends that further research be undertaken to determine the most appropriate manner of providing patient and whānau support and advocacy, including exploring the need for and the accessibility and feasibility of developing an ISG for RF/RHD information and support.

Strengths and limitations

This study provides a qualitative context for research on RRF/RHD in Aotearoa, seeking to understand the experiences and narratives of people living with RRF/RHD. Both nationally and internationally, this is the first research to hear the personal stories and experiences

behind the numbers presented in epidemiological and other reports on RF/RHD. The study emphasises the value of Māori and Pacific whānau voices, alongside the narratives of health care professionals, to provide a comprehensive understanding of RF/RHD experiences.

The recruitment strategies used for this research may have resulted in selection bias. RF/RHD patients and their whānau who were lost to follow-up care and could not be contacted and those who did not want to participate in the study may have had different experiences from those participants who did consent to participate in this research. The findings may not, therefore, represent the diversity of whānau experiences.

The health care professionals interviewed were merely a sample of the providers involved in the assessment, diagnosis and management of children, young people and adults with RF, RRF or RHD. Attempts to recruit HCPs less directly engaged in the provision of care for RF/RHD were unsuccessful. The perspective provided by the HCPs who participated in this study is therefore that of HCPs actively involved in the provision of care for RF/RHD and is thus not considered representative of all HCPs.

Conclusion

This study applied an innovative, qualitative research approach that undertook a kaupapa Māori methodology and talanga and kakala Pacific research methods. Participants (n = 113) included Māori and Pacific patients who had RRF, RHRF or unexpected RHD and their whānau. Health care professionals who worked within RF/RHD contexts were also included in the sample. Thirty-eight whānau interviews (with a total of 80 whānau members), six focus-group interviews (with a total of 24 secondary prophylaxis providers) and nine semi-structured, individual interviews with other health care professionals were undertaken in seven DHB regions within Aotearoa: Northland, Auckland, Waitematā, Counties Manukau, Waikato, Hutt Valley, and Capital and Coast.

Recurrent episodes of RF and RHD had significant physical, emotional, social and economic impacts on whānau and often compounded existing difficulties within the complexity of their daily-life contexts. Awareness of the importance of sore throats in relation to RF has improved as a consequence of targeted health-promotion campaigns. However, understandings of RF causation, as a result of these campaigns, were commonly based on deficit cultural constructions that produced internalised racism, conflict and stress for participants. Knowledge about the secondary prevention methods for RF was found to be limited.

It was evident from the whānau experiences of their pathways through health care—from the onset of symptoms until their eventual diagnoses—that barriers to accessing health care, poor rapport and communication with primary health care providers and the lack of awareness of sore-throat and RF guidelines on the part of HCPs led to missed and delayed diagnoses of ARF/RRF for whānau.

The key barriers to the treatment and management of ARF/RRF/RHD identified were barriers to accessing RF and GP clinics for secondary prophylaxis; the costs of prophylaxis (from GP clinics); the mobility of whānau and the difficulty for RF services in tracking the whānau when moving within and between DHB regions; racism, lack of rapport and communication with HCPs; lack of age-appropriate services for youth; the pain caused by the bicillin injections; and lack of health literacy in secondary prophylaxis.

The key facilitators for the treatment and management of ARF/RRF/RHD identified were whānau-oriented, community-based models of care; good communication and rapport with HCPs; jargon-free communication and the use of visual aids in health-information provision; whānau advocacy and support; and good communication and referral pathways within and between DHBs.

This research was able to elucidate the broad impact of RF/RHD experiences on whānau and to identify barriers and enablers of pathways to health care and to the management



of RRF/RHD. The recommendations in this report are made to facilitate better experiences of RF/RRF/RHD for whānau and to improve health literacy as well as the diagnosis, treatment and management of RF/RHD in Aotearoa (refer to page ii for a summary of recommendations). The next phase of service delivery and research should be to consider the implementation of these recommendations and to evaluate future interventions.

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Appendix A: Whānau summary information sheet—English

Whānau experiences of rheumatic fever

Kia ora to you and your whānau.

Thanks for being part of our study on rheumatic fever and rheumatic heart disease. Your part in this study will help the Ministry of Health to make changes to improve health for our whānau in the future. We will have or will be inviting your whānau to a hui to hear about this study and will ring you to talk about this. We ended up having 113 people take part in this study. They were people like you and your whānau as well as doctors and nurses. We found a lot of interesting things about rheumatic fever and rheumatic heart disease that we would like to share with you, they are:

Experiences with healthcare

- Often it was difficult for whānau to get to see their doctors or get to clinic and hospital appointments for lots of different reasons.
- Doctors and other health providers often did not explain health information very clearly to whānau and did not treat patients in a way that created trust.
- Doctors often did not swab sore throats when people came to see them about a sore throat.
- Nurses and community health care people often helped whānau get to appointments, go shopping and with WINZ and housing.
- Whānau sometimes found hospitals and health care providers were racist and did not treat them the same as everyone else.



Information about rheumatic fever

- Because of ads on TV most whānau know that sore throats can cause rheumatic fever and that if you get a sore throat it should be swabbed by a health care professional. But lots of whānau felt angry and upset that these ads seemed to blame Māori and Pacific people for having rheumatic fever.
- Whānau liked having pictures and videos to watch about rheumatic fever rather than reading information about it or having doctors explain it to them.
- Lots of people who have injections for their rheumatic fever and rheumatic heart disease do not know why they had to have these or why they have to keep having them for so long.



Experiences with injections

- People found getting their injections painful and liked it when they were given injections that were slow, and when numbing medicine and buzzy ice packs were used.
- People often were not able to get their injections when they left school, moved home or left New Zealand.
- Most whānau liked having nurses come to them to give their injections so they did not have to go to doctor or clinic to get them.



Impacts of rheumatic fever

- Rheumatic fever and rheumatic heart disease have big influences on whānau emotionally, on their body and health, on their relationships with people and communities, and can have money impacts from not being able to work.



If you would like to know more about this study or if you have any questions for us about it please feel free to contact Anneka, one of our researchers. Her email is a.anderson@auckland.ac.nz, or you can ring her on 09 373 7599 ext 83373.

Appendix B: Whānau summary information sheet—Tongan

Taukei 'ae fanau 'ihe Mofi Hui

Malo e Lelei,

'Oku mau fakamalo atu 'i ho'omou tokoni kihe fekumi felave'i moe Mofi Hui moe Mahaki Mafu. Ko ho'o tokoni 'e 'aonga lahi ia kihe Potungau Mo'ui ke fakalelei 'aki 'ae ngaahi ngaue kihe mo'ui 'etau fanau 'ihe kaha'u. Temau fakafaafe'i koe kiha fakataha kemou fanongo kihe ola 'oe fakumini, pea temau telofoni atu felave'i moe me'ani. Hilli 'ae fekumini na'e lava ke kau mai kiai 'ae toko 113. Koe fa'ahinga hange pe ko koe mo ho'o fanau pea pehe kihe kau toketa moe kau neesi foki. Ne mau 'ilo'i 'ae ngaahi me'a mahu'inga felave'i moe Mofi Hui moe Mahaki Mafu 'ihe fekumini pea 'oku mau loto ke vahevahe mo kimoutolu kau ai 'ae ngaahi me'ani:

Taukei moe ngaahi ngaue kihe Mo'ui

- Koe taimi lahi 'oku faingata'a ke 'ave fanau ke sio kihe toketa pe a'u kihe kiliniki pe 'ai ha 'apoinimeni tupu meihe ngaahi 'uhinga kehekehe.
- Koe taimi lahi 'oku 'ikai ke fakamatala'i mahino 'ehe kau toketa moe kau ngaue kihe fanau 'ae Mofi Hui pea 'ikai ke faito'o fakalelei kinautolu 'iha founga fefalala'aki mo'oni.
- Koe taimi lahi 'oku 'ikai ke to'o pe sivi fakalelei 'ehe kau toketa ha tokotaha mahaki 'oku ha'u 'o talatala felave'i moe mamahi hono monga.
- Koe taimi lahi 'oku fa'a tokoni 'ae kau neesi moe kau ngaue kehe kihe 'ai 'oe 'apoinimeni 'ae fanau, 'ave kinautolu ke fai ha'anau fakatau pea pehe kihe WINZ moe kautaha fale.
- Koe taimi lahi 'oku fakatokanga'i 'ehe fanau 'oku lau lanu 'ae kau ngaue falemahaki moe kau ngaue kehe pea 'oku 'ikai ke tatau 'enau tokanga'i 'ae tokotaha kotoape.



Ma'u'anga Fakamatala kihe Mofi Hui

- Koe'uhi koe ngaahi tu'uaki 'ihe TV, 'oku 'ilo'i ai 'ehe fanau 'ae tupu'anga 'oe Mofi Hui, pea kuopau ke sivi 'ehe toketa kapau 'e mamahi honau monga. Ka koe taimi lahi 'oku loto mamahi mo 'ita lahi 'ae fanau moe famili 'ihe hanga 'ehe ngaahi tu'uaki ia 'ihe TV 'o tukuaki'i 'ae kau Maui moe kau Pasifiki he'enau puke he Mofi Hui.
- 'Oku leleiange kihe fanau kenau sio vitio pe mo sio fakatataa kihe Mofi Hui kae 'ikai koe lautohi pe ihe ngaahi pepa fakamatala pe koha fakamatala'i 'ehe kau toketa kiate kinautolu.
- 'Oku tokolahi 'ae kakai 'oku huhu kinautolu kihe Mofi Hui moe Mahaki Mafu, ka 'oku 'ikai kenau 'ilo'i 'e kinautolu pe koe ha hono 'uhinga 'oku huhu ai kinautolu he fu'u taimi loloa pehee.



Taukei 'ihe huhu faito'o

- 'Oku mamahi'ia 'aupito 'ae kakai 'oku huhu faito'o kinautolu kihe Mofi Hui. 'Oku nau sai'ia he 'ikai huhu fakavavevave'i kinautolu pea ki'i fakaongonoa 'aki ha faito'o mo ngaue'aki 'ae 'aisi poloka.
- Koe taimi lahi 'oku 'ikai ke fa'a lava ke huhu faito'o 'ae fa'ahinga tokolahi he 'osi 'enau ako pe ko ha'anau hiki pe mavahe mei Nu'usilani.
- Koe tokolahi 'oe fanau 'oku nau sai'ia ange ke ha'u 'ae neesi kiate kinautolu 'o fai honau huhu kae 'ikai ko 'enau oo kihe toketa pe koe kiliniki.



Koe nunu'a 'oe Mofi Hui

- 'Oku uesia lahi 'aupito 'ehe Mofi Hui moe Mahaki Mafu 'ae mo'ui faka 'atamai mo faka sino 'ae fanau, pea pehee kihonau va moe kakai moe komiumiti pea kau ai mo 'enau mo'ui faka 'ekonomika he 'ikai kenau ngaue.



Kapau 'oku ke toe fie 'ilo kiha me'a felave'i moe fekumi ni, pe 'oku iai ha'o toe fehu'i felave'i moia, kataki kae fetu'utaki mai kia Anneka, koe taha ia 'oe kau fakatotolo.

Ko'ene Emeili koe:

a.anderson@auckland.ac.nz, pet eke telefoni kihe 'ene fika koe: 09 373 7599 ext 83373.

Appendix C: Whānau summary information sheet— Samoan

Silafia o aiga I a'afiaga I le fiva rumatika

Si o'u alofa talofa ia te oe ma ou alo i la tatou su'es'uega I le fiva rumatika fa'apea le fiva ma'i fatu. O lau fesoasoani i lenei galuega o le a fesoasoani ai i le Matagaluega o le Soifua Maloloina o e fesoasoani ai I le fa'alelei atili o latou soifua maloloina i le lumanā'i. O le a matou valaauina outou alo i se fonotaga e fa'afofoga I lenei su'es'uega ma o le a matou telefoni atu ai i se taimi. E atoa le 113 tagata na auai I lenei su'es'uega. O I latou o ni tagata e pei o lau susuga ma foma'i ma teine tausima ma'i. E tele ni mea lelei na matou maua I la matou su'es'uega e uiga i le fiva rumatika ma le fa'ama'i fatu ma ou te mana'o e auai fa'atasi ma oe:

O le masaniga ma le tausiga o ma'i (Health care)

- E masani la ona faigata le fanau e va'ai la latou foma'i pe o i le fale ma'i pe tausima la latou taimi fuafuaina I le fale ma'i mo le tele o ala 'ese'ese.
- O foma'i ma isi tagata tausima ma'i e le manino la latou fa'amalamalama I le fanau pe lē maua e i latou le fa'atuatuaga o le fanau.
- E masani i all'i foma'i ona le solo fa'ai o le fanau i le taimi e saili ai e i latou se filemu.
- O le masaniga a teine tausima ma'i ma isi tagata e tausima le soifua maloloina o tagata lautele e fesoasoani i tagata e fai la latou fa'atuga, WINZ fa'apea le su'ega o latou fale.
- O le fanau e masani ona va'ai i latou i le fa'aaloga lanu o falema'i ma tagata tausima ma'i ma e lē tutusa le faiga o i latou ma isi tagata.



Talaaga I le fiva rumatika (information)

- Ona o le tele o fa'aaliga I luga o le televise o le to'atele o le fanau latou te iloaina e mafai e le fa'ai mafatia ona maua ai le fiva rumatika ma afai fo'i e te mauaina le fa'ai mafatia ua tatau on fufulu ese e se tagata polofesa fa'apitoa. O le lē ausia o lenei fa'amoemoe ua tu'ua'ia e tagata Maori ma tagata Pasefika ile va leaga oi latou ma tagata tausima ma'i.
- E manana'o le fanau I matamata I ata ma video e uiga I le fiva rumatika fa'apea le fama'i fatu. Latou te le fia iloa pe aisea latou te maua ai I le fa'ama'i pe o le a fo'i le umi. Latou te le mana'o I se foma'i e fa'amatala ia i latou.



O le masaniga ma Tui Ona (injections)

- O le to'atele o tagata e tiga o latou tui ona. O le ala lea ua latou fa'atuai ai le galuega ma fa'aoga ai le aisa malūlū.
- E tele tagata e lē maua o latou tui ona pe'a o ese mai le a'oga, o ese mai o latou aiga ma o ese mai NiuSila.
- O le to'atele o le fanau e fiafia tele e omai teine tausima'i e fai latou tui ona ona e le mana'omia ai le o i foma'i po'o fale ma'i.



A'afiaga o le fiva rumatika

O le fiva rumatika ma le fiva mo le ma'i fatu e tele lo la a'afiaga i le lagona o le fanau, io latou tino ma lo latou soifua maloloina, i lo latou va ma isi tagata ma isi nu'u, ma e a'afia ai fo'i le tupe pe'a fai e lē faigaluega.



Afia e te toe fia malamalama atili I lenei su'es'uega e mafai ona e fesili mai ia i matou. Fa'molemole faafesota'i Anneka, o se tasi oa matou tama'ita'i sue'su'e.
O lana imeli o le "a.anderson@auckland.ac.nz," pe telefoni ia te ia i le 093737599 ext. 83373.