Health care experiences of Pacific families who have children with rheumatic fever

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Executive Summary

This report outlines a Counties Manukau Health (CMH) and Ministry of Health (MOH) commissioned study about the health care experiences of Pacific families in the Auckland region who have had children admitted to hospital with rheumatic fever. The goal of this project is to contribute to improving health services provided to Pacific children with rheumatic fever, and their families.

The project used an experience-based design approach, enabling families to tell their stories and focusing the research on what matters to families through an enhanced understanding of their experiences and perspectives.

Study procedure

The study used predominantly qualitative data with relevant quantitative data, collected through multiple sources and methods. Information was captured through four mechanisms:

- focus groups with families discussing rheumatic fever and related health care experiences,
- individual interviews with family members and/or caregivers of children with rheumatic fever,
- telephone interviews with families about the social housing services accessed during their child's illness, and
- an iterative review of relevant health services literature.

Patient characteristics

Information about 20 patients and their families, who participated in one or more of the research approaches, has been used as the basis for analysis and discussion in this report. Information is set out in six main sections and key results include:

Demographic information

- The rheumatic fever patients in the study are young, ethnically diverse and predominantly NZ born.
- Parents and/or other main caregivers are predominantly migrants to NZ (Pacific born).
- Families live in large and multi-generational households in comparison to regional and national averages, composed of parents, grandparents, extended family, non-related families and high numbers of children.
- Households have frequent visitors and household composition is fluid.
- Families provide the main source of support to patients and parents/caregivers.

Other sick family members

- Many households have multiple family members (often children) with serious health conditions.
- Several families have one or more family member previously diagnosed with rheumatic fever.

Housing and experience of social services

- Almost all families live in the most deprived areas of Auckland.
- Home ownership rates are low. The majority of families rent their homes – predominantly Housing New Zealand properties.
- Almost all families live in households that experience structural overcrowding and, to a lesser extent, functional overcrowding. Families are less likely to perceive their living arrangements to be crowded.
- Very few families were referred to a social housing provider during their child's illness.
- Most families had an awareness of available social support, but could not - or did not - access the assistance they needed.

- The place of residence and household composition changed for some families after a rheumatic fever diagnosis.

Rheumatic fever prevention and health promotion

- In many families, more than one family member had been treated for a Group A Streptococcus infection.
- Most participants had limited or no knowledge about rheumatic fever before their child became unwell.
- There was possible confusion amongst families with rheumatic fever health promotion messages and other health messages targeting Pacific communities.
- There was a high awareness of rheumatic fever sore throat campaigns, but many families wanted more information solely about rheumatic fever.
- There were high levels of engagement with school and community sore throat swabbing and antibiotic treatment initiatives.

Primary health care

- Almost all families were enrolled with a primary health care service provider.
- Directly prior to rheumatic fever diagnosis, many families made multiple visits to their primary care provider for the same health complaint. Many families reported dismissal of concerns and delayed diagnosis and referral for specialist rheumatic fever testing or treatment.
- Some families felt that they received improved primary health care services after changing provider.
- The most common presenting symptom related to painful, swollen joints.
- Families respected the clinical skills and expertise of health professionals, but wanted greater input and involvement during consultations and treatment.
- Communication and language barriers were a common theme. Waiting times, brief consultations and clinic opening hours were other identified barriers to receiving appropriate care.

Hospital treatment and secondary care

- During the stress of rheumatic fever diagnosis and admission to hospital, language assistance and clear explanation of complex information were available and were important to families.
- Most children were receiving prophylactic penicillin injections. A few families reported difficulty in scheduling convenient appointments for monthly injections.
- Many families received care that they felt was inappropriate or substandard, but few had made a complaint through formal or informal channels.
- Understanding of rheumatic fever, even after hospitalisation and treatment, was poor amongst many families.
- There was a desire to share experiences and learning with other families of children with rheumatic fever.
- The impact of rheumatic fever on children and their families' well being.

Individual case studies of five patients are also included in this report.

Key findings

The research identified the following three main areas of particular relevance to rheumatic fever services:

Families are endeavouring to do the best for their children in challenging socio-economic and other circumstances

The central role of family and the efforts of families with high health and social needs to do the best for their children in challenging circumstances is a key finding of this research. Extended families provided the main source of support to children and their caregivers during rheumatic fever diagnosis, hospitalisation and treatment. This is a sign of cohesion and strength within the family unit, but is also a considerable strain for families with already stretched resources.

Well resourced secondary services, particularly for rheumatic fever, provide acute focused, thorough and prolonged treatment (typically weeks or months) for an affected child, while family members at home remain at risk. These issues are compounded when, as was the case in this study, other family members (frequently other children) suffer from serious health conditions, including rheumatic fever.

In addition, unmet social needs due to fragmented, reactive and often poorly coordinated health and social services, further highlight the need for a 'family' model of care, that understands these specific circumstances and offers meaningful and coordinated responses that recognise the needs of the family unit as a whole.

Health literacy has a central, yet complex role in rheumatic fever prevention and primary care pathways and needs to be better understood

While some participating families felt positive about the rheumatic fever messages and information they received, many raised questions about the effectiveness of health promotion campaigns. Knowledge gaps amongst families about rheumatic fever, both at the time of diagnosis and after diagnosis, hospitalisation and treatment, were apparent and suggest a need for further consideration of how to tailor messages to engage and inform Pacific communities more effectively.

Multiple presentations for the same health complaint, dismissal of symptoms by clinical staff and a clear pattern of delayed diagnosis, point to concerning issues around primary health care's 'gatekeeper' role for access to secondary services through the timely diagnosis and referral of children with suspected acute rheumatic fever. It is increasingly recognised that health literacy must be defined as a two sided concept, with professional health literacy as important as patient health literacy. Quality primary care for Pacific people requires highly skilled practitioners that understand the needs of Pacific patients and families. Critical to this is a more in-depth understanding of the 'triple threat' to health communication - a broad conceptualisation of health literacy, alongside consideration of the complex barriers related to English proficiency and cultural competence.

The beliefs, attitudes and previous experiences of Pacific families are key to developing a model of care for Pacific families

Many families hold the health profession and skills, knowledge and expertise of clinical staff in high regard – often reverence. For Pacific people, the quality of the healthcare they experience is often measured by the establishment of respect and observance of relational boundaries. Positive and negative experiences for families were usually focused around communication and relational aspects of care (the presence or absence of an ability to be understanding, caring, personable and culturally respectful and sensitive).

When instances of inappropriate and often sub-standard treatment were experienced, it was repeatedly found that families rarely complained through formal or informal channels. These kinds of practical

challenges can confront Pacific families at any number of stages during their journey through the health system. A lack of empowerment, lowered expectations and not feeling entitled to quality services and care characterised many family experiences of their rheumatic fever primary and secondary care.

This research was guided by Pacific cultural values as outlined by the HRC and used Pacific cultural methodologies. Rich information was gathered about families' experiences of services. The level of unmet needs reported by families in relation to health and social services as well as emotional well-being demonstrates the importance of research approaches that contribute to enlightenment and empowerment of Pacific communities.

Conclusion

The research highlights that the persisting prevalence of rheumatic fever in Pacific populations is influenced by a vast and interrelated array of socio-economic, cultural, systemic and clinical factors. Despite a considerable level of activity to address this significant health burden in New Zealand, knowledge about the aetiology of rheumatic fever is still lacking and there is a notable lack of evidence about how effective rheumatic fever interventions are for Pacific communities.

Recommendations

- Further research, drawing on the perspectives and experiences of Pacific patients and families, to develop a Pacific family model of care that:
    - recognises the characteristics of Pacific family units that are very different to the New Zealand norm,
    - supports the needs of family members in their role as primary caregivers to children with rheumatic fever, and
    - supports family knowledge, understanding and ability to access social services at key points of need.
- Further consideration of the role of health literacy in relation to health promotion and pathways to and through primary health care.
- Further development and use of research methodologies based on Pacific cultural values to ensure safe engagement with families and to enhance the richness and knowledge of diverse patients and their families experiences of health services within the New Zealand context.

Table of Contents

Table index

Figure index

1. Introduction

This report outlines a Counties Manukau Health (CMH) and Ministry of Health (MOH) commissioned study about the health care experiences of Pacific families in the Auckland region who have had children admitted to hospital with rheumatic fever. The goal of this project is to contribute to improving health services provided to Pacific children with rheumatic fever, and their families. The project used an experience-based design approach, enabling families to tell their stories and focusing the research on what matters to families through an enhanced understanding of their experiences and perspectives.

Patient and family experiences were explored through broad themes relating to their personal circumstances and understanding of their child's health and illness. Families understanding and experience of rheumatic fever and rheumatic fever services were explored specifically through:

- personal circumstances and risk factors at the time of their child's diagnosis with rheumatic fever,
- housing circumstances,
- access to social services that families required to meet their child's health needs,
- knowledge and understanding of what causes rheumatic fever and how it can be prevented,
- experiences of health promotion and prevention initiatives for rheumatic fever and rheumatic heart disease, and
- experiences of the pathways to and through primary and secondary health care services during their child's illness.

2. Method

This project was designed to capture the experiences of Pacific families in the Auckland region who had children admitted to hospital with rheumatic fever in 2013 and to provide a demographic and socio-economic context for these findings. The project was run in parallel with a CMH project about the social housing situation of Pacific families in Auckland (*Access to social housing for Māori and Pacific families in Auckland who have experienced rheumatic fever*, March 2015). Relevant evidence from the social housing research is used in the analysis for this report.

2.1. Study Procedure

This was a multimethod study using predominantly qualitative data with relevant quantitative data collected through multiple sources and methods. Information was captured through four mechanisms:

- focus groups with families discussing rheumatic fever and related health care experiences,
- individual interviews with family members and/or caregivers of children with rheumatic fever,
- telephone interviews with families about the social housing services accessed during their child's illness, and
- an iterative review of relevant health services literature.

This report synthesises data collected from research projects that occurred in parallel. The multiple methods used to collect the data enabled the research team to respond to emerging themes.

Qualitative research methods using focus groups and in-depth interviews with individual participants and/or their families were chosen as the main method to capture the richness and depth of patient experience (Patton, 1990). Pacific cultural research methodologies using the process of talanoa (Southwick, 2012) provided the overarching framework for the research design. The talanoa is embedded in the context of ongoing relationships (or "va") with communities, families and individuals.

Although a semi-structured interview schedule was developed to guide the interviews (Appendix A), Pacific Perspectives' (PPL) approach was to facilitate a narrative or 'story telling' approach about **what mattered to the patient**. This enabled participants and their families to raise aspects of their experiences that were important to them, in their own voice (Moekawa Barnes, 2000).

Each family contacted was provided information about the research projects, and asked for written or verbal consent to participate in the research (refer Appendix B for consent questions). All interviews and focus group sessions were recorded on a dictaphone, transcribed and where required, translated into English. Figure 1 shows the four information gathering mechanisms.

Figure 1. Four research mechanisms

Rheumatic Fever Research	Social Housing Research	One-on-one Interviews	Literature Reviews
•Research the health care experiences of Pacific families with children treated for rheumatic fever in 2013. •Initiated through focus groups.	•Research access to social housing for Māori and Pacific families in Auckland who have experienced rheumatic fever. •Initiated through survey conducted over the phone in an interview style.	•Selected participants from the rheumatic fever research (focus groups) and social housing research (survey) were chosen for further interviews to explore themes in more detail.	•Background to focus groups and survey. •Targeted review of rheumatic fever literature. •Targeted review of overcrowding literature. •Further exploration of themes, including Pacific people, migrant and minority populations, to inform discussion.

Rheumatic fever focus groups

Focus groups were hosted by CMH (Ko Awatea) in December 2014 and facilitated by the PPL research team. CMH recruited 23 Pacific families to participate in the focus groups from a total database of 119 patient records (for more detail see Appendix C). An initial session to introduce the research project and provide information about rheumatic fever was followed by facilitated ethnic-specific focus groups conducted in participant's preferred language. Focus groups were conducted in Cook Island Māori (1), Samoan (2), Tongan (1) and English (1).

Facilitators were provided with a set of themes and questions to guide the interviews and draw out patient and family perspectives about:

- their understanding of rheumatic fever,
- their experiences of health services for the prevention and treatment of rheumatic fever, and
- aspects of coordination, communication, partnership, physical, emotional and cultural needs.

Social housing survey

In January 2015, the MOH commissioned PPL to undertake a project on Social Housing (called *Access to social housing for Māori and Pacific families in Auckland who have experienced rheumatic fever*). The research included a survey designed to answer a list of eight questions asked by the MOH. The survey included a mixture of open and closed questions in four areas:

- demographic information,
- information about the patient's housing situation,
- referrals to social housing services, and
- referrals to other social services.

201 patient records from CMH (119), Auckland DHB (63) and Waitemata DHB (19) were supplied for the research. In total, 53 families were surveyed through phone interviews during February 2015. Of the 53 families, eight patients were identified as of Māori and 45 as of Pacific ethnicities. Interviews lasted an average of 40 minutes, and were conducted in English (for more detail see Appendix C).

In-depth interviews

To explore emerging themes from the rheumatic fever focus groups and social housing survey, in-depth interviews were conducted with families purposefully selected from the focus group and survey

participants. Families were selected on the basis of ethnicity – to capture information from the range of Pacific ethnicities identified; and experience – to capture the range of experiences had by families. Eight families who had participated in either the focus groups or survey were interviewed during April 2015. The interviews were conducted face-to-face in the family home or by phone in the participant's chosen language (English and Tongan).

Literature review

An iterative process of review of health services literature was conducted throughout the project. Literature reviews provided the basis for engagement with patients and patient's families. Two targeted literature reviews were also undertaken – one with a focus on rheumatic fever, the other with a focus on overcrowding. Relevant health services literature for Pacific people and similar migrant, minority populations with complex health and social needs due to multiple chronic conditions was reviewed and informs the discussion in this report.

Koha and reciprocity

All participants received a koha as recognition for their contribution of information to improving health services for the community.

PPL have committed to taking the findings of this research back to patients and families. Our intention is to provide more than a summary of individual information back to the participants, and we are working with CMH to determine a process for sharing information that responds to the participant's preferences for group learning (expressed during focus groups).

These approaches reflect the "uluulumatafolau"[1] phase of the Pacific research methods used by PPL (Southwick et al, 2012; Pacific Perspectives, 2013) whereby the researcher investigates opportunities to reciprocate the gift of knowledge imparted by participants. This is different to the giving of koha, as the concept of reciprocity in this context is not usually a monetary transaction.

This approach to translational research is also consistent with Durie's (2014) recommendation that effective research for Pacific communities includes activities that contribute to enlightenment through new models for learning (research reporting suitable for community consideration) and empowerment of Pacific communities (the fono principle).

2.2. Qualitative interview analysis

Analysis involved multiple readings of the transcribed focus groups and interviews (survey-based and in-depth interviews) by members of the research team. Data from each source of information (focus group, survey and in depth interviews) was sorted into key ideas or themes. Those common to all or several interviews were identified and are discussed in this report.

2.3. Individual case studies

Interview summaries for five participants has been presented in section four of this report. The case studies include the five Pacific ethnic groups that participated in the study. Case studies are made up of the information about the participant's personal circumstances and a summary of their stories from the focus group, survey and individual interviews.

[1] Uluulumatafoalu translates to "from one heart to another"

2.4. Research team

The PPL research team was led by Dr Debbie Ryan, who had overall responsibility for the research design and integrity of the data. Pacific researchers with appropriate health sector knowledge and experience were recruited to conduct the interviews.

An information package was developed by PPL for all researchers to provide background information and context about the project. All researchers were of the same major ethnicity as the families they were interviewing. Researchers were highly skilled in their specific Pacific language and culture and understood how to apply these skills in appropriate situations and according to the needs of each patient and family. Families had the opportunity to be interviewed in their Pacific language.

2.5. Ethics

This research was commissioned by CMH and MOH to inform efforts to improve the quality of health services for Pacific patients and their families. It was conducted in accordance with National Ethics Approval Committee (NEAC) Guidelines (NEAC, 2012) and the Health Research Council (HRC) Pacific Guidelines (HRC, 2014). Particular care was taken to ensure the safe participation of patients and families and that culturally appropriate processes were employed.

3. Participant characteristics

Information about 20 patients and their families has been used as the basis for analysis and discussion in this report. These 20 families all participated in the social housing survey, 18 participated in the focus groups and 8 were interviewed (see Appendix C for more detail).

Figure 2. How the 20 research participants were reached

This research approach, using multiple methods, provided rich detail about the individual circumstances of participants[2] and their experiences of the range of services they received for the prevention, diagnosis and treatment of rheumatic fever and its sequelae. Information on participants is set out in the following sections:

- demographic information,
- other sick family members,
- housing and experience of social services ,
- rheumatic fever prevention and health promotion,
- primary health care, and
- hospital treatment and secondary care.

3.1. Demographics

Summary

- The rheumatic fever patients in the study are young, ethnically diverse and predominantly NZ born.
- Parents and/or other main caregivers are predominantly migrants to NZ (Pacific born).
- Families live in large and multi-generational households in comparison to regional and national averages, composed of parents, grandparents, extended family, non-related families and high numbers of children.
- Households have frequent visitors and household composition is fluid.
- Families provide the main source of support to patients and parents/caregivers.

The age of the patients ranged from 7 years to 17 years, with an average age of 12 years. Five Pacific Island ethnicities were represented: Cook Island Māori (5), Niuean (1), Samoan (8), Tongan (5) and Tuvaluan (1) (see figure 3). The gender of the patients was split evenly with 10 male and 10 female participants.

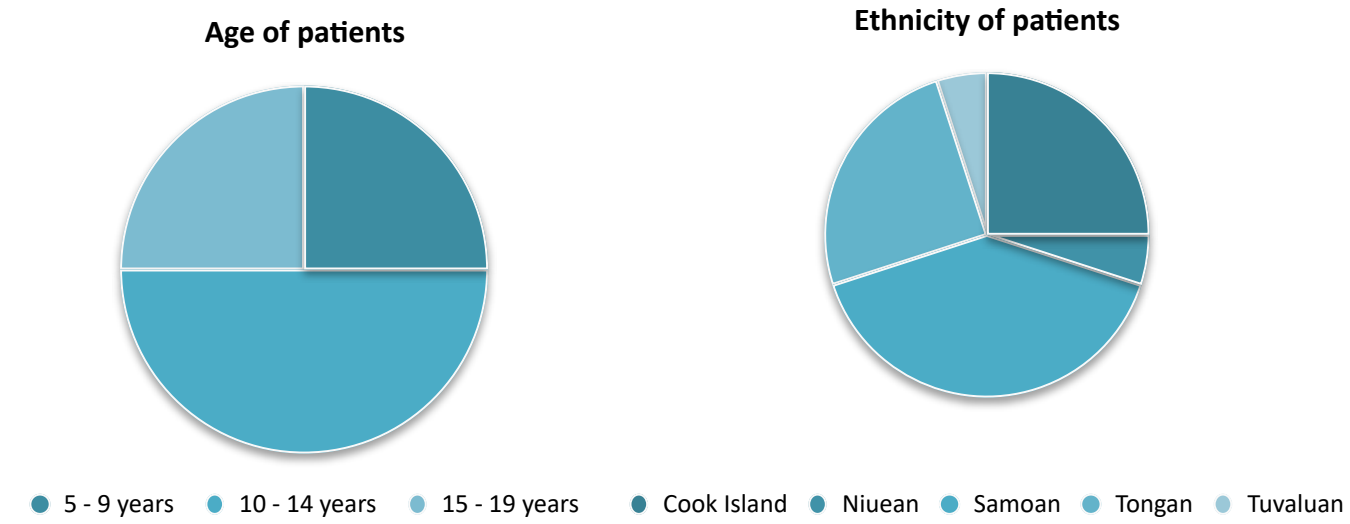
Of the 20 patients, two identified with more than one ethnic group.

- One patient identified with four ethnic groups (Niuean, Samoan, Māori, English).
- One patient identified with two ethnic groups (note however that different information was collected through two mechanisms. The patient identified as Samoan and Scottish in one instance, and Samoan and Fijian in another).

[2] The patient and their family are referred to as the 'research participants' in this report. Where information is specifically related to the individual patient only, this is specified.

Patients were not asked to prioritise ethnicities. Researchers took the first listed as the primary ascribed ethnicity, so these two patients are counted as Niuean and Samoan respectively.

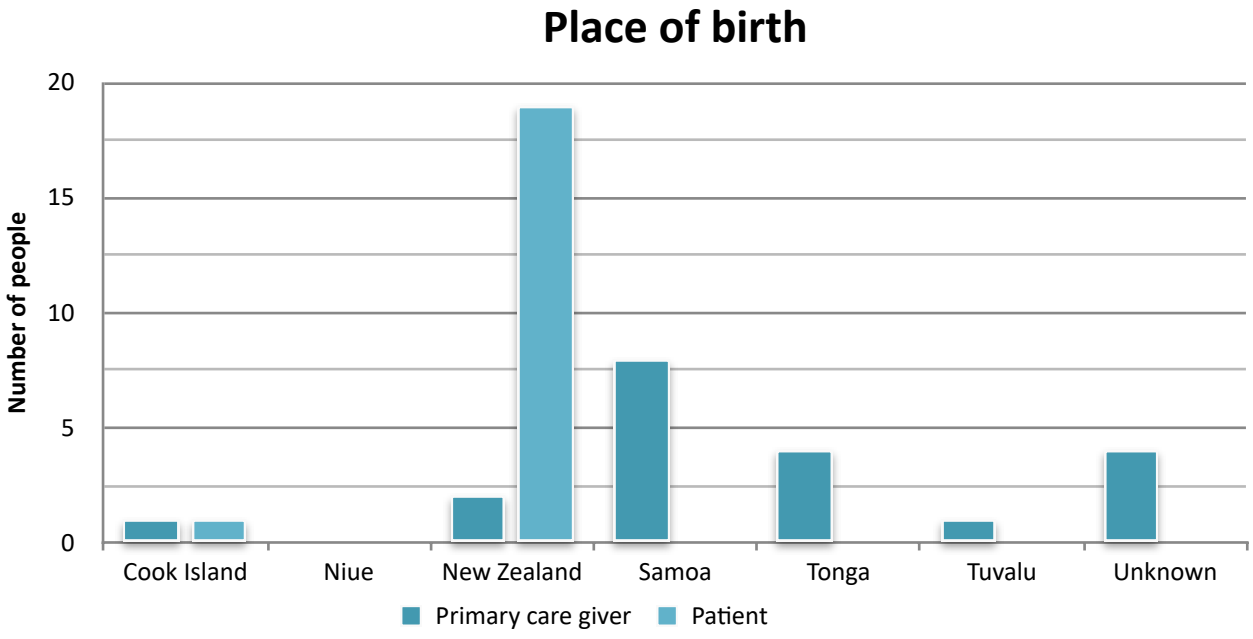
Figure 3. Age and ethnicity of patients



Migrant population

Figure 4 shows 19 out of 20 patients were born in New Zealand and two of the patient's primary caregivers were born in New Zealand. Primary caregivers whose place of birth outside of New Zealand we have identified included the Cook Islands (1), Samoa (8), Tonga (4) and Tuvalu (1) (the question was not completed by four families).

Figure 4. Place of birth of patients and their primary care giver.



Composition of households

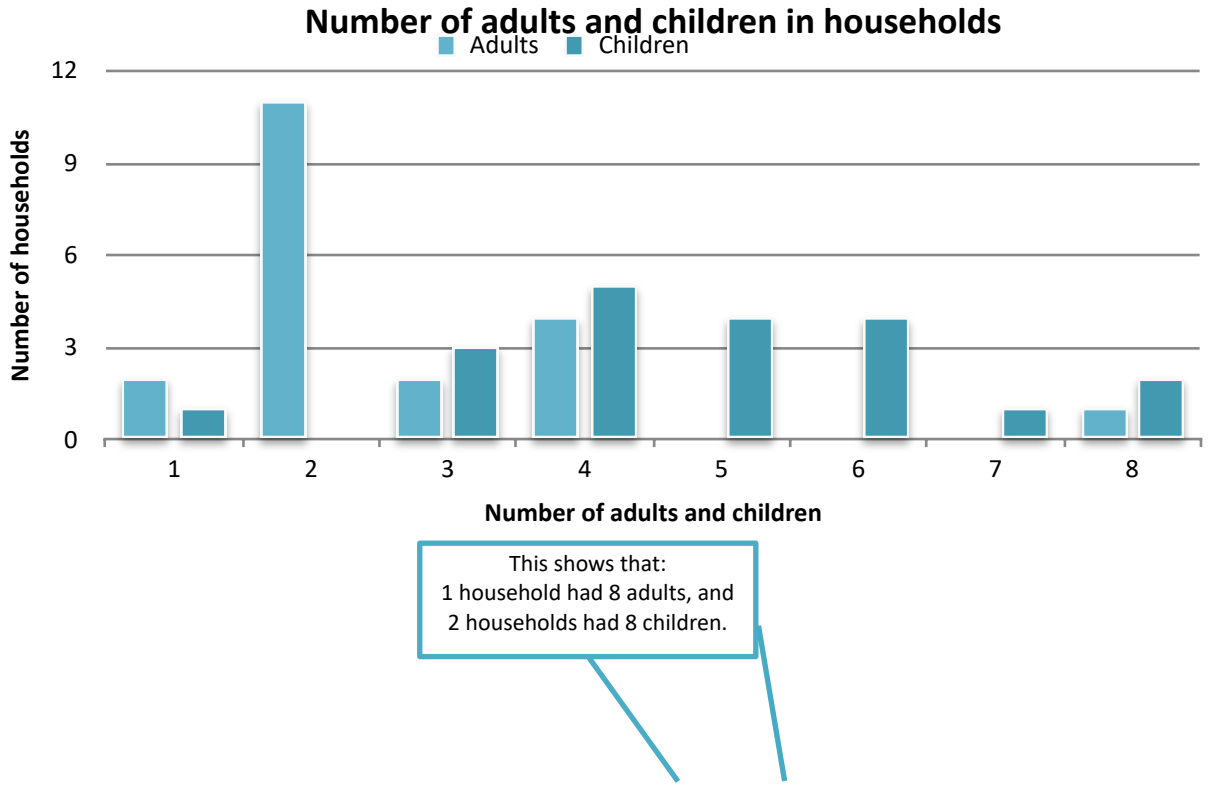
Table 1 shows the number of households with seven or more occupants in Auckland and New Zealand for 2013 and compares that to the rate for the research participants. The research participants were considerably more likely to live in large households (60.0 percent) compared to the average for Auckland (9.5 percent) or New Zealand as a whole (1.2 percent).

Table 1. Large households in New Zealand in 2013 compared to research participants

Locality	Households with 7 or more occupants 2013	% of households 2013
Research participants	12	60.0
Auckland	15,627	9.5
New Zealand	29,226	1.2

Figure 5 shows that 11 out of 20 (or 55.0 percent) of participants' households were made up of two adults. Households that were composed of three or more adults usually included grandparents and other extended family members (for example aunts and uncles, nieces and nephews). Four households had three or fewer children, 13 households had four to six children, and three households had over seven children.

Figure 5. Number of adults and children in each participant's household.



Eight families had extended family visit during 2014. Families had from 2 to 13 people stay with them for a length of time that ranged from three days to six months.

> *"We have guests who come and visit us for a few days during the year. We have no choice but to make space for them. The kids end up sharing their rooms with the children that are visiting and the adult guests end up sleeping in the lounge." Tongan parent 3.*

> *"When our visitors come over, we do marae styles to cater for everyone. My girls love it because they have so much fun." Niuean parent 1.*

Households included extended family members and adopted children. One family included two adults over 65 years old and three children under five years old, which might suggest multiple generations residing in the same house.

> *"I have seven children that aren't biological, some are my biological nieces and nephews, they are my babies because I have had them from birth." Niuean parent 1.*

> *"[child] he's our eldest boy but in our family he's number four, we adopted other kids." Samoan parent 6 (there are five children in the family).*

There was fluidity in the composition of households with other children staying at different times.

> *"[child] is my youngest but [he's not the] the youngest in the house… he's the biggest one in the house. There are smaller children, they're not mine, they're my grandchildren…but three weeks ago I just received another one [child to care for], I'm just caring for this new one because the parents, their lives are not ok. I just grabbed that one for the mean time." Cook Island parent 2.*

Families were the main source of support. Grandparents, aunts and uncles assisted with care of children while in hospital as well as care of other children left at home.

> *"Trying to juggle and get everything and work done, tele a aiga e fesaosaoni ia maua (we had lots of family who helped us), our immediate family took our children." Samoan parent 6.*

> *"For me especially my dad [and the children] they had that special relationship…he would make sure they were up, he would drop all the kids off [to school], he would make sure their lunches are prepared…if I am not here and I have to be somewhere [else]." Niuean parent 1, mother of 7 children.*

3.2. Other sick family members

Summary

- Many households have multiple family members (often children) with serious health conditions.
- Several families have one or more family members previously diagnosed with rheumatic fever.

Children with rheumatic fever often lived in households with other family members, frequently other children, who also had a serious medical condition.

> *"I'm very confident with heart, I know about valves and things, she [sibling] was born with a heart defect, but obviously rheumatic fever I have never really known much about it…I ended up having both daughters in the hospital for two months in the same room. It was stressful at the time and having all my other children, it was really hard." Niuean parent 1.*

> *"The house [we were living] in was very cold, the windows were wet and the house was damp. We had another two children with asthma." Tongan parent 1*

> *"You know I am living on one kidney…I was in hospital nine months." Samoan parent 3.*

Other family member with rheumatic fever

The clustering of rheumatic fever in families is reported in the research literature, although the evidence for genetic susceptibility is conflicting (Ministry of Health, 2010).

Five participating families had a close relative who had previously had rheumatic fever. In two cases the other family member was a sibling and in the other families, the family member was a parent, a cousin and an uncle.

> *"He [sibling] got rheumatic fever last year in 2014. He went to Middlemore hospital and had heart [surgery] at Starship Hospital." Samoan parent 7.*
>
> *"My older brother…was diagnosed with rheumatic fever in 1993. He is 36 now and doesn't have it anymore." Tuvaluan parent 1.*
>
> *"But before my daughter got rheumatic fever my cousin also had rheumatic fever but back in [Cook Islands], so I knew then what rheumatic fever was." Cook Island parent 6.*

3.3. Housing and experience of social services

This information covers:

- housing (data collected primarily through the social housing survey),
- experience of social services and unmet social needs, and
- place of residence (data collected primarily through the social housing survey).

Summary

- Almost all families live in the most deprived areas of Auckland.
- Home ownership rates are low. The majority of families rent their homes – predominantly Housing New Zealand properties.
- Almost all families live in households that experience structural overcrowding and, to a lesser extent, functional overcrowding. Families are less likely to perceive their living arrangements to be crowded.
- Very few families were referred to a social housing provider during their child's illness.
- Most families had an awareness of available social support, but could not - or did not - access the assistance they needed.
- The place of residence and household composition changed for some families after a rheumatic fever diagnosis.

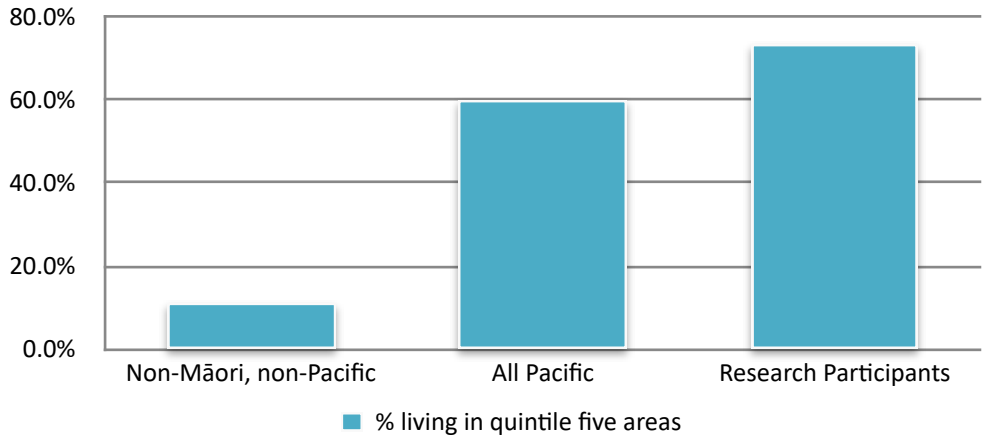
Participants residence against the New Zealand Deprivation Index

Out of 19[3] research participants, 14 (73.7 percent) lived in the most deprived (quintile five) areas of Auckland, with a New Zealand Deprivation Index score of either 9 or 10[4]. This result is consistent with research findings that 74.0 percent of Pacific families in the CMH region live in the most deprived neighbourhoods, compared with 60.0 percent of Pacific families in the Auckland region (Health Partners Consulting Group, 2012). Figure 6 shows the marked contrast with non-Māori, non-Pacific populations with 11.0 percent in the Auckland metropolitan region living in the most deprived neighbourhoods.

[3] Valid address information was not provided by one participant and they were excluded from this calculation.

[4] The New Zealand Deprivation Index is normalized to a ten-point ranking scale from least (1) to most deprived (10) (University of Otago, 2014).

Figure 6. Percentage of groups living in quintile five areas of Auckland



Housing tenure

Housing is a fundamental component of health and the quality of families lives and supporting families into healthy housing is a component of the Rheumatic Fever Prevention Programme (RFPP). In this study we found low rates of home ownership by Pacific families and problems with access to affordable and quality rentals.

Of the 20 families, 16 (80.0 per cent) reported through the survey that they lived in a rented house and four stated the house they lived in was owned by a family member. This compares with two thirds of Pacific households in 2006 (Koloto & Associates, 2007) and one third of all NZ families living in a rental home (Statistics NZ, cited in Oliver et al, 2014).

Additionally, 12 families (60.0 percent) were renting a house from Housing New Zealand. This is consistent with reports that Pacific people are overrepresented in social housing. A report on Pacific households by Housing New Zealand in 2006, found that an estimated 37.0 percent of Pacific households were Housing NZ tenants (Koloto & Associates, 2007). In 2015, MBIE reports that Pacific people make up 25.0 percent of Housing NZ tenants nationally compared with only 5.0 percent of the general population renting homes from Housing NZ (MBIE, 2015).

Other research in NZ on rheumatic fever has reported the association between rheumatic fever and housing tenure. The SHOW study found that 32.0 percent of rheumatic fever cases between 2004 and 2010 rented their homes from Housing NZ, however most of this excess risk was attributed to ethnicity and deprivation (Baker, Zhang & Howden-Chapman, 2012).

Household crowding

To assess the level of household crowding (this was done through the social housing survey) we collected information about the number of bedrooms in each home, the mix of people living in each home, and how families perceived their living situation. We analysed the information using three dimensions:

- The extent of structural crowding – did the family have enough bedrooms to house all of the people living in the house? The Canadian National Occupancy Standard (CNOS)[5] was used to measure this information.
- The extent of functional crowding – did the family 'crowd' together for reasons other than the availability of bedrooms? To understand the level of functional crowding we asked families if they slept together in the same room because the house was hard to heat.

[5] See glossary for more information

- The extent of perceived crowding – did the family feel that they had enough personal space in the home? We asked the families if more people than was comfortable slept in the same room, or if they considered that everyone had sufficient personal and living space.

Structural crowding

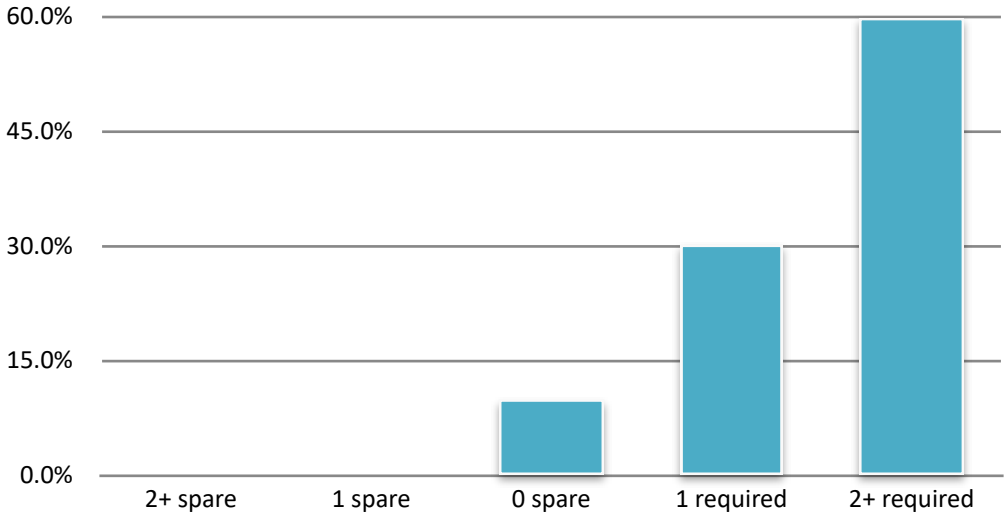
Research participants experienced high rates of overcrowded housing conditions. Based on the mix of people living in each house and the available bedrooms, 18 families (90.0 percent) were living in households that experienced structural crowding (Table 2). This compares with 45.0 percent of Pacific households nationally living in overcrowded conditions (2013 census).

Table 2: Prevalence of structural crowding among participants

Crowded households	Total households	Percent
18	20	90.0

Figure 7 shows the number of additional bedrooms that each household would require in order to have sufficient bedrooms (using the CNOS definition). No families had a surplus of bedrooms. Two families (or 10.0 percent) had sufficient bedrooms and six families (or 30.0 percent) required one additional bedroom. Thirteen families (or 60.0 percent) required two or more bedrooms. This compares with just 3.5 percent of New Zealanders reporting a bedroom deficit of 2 or more bedrooms in 2006. These figures are also much higher than the rates of overcrowding found in the SHOW study, which investigated the relationship between hospitalisations and housing conditions in a large cohort of Housing NZ tenants. A deficit of two or more bedrooms was reported by 14.0 percent of Housing NZ tenants and 24.0 percent of applicants for Housing NZ homes (Baker, et al, 2012).

Figure 7. Distribution of insufficient bedrooms, focus group participants



The median number of insufficient bedrooms was two. Half of all households had a deficit of between one and three bedrooms. The most extreme deficit recorded was seven bedrooms fewer than the needs of the household.

Functional crowding

We collected information about whether families shared living spaces because their homes were difficult to heat (known as functional crowding). Sharing of rooms was relatively common, but appears to be less so than the prevalence of structural crowding. Ten families (or 50.0 percent) shared rooms for sleeping because their homes were difficult to heat (Table 3).

Table 3: Prevalence of functional crowding among participants

Crowded households	Total households	Percent
10	20	50.0

> *"We slept in the sitting room sometimes in the winter so we could get warmth off the fireplace." Samoan parent 7.*

> *"Our house gets very cold especially in the winter. My children end up sleeping marae styles to stay warm. It is also at this time where I'm taking my kids to the hospital the most. I believe it's because of the cold house. I appreciate everything we have, and we make do with what we get but we really need a transfer. We need a transfer to a warmer and bigger house." Niuean parent 1.*

Perception of crowding

We collected information about whether participants considered members of the household to have sufficient living or personal space. We considered a household to be perceived to be crowded if a respondent either agreed or strongly agreed with the relevant statement in the housing survey.

> *"We mainly had to sleep in the same room when it was really really cold. Our personal space seemed crowded but this is all we could afford, so I would say it was okay." Samoan parent 1.*

The survey results indicate that families are less likely to perceive their living arrangements to be crowded when compared to the (normative) structural crowding measure. It is not clear whether this result is indicative of cultural norms relating to the sharing of living spaces among the families surveyed or reluctance on the part of the respondents to describe their living situation in negative terms, although these may provide possible explanations.

12 families (or 60.0 percent) perceived their living arrangements to be crowded (Table 4).

Table 4: Prevalence of perceived crowding among participants

Crowded households	Total households	Percent
12	20	60.0

Unmet social needs

MOH sought specific information about families referred for social housing support. Only two (or 10.0 percent) of the research participants reported, through the housing survey, that they were referred to a social housing provider during their child's illness (Table 5). One family was referred by a doctor to Housing NZ, and another family was given an application form for the AWHI Housing Support Service. Neither family reported a change in their living circumstances following this referral.

Table 5. Proportion of research participants referred to a social housing provider

Status	Number referred	Rate(%)
Referred	2	10.0
Not referred	18	90.0
Total	20	100.0

Experience of social services

Participants reported significant levels of unmet financial and social needs. Most families indicated some awareness that social services support was available however many families reported that they could not get the social services assistance they needed.

> *"We didn't know about any social services when [our son] was being treated, probably because it was the rheumatic fever team that were looking after us…nobody asked us about giving us help." Samoan parent 7.*

> *"No I feel I wasn't referred to social services. It's not because I didn't want their help, I just didn't know there was any help available. I lack the knowledge of where to go and what we are entitled to…In regards to any other social services, I just don't know what kind of help is available for my son. I'm unsure where to apply for these things." Tongan parent 5.*

Although some parents were aware of benefit entitlements or provided with information about how to apply, they did not complete the forms required to access social services support.

> *"The only help I have been offered is the district nurse. She told me that I might be eligible for free insulation. She gave me the form to fill out but I didn't end up doing it because I was so busy at the time and forgot." Tongan parent 5.*

> *"We are looking for help with our transport, for example fuel costs. We haven't yet applied to WINZ for the disability allowance but we will." Tongan parent 2.*

> *"I've always been quite proud and was ashamed to ask for help, somehow I would always [manage], even if I had to go for a loan and make sure that there was food, pay the parking which was $20 that wasn't cheap, food to feed me [while in hospital], I struggled financially a lot at that stage." Niuean parent 1.*

Others reported that processes were overly complex, for comparatively little gain. Many parents were also struggling with work or childcare commitments and there was a lot of feedback about unmet social needs.

> *"WINZ did not help when I asked for a benefit for [child]. They made me go back to the doctor to get a letter even though I had a letter from the hospital. It is hard as I have no one to look after the other children." Tongan parent 1 (mother of 6).*

> *"The social worker talked to me about WINZ, as I was the only income earner…I had to take time off work and we need some support. We did receive support from WINZ but it was a bad experience as it was very hard to get support. WINZ asked me so many questions for me to get a small amount of money…it was a terrible experience." Samoan parent 6.*

> *"Why do they waste time coming to me and I took my lunch time off work to fill in the form and then they tell me my application is declined…" Samoan parent 4 (noted in housing survey that their application for insulation in their home was declined because they did not have a community service card).*

Place of residence

Six of the 20 families (30.0 percent) have moved house since their child was diagnosed in 2013. One child was sent overseas (Australia) to live with family, one family moved out of Auckland to a different part of

New Zealand. The other four families have remained in the same suburb or moved to a neighbouring suburb in South Auckland (across Otara, Otahuhu and Flatbush).

For five of the families that moved, the composition of adults and children in their household also changed. The number of adults changed from 17 to 14, and children from 22 to 29 children.

> *"The house is warmer and we have carpet. We have a big space at the back and front yard." Tongan parent 1.*

> *"I needed to move because it was too expensive for me, my parents have gone [overseas] for three months and I am now looking after the house while they are away…I am going to live here now with my sons long term." Samoan parent 8.*

3.4. Rheumatic fever prevention and health promotion

Summary

- In many families, more than one family member had been treated for a Group A Streptococcus infection.
- Most participants had limited or no knowledge about rheumatic fever before their child became unwell.
- There was possible confusion amongst families with rheumatic fever health promotion messages and other health messages targeting Pacific communities.
- There was a high awareness of rheumatic fever sore throat campaigns, but many families wanted more information solely about rheumatic fever.
- There were high levels of engagement with school and community sore throat swabbing and antibiotic treatment initiatives.

Treatment for Group A Streptococcus

Through the survey we asked participants whether they were aware of other family members who had been treated for a Group A Streptococcus infection.

Eight families reported that one or more family members (11 family members in total) had been treated for a Group A Streptococcus infection. The most common relationship between the person hospitalised with rheumatic fever and the other family member who was treated for Group A Streptococcus was that of a sibling. This relationship type accounted for 9 cases.

> *"Four times the doctor gave antibiotics...four times and the doctor gave him penicillin injection." Samoan parent 1.*

> *"Two of my children had positive throat swabs but after taking the antibiotics they are okay now." Samoan parent 5.*

Health literacy

Most participants had limited or no knowledge of rheumatic fever before their children became unwell.

> *"… But at that time I know nothing about rheumatic fever." "I didn't think it was that serious until they gave us the information." Tongan parent 5.*

> *"I didn't really understand what rheumatic fever was because I had never heard of it before or how it was caused." Tongan parent 3.*

> *"I even approached the Samoan healers to get some help because some people said that it is gout which causes the problem." Samoan parent 4.*

> *"When it [rheumatic fever] first started, I didn't know what this illness is about and how it happened." Cook Island grandparent (parent 1).*

Participant's understanding of what causes rheumatic fever was often linked to diet and nutrition and a couple of parents talked about sharing drink bottles suggesting the influence of, and possible confusion with other prominent health promotion messages targeting Pacific communities, for example MENZ B (don't share spit) and obesity prevention campaigns (exercise and diet).

> *"I blamed myself that my son is affected by rheumatic fever, because I am not doing my duties as a mother. I am not feeding them the right food." Samoan parent 7.*

> *"…so I blame myself and I thought that there must be something wrong at home or maybe it's their diet." Samoan parent 4.*

> *"People tell me it could be overcrowding or it could be an unclean home, I always make sure it (home) is clean…Well I think it's maybe the food." Niuean parent 1.*

Health promotion

All participants were aware of the rheumatic fever and sore throats health promotion campaign. Parents had mixed responses to the radio and television advertisements. A few were positive.

> *"Watching TV and getting info does open your eyes, not only for your child but for the rest of the family." Tongan parent 5.*

> *"I remember there was a TV ad that featured a boy…I think it's great that they have that so people can learn from it." Tongan parent 3.*

Others were less so. A strong theme was that parents wanted more information about rheumatic fever, not just sore throats.

> *"We are not interested in TV ads and radio. It's a waste of money, we are still not informed." Samoan parent 2.*

> *"The only thing I've seen is the ad on the TV where that little boy had an operation, so what I'm asking is that a bit more about that [rheumatic fever] not just about sore throats." Cook Island parent 1.*

Some parents doubted messages about overcrowding as a cause of rheumatic fever because of their experiences growing up in small houses with many siblings and raising their own children in similar circumstances without getting rheumatic fever.

> *"All I could hear is that it is because of overcrowded homes. My house has been overcrowded because I have nine children, but this is the first time it is happened to our family. So I always wonder how I have nine children and we have been living together in a three bedroom home for a long time and no one was sick." Samoan parent 1.*

"I didn't think it was overcrowding because I was brought up living marae style." Niuean parent 1.

Families were sometimes slow to take note of, or dismissed signs of illness in their children.

> *"We thought he was playing around with us, augata e fai feau (trying to get out of chores) and stuff like that." Samoan parent 6.*

> *"They just brushed it off because all my cousins were there." Rheumatic fever patient aged 14 years, Tongan parent 2.*

> *"That morning she couldn't walk and her left ankle was swollen so she just limped and jumped around on her other leg to get around. So that evening I hadn't taken her to the doctor yet because I thought it was a minor swelling and things would get better." Tongan parent 3.*

> *"We didn't really notice anything about rheumatic fever till she started complaining about her knees being sore and us being islanders we used to tease, like you know, 'you're just petepete (fat)', and I think that's the downfall for us islanders, teaching them that they're just too weak, instead of taking it serious." Cook Island parent 4.*

A few parents discussed the use of traditional therapies and self-management approaches.

> *"I told my Mum and my Mum just thought; you know the Samoan way just fofo me (traditional massage)." Rheumatic fever patient aged 11 years, Samoan parent 6.*

> *"…with us being islanders, when we say we've got a sore throat, your parents will say go get a lemon drink or get a Panadol. It's things like that, we're doing things the 'island way'…" Cook Island parent 4.*

> *"So I told my husband to go and get some tea leaves and boil some water to try and soak her feet in." Samoan parent of daughter who presented with swollen feet (Samoan parent 3).*

Parents reported that their children were reluctant to say they were unwell as they were concerned that they would be prevented from playing sports or were focussed on school work.

> *"…but I couldn't stop him from going to school as he was more worried about missing his NCEA exams." Samoan parent 2.*

Health prevention and throat swabbing services

A school based programme targeted at children of primary and intermediate age has been a major part of rheumatic fever prevention efforts in New Zealand over the past decade. This has been rolled out to more schools recently as part of the Rheumatic Fever Prevention Programme (RFPP). Participants reported high levels of engagement with school and community sore throat swabbing and antibiotic treatment programmes.

Many children had multiple throat swabs and antibiotic treatment for sore throats prior to being diagnosed with rheumatic fever. Some siblings and other family members also had throat swabs taken and were given antibiotic treatment.

Participants were positive about sore throat services provided in schools.

"They do the swabs in schools, my kids did it like 4 times." Samoan parent 7, mother of 2 children with rheumatic fever.
"It was the school that picked it up and they were really good. The nurses are always there asking if the kids have a sore throat." Cook Island parent 5.

"My kids are always having throat swabs at school, which I'm glad [about], because when they have sore throats, they get the antibiotics." Tongan parent 5.

However one participant was concerned about the lack of coordination between the programmes at schools and the role of the GP.

"There are so many people going through the schools, I want to ask them about the results of the swabs because another one [swab] is done at the family doctor…but there are no follow ups of the ones done at school." Samoan parent 1.

Participants reported that other family members had also been tested for sore throats. Eight of 15 families who answered this question in the survey indicated that other family members had received treatment for a sore throat.

3.5. Primary Health Care

Summary

- Almost all families were enrolled with a primary health care service provider.
- Directly prior to rheumatic fever diagnosis, many families made multiple visits to their primary care provider for the same health complaint. Many families reported dismissal of concerns and delayed diagnosis and referral for specialist rheumatic fever testing or treatment.
- Some families felt that they received improved primary health care services after changing provider.
- The most common presenting symptom related to painful, swollen joints.
- Families respected the clinical skills and expertise of health professionals, but wanted greater input and involvement during consultations and treatment.
- Communication and language barriers were a common theme. Waiting times, brief consultations and clinic opening hours were other identified barriers to receiving appropriate care.

Improving access to primary health care is important for prevention, but also critical for diagnosis and referral of children with suspected acute rheumatic fever to secondary care for further testing and treatment.

Of the 20 participants, 19 are enrolled across 13 medical centres. 7 families are enrolled with the same provider, the remaining 12 are across 12 different providers.

Many participants reported taking their children multiple times to their GP immediately prior to rheumatic fever diagnosis.

"From the first day she felt, maybe a bad bug, a flu coming on, I kept going back, [child] went back more than five times [to the GP]." Niuean parent 1.

"*We went to the doctor so many times when [our son] was sick and the doctor said it was the flu so many times." Samoan parent 6.*

Families expressed concern that their children remained unwell and some asked the GP to do more tests.

> *"The third visit we questioned the doctor and said you have told us that repeatedly it is a flu infection but if so my son should have improved, so we asked for an x-ray. The doctor agreed to do a throat swab and a urine test. The GP phoned us a few days later to say the test results were clear, he said everything is okay, nothing will happen to your son he's fine." Samoan parents 6.*

> *"Then the third visit I asked if she could listen to my child's heartbeat to see if it was normal and if my daughter could get a blood test." Tongan parent 1.*

> Interviewer: Do you think the doctor would have checked your child's heartbeat or given her a blood test if you had not insisted?

> *"I don't think so, because that was our third time visit to the doctor. The only reason I asked for it was because they kept doing and saying the same thing every time we went back to see them." Tongan parent 1.*

Families recalled that GPs sometimes dismissed their concerns.

> *"I told them the symptoms and said it got so bad that her joints were sore that she couldn't walk, [and she had] headaches, but the doctor told me all I needed to do was drop her off and to make her walk, because she was so big." Niuean parent 1.*

> *"They suggested it was probably because he didn't have breakfast that morning before he went to play." Tongan parent 4.*

> *"My daughter started having headaches and a sore ankle, we went to see the family doctor and he said it was probably just a cold." Tongan parent 1.*

> About a month later, symptoms persisted and they went to see the GP again and were told the same thing.

> *"He told us again that it was just a cold and told me to make sure she wears socks and keeps warm." Tongan Parent 1.*

For many families, their child had become very sick before being referred for further testing and/or specialist care by their GP.

> *"When I told him to stand up, he said he couldn't as his ankles were aching. So I piggy backed him to the doctor. When we got to the doctor he [the doctor] said it must be an infection in his foot….[my son] was again prescribed more antibiotics ... and we were sent for a blood test and we were sent home, but I was hoping to get transferred to Middlemore Hospital…" Samoan parent 1.*

> *"…she couldn't walk at all. So we took her to the family doctor during the day. They swabbed her and took a blood test and told us to go home." Tongan parent 3.*

> *"[child] was very weak and she couldn't move, she was bedridden and I thought something has to be going wrong." Niuean parent 1, after presenting to the GP 5 times.*

> *"The beginning of this illness was through the flu, I took him to the doctor the first time and got him antibiotics, he didn't get better. Went back the second time…more antibiotics. The third time his joints started to swell and get sore especially his toes and my son told us that we shouldn't go back to the same doctor, we should go back to another doctor and as soon as we walked through the door the new doctor told us to go straight to Middlemore." Cook Island parent 2.*

One teenager who had rheumatic fever, described his experience.

> *"I just couldn't stand and I held onto the walls, I just couldn't hold myself up and then I had to use crutches all the time." Rheumatic fever patient aged 14 years, Tongan parent 2. Although his mother required a wheelchair to take him into the general practice clinic, they were sent home and referred to hospital the next day.*

Some parents recalled trying to get their GP to order more tests or refer their child to secondary care.

> *"…I kind of pushed, I was trying to get them to [act], even my husband was standing there saying you guys have to do this but they [GP] just say oh nah they're fine…" Tongan parent 5.*

> *"I begged them to do a scan or x-ray but the family doctor said that was unnecessary because my son was fine. As a mother I had an intuition to keep pushing for more…I persisted at the family doctor by asking them if they could refer me to Middlemore hospital instead." Tongan parent 4.*

Participants actively sought other ways to get their child reviewed and some reported that their child was finally diagnosed when they attended another general practice clinic.

> "*So I went to the [rugby] club he played for and asked if they had a doctor who could see my son…so the club referred us to the doctors at [clinic name]." Tongan parent 4.*

> *"…not until we changed the doctor and took him to another branch and a different doctor, she saw his body was [weak] and there was no redness in his fingers. It was 8 o'clock at night, the family was waiting for us to come back, we didn't go back home we [were sent] straight to Middlemore." Samoan parent 6.*

Family (and patient) stories about when their children were first unwell are also notable in that the most common presenting symptoms were related to painful, swollen joints. This is consistent with other New Zealand research that joint inflammation was the most common presenting symptom (Wilson et al, 2013).

Parent's relationships with Primary Health Care

Families respected health professionals and relied on their clinical and professional skills to care for their children.

> *"I didn't know much so obviously went to a professional doctor." Niuean parent 1.*

> *"So you leave it to the people who you trust have the expertise, skills and knowledge to make the decisions. We left it to the doctors as my daughter was really sick and she couldn't move…" Samoan parent 5.*

> *"We put our trust in these doctors, they've been to school for like 10 years so we put our trust in them, they are the ones who should pick it up." Samoan parent 1.*

"I believed them because they are professionals at what they do." Tongan parent 4.

However, many families perceived that doctors were not willing to discuss clinical decisions or value parents input. Families expressed a desire for greater involvement during consultations. For many families, this was central to their rights and responsibilities as parents or caregivers.

***"…** Because we are the doctors and we know what we are doing." Tongan parent 4 (reporting a response to her request for the reason her child was not being referred to hospital).*

"Doctors [should] hear us out, don't think that yous are up there and we don't know anything, we are parents - we are trying to look out for our kids and ourselves." Samoan parent 2.

"It's like they get offended if you try and ask them and then you sit back and think they went to school and I didn't so yeah they probably know what they're talking about." Samoan parent 7.

"So now I'm complaining to you about the doctors, they don't seem to take what we have to say serious enough, especially through this rheumatic fever. I now know it's not always that easy to diagnose…If only they check our kids properly instead of telling us to take our kids home, hopefully that'll stop our children from getting rheumatic fever." Cook Island parent 2.

Language problems were a recurring theme.

"For me, the only barrier would be the communication between the health professionals and us. I'm sure there are things they explain to me but because of the lack of understanding, I cannot fully comprehend the information." Tongan parent 3.

"Our family doctor asked us if we understand rheumatic fever. When I said no, he gave us a pamphlet to read." Samoan parent 5.

Some parents expressed a preference for providers of the same ethnic group.

"There's a Tongan doctor [working at the clinic they attend]…easier for my husband to understand if he goes there by himself." Tongan parent 5.

"Why is there no Cook Island people working with rheumatic fever [services]?" Cook Island parent 1.

Although comfortable speaking English, some parents expressed a preference for their first language to be able to fully engage with the issues.

"Even though we understand English, it is different when your own language is used. You understand your identity. When the [Samoan] words are used they are much more meaningful. And with the words used you can pick up the concepts easily, and you can be fully immersed in the conversation. You fully understand the meaning of the words used." Samoan parent 2.

"I think it's because it's my native tongue and you could explain something better to somebody who's from where you are from. I don't know I didn't feel awkward or uncomfortable, not that I did with my other GP, I was just myself." Tuvaluan parent 1.

Some parents who were comfortable speaking English required a translator to assist with communication with their partner who had low-English proficiency.

> "*Just because sometimes like for me I'm alright but there are some words that I need to tell my wife and that, it's hard for me to explain it in Samoan, but there's [doctors] speaking both languages and really understands and it helps." Samoan parent 5.*

One parent expressed concern about confidentiality of information when discussing her preference for attending a Non-Pacific GP.

> "*To me honestly [name of interviewer], I have that feeling with the Samoan doctor they don't keep things confidential and that's why I prefer the palagi." Samoan parent 6.*

Access barriers

Families faced barriers to getting the primary care they needed, including long waiting times, brief and rushed consultations and early closing times.

> *"[At the clinic we attended] no appointment made and you could be waiting for hours." Niuean parent 1.*

> *"The medical centre I was at, they rush things and they don't give you the information that you really need…sometimes with the hours you are going in…I feel like you're kind of rushed to hurry up and get to the next patient…they say they're [sick child is] fine and just take Panadol." Tongan parent 5.*

> *"…[at the GP clinic] too many people, we are about to close, 10 more minutes…" Samoan parent 6.*

> Interviewer: How long did you have to wait to be seen by the GP?

> *"Two hours, three hours and be seen for 2 minutes." Samoan parent 6.*

> *"When we go to the family doctor, it's totally different [from hospital]. They tell us to wait and wait and wait [at the GP]. We are already in a difficult situation and we need urgent help…but no they look angry at me, the receptionist looks angry at me…" Tongan parent 4.*

> *"When he had a sore throat, [PHC provider] closed too early so I went to Middlemore Hospital." Samoan parent 2.*

Participants were sometimes aware that clinics varied in quality, but choice was determined by cost and proximity.

> *"It's not the doctor that we prefer to go, it's the closest one, why go all the way over there, it's costing us from here to there." Samoan parent 7.*

> *"We Pacific Islanders choose to attend the cheapest services, although we know there are better options but cost is a barrier." Samoan parent 6.*

> *"…it was obviously because it was free [the delayed diagnosis of her child's rheumatic fever], so that was the honest truth, I think it was not worth it. I would rather pay money for my children even if my doctors let me pay later if I couldn't pay it on the day." Niuean parent 1.*

While few participants reported making formal complaints when they were not satisfied with the treatment their children had received, a common response was to move their family to another primary care provider.

> *"…so that made our decision to go somewhere else because we weren't happy with their service." Tongan parent 5.*

> *"I really want to go to Middlemore because they check everything, but the doctor. [GP] kept saying no. So that's why I went to look for another doctor". Tongan parent 4.*

The depth of feeling and loss of trust was expressed by one parent.

> *"And that's the scary part, they [GPs] can just lie or just to stop you asking questions, but you're not getting the right information or what you are after and that's why you need to go to a different doctor." Samoan parent 6.*

However, all participants also had positive stories about finding a new provider in whom they had confidence.

> *"Yeah the service is good now because they [new provider] care. But before, the family doctor didn't really put an effort into testing or finding out what was wrong…you know saying they haven't found anything without doing any proper testing…" Tongan parent 1.*

3.6. Hospital treatment and secondary care

Summary

- During the stress of rheumatic fever diagnosis and admission to hospital, language assistance and clear explanation of complex information were available and were important to families.
- Most children were receiving penicillin injections. A few families reported difficulty in scheduling convenient appointments for monthly injections.
- Many families received care that they felt was inappropriate or substandard, but few had made a complaint through formal or informal channels.
- Understanding of rheumatic fever, even after hospitalisation and treatment, was poor amongst many families.
- There was a desire to share experiences and learning with other families of children with rheumatic fever.
- The impact of rheumatic fever on children and their families' well being.

18 of the 20 participants were registered with CMH and two were registered with Waitemata DHB.

Participants had mainly positive experiences of the care their children received in hospitals.

> *"Middlemore hospital always looks after us…we try and tell them [family doctor] please let us go to Middlemore, if they give us a letter for the hospital it will be faster and when we ask them for a letter they say no." Tongan parent 4.*

> *"In Auckland, they were amazing, everybody was there and there was a lot of information given to us at the hospital about rheumatic fever, even people coming in like the doctors helping us and just educating us about things…" Tuvaluan parent 1.*

> *"The hospital stay was very good; the doctor's service was good and they were there the whole time." Tongan parent 2.*

> *"…They [hospital staff] got me involved. The information and keeping me informed of it was great." Tongan parent 5.*

> *"Sometimes my daughter gets scared when they take her blood but I like the way they ease the situation by giving her colouring books so she isn't as scared. It gives me satisfaction knowing they are always considerate of my daughter's feelings as well as mine as a parent." Tongan parent 3.*

And one parent noted the difference in resources between the hospitals.

> *"We loved it there [Starship Hospital]…when we had to come back to Middlemore it was like moving from a 5 star hotel to a motel…" Samoan parent 7.*

Access to interpreters was important for some participants.

> *"For me when I went with him to the hospital, when they said he has rheumatic fever I didn't even understand what that meant. I asked for an interpreter to come and explain to me in the Tongan language. The way they explained it to me, I did understand." Tongan parent 5.*

Although some families were proficient in English, extra assistance was required when non-English speaking grandparents were actively involved in providing care. In this example, although translators may not have been available, staff attitudes made a difference.

> "*No, we are okay with both languages [English and Tuvaluan], but my adopted mum who [child] is close to, she would look after and sleep there [in hospital] with her. There was a language barrier there, but she really loved the night staff, they would speak slowly to her and explain things to her…I think she made friends." Tuvaluan parent 1.*

However some families did not get all the information they needed.

> *"When the hospital gave us information, it was all in an English booklet…I like talanoa and I got lots of information from the focus group…face to face is better." Samoan parent 2.*

> *"I didn't really understand what rheumatic fever was when I first heard about it. The doctor at Starship hospital tried to explain rheumatic fever, but I asked the doctor if a Tongan person could come and help translate what the doctor was saying. The hospital couldn't get a Tongan interpreter; however, they gave me a pamphlet written in the Tongan language that helped to better my understanding of rheumatic fever." Tongan parent 3.*

Complex information was difficult to process at the time of diagnosis as parents were stressed.

> *"When they came and talked to me, my mind was somewhere else. I did not understand a thing they were saying. I was worried about my son. I have other children and on top of that, this child is now sick but I have another child who is also sick…this was the first time I had a meeting with the doctors, and I was not really concentrating as I was under a lot of pressure." Samoan parent 1, father of 9 children.*

> *"I know at Starship [Hospital] as soon as he finished his surgery we had the social workers and the psychologist, like they came and asked us if they could talk to us about how to accept what's happened, I think they came to us at an early time but it would have been better like afterwards." Samoan parent 7.*

Experience of secondary prevention

Once a child has been diagnosed with rheumatic fever, secondary prophylaxis with long term antibiotic treatment is the only proven cost-effective intervention (Carapetis et al, 2005).

Eighteen participants reported that their children were receiving prophylactic penicillin injections. One participant didn't answer this question. One parent reported that they were told their child was not high risk so didn't require injections.

Most parents reported that the service worked well and that they had good relationships with the nurses who administered the injections. A few families reported difficulties with scheduling appointments at a time that was convenient.

> *"If we scheduled it for a time to suit us and the children's school time, the nurses time did not fit our time…and if we make an appointment for her to come, she does not keep time, she is always late." Samoan parent 5.*

> *"The only thing I want to add is about the injection appointments. Sometimes they say they will come between 9 am and 3 pm…that is a long wait...I always ask them if they could make a time especially in the morning…they always come on Saturday but sometimes we want to go somewhere and we wait here until whenever they come…" Tongan parent 2.*

Given the number of other children in most of these households that also require care, it is understandable that the long waiting times are difficult for families. What is notable is the frequent difficulty families experience when negotiating reasonable requests.

> *"Sometimes I give them a call early in the morning and if we want to go somewhere I ask them if they can come early and they said if you want to go somewhere then we have to go to the GP or reschedule." Tongan parent 2.*

This family had previously had a bad experience with having their son's injection at the GP, so were resigned to waiting at home.

Failure to complain

We were told many stories about participants and their family's experiences of substandard care. We specifically asked families how they responded to these experiences and what action they took when the care their child received did not meet their expectations. Only a small number of participants said that they had made a complaint either to the practice or through other health sector processes, for example, the Health and Disability Commissioner.

This parent had already had a difficult experience with delayed diagnosis of her child's rheumatic fever despite repeated visits to the GP and then they did not receive a planned follow up appointment with secondary care specialists on more than one occasion. Although she was concerned she did not take the matter further.

> *"I called them last week because it felt like it had been over 6 months since the last check up and they told me they are going to send me a letter. It's happened before where they haven't checked up on my daughter after 6 months and I have had to call them about it and the receptionist told me it must have been a mistake in the schedule, so they rescheduled then and there. Lucky I called though." Tongan parent 1.*

Participants focus was how to care and support their children now and in the future. One parent responded when secondary care clinician's raised patient's rights and asked whether he wished to make a complaint about the quality of primary care his son had received.

> *"…Is it going to heal the large scar on [my son's] chest?" Samoan parent 6.*

This parent expressed a preference that the GP receive appropriate training.

> *"If there's a chance that the doctor can go through training to avoid it happening again…and to help other kids who attend that practice." Samoan parent 6.*

Another parent also stated that their motivation in making a complaint was to improve the services provided to other families.

> *"Yeah but then when I sort of cooled down I didn't want to get anyone into trouble, I just hope that she'd learnt from it and maybe the next person that comes in, she won't be so judgemental towards another family, because like I said, they have no idea, they just look at you and judge you." Niuean parent 1.*

Parents described sometimes challenging professionals immediately about sub-standard care. For example, a parent described an incident where they were told there was a problem with the penicillin injection given to their son for secondary prophylaxis of rheumatic fever.

> *"Afterwards the District Health Nurse rang to say sorry that the injection that my son had was not as effective as it should be. I asked why? And I was told because the fridge was off…I said you know I can sue you for that…I am letting you off now, but if this happens again, I will sue you." Samoan parent 1.*

Other parents found that taking action was futile.

> *"I did sue the doctor for not diagnosing my son but nothing happened." Cook Island parent 2.*

> *"I talked to the head nurse in charge and one of the doctors, they apologised, but I didn't find it very genuine. It was a cold apology…" Niuean parent 1.*

> *"I am grateful for this opportunity because I don't know who to ring, because when you ring the numbers they give you, you get transferred around to different people and sometimes they hang up on you. You don't know the main office or the main person to talk to." Samoan parent 5.*

Persisting knowledge gaps post rheumatic fever diagnosis and hospital admissions

A recurring theme was that even after their children had been hospitalised, sometimes more than once, parents did not understand rheumatic fever.

"When I went with my son to the hospital, I thought he had a heart problem but later we found out it was rheumatic fever. I asked the doctor what is the connection between the heart and rheumatic fever? The doctor didn't really explain to me the connection. He just said that if rheumatic fever isn't treated properly then it has the potential to affect the heart. Right now I am still trying to understand the connection between the heart and rheumatic fever in more detail." Tongan parent 4.

"My son is alright now, but my understanding of rheumatic fever is still limited. I am not clear about how it starts and why." Samoan parent 1.

"All I know is that it starts from a sore throat and we need to see a doctor as soon as we can to check it out to prevent further problems with your heart." Tongan parent 3.

"All we got was information from here and there, but there were no formal discussions about the disease." Samoan parent 3.

Parents wanted to talk with other parents of children with rheumatic fever.

"We wanted rheumatic fever Pacific people to talk to… we were in the heart ward and it was just like kids that were born with heart problems…to this day there was nothing. I was happy when they called for us to come and I wanted to meet other people because no one in my family or my friends had kids with rheumatic fever I was actually happy to come here and share and hear other people's stories." Samoan parent 7.

"There was a Samoan patient at the hospital that was like my son. He left 2 days before my son. We asked him how he felt so we could compare it to my son's experience and learn from it." Tongan parent 2.

"That is also the main reason for attending this meeting, because I really want to know more about this disease affecting my family. On my way to here…I heard my children asking each other, 'Why did I get this disease?' I really want to know…we are still wondering and we still haven't got the answers for our questions." Samoan parent 3, parent of 2 children with rheumatic fever.

Impact on family

The impact of rheumatic fever on children's self-esteem and their family's emotional well-being is rarely mentioned in the literature, which focuses mainly on biomedical aspects of the condition. As researchers we noted consistently across focus groups, face to face interviews and phone interviews, the level of raw emotion and in many cases, self-blame amongst participants for the harm their children had experienced.

"Our lives have changed, now we spend a lot of time monitoring him and his health…we are strict with his activities and we are very alert with our other children…" Tongan parent 2.

"That is my support for my son, because he is really stressed when it is time for his injection. I encourage him to be brave…I don't care if he doesn't pass his exams, but I am more worried about his health." Samoan parent 4.

"I feel sorry for my daughter" (too emotional to talk). "Before she used to always run and she was a fast runner at school. Now she doesn't really run anymore and she doesn't want me to go watch her athletics anymore…" Tongan parent 3.

> *"Yeah, I think sometimes that I won't be able to reach my full potential, like in my strength and all. Sometimes it stops me from participating in the sports that I like." Rheumatic fever patient aged 14 years, Tongan parent 2.*

> *"Yeah we feel so shocked about this because my daughter was so healthy before." Tongan parent 1.*

Some participants described how they had struggled with the decision to contribute to the research because of the painful memories.

> *"Before we came [to the focus group] I thought, I don't want to go, because I don't want to revisit the memories, and then [I thought] staying at home, there's a lot of things to distract me, so I don't focus on the one thing, but focus on my son's future." Samoan parent 3.*

Many participants discussed the longer term impacts of rheumatic fever on their children's future.

> *"I feel a bit sad. To me rugby was his future because he told me he wanted to be a rugby player when he grew up" (unable to continue due to emotion). Tongan parent 4.*

> *"What really saddens me now is…her dream (when she finishes school) is to become a police woman as well/or to join the navy. However we know that to be a police woman your fitness is really important but at the moment she is not able to do too many physical things but time will tell if she can fulfil her dream." Cook Island parent 1.*

4. Participant case studies

Individual case studies of five patients are included in this section. A case study is made up of the information about the participant's personal circumstances and a summary of the information provided by them through focus groups, the housing survey and interviews. We have not included the ethnicity of participants in this section to ensure the confidentiality of participant's information.

Patient 1

Patient 1 is a nine year old girl. She was born in Auckland and is the fourth of six children. Her mother was born in [Pacific nation] but migrated to New Zealand when she was 20. Her mother's family now all reside in New Zealand and she has not been back to [Pacific nation]. Both [Pacific language] and English are spoken at home, but [Pacific language] is the preferred language. When speaking with health professionals, her mother prefers to speak in English. Her mother has never seen a [Pacific] doctor or nurse because she says she does not feel a need for it.

Patient 1 was first diagnosed with rheumatic fever in February 2013, aged eight. Her mother had taken her to the GP at least three times over a one-month period with complaints of headaches, body aches and lethargy. The first two times she was told it was probably a cold and that she needed to dress her child more warmly. Following diagnosis, the patient stayed in Middlemore Hospital for two to three months. Her parents were told at the time that she had two damaged heart valves and high blood pressure. She underwent valvular surgery at Starship Hospital in September 2013 and is currently on monthly Penicillin injections. Her mother has been told that she will require further surgery as her heart valves are still damaged. Her health has improved since the first operation, but she still gets headaches every three weeks or so. Her mother expressed disappointment with their GP, saying that if the doctor had tested her at the first visit, the problem would have been detected while it was still small:

> *"Sometimes I feel they don't take the check-ups seriously…I don't want any of my other kids to experience what she has. I hope that [the doctors] can be more attentive to us when I explain what has happened to my daughter, so they can do a better job at detecting the real problems. My daughter wouldn't have had an operation if there was an early detection."*

However, her mother praised the hospital doctors, who treated her family with dignity and respect. She said she knew nothing of rheumatic fever before her daughter became unwell. Having had the illness explained to her in detail by the hospital doctors, she is now alert to the symptoms:

> *"Whenever someone tells me their throat or chest is sore, I do all I can to take them to see a doctor right away. I ask the doctor to check them and give me a letter to test their blood."*

At the time the patient became unwell, the family of eight was renting a three-bedroom, one-bathroom home from Housing New Zealand. The house was small, cold and damp, and three of the six children suffered from asthma. The family were not referred to any social services during the patient's hospital admission, but the patient's mother asked their family doctor for a letter to support their application for a larger house. The family have since moved into a five-bedroom Housing New Zealand house, which is warmer and has carpet and a big backyard.

Patient 1's mother reported difficulties interacting with WINZ. Her husband had to take time off work while her daughter was in hospital, but she said WINZ would not help them. She has good family support: both her sister and sister-in-law help take care of her children when her child is in hospital and her husband is at

work. She says that the only outside help they received while her child was unwell was from her child's teacher, who would visit the family and bring her daughter schoolwork.

Patient 2

Patient 2 is a nine year old boy. He was born in Auckland and is the seventh of nine children. His mother was born in [Pacific nation] but migrated to New Zealand when she was 18. She visited [Pacific nation] in 2013, but prior to that had not been back for over 20 years. The family speaks both English and [Pacific language] at home. His mother prefers to see non-[Pacific] doctors, with whom she speaks English, as she is wary of the ability of [Pacific] doctors to maintain confidentiality.

Patient 2 was diagnosed with rheumatic fever in October 2013, aged eight. He had been identified at school as having strep throat three times previously. The fourth time he was given antibiotic treatment but still became unwell with fever and joint aches. His mother took him to the GP and was told that he had an infection in his foot. He was prescribed more antibiotics, given a blood test and sent home. The next day he was called to Middlemore Hospital for a suspected joint infection. At that time, he was seen by orthopaedics and sent home. However, the next day he was readmitted with suspected rheumatic fever, and his family was told that his heart valves were leaking.

Prior to her son's diagnosis, the patient's mother had no knowledge of rheumatic fever. She says she had seen advertisements on television, but had no understanding of how the illness starts. She recalls feeling under a lot of pressure and not being able to concentrate when doctors explained the diagnosis to her. She says that, even now, her knowledge of the illness is limited. She is aware of the link between rheumatic fever and overcrowded homes, but finds it hard to reconcile the fact that the family have lived in overcrowded conditions for many years without any of her other children being affected.

Patient 2 was put on monthly penicillin injections, but later developed a recurrence of rheumatic fever. His mother received a phone call from the district nurse at this time and was told that one of the injections her son received was not as effective as it should have been, as the fridge in which the injections had been stored was inadvertently turned off. His mother was extremely upset by this.

> *"I said to the doctor, 'It sounds as if you are using my son as a guinea pig. You know I can sue you for that. I want you to come and sort something out for my son.' So they came the next day and gave my son an injection, so he had two injections in one month. My son is better now, but I said to them, 'I am letting you off now, but if this happens again, I will sue you. So don't ever use my son as a guinea pig.'"*

Following hospitalisation, the school social worker, who the mother describes as "awesome", organised for patient 2 to receive a disability allowance. WINZ, too, was apparently very helpful.

The family of 11 have lived in a three-bedroom Housing New Zealand house for the past 14 years. It is extremely overcrowded, both physically and functionally, as family members often have to sleep together in the same room to keep warm. According to the patient's mother, they have been waiting for a bigger house since 2008 and have no idea when this might happen, despite a letter from doctors supporting their application for a bigger house.

> *"At the moment our children are growing up and the children have to share bedrooms and we are squashed together; we need more space for my kids, the house is too small…nobody helps with housing even though Housing New Zealand know my son has rheumatic fever."*

Patient 14

Patient 14 is a 13 year old girl. Her mother is a single mother of seven children (four biological children and three whangai). Patient 14 was first diagnosed with rheumatic fever in June 2014, following a two-week period of experiencing sore throat, headaches and sore joints. During this time, she was taken to the GP, increasingly unwell, on five separate occasions. However, her mother was initially told that her daughter just needed to lose weight:

> *"I told them the symptoms and said it got so bad that her joints were sore that she couldn't walk… but the doctor told me…to make her walk because she was so big. (I) felt that it was really cold...telling me that my daughter was obese…and that's when my daughter collapsed and…ended up being hospitalised for about three months."*

Her mother believes that the delay in diagnosis was unnecessary and led to a worsening of her daughter's condition. She felt that her trust in the medical profession had been betrayed:

> *"I was pretty much destroyed…I was quite angry and bitter towards the doctor and I think I still am till this day, and [the GP] still practices where I feel, she doesn't deserve to be a doctor…"*

During the patient's three-month hospitalisation, the family had very positive experiences with the hospital doctors; her mother felt that the doctors were always thorough, open and communicative. While most of the time, her mother felt that she had been treated with dignity and respect, she recalled a particularly upsetting episode with members of the nursing staff:

> *"They were very rude, it got to the stage where I did cry…they pretty much put me in a room and asked personal things, testing my integrity and parenting. I was quite offended. I have seven children that aren't all biological, some are my biological nieces and nephews, they are my babies because I've had them from birth, one nurse came up to me and asked where's all the fathers at? I just looked shocked…they've just judged me without knowing the underlying part of it and just assumed that I'm this bad mother. I found that very offensive."*

This experience was particularly stressful for the mother, since she was already struggling with the financial burden of her daughter's hospital stay. The family of nine (mother, seven children and maternal grandfather) live in West Auckland, and a prolonged admission in Starship meant much higher-than-usual petrol and carparking costs. Over this time, the family gave up meat and lived mostly on bread. The patient's mother did not receive any additional benefits from WINZ over this time, relying instead on her own father, who helped with bills and childcare. She says that she asked to see a social worker while in hospital, and through this was able to organise a disability allowance for both patient 14 and another daughter, who has congenital heart disease. This daughter, an 11 year old, has had two open heart operations and is awaiting a third.

The family rent a four-bedroom one-bathroom home from Housing New Zealand. It was brand-new when the family moved in a few years ago, and her mother believes that they were given priority for it because of her younger daughter's congenital heart condition. However, the house is cold during the winter, which means the family often huddle together in one room (*"marae styles"*) to keep warm. It is also too small for the family's needs, and their case manager at Housing New Zealand has told her mother that they are on the waiting list for a larger, warmer house. She is hopeful that it will be in the same area, as the children are currently all settled in school.

Patient 17

Patient 17 is a 13 year old boy born in Auckland. He is the fifth of six children. He was diagnosed with rheumatic fever in August 2013, after three separate visits to the GP. The first time he presented, he was told he had the flu and treated with antibiotics. Having failed to make a recovery, the family returned and he was given another course of antibiotics. When his joints started to swell and he complained about sore toes, the family consulted another doctor. At this point, he was rushed to Middlemore, where he stayed for about a month. He was also referred to Greenlane Hospital, but did not require surgery. His mother was extremely upset with their family doctor for failing to recognize how unwell her son was, and the subsequent delay in his diagnosis:

> *"So here the blame is for the doctor, this illness. I went on radio and made comments about the doctors and I did sue the doctor for not diagnosing my son but nothing happened…So now I'm complaining to you about the doctors, they don't seem to take what we have to say serious enough…If only they check our kids properly instead of telling us to take our kids home, hopefully that'll stop our children from getting rheumatic fever."*

The patient's seven year old nephew, who lives in the family home, was also diagnosed and treated for rheumatic fever in [Pacific nation]. According to his mother, there were no serious sequelae.

Patient 17 lives in a three-bedroom, one-bathroom home with 13 other members of his family (two adult couples, four single adults, three children aged 5-17 and three children younger than five). It is owned by the family and his mother says they have lived there for the past 40 years. In addition to being small for the large family, it is cold, which often means the family stay in the same room during the wintertime.

Patient 26

Patient 26 is a 14 year old girl. She is the eldest of seven children. Her mother was born in [Pacific nation] and her father in [Pacific nation]; her mother moved to New Zealand 26 years ago and her father 15 years ago. The family speaks both [Pacific language] and English at home.

Patient 26 was first diagnosed with rheumatic fever in May 2012. Her symptoms included a sore throat, rash, reduced appetite and extreme lethargy. She was bedridden by the time the family sought medical treatment and was transferred straight to Waitakere hospital from the GP surgery. She subsequently spent over two months in hospital. Her mother was full of praise for the hospital staff:

> *"They were actually amazing…there was a lot of information given to us at the hospital about rheumatic fever…they didn't just dump it on us they actually walked us through it, they would tell us what was happening, what the tests were, what the outcome was…they did actually educate us on it, the medication that they were giving her and if they had to change it, they were telling us why they were changing it, we were actually informed."*

Her mother also praised social support staff, including a Pacific social worker, who helped the family organise a child disability benefit through WINZ and home schooling for a few weeks following discharge from hospital. Her daughter is now on monthly penicillin injections, and she has also been impressed by the calibre of the district nurses. The family has received a great deal of support from extended family, members of their church, and the wider [Pacific] community. The employer of the patient's father was also extremely supportive, encouraging him to take stress leave and allowing him to leave work early when needed.

However, the family had a very stressful time trying to sort out their housing situation. At the time the patient first became unwell, the family of eight (six children plus dad and mum, who was eight months pregnant at the time) were living in a three bedroom Housing New Zealand home in West Auckland. The house was cold and overcrowded. They obtained a letter from medical staff to support their application for a larger home, but somehow this was overlooked, and the family were left waiting for months.

> *"Housing NZ mucked us around big time…The lady who did our housing application didn't put down that we had a child with rheumatic fever. As a result, we weren't put as priority and therefore had to wait for a long time just to get a bigger house, which in the end - we didn't…We really went through a lot with them. I felt we weren't heard. I feel let down by them…I have seven children to take care of and they didn't care. I hope they take into consideration other families who have sick children and get their priorities right."*

The family moved to Whangarei in December 2013 in the hope of finding larger, cheaper accommodation. Unfortunately, Housing New Zealand was not helpful, and they ended up renting from a private landlord. Initially, they lived with another family (a total of 17 people living in one house), but in April 2014, the family of nine were able to move into a five-bedroom home on their own. They receive support from WINZ in the form of Working for Families tax credits and an Accommodation Supplement. While the house has more bedrooms than their last home, it is uninsulated and cold, and the children sleep in the same room during the winter to keep warm.

5. Discussion

This research design aimed to capture Pacific patient and family perspectives of rheumatic fever services and provide insight to the broader social circumstances and health, wellbeing and care journeys that families experience. This section discusses the information collected and analysed from the focus groups, social housing survey and in-depth patient and family interviews, with reference to relevant research and evidence.

5.1. Rheumatic fever and the health of Pacific children and their families

Rheumatic fever is a preventable disease associated with marked ethnic disparity in New Zealand. Persisting high rates of rheumatic fever and other preventable diseases in Pacific (and Māori) children have been attributed to the "triple jeopardy" for child health; that is, the combination of poverty, unhealthy housing and inadequate basic health care (Asher, 2010 cited in Child Poverty Action Group, 2014). The annual incidence rate of acute rheumatic fever of 109 per 100,000 for Pacific children living in decile 10 areas, underlines the association of rheumatic fever with socio-economic factors and suggests the compounding impact of disadvantage (Milne et al, 2012).

Recognising the significant social and financial cost of rheumatic fever and its consequences to patients, families and the New Zealand health system, the Government in recent years has committed to reducing New Zealand's incidence of rheumatic fever and reducing (ethnic) inequalities for rates of rheumatic fever. The Rheumatic Fever Prevention Programme (RFPP), initiated in 2011, established a range of initiatives, including school based throat swabbing services; health promotion and awareness; clinical tools and training; and a rheumatic fever surveillance and monitoring programme.

However, despite this commitment, rheumatic fever remains an unsolved public health burden in New Zealand. Concerningly, the disparities between Pacific and Māori children and other children are widening (Webb & Wilson, 2013). Recent Ministry of Health reports show Pacific rates of rheumatic fever hospital admissions remain unchanged in 2014 (HPA briefing paper, unpublished).

There is a lack of evidence about how effective rheumatic fever interventions are for Pacific communities (Litmus, 2013). Many initiatives have been implemented in New Zealand without robust evaluation to support their application to populations like the mainly urban, multi-ethnic Pacific communities clustered in the metropolitan Auckland region and other main centres in New Zealand. A review of the RFPP stated that the RFPP has had a "…limited focus on Pacific people at strategic and service delivery levels…". Furthermore "Pacific providers had limited (if any) involvement in the service delivery or planning for the RFPP..." and there was "…no (Pacific) specific community awareness raising (CAR)…" (Litmus, 2013).

5.2. Key findings of the study

Our review of the health care experiences of Pacific families of children with rheumatic fever who were admitted to hospital in 2013 has identified the following three main areas that are particularly relevant to rheumatic fever services:

- Families are endeavouring to do the best for their children in challenging socio-economic and other circumstances.
- Health literacy has a central, yet complex, role in rheumatic fever prevention and primary care pathways and needs to be better understood.
- The beliefs, attitudes and previous experiences of Pacific families are key to developing a model of care for Pacific families.

The interrelated and overlapping issues between these findings highlight the complexity of rheumatic fever prevention and treatment in relation to Pacific children and their families.

5.2.1. Families are doing the best for their children in challenging socio-economic and other circumstances

The central role of family and the efforts of families with high health and social needs to do the best for their children in challenging circumstances, is a key finding of this research.

The data collected in this study describes a family context for Pacific rheumatic fever patients that is significantly different to the New Zealand norm. All of the research participants lived in large households (60 percent of households have seven or more occupants) with extended family members, non related families and high numbers of children, including siblings, cousins and whaangai adoptions. Household composition was subject to transience and constant fluctuation, with members moving to live with other parts of the family and visitors frequently hosted for temporary periods.

The significance of the family within a Pacific context is well understood in New Zealand policy and research. Family connections for Pacific people underpin a sense of holistic health and wellbeing (Southwick et al, 2012). The family unit is the basis for sharing income, resources and housing, as well as decision making and responding to external demands (Pacific Perspectives, 2013).

In this study, extended families clearly provided the main source of support to children and their caregivers during rheumatic fever diagnosis, hospitalisation and treatment. The level of support and care provided by participating families emphasises the cohesion, strength and sense of communal responsibility within the family unit.

Providing support after a rheumatic fever diagnosis and hospitalisation, however, also placed considerable strain on families with already stretched resources. The additional pressures and costs shouldered by, particularly low income families of sick children is well documented in the literature. In a study of child hospitalisation due to injury, researchers reported that while the support of extended family was perceived to be very important, providing care while also managing other daily responsibilities, work and child care, created stressful, conflicting demands on family members (Arlidge, 2009). Southwick et al (2012) further noted that 'health' is just one of many competing commitments and that other demands often need to take precedence. The interviews and focus groups show that well resourced secondary services, particularly for rheumatic fever, provide acute focused, thorough and prolonged treatment (typically weeks or months) for an affected child, while family members at home remain at risk.

For families, especially those with other children to care for, the struggle to manage extra medical costs, transport costs, hospital parking costs, childcare arrangements, time from work, children missing long periods of school and numerous other issues is a crucial obstacle to improved and enduring well being and long term outcomes.

These issues are compounded when, as was the case in this study, other family members (frequently other children) suffer from serious health conditions, including rheumatic fever. Family members can find themselves in the position of requiring care and support, but also providing it. The *Pacific Health Workforce Service Forecast* report, showed in the Misi family case study (Pacific Perspectives, 2012) how a multigenerational family of ten people (five adults and five children) that operated as a collective unit, was required to respond to systems and services designed for individuals. The resulting narrowly focused and fragmented service delivery did not address key issues for the family (Pacific Perspectives, 2012). Similarly,

the limitations of what families can achieve within such challenging circumstances were evident in this study - while efforts may provide a temporary respite to a problem, other housing, financial and health issues can arise simultaneously. An in-depth understanding of these specific circumstances is critical in order to develop meaningful and coordinated responses that recognise the needs of the family unit as a whole.

Findings of the study reinforced an increasing body of evidence describing the unmet social needs of Pacific families and the demands of navigating a complex and often fragmented bureaucracy, and complex systems and processes, with the added burden of existing financial and time constraints (Sheridan et al, 2012; Southwick et al, 2012).

Pacific families of patients with rheumatic fever live predominantly in the most deprived areas of Auckland, reliant on rental properties and overrepresented in the social housing sector, particularly in Housing NZ properties. Access to affordable, quality housing is difficult for larger households. Structural crowding and, to a lesser (but nonetheless significant) extent, functional crowding was evident for a large proportion of the study group. Housing quality issues, such as cold and damp homes were reported.

For many families, a rheumatic fever diagnosis and hospitalisation provided added impetus to change their living circumstances or make quality improvements to their existing home. However, the study found that while participating families understood the benefits of 'healthy housing' and were aware of the existence of available support, many lacked a critical understanding of how to get the assistance needed. Furthermore, examples of social services installing carpet in the bedroom of one rheumatic fever patient, while neglecting to intervene and protect other children living in the same household with illnesses (and shared risk factors), suggest a fragmented and reactive approach to housing needs. Low referral rates to housing support for families (two participating families or 10 percent) indicate poor coordination of support between health and social services. Furthermore the decision made by some families not to undertake time consuming and complex application processes for social assistance, highlights an excessive administrative burden and critical barriers to accessibility. A 'family' model of care, that understands this context and improves system responsiveness for meeting family specific needs, has yet to be developed.

5.2.2. The central role of health literacy in rheumatic fever prevention and primary care pathways needs to be better understood

Rheumatic fever is a complicated condition that requires responses spanning primordial health prevention, health promotion (improving health literacy and knowledge), primary and secondary services and social services. This multifaceted approach, including the range of activity established as part of the RFPP (described earlier), is central to Government strategy to address rheumatic fever incidence and associated inequalities.

While some participating families felt positive about the rheumatic fever messages and information they receive, many raised questions about the effectiveness of health promotion campaigns. There was a high awareness of the risk of sore throats and the importance of throat swabs and antibiotic treatment. Many reported positive experiences and engagement with school throat swabbing and testing. This is consistent with an evaluation of the 2014 rheumatic fever campaign, which found that Pacific people were more likely than other groups to see or hear about rheumatic fever through a school based clinic, than any other group (21 percent compared to 12 percent for the total population). Furthermore Pacific and Māori people were most likely to agree that all sore throats should be checked by a doctor or nurse, even if there are no other symptoms (TNS New Zealand Limited, 2015).

Knowledge gaps amongst families about rheumatic fever, both at the time of diagnosis and after diagnosis, hospitalisation and treatment, were apparent. Many families felt that campaigns did not adequately convey information about rheumatic fever. Confusion about the messages of various health promotion campaigns aimed at Pacific communities or being slow to note signs of illness in their children (it is important to note however, that children were frequently suffering from inflamed joints - a symptom that does not feature in rheumatic fever health promotion campaigns), indicate a critical need for improved information and explanation about the links between sore throats and other symptoms, rheumatic fever and heart disease. Findings in the rheumatic fever campaign evaluation, that Pacific people are most likely to believe that Pamol will stop rheumatic fever from developing (14 percent compared to 2 percent of the total study population) and that 3 out of 5 Pacific people are not aware of the heightened risk of rheumatic fever among Pacific children (TNS New Zealand Limited, 2015), similarly suggest a need for further analysis and consideration of how to tailor messages to engage and inform Pacific communities more effectively.

A concerning finding of this study, related to primary health care services and its role as the 'gatekeeper' for access to secondary services through the timely diagnosis and referral of children with suspected acute rheumatic fever to secondary care. An overwhelming number of participant families described multiple presentations for the same health complaint to their primary health care provider, dismissal of symptoms by clinical staff (again, it is notable, and consistent with other NZ research, that the most common presenting symptoms were related to painful, swollen joints) and a clear pattern of delayed diagnosis. Children were often demonstrably unwell and unable to walk, before they were referred for further testing or urgently admitted to hospital for lifesaving treatment.

It is increasingly recognised that health literacy must be defined as a two sided concept, with professional health literacy as important as patient health literacy. The underdiagnosis of rheumatic fever by primary health care has been identified as a key issue and is well documented in the literature (Wilson et al, 2013; Milne, 2012; Ministry of Health, 2010). Rheumatic fever is reliant on the timely recognition and referral of families for more advanced treatment, factors that were lacking in many of the participating families interactions with primary care services. That these issues extend beyond access (getting *to* primary health care services) is supported by high levels of enrolment with a primary care provider (19 out of 20 participating families), multiple presentations to primary healthcare services and previously discussed engagement with throat swabbing programmes. The study strongly suggested that the journey *through* primary care was problematic on many levels for Pacific families.

Quality primary care for Pacific people requires highly skilled practitioners that understand the needs of Pacific patients and families and the interrelatedness of resourcing issues, consultation times, translators, access to testing. Critical to this is a more in-depth understanding of the 'triple threat' to health communication - a broad conceptualisation of health literacy, alongside consideration of the complex barriers related to English proficiency and cultural competence.

5.2.3. Beliefs, attitudes and previous experiences are key to developing a model of care for Pacific families

Participating families represented a varied range of extended, multigenerational, family units sometimes including for variable periods of time multiple households or other family members . Migrant parents, grandparents or other caregivers to New Zealand-born children, multilingual households, value and belief systems that are strongly rooted in Pacific traditions and culture, influence family care experiences, when and how they seek treatment, and how they make health decisions.

Many families hold the health profession and skills, knowledge and expertise of clinical staff in high regard. A reliance and trust is placed in doctors and nurses to make the best decisions for family members. Southwick et al (2012) suggests that the importance of reciprocity and obligation within a Pacific worldview of interpersonal relations, makes visiting a doctor more than a commercial transaction in which a doctor provides a service and the patient pays. For many Pacific people, the quality of the healthcare they experience is measured by the establishment of respect and observance of relational boundaries.

Mirroring these concepts, positive experiences for families were usually focused around communication and relational aspects of care. In the secondary care setting, many felt that they received help and information, staff attitudes were welcoming and they were encouraged to be involved. The recognition that older family members or caregivers may need extra support, particularly for language needs was also noted. Phillips et al (2014) explored the value of relational aspects of care in a recent study of a community based health programme. The study argued that relational qualities - the ability to be understanding, caring, personable and culturally respectful and sensitive - were fundamental to facilitating trust and compliance. Negative experiences were similarly focused (albeit inversely), ranging from inadequate or difficult to understand information and explanations, language barriers, feelings that input or opinions were not valued to feeling stigmatised or alienated by hospital staff.

When instances of inappropriate and often sub-standard treatment were experienced, it was repeatedly found that families rarely complained through formal or informal channels. There were suggestions that participants did not see the value of pursuing a complaint process or felt that little would change from them doing so. In this aspect, previous experiences of unsuccessful or unregistered complaints may act as a discouragement. Indeed the impact of previous experiences in general, whether positive or negative, can influence ongoing expectations, interactions and health decision-making for Pacific families. Arlidge (2009), has reported that amongst Māori and Pacific families, expectations of health services and professionals were often based on negative previous experiences. The research notes that this appeared to undermine confidence and curtail the ability to challenge hospital processes where necessary. Other research has suggested that experiencing a perceived lack of respect or previous attendance with an unresponsive or unsympathetic doctor may discourage future attendance (CBG, 2008 unpublished). These causal factors were not explored in this study.

Practical challenges can confront Pacific families at any number of stages during their journey through the health system. A lack of empowerment, lowered expectations and not feeling entitled to quality services and care characterised many family experiences of their rheumatic fever primary and secondary care. In lieu of making a complaint, for example, families often made choices that provided a simple resolution to a problem, such as changing primary healthcare providers when dissatisfied with the treatment received. The difficulties of negotiating and scheduling suitable appointments for penicillin injections repeatedly expressed in interviews, suggest that many Pacific families reluctantly feel they are passive recipients of care.

The New Zealand Health Quality and Safety Commission identifies patient experience as a core component of its Triple Aim model for patient quality and safety. Patient experience is central to integrated care approaches designed to improve the quality of services for patients requiring complex health and social interventions. However this research highlights that little is done to gain insight to what matters for Pacific families. Models of care are designed around biomedical concepts that address the needs of patients as individuals, rather than families - and even less so the diverse characteristics of Pacific families which are different from the New Zealand ‘norm’.

For many families engaging in research is a part of their journey through the health system. The importance of the relational aspects of care for Pacific families applies equally to research processes for engaging with families. Given the research findings that vulnerable Pacific families were struggling with the impact of rheumatic fever on their children, had unmet health and social needs and poor experiences of health services; appropriate research methodologies are essential. The Health Research Council provides guidance for working with Pacific communities, recommending the use of research methodologies based on Pacific cultural values of communal relationships, reciprocity, holism and respect (HRC, 2014). Durie (2014) shows how the Guidelines should be applied in order to support empowering and enlightening participants and their communities. In this way, research can contribute to rebuilding trust in the health system that families perceive researchers as part of.

Critical factors for this research included facilitation of focus groups and interviews by experienced field workers with cultural and linguistic skills, who were respected by their communities and brought knowledge of health and social services to the discussions; the use of narratives which allowed participants to discuss what mattered to them; Pacific cultural protocols for engagement including (using Māori language terminology described by Durie, 2014) kawa, karakia, and provision of koha and kai; and allowing adequate time for engagement, rather than just focusing on extracting the information required for narrow research questions. For example, our experience was that our phone survey of 57 questions required up to 90 minutes of interviewer time to complete. This compares with a similar 2013 research project commissioned by the Ministry of Health which included a phone survey of 41 questions which was completed on average in 5 minutes (Oliver et al, 2014). While HRC's Pacific Health Research Guidelines have existed since 2005, our review of the published research with Pacific communities shows the need for a deeper understanding of how the Guidelines are applied. In particular, greater appreciation by researchers that their actions are not discrete events for families; and of the importance of being mindful of their impact on families' experience of the health system as a whole, is essential. Researchers also have responsibility to follow up on instances where unmet need is identified. Commissioners of research have the responsibility to use their best endeavours to address the findings of the research.

Research and action, incorporating Pacific patient and family experience, and Pacific cultural values; about models of care that will address the needs of Pacific families is urgently needed.

6. Conclusion and Recommendations

The research highlights that the persisting prevalence of rheumatic fever in Pacific populations is influenced by a vast and interrelated array of socio-economic, cultural, systemic and clinical factors. Despite a considerable level of activity to address this significant health burden in New Zealand, knowledge about the aetiology of rheumatic fever is still lacking and there is a notable lack of evidence about how effective rheumatic fever interventions are for Pacific communities.

Throughout this research, the importance of better supporting the families of children with rheumatic fever was a central and recurring theme. While children with rheumatic fever in this study received well resourced and thorough secondary care of a high standard, little to no support was available to parents, caregivers and other family members who remained at need and at risk. Many families in the study faced frequent health, financial or social events or crises. Health and social services are relatively well equipped to respond to acute events, but there is less capability for a comprehensive and broad anticipation of when and how to support a family, as a whole, before these urgent situations arise.

That patient and family understanding and knowledge of rheumatic fever often remained poor, even after experiencing the range of preventative, primary care, hospital treatment and secondary preventative care, strongly suggests that the effectiveness of health literacy improvement efforts has been limited. The role of professional health literacy in ensuring access to and through primary care and community services, must be acknowledged and better understood. Furthermore, while ethnicity is recognised as a significant risk factor for health (independent of socio-economic status, and other health risk and demographic variables), more in-depth understanding is required of how ethnicity impacts on health. This research contributes to emerging New Zealand studies identifying the need for more in-depth understanding of the linguistic, cultural and migrant factors which health interventions may be designed to address.

Rossi (2004) (cited in Bardsley et al, 2013) attributes the failure of complex social programmes in the USA to show impact, to three main reasons:

- *Faults in problem theory*: inadequate analysis of the problem.
- *Faults in programme theory*: translation of theory into programmes.
- *Faults in programme implementation*: problems in the organisations, resources levels and/or activities used to deliver the programme.

Applying a similar framework to the insights gained from patient experience about how effectively the RFPP addresses the needs of Pacific families, may assist with unpacking the complex range of issues, concepts and processes around rheumatic fever.

Recommendations

- Further research, drawing on the perspectives and experiences of Pacific patients and families, to develop a Pacific family model of care that:
    - recognises the characteristics of Pacific family units that are very different to the New Zealand norm,
    - supports the needs of family members in their role as primary caregivers to children with rheumatic fever, and
    - supports family knowledge, understanding and ability to access social services at key points of need.
- Further consideration of the role of health literacy in relation to health promotion and pathways to and through primary health care.

- Further development and use of research methodologies based on Pacific cultural values to ensure safe engagement with families and to enhance the richness and knowledge of diverse patients and their families experiences of health services within the New Zealand context.

Glossary

Canadian National Occupancy Standard (CNOS)

CNOS has been developed by the Canada Mortgage and Housing Corporation to help determine the number of bedrooms a dwelling should have to provide freedom from crowding. The CNOS is based on the number, age, sex and interrelationships of household members.

The CNOS states that:

- no more than two people shall share a bedroom,
- parents or couples may share a bedroom,
- children under 5 years of age of the same or opposite sex may share a bedroom,
- children under 18 years of age of the same sex may share a bedroom,
- a child from 5 to 17 years of age should not share a bedroom with a child under 5 years of age of the opposite sex, and
- single adults 18 years of age and over and any unpaired children require separate bedrooms.

(Ministry of Health, 2014)

New Zealand Deprivation Index (NZDep)

A census-based New Zealand small-area index of relative socio-economic deprivation. The index is used in research on mortality, morbidity and determinants of ill health, and in needs assessment, resource allocation and advocacy.

(University of Otago, 2014).

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Appendix A: Interview Guide

Our aim is to allow parents and caregivers of children with rheumatic fever to discuss their experiences of health services. The following questions are provided to assist with guiding and prompting patient stories for clarification. A key principle of the research is to capture **"what matters to patients and caregivers"** and hence the focus groups will be facilitated to capture patient stories.

1. **What is your level of understanding of rheumatic fever?**
   - The link between sore throats and rheumatic fever?
   - The need to take antibiotics to treat sore throats?
   - What are the signs of rheumatic fever?
   - What are the causes of rheumatic fever?
   - What does it mean for your child's health to be diagnosed with rheumatic fever?
   - Probe consequences including heart diseases, need for prophylactic penicillin injections. For example what can you do to prevent heart disease once your child has been diagnosed with rheumatic fever?

2. **What are your experiences of health services for prevention, treatment of sore throats, rheumatic fever and or rheumatic heart disease?**

   - Prevention – TV ads, other heat promotion information, eg newspapers, internet, other….state
   - Primary care – GP, family doctor, nurse led clinics, hospital ED, A&E clinics? Where did they seek care for initial signs and symptoms? What happened? What worked well? What were the barriers?
   - Probe access to see doctor/nurse, process of care, throat swabs, results, antibiotics, follow up
   - Hospital admissions – describe experience. What worked well? What were the barriers? Probe cost, transport, language, understanding, rapport/trust, other priorities
   - Probe access – cost, transport, language, understanding, rapport/trust, other priorities
   - Secondary prevention – penicillin injections. describe experience. What worked well? What were the barriers?

   Communication
   - When you had questions to ask did you get the answer that you could understand?
   - Was your child's condition described to you in a way that you could understand?

   Partnership
   - Did you feel you were involved in decision making about your child's treatment

   Physical, emotional and cultural needs
   - Did you feel treated with dignity and respect?

   Coordination
   - Were the different services you needed coordinated?

Appendix B: Participant Consent

The main parent or caregiver of each patient chosen to participate in the research was asked to confirm that they understood a set of questions. Cook Island Māori, Samoan and Tongan translations of the questions were also available. For those who participated in the Social Housing Survey (February 2015), the consent questions were asked by interviewers over the phone. Verbal agreement to consent was recorded

Patient consent questions (English version)

- I have read the Information Sheet explaining this project and have had the opportunity to have my questions about the project explained to me. My questions have been answered to my satisfaction and I know I can ask for more information at any time.
- I agree to participate in an individual or family interview or group interview and understand that this will involve a meeting of approximately 1 to 1.5 hours. I understand that I am free to withdraw from the interview at any time.
- I understand that interview sessions will be recorded for the purpose of gathering information for the research and these records will be held by the researchers for 10 years.
- I understand that my identity or any identifying features of the information will be removed by the researcher to maintain me and my families anonymity and confidentiality.

Four consent questions from Social Housing Survey (February 2015)

- I understand the purpose of this research and have had the opportunity to have my questions about the research answered and explained to me. My questions have been answered to my satisfaction and I know I can ask for more information at any time.
- I agree to participate in the phone survey and understand that this will take about 30 minutes. I understand that I am free to withdraw from the interview at any time.
- I understand that the information I provide will be used by the researchers to provide information to the Ministry of Health.
- I understand that my identity or any identifying features of the information will be removed by the researcher to maintain me and my family's privacy and confidentiality.

Appendix C: Participant Selection

This appendix provides a detailed breakdown of participant selection and recruitment for this report.

Rheumatic Fever Focus group, December 2014
In November 2014, Counies Manukau Health (CMH) commissioned this report on the experiences of families with children who have been diagnosed with Rheumatic Fever. CMH managed the recruitment of families to participate in the focus group. A set of selection criteria was provided by PPL that included: ethnicity, gender, region of residence, parent's birthplace, frequency and number of admissions to hospital, if the patient had had heart surgery, and the time since the patient was last admitted to hospital. CMH provided a data set of 119 patients who had been admitted to hospital with rheumatic fever. Only the patient's current age and residential location were able to be identified from this data sets so it was decided to prioritise the age distribution of patients selected for the research.

AGE distribution:

- 5 – 9 years. Criteria - select up to 10. Total 8 in database. 5 participants (5 included in final 20)
- 10 – 14 years (select up to 23, total 47 in database. 8 participants (8 included in final 20)
- 15 – 24 years (select up to 7, total 42 in database. 10 participants (5 included in final 20)
- Exclude >25 years (22 in database). 1 attended focus group (not included in final 20)

We tried to exclude patients over the age of 25 years as the target age range was 5 – 19 as that is the age range at which rheumatic fever is reported to be most prevalent. 41 patients were not able to be contacted due to phones being disconnected, it was a wrong number, or phones were not being answered. 32 families were interested in being part of the research project, 27 families said they were able to attend the focus group and 23 families attended on the day.

- Six of the patients in the CMH database were from the same family. Bringing the total unique families to 113.
- 5 families didn't have phone numbers.
- 41 families couldn't be contacted because either their phones were disconnected, it was a wrong number or the phones were not being answered
- 22 families excluded as the patients were over 25years.
- Total of 45 families contacted.

Social Housing Survey, February 2015
In January 2015, the Ministry of Health (MOH) commissioned a report on Social Housing (called "Access to social housing for Māori and Pacific families in Auckland who have experienced rheumatic fever"). This study involved a survey of Māori and Pacific families who had at least one family member hospitalised with rheumatic fever during the 2013 calendar year.

The Ministry of Health commissioned research on 108 patients based on their evidence of 108 patients admitted to hospital in 2013 for rheumatic fever. The data supplied by the DHBs came to a total of 201 patient records. We do not have an explanation for the discrepancy of records between the MOH and the DHBs of patients admitted to hospital in 2013 with rheumatic fever.

Data supplied by CMD (119 records), Auckland DHB (63 records) and Waitemata DHB (19 records) included 201 patient records. Five families had more than one family member living in the household who had been diagnosed with rheumatic fever. In these cases only one interview per household was done. 18 records

were invalid, leaving a total of 183 unique valid patient records. Out of the 183, 25 identified their ethnicity as Māori, 157 as Pacific, 1 as 'other'.

A total of 53 families were surveyed. 12 of the families contacted declined to participate in an interview, and 118 families were unable to be contacted. Out of the 53 families survey, 8 of the patients identified their ethnicity as Māori and 45 as Pacific.

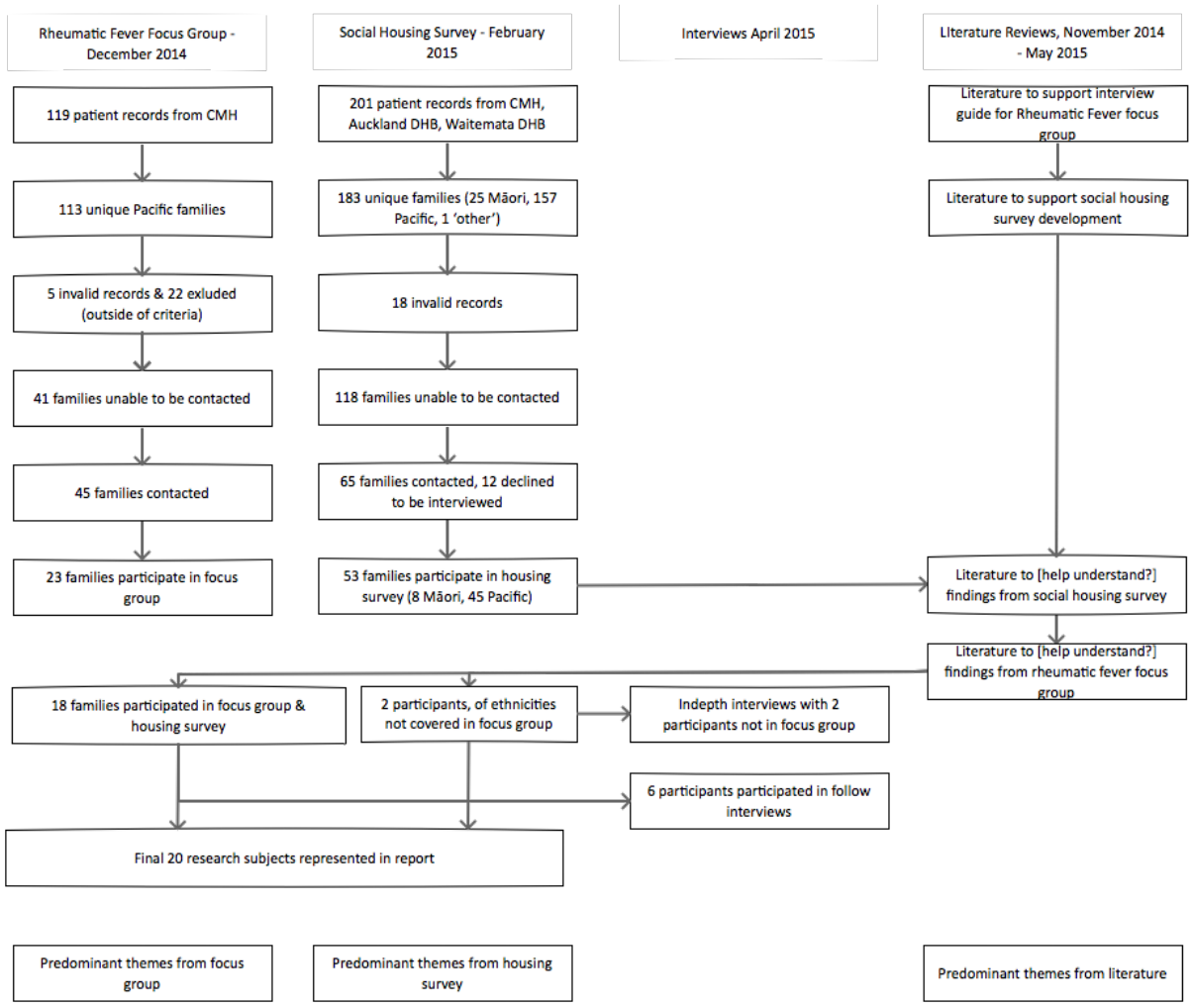
From the list of 183 unique families, 108 records were randomly selected as this was the number the Ministry of Health had commissioned research for. As there were so many families that couldn't be contacted the research team continued to contact all families on the data base until all families were contacted (or attempted to be contacted).

- Ten of the patients in the MOH database were from the same family. Bringing the total unique families to 183.
- 18 records were invalid
- 118 couldn't be contacted because the phone was disconnected, wrong number or the phone wasn't being answered.
- 12 declined
- 53 interviewed

Note on "counting by family unit"

- The research was focused on the experience of the family as a whole unit. As such, were there were multiple patients in one family that family was counted once.

Diagram of how the 20 research participants were chosen.


Rheumatic Fever Focus Group - December 2014
Social Housing Survey - February 2015
Interviews April 2015
LIterature Reviews, November 2014 - May 2015
119 patient records from CMH
113 unique Pacific families
5 invalid records & 22 exluded (outside of criteria)
41 families unable to be contacted
45 families contacted
23 families participate in focus group
201 patient records from CMH, Auckland DHB, Waitemata DHB
183 unique families (25 Māori, 157 Pacific, 1 'other')
18 invalid records
118 families unable to be contacted
65 families contacted, 12 declined to be interviewed
53 families participate in housing survey (8 Māori, 45 Pacific)
Literature to support interview guide for Rheumatic Fever focus group
Literature to support social housing survey development
Literature to [help understand?] findings from social housing survey
Literature to [help understand?] findings from rheumatic fever focus group
18 families participated in focus group & housing survey
2 participants, of ethnicities not covered in focus group
Indepth interviews with 2 participants not in focus group
6 participants participated in follow interviews
Final 20 research subjects represented in report
Predominant themes from focus group
Predominant themes from housing survey
Predominant themes from literature