

**IMPLEMENTING THE RHEUMATIC FEVER GUIDELINES: IDENTIFYING THE
CHALLENGES AND CROSSING THE THEORY/PRACTICE DIVIDE**

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i. Abstract

Background

The 2006 New Zealand (NZ) Guidelines for Rheumatic Fever (RHF) (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006) have an over-arching objective to support appropriate management of RHF to prevent recurrent attacks and reduce mortality and morbidity from RHF and Rheumatic Heart Disease (RHD) (Craig, Anderson, & Jackson, 2008; National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006).

Aims

The aims of this study were to audit current practice and service provision associated with RHF programmes and initiatives in NZ's District Health Board's (DHB's) against the 2006 NZ Guidelines for RHF and to identify the barriers and facilitators to clinicians meeting the guidelines.

Methods

A two phased approach was conducted. An observational retrospective quantitative audit assessed practice against the guidelines for the 15 DHB's of the North Island of NZ. The exploratory qualitative phase investigated the barriers and facilitators to meeting the guidelines by using semi-structured interviews with RHF coordinators from six DHB's in the North Island of NZ.

Findings

The findings of the two phases showed that the context of the environment and the population has an impact on the attainment of the guidelines. Higher achievement of the standards was seen in those activities relating to diagnosis, management, provision of secondary prophylaxis and some of the register aspects of the guidelines. Yet the guidelines have made little impact on practice relating to the lowest scoring standards of the guidelines from the secondary services section.

Conclusions

Improvements in these outcomes can be assisted by implementation of the strategies outlined, which were based on a foundation of cultural appropriateness and driven by national leadership. Ultimately, the practical utilisation of these research recommendations will see; more targeted RHF services aimed at reducing inequalities based on the at-risk populations; and, effective decreases in RHF related morbidity and mortality throughout NZ.

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1. Introduction

Background - Rheumatic Fever

Rheumatic Fever (RHF) is a disease of poverty that has been eliminated from most developed countries and now generally only exists in third world nations (Christmas, 1984). Programmes to improve general conditions of living saw a drastic decline in rates of this disease throughout North America and Western Europe during the 1970's (Gray, 2009). New Zealand (NZ) still has some of the highest rates of RHF in the World, alongside Indigenous populations in Australia, sub-Saharan Africa and south-central Asia (Carapetis, Steer, Mulholland, & Weber, 2005).

In NZ between 1996 and 2005, an average of 125 new cases of RHF were diagnosed each year, with a total of 61 recurrences during that time period (Jaine, Baker, & Venugopal, 2008). During 1980 – 2004, the average number of deaths from Rheumatic Heart Disease (RHD) in NZ was 146 per year (Lennon, 2009). Increasing disparities are seen as rates of initial attack, recurrences and RHD related deaths are significantly higher amongst Maori and Pacific peoples (C. Jackson & Lennon, 2009; Jaine, et al., 2008; Lennon, 2009; Wilson, 2010).

The burden of this disease is primarily on Maori and Pacific children and families, generally from areas of high social deprivation, who have poor access to primary and secondary care. They are often overwhelmed with other significant health and socio-economic factors (Jaine, et al., 2008). Acute cases of RHF are indicators of failed primary prevention, and recurrent cases of RHF, often causing cardiac damage, are evidence of failed secondary prevention.

Regardless of these factors, little has been done to effectively address the primary and secondary failures at regional or national levels. These combined factors have provided the motivation and rationale for RHF to be the topic of this Masters portfolio.

Background – Researcher's Role at Public Health

RHF was the first project given to the researcher to investigate, soon after starting a new job in 2003 at a District Health Board (DHB) Public Health Unit. This role was a nursing role doing clinical support for the communicable diseases and immunisation contracts. One of the Medical Officers of Health (MOoH's) for the unit had been receiving haphazard reports from Community Nurses and was concerned that the care being given across the DHB may not have met expected standards. Consequently there was an investigation into current practice, including the development of a scoping document and recommendations for the DHB.

Local RHF Activities

Following the completion of the scoping document and recommendations, a regional RHF group of expert representatives was formed, a local register developed, standardised pathways of care and lines of communications instigated, an audit of the patient population and services conducted, and contribution made to the 2006 NZ Guidelines for RHF (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006). Smaller subgroups were formed as quality initiatives to improve processes and services for; dental care, transfers between DHB's, communications within the DHB, transition planning for young people, discharge planning from the ward, and professional development needs of staff.

Momentum gathered throughout the country in 2008, culminating in a National RHF workshop and also a regional workshop with representatives from four DHB's invited. These provided opportunities to discuss local initiatives, challenges and areas of concern.

When the opportunity was presented to enrol in Masters Study, it provided an avenue to summarise local RHF milestones and to share with other DHB's that were yet to explore some of the activities we had.

The Research Topic

The NZ Guidelines for RHF (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006) were published in 2006. This followed evidence from audits showing a lack of standardised and evaluated care being given throughout regions resulting in poor health outcomes, particularly for Maori and Pacific Peoples (C. Jackson & Lennon, 2009; Jaine, et al., 2008; Purchas, Wabitsch, Taikato, & Miles, 1984; Thornley, McNicholas, Baker, & Lennon, 2001; Wilson, 2010).

The guidelines provide national consistent standards for RHF diagnosis, management and secondary prevention. They identify areas where current management strategies may not be in line with available best practice and provide guidance to ensure that high-risk populations receive high quality care founded on evidenced-based standards. The over-arching objective of the guidelines is to support appropriate management of RHF to prevent recurrent attacks and reduce mortality and morbidity from RHF and RHD (Craig, et al., 2008; National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006).

There is a paucity of NZ literature describing how the RHF guidelines are being implemented and utilised, what service gaps exist and what targeted services are required to meet the specific population needs (Atatoa-Carr, Bell, & Lennon, 2008; Best Practice, 2008; Carapetis, McDonald, &

Wilson, 2005; Jarman, 2007; Thornley, et al., 2001). As such, the research topic was selected to help fill this gap in the literature and provide outcomes that were meaningful at both national and local levels.

Anecdotally, there were a number of standards that were being met well in most areas throughout the country, but there were also a number that were posing large challenges. At a national level, the outcomes of the research were designed to isolate those standards in the guidelines that were being met well and those that were posing challenges and to provide evidence of this. The goal of this research was to provide a list of recommendations on how to cross the theory/practice divide to meet these challenges and improve practice outcomes.

Consequently, the research question to be answered in this portfolio was:

To what extent are the 2006 New Zealand Guidelines for Rheumatic Fever being met and what are the barriers and facilitators to implementation?

The aims of this study were to:

- Audit current practice and service provision associated with RHF programmes and initiatives in NZ's 20 DHB's against the NZ Guidelines for RHF
- Identify the barriers and facilitators to clinicians meeting the guidelines

Structure of the Research Portfolio

This research portfolio achieves these aims through five chapters, including this one.

The second chapter is a literature review. A summary of international and NZ RHF guidelines, initiatives and audits is provided. Examples of these lay the historical foundations, identify recent developments and highlight best practice methods for conducting this research. The literature chapter concludes with the research question being stated and the research direction and methods outlined.

The third chapter answers the question of: **To what extent are the District Health Board's meeting the 2006 New Zealand Guidelines for Rheumatic Fever?** It contains the quantitative section of the research, and describes the methods, analysis and discussion surrounding the audit of the guidelines.

The fourth chapter explores the following question: **What are clinician's perspectives on the barriers and facilitators to implementing the 2006 New Zealand Guidelines for Rheumatic Fever?** It presents some of the stories and lessons learnt from the participants through qualitative interviews. Participants were asked in the interviews what recommendations they would make for

targeted public health interventions to meet the needs of RHF patients in their area. These were not discussed in chapter four as it was outside of the scope of investigating the barriers and facilitators to implementing the guidelines. Instead the recommendations from the interviews were summarised in chapter five.

The fifth and final chapter brings the previous chapters together. The two phased approach adopted used qualitative interviews to describe the complex reasons behind the quantitative findings of the current standard of care being delivered in relation to the guidelines. This enabled both a description of the extent of the public health problem and an understanding of the reasoning behind it (Baum, 1995). Recommendations from previous chapters are summarised, conclusions are drawn and implications for practice are presented, including a list of recommendations to assist in crossing the theory/practice divide. Implementation of these strategies could assist with improving the general attainment of the standards of the guidelines across all DHB's through a nationally driven, culturally appropriate, responsive, holistic public health programme, based on the needs of Maori and Pacific RHF populations.

2. Literature

Introduction

The epidemiology, aetiology and risk factors for Rheumatic Fever (RHF) have been well documented throughout the century. This review does not look to re-illustrate these factors. It is focussed on literature informing the diagnosis, management and secondary prevention of RHF, as captured by the New Zealand Guidelines for Rheumatic Fever (2006). Primary prevention literature has not been included in this review as it is outside of the scope of this research.

This chapter reviews the New Zealand (NZ) guidelines alongside international guidelines; compares and contrasts comprehensive public health initiatives that strive to meet these best practice standards; and, identifies models for RHF practice and service audit.

The aim of this review is to provide a context for current RHF best practice against the NZ guidelines, and highlight some of the gaps in local knowledge in this area. Recommendations are made for further study to close the gaps in local literature. The research question and the research direction and methodology conclude this chapter of the portfolio.

Methods

The search strategy began by electronically searching for “Rheumatic Fever”, “Rheumatic Fever Management” and “Rheumatic Fever Audit” within Medline (OvidSP database) and Science Direct. Articles were selected by currency and relevance to the scope of national guidelines, local comprehensive public health initiatives and audit of secondary prevention programmes.

A snowball search strategy continued via the related articles section of Science Direct. Targeted searching was conducted under the term “Rheumatic Fever” in the World Health Organisation (WHO), NZ Ministry of Health, Medical Journal of Australia, South African Medical Journal, Australian and NZ Journal of Public Health and NZ Medical Journal sites.

Grey literature was accessed via google scholar and colleagues within RHF networks to gather relevant unpublished local documents.

Finally, to ensure the key literature had been obtained, three reference libraries of the researcher, the researcher’s supervisor, and another colleague from the RHF research field were combined and sorted to those references relating to diagnosed RHF – excluding primary prevention and group A streptococcal management.

Results

Of the 1,400 identified references and abstracts, 108 full text English language articles have been included for this review. They were selected according to the above criteria.

The literature was categorised and summarised on a spreadsheet (appendix one), covering four main themes:

1. General RHF background articles
2. RHF Guidelines
3. RHF initiatives
4. RHF audit

The articles from theme one were used by the author as background data for the development of this review, but not included, as it is outside of the scope of the review, as outlined in the introduction.

The remaining three themes reviewed in this chapter are categorised to illustrate the international and NZ literature and examples.

Together, this collection of literature outlines what best practice RHF care looks like. International initiatives have demonstrated what can be done to adapt those best practice guidelines to meet the challenges and gaps in services.

In NZ, the collection of literature has been built on the foundations of the studies conducted in the 1970's and 1980's, identifying local RHF populations (Flight, 1984; Frankish, 1974, 1984; Neutze, 1988; Neutze & Clarkson, 1984; Prior, Evans, Morrison, & Rose, 1970; Purchas, et al., 1984; Talbot, 1984a, 1984b; Wabitsch, Prior, Stanley, & Pearce, 1984).

Momentum has been gathering in the past decade, resulting in further study, providing a better understanding of who the RHF populations are, who are most at- risk, and what determinants affect positive health outcomes (Atatoa-Carr, Bell, et al., 2008; Gray, 2009; C. Jackson & Lennon, 2009; Jaime, et al., 2008; Lennon, 2009; Loring, de Wit, Shoemack, & Hewison, 2008; Martin, 2008; Spinetto, Lennon, & Horsburgh, in press).

What have not been identified is where the gaps are in the implementation of the guidelines in NZ, what barriers exist in the delivery and receipt of care in these areas, and what strategies can be recommended to ensure the gaps are closed.

Rheumatic Fever Guidelines

Five guideline documents from the WHO (World Health Organisation, 2004), India (Working Group on Pediatric Acute Rheumatic Fever and Cardiology Chapter of Indian Academy of Pediatrics et al., 2008), America (Gerber et al., 2009), Australia (Carapetis, Brown, Wilson, Edwards, & Rheumatic Fever Guidelines Writing, 2007; National Heart Foundation of Australia & Cardiac Society of Australia and New Zealand, 2006) and NZ (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006) have been reviewed to identify best practice standards of RHF care. Each of these guidelines recognise that, regardless of the presence for over 50 years of high level evidence of effective prevention of RHF and Rheumatic Heart Disease (RHD), it is still a leading cause of cardiovascular disease and death in many developing and industrialised countries (Robertson, Volmink, & Mayosi, 2006).

Consequently, guidelines have been updated (World Health Organisation, 2004) and adapted to suit local circumstances (Carapetis, et al., 2007; National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006; Working Group on Pediatric Acute Rheumatic Fever and Cardiology Chapter of Indian Academy of Pediatrics, et al., 2008). They reflect the technical developments within the past few decades, such as Echocardiography and laboratory advancements; updated best practice standards drawn from both sentinel documents and a growing collection of literature and research; and, population based lessons that require specific consideration.

The guidelines are generally consistent in their research bases and evidence-grading. It is interesting that the Indian guidelines (Working Group on Pediatric Acute Rheumatic Fever and Cardiology Chapter of Indian Academy of Pediatrics, et al., 2008) have utilised the highest grade of evidence, but the patient and population needs do not feature. Whereas the Australian guidelines (Carapetis, et al., 2007) have a lower grade of evidence for local recommendations that are highly targeted towards high risk populations.

This appears to be reflective of the relative newness of revising highly evidenced best practice and adjusting it to make it more specific to target populations. Less evidence exists in such activities; not necessitating a rejection of the evidence, but perhaps suggesting further investigation into such initiatives.

Following the review of these guidelines, the key factors include the importance of uniformity of approach and coordination of strategies across the continuum of care. Value is placed on evidenced based practice with graded levels of evidence. Finally, adaptability to the changing environment and population is crucial in utilising guidelines to develop a comprehensive public health approach.

New Zealand Rheumatic Fever guidelines.

One of the aims of this research is to audit practice against the NZ guidelines for RHF. As such, this section will explore the background to, and objectives of, these guidelines.

Although the Ministry of Health highlighted RHF as part of the priority group of infectious diseases to be addressed in its overarching goal of reducing health inequalities for Maori and Pacific Peoples (Ministry of Health, 2001), it had not developed a strategy for control and management of RHF to support and lead local initiatives (Christmas, 1984; Craig, et al., 2008; Newman, Lennon, & Wong-Toi, 1984; Purchas, et al., 1984; Wilson, 2010).

The need for nationally consistent standards of RHF management became increasingly evident as regional audits illustrated the lack of standardised and evaluated care being given throughout regions, let alone between DHB's (C. Jackson & Lennon, 2009; Purchas, et al., 1984; Thornley, et al., 2001; Wilson, 2010).

Recognised guidance came in the form of published seminar papers and a circular letter outlining RHF epidemiology in NZ, RHF pathogenesis, disease features and diagnosis, and best practice approaches to secondary prophylaxis to prevent recurrent attacks of RHF and RHD (Carapetis, McDonald, et al., 2005; Department of Health, 1988; Lennon, 2004). Coordinated recurrent RHF prevention programmes were promoted as effective strategies for reducing recurrent attacks of RHF and the ensuing cardiac complications (Talbot, 1984b; Thornley, et al., 2001; Wilson, 2010).

The gap in NZ literature of a consistent National Guideline was filled in 2006 by the National Heart Foundation of NZ and the Cardiac Society of Australia and NZ. Following an extensive literature review and consultation period, the NZ Guidelines for RHF were developed with four key objectives:

- To identify and present the evidence for best practice in RHF diagnosis
- To identify the standard of care that should be available to all people in NZ
- To identify areas where current management strategies may not be in line with available evidence
- To ensure that high-risk populations receive the same standard of care as that available to other New Zealanders

(National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006, p. 5)

Adaptations in the NZ guidelines were based on local studies of high-risk populations and local interventions. The NZ guidelines include modified diagnostic criteria for greater sensitivity to these populations (White et al., 2010) and recommended interventions to reduce mortality and morbidity from RHF and RHD (Craig, et al., 2008). As such, their grades of evidence were mixed, similar to

those seen in the Australian guidelines, with pockets of lower grade evidence for local recommendations which are highly targeted towards the high risk populations. The guidance with higher grades of evidence, as seen in the Indian Guidelines, includes the foundational evidenced-based standards of diagnosis, management and secondary prevention.

The NZ Guidelines were developed following review and adaptation of the Australian Guidelines on diagnosis and management (National Heart Foundation of Australia & Cardiac Society of Australia and New Zealand, 2006). They were expanded to include a second and third guideline on sore throats and primary prevention, which is not addressed in the Australian guidelines, and are outside of the scope of this research. The final draft was endorsed by key Maori and Pacific organisations, along with numerous clinical boards and organisations (Atatoa-Carr, Lennon, & Wilson, 2008).

Rheumatic Fever Initiatives

International initiatives.

Over the past two decades, international comprehensive public health programmes have highlighted the challenges in meeting best practice guidelines. These challenges are generally related to the determinants of the disease that lie outside of the health sector. The economic state of countries that are heavily burdened by RHF reflects on the scarcity of health care staff; health literacy of health care workers, patients and families; logistics of drug supply (World Health Organisation, 1992); and, availability and affordability of technology, laboratories and specialist tertiary cardiology services (Eisenberg, 1993; MBewu, 2006). Additionally, the socio-economic position of those most at risk of developing RHF influence access to services, prioritisation of health needs and continuity of care (McDonald, Brown, Noonan, & Carapetis, 2005; Omokhodion, 2006; Robertson, et al., 2006).

Local initiatives to address these challenges identify upstream, midstream and downstream interventions. Upstream interventions involve advocating for improvements in the social determinants of health that span across various Ministries (Mayosi et al., 2006; MBewu, 2006), particularly the Ministries of Health, Education, Housing and Social Development. Collaboration amongst these Ministries would provide the platform to make an impact on the underlying factors that result in RHF, and many other illnesses of poverty and overcrowding. To enable this to happen, RHF needs to feature on the agenda of Ministries, funders and policy makers (Robertson, et al., 2006).

Midstream initiatives include analysis of the structures, resources and capacity that are required within communities to successfully treat and sustainably manage RHF. These initiatives recognise the importance of collaborative capacity building programmes located centrally that include training of personnel, development of infrastructure (Brown, Purton, Schaeffer, Wheaton, & White, 2003; Omokhodion, 2006) and regular evaluation (World Health Organisation, 1992).

Downstream initiatives include comprehensive, long term programmes for control of RHF. These programmes include interconnected activities such as: identification and ongoing surveillance of at risk communities via management registers; community-based education programmes aimed at raising awareness of RHF and its associated complications; integration with the primary health care network; and, educating community workers to support patients in the long term follow up of their secondary prophylaxis programme (Bach et al., 1996; Brown, et al., 2003; Eisenberg, 1993; Mayosi, et al., 2006; McDonald, et al., 2005; McLaren, 1994; Robertson, et al., 2006).

Such multi-streamed, collaborative, and comprehensive programmes have seen successful outcomes internationally. Communities have become more aware of RHF, health professionals have become more aware of the RHF communities, rates of RHF and recurrences have decreased, and lessons have been learnt and shared across the international RHF community.

New Zealand initiatives.

Over the past five to ten years, NZ research has focussed on identification of the populations at risk (Atatoa-Carr, Bell, et al., 2008; Jaine, et al., 2008). Sadly, NZ's incidence rates of RHF have failed to decline since the 1980s, and widening disparities are seen, with Maori and Pacific peoples having far greater rates of acute RHF, recurrent RHF and RHD than NZ Europeans (Jaine, et al., 2008). Clear links are seen between RHF and poverty, household crowding and inadequate access to healthcare (Atatoa-Carr, Bell, et al., 2008; Baker, Goodyear, & Howden-Chapman, 2003; Best Practice, 2008; Christmas, 1984; G. Jackson et al., 2009; Lennon, 2004; Neutze, 1988).

In response to these findings, NZ RHF guidance documents have been adapted to increase their sensitivity to the RHF populations and service environments (Carapetis, McDonald, et al., 2005). Recommendations from such studies include initiatives to improve national uniformity in line with the guidelines, with the objective of consistently improved standards of practice.

Additionally, regular evaluation of the current state of RHF/RHD is recommended, using epidemiology and programme evaluation of local/national initiatives. In particular, this includes new initiatives to; instigate regional register-based control programmes (Thornley, et al., 2001); standardise the use of diagnostic tools, coding and notification (Atatoa-Carr, Bell, et al., 2008; Carapetis, McDonald, et al., 2005; Jaine, et al., 2008); enhance ethnicity coded surveillance (Jaine, et al., 2008; Martin, 2008); and review resources and targeted education strategies for community and health professionals (Martin, 2008).

There is a paucity of NZ literature describing how the RHF guidelines are being implemented and utilised, what service gaps exist and what targeted services are required to meet the specific

population needs (Atatoa-Carr, Bell, et al., 2008; Best Practice, 2008; Carapetis, McDonald, et al., 2005; Jarman, 2007; Thornley, et al., 2001).

International Rheumatic Fever Audits

Established programmes and initiatives have been evaluated, both in line with programme objectives and with national guidelines. These have included programme audits, adherence audits, investigation into the impact of the disease on patient and family and assessment of clinical practice against guidelines. A brief summary of the findings and future direction of these audit categories are outlined below.

Programme audit.

A three phased, step-up programme was developed by the WHO in 1984 with the aim of reducing the impact of RHF/RHD by establishing local and/or regional programmes in 23 countries. It included the strategies of case finding, development of a registry, management of secondary prophylaxis, personnel training and health education, and evaluation of the process and outcomes at each of the three phases (World Health Organisation, 1992).

Phase one was the short term pilot phase, starting in a small town or community, moving to a town or region in phase two, finally escalating to a city or country in phase three (World Health Organisation, 2005).

Audit of this programme showed successes in establishment of the processes required to manage an RHF/RHD control programme; improvements in the quality of care for RHF/RHD patients in participating areas and a decrease in the severity and impact on those with RHF (World Health Organisation, 2000). Yet many of the participating countries struggled to progress to phases two or three, mostly due to resource and funding limitations (World Health Organisation, 2000, 2005).

Key recommendations from these reports and evaluations included the need for coordination between services, Ministries of Health and the WHO to see progression to phases two and three in participating countries; ongoing and sustainable health education and training of personnel; securing a reliable supply of readily available and affordable, injectable, long acting penicillin; continued epidemiological surveys of RHF/RHD; development of RHF/RHD country profiles, assessing the prevalence of RHF and RHD and an operations plan to suit local need and circumstances (World Health Organisation, 2004); and updating RHF/RHD guidelines (World Health Organisation, 2000), which was completed in 2005 (World Health Organisation, 2005). Despite these recommendations, funding from the WHO ceased in 2001, leaving many of these countries unable to complete the three phases of the programme.

Audits of those programmes that did continue or had adapted the principles of the WHO control programmes, include such examples as the Cuban experience (Nordet, Lopez, Duenas, & Sarmiento, 2008), the Central Australian Heart Disease Control Programme (Brown, et al., 2003), the Top End RHD programme (Kelly, 2003), the Awareness Surveillance Advocacy Prevention Programme in Africa (Robertson, et al., 2006), and a follow up review of ARF programmes in North Queensland (Hanna & Clark, 2010).

Reports of these audits summarised success factors, barriers and recommendations for future activities; including:

- Obtaining support and approval from multiple levels of influence throughout healthcare organisations
- Creating National Advisory Committees with key stakeholders and decision makers to assess the local situation; identify barriers; adapt RHF control programmes to suit; and plan, implement, monitor and evaluate programmes
- Adapting the WHO programme to suit local healthcare systems and populations
- Implementing RHF programmes in an integrated and collaborative manner into existing healthcare system's structures and facilities
- Conducting ongoing surveillance of the incidence of RHF and prevalence of RHD to track high risk groups and direct control efforts on a needs basis
- Utilising scarce resources efficiently – e.g. gaining quality data in smaller sentinel sites; providing RHD programmes to those groups most at risk and rolling out to the wider population in a stepwise approach; integration of RHF programmes into existing services to reduce cost and improve sustainability
- Raising and maintaining awareness about RHF amongst medical professionals, particularly those in high risk areas, to minimise misdiagnosis and to reduce recurrence rates
- Raising and maintaining awareness about RHF amongst high risk communities using multiple modalities with appropriate language and cultural considerations
- Developing specific strategies to follow-up high risk clients, including multidisciplinary outreach services to reach remote communities and allocation of dedicated carers to improve prophylaxis adherence
- Advocating to government to spot-light the unnecessary consequences of poorly managed and under-resourced RHF programmes

These recommendations set the platform for targeted interventions to specifically meet the most challenging aspects of the guidelines and the needs of the population.

Adherence audit.

Successful control programmes involve an integrated collection of strategies, with secondary penicillin prophylaxis as a key cornerstone to effective RHD prevention (Nordet, et al., 2008). Audit of the barriers to secondary prophylaxis adherence is necessary to challenge the perceptions of “non-compliance” and improve completion of secondary prophylaxis programmes.

Researchers have taken a holistic approach to studying adherence to prophylaxis and have discovered that the social, cultural and environmental contexts in which prophylaxis programmes operate in are more influential than the clinical significance of the disease (Harrington, Thomas, Currie, & Bulkanhawuy, 2006).

Factors influencing adherence, both to secondary prophylaxis programmes and clinic appointments, were identified by interviewing patients, retrospective study of patient files and review of existing literature (Brown, McDonald, & Calma, 2007; Harrington, et al., 2006; Robertson, et al., 2006; Stewart, McDonald, & Currie, 2007). Factors were identified under five themes:

- Concepts of good care for patients
- The process of giving and receiving injections
- The entrenched effects of disadvantage and the resulting barriers to adherence
- Patients knowledge and understanding of RHF in the context of beliefs of the origins of disease
- Allocation of responsibility for culturally responsive and coordinated health care, within an environment of competing health services for scarce resources

Care, nurture and belonging were the resounding messages for successful services based on trusting relationships and holistic models of care. Transparent roles and expectations also assisted with maintenance of successful relationships and positive health outcomes. Finally, government commitment and investment is required to see that the passion and dedication of local providers is supported, resulting in decreased impact of this disease on vulnerable populations.

Impact on patient and family.

Environmental, social and cultural factors that impact on the patient and family can affect the success of an RHF programme. If these factors are not recognised, services may not be appropriate for the needs of the population and are therefore likely to be inefficient.

An early study in which parents of children with RHF were interviewed and data was gathered on their knowledge of RHF, beliefs and anxieties, and factors influencing their knowledge and beliefs (Kennell, 1969). The study found that regardless of the perceived quality of education that was given, the underlying fear of heart disease and death pervaded. This resulted in unrealistic restrictions being

placed on children, and a low level of understanding of the disease, the purpose of prophylaxis and the long term effects of RHF.

This study also found that many children were not actively involved with their care. Parents reported that their children had very little if any understanding of their condition. As highlighted in this research, if the parent and child have very little understanding and high levels of fear, completion of secondary prophylaxis remains unlikely.

The practice implications identified in the study provided suggestions to review the timing and methods of education, both with the parent and the child. Social workers or paediatricians were encouraged to meet regularly with patients and parents to discuss their anxieties, reflections and misconceptions. A whanau centred approach was suggested as a means to improve the internal lines of communications for the wider family, making the transition back into the home environment an easier one with a greater understanding by all.

In summary, this study provides insightful challenges to health professionals when imparting health information to patients and families. It also makes implicit the need to tend to both the emotional and physical needs of the patient and family.

In another study (Arafa et al., 2008), the researchers interviewed a comparative cross-sectional group of children and their parents to identify the factors that impact on quality of life. The comparative groups consisted of children with cardiac diseases (including RHD) and another group of children with minor illnesses. The data showed that quality of life for the children with cardiac disease was much lower than their comparative group. This was amplified by the multiple factors impacting on this group of children.

The data identified severity and type of disease, age of child, family composition, financial situation and presence of co-morbidities as factors affecting quality of life amongst parents and children with heart disease (Arafa, et al., 2008). In line with the study described above, implications for practice include the need to analyse the impact of the diagnosis of RHF on patients and families, identify the compounding factors impacting on the patient and their family, and to provide appropriate psychological and practical support to enable families to make appropriate treatment decisions for their children.

Although this only outlines two audits of the impact on the patient and family, it clearly illustrates the importance of such studies in planning appropriate holistic multi-faceted interventions to suit population need.

Practice versus guidelines.

National Guidelines provide best practice guidance, but need to be audited to determine the impact they have on practice and the overall burden of disease associated with RHF/RHD (Robertson, Volmink, & Mayosi, 2005). Such audits have been undertaken in the past decade in Aboriginal communities throughout Australia (Eissa et al., 2005; McDonald, et al., 2005; Mincham, Mak, & Plant, 2002; Stewart, McDonald, & Currie, 2005), and practice settings within South Africa (Nkgudi, Robertson, Volmink, & Mayosi, 2006; Robertson, et al., 2005).

These audits included reviewing best practice guidance against; case detection and accuracy of diagnosis according to the Jones criteria (Eissa, et al., 2005; Robertson, et al., 2005; Stewart, et al., 2005); notification of new cases (Nkgudi, et al., 2006; Robertson, et al., 2005); accuracy of the register in relation to the community and to other databases (Eissa, et al., 2005); secondary compliance – including injections, clinics, dental and blood testing (Eissa, et al., 2005; Mincham, et al., 2002; Robertson, et al., 2005); and effectiveness of health education and promotion (Robertson, et al., 2005).

The results of these audits showed poor clinical outcomes. The following summarises the findings of each of the studies, and outlines their recommendations.

Two South African studies (Nkgudi, et al., 2006; Robertson, et al., 2005) found very little progress in practice standards since the publication of the South African guidelines in 1997. Patient knowledge on the disease was almost non-existent, as was clinician's knowledge on the notification process and the resulting notification rates. The guidelines were found to be unclear in how increased case detection would be achieved and what degree of notification is required (only acute cases, or acute and recurrent cases). Yet despite this, secondary prophylaxis adherence was high.

Recommendations included review and rectifying of both internal and external surveillance and notification processes; updating the guidelines to provide further clarity around case detection and notification; and appropriate education for health professionals, patients and communities to raise RHF awareness (Nkgudi, et al., 2006; Robertson, et al., 2005).

An audit was conducted in a remote hospital in an Australian rural setting to determine the accuracy of diagnosis according to the Jones Criteria (Stewart, et al., 2005). The audit was conducted to assess if best practice was being provided at the remote setting, or whether RHF diagnosis was best made at a tertiary hospital. The results of this audit concluded that the degree to which diagnoses were being made accurately, according to the Jones Criteria, were consistent with findings in larger, tertiary hospitals. It did find better results for the acute diagnosis than the recurrent one and raised practice implications to refine and evaluate the diagnostic guidelines for recurrent RHF. Additionally,

the study highlighted the social, environmental and emotional benefits of local hospitalisation rather than the dislocation that transfer to a tertiary hospital would bring (Stewart, et al., 2005).

Poor prophylaxis adherence and echocardiography attendance rates, delayed clinic and surgical attendance, inaccurate register data, lack of linked or regional registers to track mobile populations, and gaps in the referral process to dental services were found in both an audit of medical records for patients in Kimberley, Western Australia (Mincham, et al., 2002), and an audit of register data and clinical files in a large remote Aboriginal community (Eissa, et al., 2005).

The second study (Eissa, et al., 2005) went further and investigated some of the contributing factors to these findings. These factors included lack of funds and dedicated resources to coordinate register-based management programmes; population mobility; poor RHF awareness amongst health staff and communities; access barriers to services; fear of the injections; and insufficient nurses and dedicated community workers.

Interestingly, the first study offered recommendations based around systems and processes only; including improving standard management protocols and baseline data; and development of indicators to describe characteristics of occurrence and timing of clinical management events (Mincham, et al., 2002). Whereas the second study, having discussed the contributing factors, included more population based solutions, including the allocation of a dedicated RHF coordinator; funding for community Aboriginal health workers to drive RHF programmes in their communities; a territory-wide register; migratory specialist clinics based in local communities of high incidence of RHF; and adequately funded and resourced programmes (Eissa, et al., 2005).

This holistic model of practice audit provides an example of what would be beneficial in the NZ setting, and is in line with the aims and objectives of this research. This research aims to identify how services are meeting the guidelines, as both of these studies set out to do. But it also aims to identify the factors influencing the attainment of the guidelines, including the population and environmental contexts.

These audits show that there is still a theory/practice divide, mostly marked by gaps in knowledge, processes, personnel and resources. Recommendations have been given to implement standard infrastructure, processes and lines of communications, and to adapt services to meet the holistic needs of patients, families and their communities.

These audits have not only illustrated the contrast between what has been done internationally and in NZ, but also provide examples of how to conduct such an audit of the local practice scene against the NZ Guidelines for RHF. Additionally, this data provides a realistic reflection of the extent that other countries are attaining the standards of their guidelines.

New Zealand Rheumatic Fever Audits

As indicated previously, NZ has a gap in its literature with regard to identifying how the guidelines for RHF diagnosis, management and secondary prevention have impacted on clinical practice and on the outcomes of RHF and RHD. However, the NZ guidelines were only published in 2006, whereas other international guidelines have more history and time for trial, evaluation and refinement.

The history of NZ RHF literature starts in the 1970's with exploration into RHF management. Perhaps an assumption was made that NZ, like many other developed nations, would see the eradication of RHF at the end of the second world war as improved living conditions began to resume (Christmas, 1984). As this did not eventuate in NZ, published studies began to ask why.

In the pursuit of the answer to this question, many school, community and hospital studies were conducted to identify incidence, prevalence, mortality, morbidity and undiagnosed cases with RHD (Christmas, 1984; Flight, 1984; Frankish, 1974; Frankish et al., 1978; Neutze, 1988; Purchas, et al., 1984; Wabitsch, et al., 1984). Within these settings, they began exploring factors that influenced the rates of RHF, sometimes with conflicting findings. Many confirmed high rates amongst Maori populations, links to socio-economic factors, particularly overcrowding, and issues of access to primary care (Christmas, 1984; Flight, 1984; Neutze, 1988). However, a high density RHF population study was conducted in a local secondary school which looked for links to residential geography, climate, socio-economic factors, and ethnicity; only finding ethnicity to be a discriminator (Frankish, et al., 1978). It is possible in this study, that the general population and the RHF population were so similar, that little discrimination would be discernable between the two groups.

Following a period of expansion in the RHF research and knowledge base on the risks of recurrence and cardiac damage, reviews of patient records were conducted to assess local recurrence rates. Higher rates of recurrent attacks were shown amongst patients taking oral rather than injectable penicillin prophylaxis, reported as 6.5% vs. 1.5% respectively (Newman, et al., 1984), and 35% vs. 2% respectively (Frankish, 1984).

These findings prompted a change of practice standard, recommending all new cases of RHF; receive injectable rather than oral penicillin; are referred to public health; have their data managed by a dynamic RHF register, and are cared for under a planned secondary prevention programme (Newman, et al., 1984). Following this study, a national policy change was made in support of these findings, making RHF a legally notifiable disease. A circular letter was distributed with guidance on preventing recurrent RHF, including; the use of injectable penicillin, notification to the health board, enrolment with community prophylaxis programmes and referral for specialist follow up (Department of Health, 1988).

As another tool to prevent recurrent attacks, studies were conducted into the value of register-based coordination programmes. They were highlighted as a vital cornerstone of; effective oversight for completion of prophylaxis; provision of comprehensive research data; and seamless transfer between regions to maintain contact with mobile patients (Christmas, 1984; Flight, 1984; Newman, et al., 1984; Talbot, 1988; Thornley, et al., 2001).

Identification of these influential factors prompted the collation of studies, which were presented to advocate for national recognition and appropriate resourcing. Recognised gaps in the designation of key roles and services were being highlighted as identified risks that resulted in recurrence, cardiac damage, expensive hospitalisation and in some cases, cardiac surgery and death (Christmas, 1984; Frankish, 1974, 1984; Neutze, 1988; Newman, et al., 1984; Purchas, et al., 1984).

Following a period when little was published on RHF diagnosis, management and prevention in the 1990's, momentum began to pick up again from around 2005. Local audits were conducted to identify the patient population within DHB regions (Atatoa-Carr, Bell, et al., 2008; Gray, 2009; Loring, et al., 2008; Martin, 2008; Spinetto, et al., in press). These audits also identified service standards that related to the guidelines and how these were being met. Similar to the international audits, these audits have reviewed practice against standards of appropriate case detection and diagnosis; adherence to secondary prophylaxis and appropriate delivery of prophylaxis programmes (Grayson, Horsburgh, & Lennon, 2006; Talbot, 1984b); data management systems; notification/under-notification of new cases; levels of knowledge in the community and amongst health professionals; and the availability appropriate resources for community promotion.

The findings of these NZ audits showed that successful prophylaxis programmes and high adherence rates could be attributed to dedicated register based management programmes, delivered by community nurses in community settings, and supported by local community workers (Grayson, et al., 2006; Spinetto, et al., in press). Additional success factors identified in interviews with nurses, included a proactive approach to beginning the follow up of patients at 21 days; provision of a flexible and innovative service to meet patient/whanau need; nurses having a complete clinical picture of their patient, contributed to by communications from other services; and resourcing of RHF nurses to coordinate nursing teams and conduct regular education (Grayson, et al., 2006; Martin, 2008).

Further analysis of local epidemiology and national RHF literature identified barriers to achieving best practice standards. Similar to international audits, the barriers related to many levels of influence. The population based barriers for the predominantly Maori and Pacific families with RHF/RHD include issues of poverty, overcrowding, urbanisation and inadequate access to health services (Atatoa-Carr, Bell, et al., 2008; Martin, 2008). Lack of national and regional support of RHF services and activities had resulted in systems failures, such as the discontinuation of a local register and the subsequent coordination of secondary prevention (Atatoa-Carr, Bell, et al., 2008), interrupted supply of Bicillin with

patients having to go onto oral medication or refusing prophylactic treatment completely, and lack of awareness amongst health professionals resulting in missed diagnoses (Martin, 2008). Each of these systems failures can be linked to increased recurrent rates.

Other systems failures resulted from a lack of a coordinated approach to RHF management. Inconsistencies were found between the multiple unrelated data sources of Episurv (a national, real-time surveillance tool for capturing and collating notifiable disease data (Institute of Environmental Science and Research, 2009)), hospital and local RHF register data. This provided an inaccurate local and national picture of RHF (Atatoa-Carr, Bell, et al., 2008; Jaime, et al., 2008).

Further findings of the NZ audits found challenges in the delivery of secondary prophylaxis and the coordination and provision of secondary services (Spinetto, et al., in press) due to mobile communities who move with no forwarding address. Other practical and conceptual barriers make it difficult for patients to attend clinic and injection appointments. These include having to juggle competing demands, lack of continuity of nursing staff, inability to understand or accept the consequences of the illness, differing cultural value systems and/or concepts of preventative health care (Martin, 2008).

The combined recommendations from these NZ audits to address the identified barriers at a local level included; education programmes to raise awareness of RHF amongst health professionals and communities; development of partnership programmes to support local capacity within communities, which are targeted to meet the needs of the high risk Maori and Pacific populations; and continuous quality improvement to analyse the effect of interventions and implementation of the guidelines on RHF and RHD rates.

At a national level, recommendations to address barriers included; development of a national register with improved links to RHF programmes throughout the Pacific; improved ethnicity coded surveillance data; appropriately resourced and funded services and personnel; collaborative action amongst secondary providers, community leaders and Ministerial departments; and specific collaboration between the departments of housing and health to address overcrowding and unhealthy homes (Atatoa-Carr, Bell, et al., 2008; Gray, 2009; Jaime, et al., 2008; Loring, et al., 2008; Martin, 2008; Spinetto, et al., in press).

At that national level of audit and influence, the most recent studies were produced for the Ministry of Health in 2009. The first was a scoping document for a national register which audited regional registers, identified gaps in knowledge that a national register could address, and gave recommendations for the essential elements of a national register (C. Jackson & Lennon, 2009). The results of the semi-structured interviews with local register coordinators found that in contrast to the five registers in existence in the 1980's (Thornley, et al., 2001), there were now nine registers,

covering 13 DHB's (C. Jackson & Lennon, 2009). Many of these registers varied in the scope, function and content; and all but two of them covered only one DHB and did not link to each other, or, in many situations, to other RHF related data sources. The value of registers that function as both management and surveillance tools was highlighted, along with the importance of a designated register coordinator, the appropriate interconnected software programmes, and coordination of the register with existing health services and steering committees (C. Jackson & Lennon, 2009).

Furthermore, the draft register report highlighted the gaps in services that occur with stand-alone local registers, particularly where populations are mobile, which a national register may fill. A national register could; enable aggregation of data for evaluation of RHF programmes and surveillance of rates, provide the data to inform primary prevention programmes for high risk populations, and assist with the challenges of providing secondary prevention care to mobile populations (C. Jackson & Lennon, 2009). To be able to attain the benefits of a national register, secure funding and support is required by the Ministry of Health, a national steering committee needs to oversee the development and continuation of the register, the appropriate web-based programme needs to be developed, and designated register coordinators need to be funded and employed (C. Jackson & Lennon, 2009). A comprehensive review of the varying functions and management of registers throughout NZ was given, and clear implications were made for best practice data management and coordination of RHF secondary prophylaxis.

The second report to the Ministry of Health followed an international workshop on RHF/RHD control in NZ, and compiled advice for best practice for RHF control (Lennon, 2009). The report began with a summary of the workshop, the streams that were covered and the issues endorsed. These issues included primordial causes of RHF, primary and secondary prevention strategies, detection of RHD by echocardiography, and activities at a national level including a national steering committee, a national register and inclusion of RHF/RHD as indicators of child health inequalities (Lennon, 2009).

Recommendations and practice implications from Lennon's report (2009), relating to the diagnosis, management and secondary prevention of RHF include; seamless and responsive secondary prevention programmes, taking lessons from existing successful programmes; development of a national web-based register to coordinate secondary prophylaxis with highly mobile populations and to enable audit of adherence rates; securing a stable supply of benzathine penicillin; development of educational tools to ensure full participation by populations most at risk; support for ongoing research into echocardiography as a tool for RHD screening; and the instigation of a national steering committee to support the Ministry of Health.

Many of the NZ audits, as outlined in this section, are similar to those conducted internationally, both in their objectives and findings. As yet, there has been no audit of the implementation of the NZ Guidelines for RHF across DHB's to identify what standards are being met and what standards are

posing challenges. This research aims to fill this gap in the literature and provide recommendations for targeted interventions required to address the current challenges in meeting the guidelines, and to fulfil the specific population needs.

Conclusion

This review has identified the literature base surrounding the diagnosis, management and secondary prevention of RHF by reviewing guidelines, new initiatives and audits conducted internationally and in NZ. These audits have illustrated the contrast between what has been done internationally and in NZ and provides a realistic reflection of the extent that other countries are attaining the standards of their guidelines.

This review shows that there is a theory/practice divide, marked by gaps in knowledge, processes, personnel and resources. The recommendations presented give suggestions for improving standard infrastructure, processes and lines of communications, and adapting services to meet the holistic needs of patients, families and their communities.

For further exploration into these identified gaps, this review has provided examples of how to conduct audit of the local practice scene against the NZ Guidelines for RHF. Eissa's (2005) research identified how services are meeting the guidelines, as well as the factors influencing the attainment of the guidelines, including the population and environmental contexts. This holistic model of practice audit provides an example of what would be beneficial in the NZ setting, and is in line with the aims and objectives of this research.

Research Question

After reviewing the literature and highlighting the context, challenges and gaps, the research question to be answered in this portfolio is:

To what extent are the 2006 New Zealand Guidelines for Rheumatic Fever being met and what are the barriers and facilitators to implementation?

To this end the study was designed to:

- Audit current practice and service provision associated with RHF programmes and initiatives within NZ's 20 DHB's against the NZ Guidelines for RHF
- Identify the barriers and facilitators to clinicians meeting the guidelines

In order to meet these aims, the study employed a two phased approach, whereby quantitative methods are used to audit practice against guidelines, and semi-structured qualitative interviews are used to explore the barriers and facilitators to implementation of the guidelines.

3. Survey of Practice

‘To what extent are the District Health Board’s meeting the 2006 New Zealand Guidelines for Rheumatic Fever’?

Introduction

The New Zealand (NZ) Guidelines for Rheumatic Fever (RHF) were produced in 2006 to provide nationally consistent standards for RHF diagnosis, management and secondary prevention. The over-arching objective of the guidelines is to support appropriate management of RHF to prevent recurrent attacks and reduce mortality and morbidity from RHF and Rheumatic Heart Disease (RHD) (Craig, et al., 2008; National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006). National Guidelines may provide best practice guidance, but need to be audited to determine the impact they have on practice and the overall burden of disease associated with RHF/RHD (Robertson, et al., 2005).

Local audits have been conducted to identify the RHF population within NZ’s District Health Board (DHB) regions (Atatoa-Carr, Bell, et al., 2008; Gray, 2009; Loring, et al., 2008; Martin, 2008; Spinetto, et al., in press). These and other studies have also reviewed particular sections of practice against best practice standards. Examples of these practice standards include; appropriate case detection and diagnosis; adherence to secondary prophylaxis and appropriate delivery of prophylaxis programmes (Grayson, et al., 2006; Talbot, 1984b); data management systems (C. Jackson & Lennon, 2009); notification/under-notification of new cases; levels of knowledge in the community and amongst health professionals; and, the availability of appropriate resources for community promotion.

However, the full continuum of secondary care had not been audited against the guidelines for all of NZ’s DHB’s. As such, there was a gap in the NZ literature describing how the RHF guidelines were being implemented and utilised, what service gaps exist and what targeted services are required to meet the specific population needs (Atatoa-Carr, Bell, et al., 2008; Best Practice, 2008; Carapetis, McDonald, et al., 2005; Jarman, 2007; Thornley, et al., 2001).

This research aims to help address this gap by presenting the findings of an audit of practice against The New Zealand Guidelines for Rheumatic Fever (2006). It begins by outlining the quantitative audit methods, and presents the outcomes of the audit in the results and discussions sections. The findings are summarised and recommendations for further study are made in the conclusion.

Methods

This observational retrospective audit assessed NZ’s 20 DHB’s practice against the first NZ Guideline on RHF, covering diagnosis, management and secondary prevention. It consisted of three phases of

audit – the first two utilised existing health record data (notification data and data from a national draft register report which outlined the functions of local registers and make recommendations for a national register) and the third used a questionnaire to get participants to rate their DHB's attainment of standards.

Recruitment and participants.

A letter (appendix two) was sent via email to Medical Officers of Health (MOoH's) and/or Paediatrician's from each of the 20 DHB's, giving an overview of the research, outlining the criteria for selection of potential participants and requesting assistance with recruitment. The MOoH or Paediatrician was asked to identify the most appropriate person to complete the questionnaire and conduct the data check, according to the criteria outlined in the letter. They were then asked to forward an information sheet (appendix three), consent form (appendix four) and covering letter for use with participant's DHB's research body and/or manager (appendix five) to the potential participant they had identified.

Potential participants were either the DHB's RHF coordinator, or the person who had an overview of the continuum of RHF care and who had good links with other key RHF practitioners in other services (as detailed in the recruitment letter - appendix two). Actual participants included Paediatricians, Cardiologists, Community Nurses, RHF and Register Coordinators and MOoH's. Some DHB's included up to three participants to complete the survey comprehensively, while two regions had central registers, covering three DHB's per region.

The five South Island DHB's declined to participate as they did not have sufficient numbers of cases or processes in place to be able to answer the survey. Thus the resulting sample consisted of participants from the 15 North Island DHB's.

Development of the audit tools.

Twenty nine practice standards to audit against were extracted from the text of the 2006 New Zealand Guidelines for Rheumatic Fever and a score out of ten was assigned to each of the standards (appendix six - standards and scores).

1. Episurv notification data.

The Institute of Environmental Science and Research (ESR) is contracted by the Ministry of Health to conduct public health surveillance. It stores this data in a programme called Episurv. This programme is a national, real-time surveillance tool for capturing and collating notifiable disease data (Institute of Environmental Science and Research, 2009). Acute and recurrent RHF have been on the schedule of notifiable diseases captured by Episurv since 1986.

Seven of the 29 standards from the guidelines were able to be audited from notification data for acute and recurrent RHF (appendix six). An Episurv information request form for aggregated data was submitted to ESR. Upon approval by the Ministry of Health, an ESR data analyst conducted a search of the codes for each DHB for the three years from 2007 – 2009 and extracted the aggregate data by year and by DHB.

2. National draft register report.

The second data source was a draft report compiled for the Ministry of Health detailing local registers and scoping a National register (C. Jackson & Lennon, 2009). Six standards of the guidelines were extracted from the report (appendix six) and presented for participants to check for accuracy for their DHB (appendix seven).

3. Survey of practice.

The third phase of audit was a survey of practice against the remaining 16 standards of the guidelines (appendix eight).

Following a literature review on conducting health surveys and rating systems, the bullet-point list of standards was translated into a questionnaire including both multi-choice questions and Likert-type scales. The multi-choice questions asked participants to select the answer that best matched their practice standard. The Likert-type scales asked participants to rate the extent that the standards are attained. The last question in the survey was an open-ended question asking participants to reflect on the survey and list their DHB's service gaps. An overview section preceded the survey of practice, which asked a series of questions about the personnel and processes behind the diagnosis, management and secondary prevention of RHF in their DHB area.

The list of standards and the first draft of the survey were reviewed by one of the authors of the guidelines to ensure that the content of the guidelines was covered by the standards, and that the survey asked questions in the right way to elicit an appropriate response. The survey was then pre-tested with both professionals similar to the sample population and lay-people to test for readability, consistency and reliability to ensure that it was user-friendly and that it measured what it was intended to measure (Parahoo, 2006).

Scoring system.

To enable a consistent comparison between DHB's and between standards, a scoring system was developed, resulting in a total score of 10 points for each of the 29 standards. The maximum ten points was allocated if best practice according to the guidelines was achieved, zero points allocated if the standard was not achieved at all, and a range between these scores given dependant upon either

the percentage or reported proportion of completion/achievement the DHB has for each standard (see scoring system in appendix nine).

Each of the 29 standards was given an equal weighting to avoid subjectively placing value on some standards over others. The guidelines recommend all of the standards are attained to provide best practice through the full continuum of RHF care.

Procedure.

Following receipt of signed consent forms, each participant was posted a package including a covering letter (appendix ten), the questionnaire (appendix eight), the register data to check for accuracy (appendix seven) and a stamped self-addressed return envelope.

This was followed up with a phone call to confirm the appropriateness of the participant against the criteria for selection, to provide any clarity required by the participants, and to improve response rates (Polit & Beck, 2008). As some DHB's did not have RHF coordinators, some participants were coordinating the completion of the survey with individuals from a number of different services.

Ethics.

Approval to conduct the research was sought and granted by the National Health and Disabilities Multi Regional Ethics Committee. In addition, the researcher's DHB research body and Maori Health Unit granted approval. A covering letter was developed and sent to participants to forward to their DHB's research body and/or managers to outline the research and explain participant's involvement in the study (appendix five).

Participants were made aware that their names and the names of their DHB would remain confidential, but their identity may not remain anonymous due to the small RHF community and the possibility that responses might lead to identification of specific DHB's. If participants were satisfied with the conditions outlined in the information sheet, they were asked to return a signed consent form.

Analysis

The Episurv data, participant checked register data and completed surveys were entered directly as raw data into a database using the Statistical Package for the Social Sciences (SPSS) version 18. A second SPSS database was made as the data was re-entered with its allocated score for each standard. This second database was used for the analysis as it held the summarised comparable scores for each standard by each DHB.

Verification by comparing the printout of the data file against the codes on the original source was conducted to check for data entry errors on both databases. The data (from the second database) was analysed and has been displayed in frequency tables to show the attainment of the standards across all DHB's.

Results

Table 1: Mean score, ranking and range on the 29 standards across all DHB's

Standard	Ranking	Mean	Minimum	Maximum
Possession of local register	1=	10.00	10.0	10.0
Service that manages register	1=	10.00	10.0	10.0
First injection given in hospital	3	9.73	8.0	10.0
Ten days oral penicillin given on diagnosis	4	9.71	8.0	10.0
Prophylaxis injections given every 28 days	5	9.47	8.0	10.0
Notified to Public Health	6	9.43	6.0	10.0
Allocation of dedicated register coordinator	7	9.33	0.0	10.0
Appropriate duration of prophylaxis	8	9.14	6.0	10.0
Accurate distinction of RHD	9	8.33	4.0	10.0
Use of echocardiography for diagnosis and review	10	8.27	5.0	10.0
Regular and appropriate education	11	8.10	4.5	10.0
Functions of Register	12	7.73	2.0	10.0
Diagnosis according to Jones criteria	13	7.60	4.0	10.0
Contact tracing conducted	14	7.57	0.0	10.0
Admitted to hospital for diagnosis	15	7.07	2.0	10.0
Recurrence course given every 21 days	16	6.80	2.0	10.0
Routine out-patient review given	17=	6.67	0.0	10.0
Frequency of updating register	17=	6.67	0.0	10.0
Opportunistic care provision	19	6.53	0.0	10.0
Case under specialist care	20	6.27	2.0	10.0
Services that access register	21	6.13	0.0	10.0
Distinction of ARF or recurrence	22	5.93	5.0	8.0
Referral for prophylaxis made	23	5.73	2.0	10.0
Process of transfer between DHB's	24	4.80	2.0	8.0
Case entered onto register	25	4.13	1.0	8.0
Dentist advised of condition	26	3.73	2.0	10.0
Appropriate vaccinations offered	27=	3.40	1.0	5.0
RHD patients six monthly dental review	27=	3.40	2.0	6.0
Surveillance and screening activities	29	2.33	0.0	7.0

Table 1, above, shows all of the 29 standards, the mean scores ordered from highest to lowest, and the range of scores shown by the minimum and maximum scores achieved for each standard.

Of the 29 standards, the top grouping with the eight highest ranking standards were:

1. Possession of a local register
2. Designated service managing the register
3. First injection given in hospital
4. Commencement of a 10 day course of penicillin V on diagnosis
5. Prophylaxis injections given every 28 days
6. Notified to Public Health
7. Allocation of dedicated register coordinator
8. Appropriate duration of prophylaxis

Conversely, the bottom grouping with the six lowest ranking standards were:

1. Surveillance and screening activities
2. Appropriate vaccinations offered
3. RHD patients given 6 monthly dental review
4. Dentist advised of condition
5. Case entered onto register
6. Referral for prophylaxis made

As seen in Table 1, the range of scores is very wide in some standards, showing considerable variance and inconsistency between DHB's. The top eight standards had mean scores between 9.14 and 10. The bottom six were under 5, and the remaining 15 standards were between 5.73 and 8.33. Twenty-three of the 29 standards had mean scores over 5, and 14 out of the 29 standards had mean scores over 7.5. Broken down into the three phases of audit, the following tables show the mean attainment of the standards in the guidelines, and the range as indicated by the minimum and maximum scores.

Table 2: Mean score and range on standards derived from Episurv Data across all DHB's

Episurv Standards	Mean	Minimum	Maximum
Diagnosis according to Jones criteria	7.60	4.0	10.0
Admitted to hospital for diagnosis	7.07	2.0	10.0
Case under specialist care	6.27	2.0	10.0
Distinction of ARF or recurrence	5.93	5.0	8.0
Referral for prophylaxis made	5.73	2.0	10.0
Case entered onto register	4.13	1.0	8.0
Dentist advised of condition	3.73	2.0	10.0

Table 2 shows the mean scores on the seven Episurv standards across all DHB's. The range of most of these scores is wide, and the mean scores are quite low, ranging from 3.73 to 7.60. One of the seven standards scored over 7.5, five scored over 5 and two scored under 5.

Table 3: Mean score and range on standards derived from Register Data across all DHB's

Register Standards	Mean	Minimum	Maximum
Possession of local register	10.00	10.0	10.0
Service that manages register	10.00	10.0	10.0
Allocation of dedicated register coordinator	9.33	0.0	10.0
Functions of Register	7.73	2.0	10.0
Frequency of updating register	6.67	0.0	10.0
Services that access register	6.13	0.0	10.0

Table 3 above, shows the mean scores of the six Register standards across all DHB's. The mean scores are generally high, ranging from 6.13 to 10 with varying ranges. Four of the six standards attained mean scores over 7.5 with all six standards scoring over 5.

Table 4: Mean score and range on standards derived from Survey Data across all DHB's

Survey Standards	Mean	Minimum	Maximum
First injection given in hospital	9.73	8.0	10.0
Ten days oral penicillin given on diagnosis	9.71	8.0	10.0
Prophylaxis injections every 28 days	9.47	8.0	10.0
Notified to Public Health	9.43	6.0	10.0
Appropriate duration of prophylaxis	9.14	6.0	10.0
Accurate distinction of RHD	8.33	4.0	10.0
Use of echocardiography for diagnosis and review	8.27	5.0	10.0
Regular and appropriate education	8.10	4.5	10.0
Contact tracing conducted	7.57	0.0	10.0
Recurrence course given every 21 days	6.80	2.0	10.0
Routine out-patient review given	6.67	0.0	10.0
Opportunistic care provision	6.53	0.0	10.0
Process of transfer between DHB's	4.80	2.0	8.0
Appropriate vaccinations offered	3.40	1.0	5.0
RHD patients six monthly dental review	3.40	2.0	6.0
Surveillance and screening activities	2.33	0.0	7.0

Table 4 above, shows the mean scores of the 16 standards derived from survey data across all DHB's. Across the continuum of care covered by the survey standards, this data shows considerable variance between standards and between DHB's, as indicated by the minimum and maximum scores. The mean scores range from 2.33 out of 10 for surveillance and screening activities to 9.73 out of 10 for first injection given in hospital. Nine of the 16 standards had mean scores over 7.5, 12 scored over 5 and four were under 5.

The NZ Guidelines for RHF are divided into two sections – Diagnosis and Management, and Secondary Prophylaxis. When the results of the audits were reviewed in the context of the guidelines, the following tables show how the gaps in services are grouped within the two guideline sections.

Table 5: Mean and ranking on Diagnosis and Management Standards across all DHB's

Standard	Data Source	Mean /10	Ranking /29 1 = Top 29 = Bottom
First injection given in hospital	Survey	9.73	3
Ten days oral penicillin given on diagnosis	Survey	9.71	4
Notified to Public Health	Survey	9.43	6
Accurate distinction of RHD	Survey	8.33	9
Use of echocardiography for diagnosis and review	Survey	8.27	10
Diagnosis according to Jones criteria	Episurv	7.60	13
Contact tracing conducted	Survey	7.57	14
Admitted to hospital for diagnosis	Episurv	7.07	15
Case under specialist care	Episurv	6.27	20
Distinction of ARF or recurrence	Episurv	5.93	22
Referral for prophylaxis made	Episurv	5.73	23
Case entered onto register	Episurv	4.13	25
Dentist advised of condition	Episurv	3.73	26

The first section, diagnosis and management, covers the inpatient episode, including diagnostic criterion, differential diagnoses, investigations, hospital care and discharge processes. The standards audited from within this section are shown in table 1, above. Generally, the activities conducted during the hospital inpatient experience audited by the survey were the higher ranking standards. All of the lower ranking standards come from Episurv data and generally refer to services outside of the hospital setting, relying on referral processes.

The second section of the guidelines covers secondary prophylaxis. This section encompasses prophylaxis regimes; duration of prophylaxis; protocol for delivery; anaphylaxis; keys to improving

adherence including education, registers, outreach and non-compliance; routine review and structured care planning; prevention of infective endocarditis; case finding surveillance and screening; and implementation. These factors can be grouped under provision of secondary prophylaxis and secondary services.

Table 6: Mean and ranking on Provision of Secondary Prophylaxis Standards across all DHB's

Standard	Data Source	Mean /10	Ranking /29 1 = Top 29 = Bottom
Prophylaxis injections given every 28 days	Survey	9.47	5
Appropriate duration of prophylaxis	Survey	9.14	8
Recurrence course given every 21 days	Survey	6.80	16

The standards relating to provision of secondary prophylaxis, as audited by survey are shown in table 6, above. Very high scores were attained in these standards, particularly for prophylaxis injections being given every 28 days, and appropriate duration of prophylaxis.

Table 7: Mean and ranking on Secondary Services Standards across all DHB's Standards

Standard	Data Source	Mean /10	Ranking /29 1 = Top 29 = Bottom
Possession of local register	Register	10.00	1=
Service that manages register	Register	10.00	1=
Allocation of dedicated register coordinator	Register	9.33	7
Regular and appropriate education	Survey	8.10	11
Functions of register	Register	7.73	12
Frequency of updating register	Register	6.67	17=
Routine out-patient review given	Survey	6.67	17=
Opportunistic care provision	Survey	6.53	19
Services that access register	Register	6.13	21
Process of transfer between DHB's	Survey	4.80	24
Appropriate vaccinations offered	Survey	3.40	27=
RHD patients six monthly dental review	Survey	3.40	27=
Surveillance and screening activities	Survey	2.33	29

The remaining standards relating to secondary services are shown in table 7, above. Interestingly, the top and bottom ranking scores come from within this section of the guidelines. The top scores

relate to the register standards and show that possession, management and coordination of registers are done consistently well across all DHB's. The remainder of the standards in this secondary services section relate to activities outside of the hospital or register environments, and may include interactions and coordination of multiple services. Apart from the standard assessing the provision of regular and appropriate education being given, these remaining standards relating to secondary services scored poorly with mean scores between 6.67 and 2.33.

Discussion

This study has shown that there is considerable variance in the attainment of the standards of the guidelines across DHB's. There are a core group of standards however that are being met consistently, particularly in those relating to possession and management of a register for coordinating secondary prophylaxis, provision of appropriate secondary prophylaxis programmes, and also of the hospital inpatient episode in general. The standards proving more difficult to achieve include those relating to the additional secondary services, such as dental care, clinics, screening and surveillance, appropriate vaccinations, and transfer processes.

When comparing the mean standard of scores between the two database standards of registers and Episurv data, it shows the register data in Table 3 attaining higher mean scores and more consistent attainment of the standards. Whereas the Episurv standards in Table 2 showed wider variance and lower mean scores. This may relate to the number of services that require coordination in the attainment of the Episurv standards in comparison to most of the standards in the register data revolving around a single service.

Alternatively, it may relate to the accuracy and completeness of data in each of these data sources. The perceived value of each database may differ between DHB's, impacting on the emphasis placed on the upkeep of each database. Many registers in NZ are operational in function and assist in the management of prophylaxis delivery (C. Jackson & Lennon, 2009). Whereas, Episurv data may be perceived as a surveillance tool only, therefore not necessitating such comprehensive attention to detail that a functional, up-to-date register would.

Timing of interventions may also impact on the attainment of the standards relating to secondary services. As some patients experience hospitalisation stays up to a number of months in length, completing all of the standards of care upon discharge and into long term care relies upon designated processes and personnel to ensure they are not missed in the myriad of interventions and the return to normality.

When the attainment of the standards were grouped into the sections of the NZ Guidelines for RHF, the findings show the highest scoring standards of the guidelines were those from the diagnosis and

management section, the provision of secondary prophylaxis and some of the register aspects of the secondary services section. The lowest scoring standards of the guidelines were from the secondary services section.

When looking at the settings in which these standards are achieved in, it appears that those hospital or single service settings, such as registers, or a community service delivering secondary prophylaxis; achieve the higher mean scores. Lower mean scores are seen in non-related secondary service settings, particularly in private dental care; or when coordination between multiple services is required to meet the standards, such as transfer processes. The achievement of the standards in non-related secondary services or multiple settings would rely upon appropriate RHF systems, processes, documentation, resources and personnel. As the standards from these settings have the lowest rankings, perhaps it indicates that these resources and personnel are not in place consistently across DHB's to appropriately manage and coordinate RHF services.

When analysing the data, a picture begins to emerge of the standards of the guidelines that are most consistently achieved and those that are not. An analogy to Maslow's Hierarchy of Needs (in Kozier, Erb, & Olivieri, 1991) can be made as the standards that are being achieved more consistently form the foundation, and those distal, non-related services that provide what may be perceived as less urgent services, extend to the tip of the triangle – or hierarchy of needs.

As Maslow would describe, behaviour is motivated by need, and the needs at one level must be met before moving onto the next level (in Kozier, et al., 1991). These distal standards may be standards which are harder to achieve, more difficult to coordinate or less of a perceived need to achieve. Additionally, the foundational standards may not have been completely met, and the need prompted for behaviour change to attain the next level of standards.

The findings of the standards attaining high levels of achievement are consistent with two South African studies which found that, despite other failures to meet practice standards, secondary prophylaxis adherence was high (Nkgudi, et al., 2006; Robertson, et al., 2005). Additionally, the high attainment of the standards relating to the inpatient episode were also demonstrated in a remote rural Australian setting, whereby the diagnosis of acute RHF according to the Jones Criteria was made with similar accuracy to larger tertiary hospitals (Stewart, et al., 2005).

Two Australian studies (Eissa, et al., 2005; Mincham, et al., 2002) presented the findings from audits of medical records and register data. They found poor prophylaxis adherence and echocardiography attendance rates, delayed clinic and surgical attendance, inaccurate register data, lack of linked or regional registers to track mobile populations, and gaps in the referral process to dental services. In contrast, this audit of practice against the NZ Guidelines for RHF found good attainment of standards for the possession and management of local registers and provision of secondary prophylaxis

programmes. Poor clinic attendance and gaps in the referral processes to dental services were seen in both the Australian studies and this audit of the NZ Guidelines for RHF.

Consistency is seen between the results of other NZ audits and the findings of this audit against the NZ Guidelines for RHF. Successful attainment of secondary prophylaxis programmes and register-based management programmes was also found in recent studies, finding the two to be co-success factors in the outcome of high adherence rates (Grayson, et al., 2006; Spinetto, et al., in press) The original audit of local registers showed the contrast between the finding of five registers in existence in the 1980's, and the presence of nine registers covering 13 DHB's in 2009 (C. Jackson & Lennon, 2009). When participants in this research auditing the NZ Guidelines for RHF were asked to conduct a data check against the findings from Jackson and Lennon's report (2009), it was found that there were, in fact, 11 registers covering the 15 DHB's in the North Island.

The high attainment of the standards relating to the inpatient episode, provision of secondary prophylaxis programmes and possession and management of registers is built on the foundations of decades of evidenced-based guidance documents. Research has been specifically focussed on the importance of; secondary prophylaxis programmes for preventing recurrences (Christmas, 1984; Frankish, 1984; Grayson, et al., 2006; Newman, et al., 1984; Spinetto, et al., in press; Talbot, 1984b); register-based management programmes to coordinate care between services (Christmas, 1984; Flight, 1984; Newman, et al., 1984; Talbot, 1988; Thornley, et al., 2001); and appropriate diagnostic criterion, differential diagnoses, investigations, hospital care and discharge processes (Carapetis, McDonald, et al., 2005; Lennon, 2004; World Health Organisation, 1988, 1992, 2000, 2004, 2005).

What is missing from this analysis, to match what has been undertaken internationally and in other smaller audits in NZ, is to identify the challenges and success factors in meeting the standards of the NZ Guidelines for RHF. This would provide a better understanding of the resulting attainment of the standards and assist in identification of strategies to address the challenges and improve the attainment of standards.

Strengths and Limitations

A high response rate and the uniqueness of this research were the strengths of this study. RHF is most prevalent in the North Island of NZ. Achieving a 100% response rate from the North Island DHB's has ensured the data gathered has been meaningful and has comprehensively captured a wide range of RHF practice.

Although audit of practice has been conducted in other NZ studies, there have been none that have audited the full continuum of diagnosis, management and secondary prevention for all of the North Island DHB's as this study has. Additionally, due to the relatively recent introduction of the NZ

Guidelines for RHF in 2006, audit had not been conducted against the guidelines to assess their impact on practice, which this study has achieved. Findings of this study provide a snap-shot of current progress against the guidelines, with implications for further improvements in the attainment of those standards proving more difficult to achieve.

Study limitations relate to the methods employed and potential researcher bias. The use of self-report data potentially compromised the validity and data quality of the audit findings. This may have been improved by using clinical audit and/or confirmatory audit (Tashakkori & Teddlie, 1998), but due to time and resource constraints, this was not possible.

Consequently, strategies were used to minimise the impact of potential biases when using self-report questionnaires. This included testing of content validity by checking with an author of the guidelines that the survey adequately covered the constructs being investigated (Polit & Beck, 2008); testing consistency and reliability by pre-testing the survey to ensure that it was user-friendly and that it measured what it was intended to measure (Parahoo, 2006); and initiating and maintaining close phone and email contact with participants to minimise selection bias and loss to follow up (Elliott & Schneider, 2007).

This close phone and email contact with participants was required throughout the survey period to; clarify that the participant met the desired inclusion criteria, encourage response, support coordination of completion and clarify issues for participants when required. This enabled the researcher to identify situations where participants were unable to complete all aspects of the survey, and offer suggestions, support, and/or for the researcher to coordinate completion of the survey with other specialists within that DHB. This follow up aimed to reduce non-response bias and response related biases to improve data quality (Polit & Beck, 2008).

Episurv data was intended for use as an objective data set, providing a reproducible standard to use in the future as a comparison and/or evaluation tool to examine trends over time (Baum, 1995; Elliott & Schneider, 2007). Unfortunately, this data spoke more of the incompleteness of Episurv data rather than the DHB's attainment of the seven standards being assessed.

This assessment of the value of the Episurv data was confirmed by other researchers who had come to the same conclusion (Atatoa-Carr, Bell, et al., 2008; Gray, 2009; C. Jackson & Lennon, 2009; Jaine, et al., 2008; Lennon, 2009; Loring, et al., 2008). As such, an "incomplete field" was added for the ESR analyst to indicate the degree of incomplete data fields in the seven standards audited showing a mean percentage ranging from 0 to 94% incomplete data.

Finally, survey participants were asked to check the data to ascertain if what was held on Episurv was reflective of actual practice (see appendix 11). Four participants conducted audit of case files against

the Episurv data, eight reported on what they perceived actual practice to be against Episurv data, and three did not complete the data check. The results of the data checks showed between 50 and 100% of the incomplete fields recorded on Episurv were inaccurate according to either audited clinical records, or reported clinical practice.

Although the audit using Episurv data only assessed seven of the 29 standards in this study, it has provided a useful illustration of the need for internal and external review of Episurv data. Internal review is required to look at the gaps in reporting and completion of those reports, and external review of the intent, use and implications of the incomplete data that Episurv currently holds for RHF notifications. Due to the incompleteness of Episurv data, suggestions have been made that an alternative national data set should be used, such as hospital discharge data (Jaine, et al., 2008), or potentially a national web-based Register (C. Jackson & Lennon, 2009). An external review of such issues is particularly important as Episurv data is commonly used in research and subsequent resourcing decisions.

An existing connection occurred between the researcher and some of the participants. This could have resulted in coercive recruitment and invalid data (Creswell, 2009). To minimise the risk of this occurring, strategies of validity were utilised to increase confidence in the findings (Creswell, 2009) This included requesting a third party – the DHB's MOoH or Paediatrician, to assist with the recruitment approach and participant selection.

Recommendations and Conclusion

This research has highlighted the attainment of the standards of the guidelines amongst the 15 participating DHB's, and has illustrated the degrees of variance both within standards and within DHB's. The findings from other studies have been compared to review the similarities and differences.

Since the introduction of the NZ Guidelines for RHF in 2006, only 48% of all standards achieved mean scores over 75%, with considerable variance in attainment between DHB's. Compared with international audit of practice against guidelines, these results are comparatively favourable. But as the standards of the guidelines have the purpose of prevention of recurrent attacks and morbidity and mortality associated with RHF and RHD, the findings from this audit may not translate to good outcomes for NZ RHF patients.

Recommendations that may improve local processes and attainment of the standards of the guidelines, as drawn from the discussions include; allocation of dedicated register coordinators to oversee and manage the completion of notification and referral processes; instigation of standardised RHF systems, processes, documentation and resources for consistent coordinated outcomes; and,

internal and external review of the processes and use of Episurv data, and potential alternative data management systems. It has not been conducted in this research due to anonymity assurances, but local analysis of individual DHB's audits would recognise their attainment of the standards of the guidelines and the resulting gaps in services. The findings could identify specific local challenges to address and improve upon.

Further investigation is also required to explore the challenges and barriers in achieving the standards of the guidelines, including the influence of contextual and environmental factors. Once a clearer understanding of these influences is obtained; targeted, comprehensive interventions can be developed and implemented to make significant gains towards reducing the impact of this disease on RHF populations and preventing the complications of RHD.

4. Qualitative Interviews

'What are clinician's perspectives on the barriers and facilitators to implementing the 2006 New Zealand Guidelines for Rheumatic Fever'?

Introduction

The first New Zealand (NZ) Guideline for Rheumatic Fever (RHF) (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006) was released to provide a national standard of diagnosis, management and secondary prevention that would support best practice care, particularly for high risk populations. The guidelines were designed to prevent recurrent attacks and the associated morbidity and mortality associated with RHF and Rheumatic Heart Disease (RHD). While these guidelines have only been in place for the past four years, success factors and new initiatives have been identified, and challenges have arisen in meeting the guidelines, resulting in gaps in services.

Historically, audits have shown that gaps in services and a lack of standardised and evaluated care have resulted in poor health outcomes, particularly for Maori and Pacific peoples (C. Jackson & Lennon, 2009; Jaine, et al., 2008; Purchas, et al., 1984; Thornley, et al., 2001; Wilson, 2010). This research aims to identify the challenges in meeting the guidelines that may cause gaps in services and non-standardised care, which may ultimately result in recurrent attacks and RHD.

This research explores the barriers and facilitators for clinicians working to meet the guidelines, through semi-structured interviews with RHF coordinators from six District Health Boards (DHB's) in the North Island of NZ. It starts by looking at the qualitative methods used for the interviews, and presents the findings in the results and discussion sections.

Methods

This qualitative exploratory study explores the barriers to and facilitators of, meeting the NZ Guidelines for RHF (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006). A qualitative approach was chosen as qualitative research investigates a phenomenon within the social context of its environment, as interpreted by the participants, conclusions being drawn from the meaning of the data collected (Whitehead, 2007). Semi-structured interviews were used as they provide the ability for participants to respond to open-ended questions in their interpretation of the barriers to and facilitators of, meeting the guidelines (Polit & Beck, 2008; Whitehead & Annells, 2007).

Recruitment and participants.

Six DHB's were purposively selected to represent those with higher rates of RHF and a coordinated management approach to RHF care across services.

A letter (appendix two) was sent via email to Medical Officer's of Health (MOoH's) and/or Paediatrician's from each of the six DHB's giving an overview of the research, outlining the criteria for selection of potential participants and requesting assistance with recruitment. The MOoH or Paediatrician was asked to identify the most appropriate person to participate in the interview, according to the criteria outlined in the letter. They were then asked to forward the attached information sheet (appendix three), consent form (appendix four) and covering letter for use with participant's DHB's research body and/or manager (appendix five) to the potential participant they had identified.

Potential participants were either the DHB's RHF coordinator, or the person who had an overview of the continuum of RHF care who also had good links with other key RHF practitioners in other services (as detailed in the recruitment letter - appendix two). All of the six DHB's consented to participate, with one having two participants in their interview and one having two participants complete the interview – one in person and one by telephone over two separate occasions. This resulted in a total of eight participants being interviewed, including two Paediatricians, five Community Nurses and one RHF Coordinator.

Development of the interview tool.

A semi-structured interview tool (appendix 12) was developed to include questions that allowed participants to share their perspectives of what the challenges to meeting the guidelines were, what barriers existed, what success factors had emerged and what new initiatives had been instigated. The final question asked participants about recommendations for targeted public health initiatives to fill any gaps in services.

Ethics.

Approval to conduct the research was sought and granted by the National Health and Disabilities Multi Regional Ethics Committee. In addition, the researcher's DHB research body and Maori Health Unit granted approval. A covering letter was developed and sent to participants to forward to their DHB's research body and/or managers to outline the research and explain participant's involvement in the study (appendix five).

Participants were made aware that their names, and the names of their DHB, would remain confidential. If participants were satisfied with the conditions outlined in the information sheet, they were asked to return a signed consent form.

Procedure.

Face to face interviews were conducted with participants in a meeting room at their workplace (with the exception of one which was conducted at a mutually agreed meeting place). The interviews took approximately 30 to 60 minutes to complete and were digitally recorded and transcribed verbatim. They were conducted between May and July 2010.

Four lines of inquiry were followed in the interviews:

1. The challenges faced by clinicians when meeting the standards of the guidelines
2. The success factors that make meeting the standards easier
3. The opportunities and new initiatives that have arisen
4. Recommendations for targeted public health interventions to meet the needs of RHF patients

Analysis

The interviews were analysed by free-form analysis, which is suited to descriptive exploratory qualitative research (Annells & Whitehead, 2007). Free-form analysis identifies themes, allowing for the development of category schemes and coding (Polit & Beck, 2008) in the data reduction phase (Onwuegbuzie & Teddlie, 2003).

The thematic framework (appendix 13) was based on the questions in the interview tool and allowed for the material to be shifted and sorted within these subject headings (Baum, 2002). Data was then reviewed by theme and interpreted to identify possible factors relating to the challenges faced by clinicians and opportunities that arose when meeting the standards of the guidelines.

Results

The first three lines of inquiry provided the themes for analysis under which the data was grouped and analysed.

1. Challenges.

Participants identified a number of challenges associated with the implementation of the guidelines. Challenges were often due to unfamiliarity with RHF as a disease, and with the guidelines. Those

“typical” cases presenting in the “normal” pathways were generally picked up and managed well. But those outside of these definitions were often missed or mismanaged.

“[Doctors] might even have come from another country like the UK and RHF at that point will not be on their radar because they have not come across it. You really need all your practitioners in New Zealand to be aware of and understand the guidelines”. (Interview 6 – Community Nurse)

Inconsistent practice was also reported to be evident in areas of high turn over, for example in teaching hospitals and large hospitals where doctors and/or nurses are frequently rotated. This results in the need to back track in order to fill the gaps in services that have arisen due to inconsistent practice.

“Knowledge is lost with new doctors. We are constantly having to update doctors”. (Interview 5 – Community Nurse)

Further challenges were associated in the provision of secondary prophylaxis relating to the adult population and mobile communities. A lot of time is spent chasing transient patients. This was made more of a challenge when addresses and phone numbers change often, and nurses have no administration or community worker support to assist with locating patients.

“These are generally kids or adults who have actually left school, are working or not working, are transient from township to township. Really hard, and I don’t think you can quantify the time that is spent looking for them”. (Interview 3 – Community Nurse)

Some DHB’s refer patients between services, for example, when patients leave school or when they are classed as being ‘adult’ therefore breaking the continuity of care and the relationship that may have built up over many years. In other instances, patients are referred to General Practitioners (GP’s) for completion of their prophylaxis programme, adding financial barriers and resulting in much lower rates of prophylaxis adherence.

“Beyond 21 [years of age, prophylaxis] is left to themselves. Public health has good data which showed that for the under 16’s we have a compliance rate of 96%, for the 16-21’s it is about 80% and for the over 21’s it is about 35%”. (Interview 1 – Paediatrician)

In this participant’s DHB, Community Nurses deliver prophylaxis to those less than 16 years of age, then a referral is made to a different group of Community Nurses for prophylaxis delivery for 16 – 21 year olds, and patients are sent to their GP, if they have one, for completion of their prophylaxis course.

Participants commented further on the challenges to implementing the guidelines associated with barriers to accessing services that some patients experienced, particularly GP and dental services. All of the six participants identified this as a challenge.

“[There are] no free services [over 18 years of age]. Patients could wait until there is major dental emergency then they could access free care via the [emergency] dental scheme. But prevention is better and there are no free preventative services. This is a very high risk scenario for a high risk group”. (Interview 4 – RHF Coordinator)

Even in free school-based services, one participant commented that resource limitations in high density areas meant that if children missed their dental appointment, they may not be seen for 12 months as many school clinics are mobile and move between school sites.

“There don’t seem to be enough dental nurses basically. So therefore if they are not there on the day that you call then you may miss them. I think they do prioritise the patients so that those they feel are at more risk they tend to try and prioritise, but when you talk about [x suburb] they’re all priority patients”. (Interview 1 – Paediatrician)

Barriers to accessing GP services were reported as participants had identified many RHF patients either do not have a GP or do not use GP services.

“We certainly have the significant proportion of our paediatric inpatients, up to about 20%, don’t have either an identified primary provider who we then contact and they say they’re not registered with us or only see us every now and then, or they don’t have a GP at all”. (Interview 5 – Paediatrician)

“During the winter time you’re going to build up a bill and then they feel embarrassed about going [to the GP] and so they might not go unless there is something they think is really important”. (Interview 1 – Paediatrician)

Hospital Emergency Departments or Accident and Emergency clinics are often used instead of GP services. But even this presents challenges in those areas where DHB’s have combined such services with GP’s, making it a fee for service provider, issuing the same access barriers that patients were trying to avoid by not using GP’s in private practice.

All of the participants identified access barriers relating to poverty that had resulted in high “Did Not Attend rates” (DNA’s) in RHF related clinics. Reasons given for DNA’s included patients not receiving an appointment due to changes in address between clinic appointments, inability to get to central

clinics that are often a considerable distance away or the multitude of social and financial hardships faced by some families.

“There is transport between [‘x’ provincial] Hospital and [‘y’ tertiary] Hospital, but you really have to book because it is quite busy and so some of the families we are dealing with, you know to ring up and make a booking might get overlooked in the other pressures of their lives that they are dealing with. Some of them don’t have a phone, some of them don’t have a working vehicle so to get from where they are in [their suburb] to [the provincial] Hospital to get the shuttle can be difficult sometimes. So there is a service there, but the ideal situation would be to hold the clinics out in [the suburb]. But it is the machinery, like the echo machinery”. (Interview 1 – Paediatrician)

“You know, some of these families lead incredibly hard lives and those barriers become real barriers to having an appointment and turning up to them”. (Interview 3 – Community Nurse)

Even when services were taken to regions where patients reside to assist with removing some of these access barriers, participants highlighted that there are still service barriers relating to resource and funding constraints. Examples given included capacity and technology constraints in clinics, funding for echocardiography programmes, appropriately resourced key RHF roles, and adequate Information Technology (IT) systems to better manage multiple data sets for coordination of care.

“We have resource constraints like unavailability of echo, ... full clinics, big waiting lists for routine clinic follow up”. (Interview 4 – RHF Coordinator)

“They did the echo programme in intermediate schools and that picked up quite a few. But it was a funding issue that made it stop”. (Interview 2 – Community Nurse)

“We have seven independent data sources per patient. Too many! And especially with no key worker coordinating data sources and services”. (Interview 4 – RHF Coordinator)

Resource constraints impact on provision of secondary prophylaxis when there are intermittent interruptions to the supply of Bicillin. The alternatives include oral penicillin, which is often not taken in an uninterrupted manner resulting in recurrences, or penicillin powder for reconstitution, which is very painful, crystallises quickly requiring administration of subsequent injections, and often results in refusal of injections. Participants commented that some patients had either opted for oral penicillin during the last shortage in 2006, or had refused secondary prophylaxis all together.

“A few years ago there was a worldwide shortage. [‘x’ DHB’s] patients went to oral and they had two relapses in 6 months”. (Interview 1 – Paediatrician)

Participants suggest that many of these challenges stem from a lack of recognition, support, leadership and direction at DHB and National levels. Funding, prioritisation, leadership and responsibility were identified as gaps hindering sustainable progress.

“When we did our audit we looked at which schools children were at when they were diagnosed and we found out that something like 70-80% of our patients came from 6 schools, so we did actually spend a lot of time planning a primary intervention program, a sore throat clinic sort of program ..., but in the end we just couldn’t get funding for it from planning and funding that we would have liked to do that because I think if we targeted just those schools and had a nurse going in every week swabbing throats and treating kids early we would probably prevent a chunk of our cases early on”. (Interview 5 – Paediatrician)

“I would like to see the projects both locally and nationally that have been done, which have been of enormous value now put widely into use and not just keep replicating them. But I think that’s only going to happen when people with all that knowledge and being able to think broadly, and with the support of the Ministry who are in a position to do that. I feel the difficulty with implementing the national guidelines across the board is the word responsibility and leadership”. (Interview 6 – Community Nurse)

2. Success factors.

The success factors shared by the participants strongly revolved around familiarity with both the disease and the needs of the RHF population. Robust processes and a core group of experienced health professionals working in team environments were put in place to appropriately manage RHF in areas with higher rates of RHF.

“Our paediatricians are an amazing bunch, they are very aware. They make it very easy for us”. (Interview 3 – Community Nurse)

“All the paediatricians know about making notifications and getting kids on the register. I mean we have it pretty well set up”. (Interview 5 - Paediatrician)

“Getting Bicillin needs to be done by an expert, it needs to be done by someone who knows what they are doing, and if it is done by an expert it is a relatively painless procedure. So we have a limited number of Community Nurses who are doing regular injections”. (Interview 1 - Paediatrician)

The smaller, experienced team approach, spanning across multiple settings ensured consistent practice and professional development for those less experienced.

“The GPs are usually the first point of contact and they know that they can telephone and speak to a consultant if necessary and so you know if they are not sure, then the case can be discussed over the phone and if there was a question about RHF, it would usually mean the child does come into hospital. And so I think that works well”. (Interview 5 - Paediatrician)

“When it comes to making the diagnosis, we frequently get second or third opinions, you know we look at it as a group. The patients are generally in hospital for enough weeks that we do a week of acute care each so during admission they can see three or four different consultants so that there is a clear consensus as to what Jones criteria they meet. I don’t think there are many cases where there’s a disagreement about diagnosis”. (Interview 5 - Paediatrician)

“Obviously the Paediatric network in New Zealand is fairly small, and I would normally just write a letter of referral to a Paediatrician in their local area”. (Interview 1 - Paediatrician)

“The advantage we have is that in the Paediatric Cardiology Clinic there are two of us who do it – I do it with a Cardiologist – and so therefore when they move into the adult service, he still sees them so it’s quite nice as there’s good continuity there”. (Interview 1 - Paediatrician)

Other successful outcomes in the clinic environment were due to addressing access barriers, resulting in improved clinic attendance. This was achieved by providing local clinics in areas that patients live, and having dedicated reminder systems.

“The children having surgery, we actually have a combined clinic with the [Tertiary Hospital] people every couple of months and so for children likely to have surgery, they tend to get reviewed in that clinic so they don’t have to go to [the Tertiary Hospital] for pre-assessment as that is all done down here, so that works well”. (Interview 1 - Paediatrician)

“A central registration part of outpatients that does ring up high risk clinics ... certainly has improved the attendance rate. Staff associated with the clinics use texting for reminders. The community nurses know the child has a clinic appointment coming up so they remind them as well”. (Interview 5 - Paediatrician)

“We use the register to coordinate clinic review and for overview of patient and clinical details. Link to designated RHF clinic to assist with communications and addressing barriers”. (Interview 4 – RHF Coordinator)

Participants shared key success factors for addressing barriers in the delivery of prophylaxis programmes. These included delivery of programmes in appropriate environments, such as homes, schools and workplaces, local connections, flexible services, inter-agency networks and sheer persistence to track patients for their Bicillin injections. Additionally, the inclusion of local kai awhina or community workers, particularly those with a similar ethnicity to the patient population in the community team, was a key success factor.

“Most of the time if they are school aged children, it will be at home for at least two or three times and then when they feel comfortable about it, they are happy to be called out of class and it’s given in the sick bay at school”. (Interview 3 – Community Nurse)

“We stretch our boundaries by making sure we transport and pick up and drop off if necessary. We try not to work after hours, but I know some of our cases are first thing in the morning for their Bicillin’s and anything up to 6pm if they particularly don’t want to be done at work”.
(Interview 3 – Community Nurse)

“We are fortunate enough to have community health workers in our office. An absolute winner for everybody to have similar ethnicity as the patients with rheumatic fever”. (Interview 2 – Community Nurse)

“We have a kai awhina who works really closely with communities ... and she will go and do house drops for our public health nurses, if she can’t find them. Generally, she knows quite a few of the families and has ways of finding people, more than how we know how to find them”.
(Interview 3 – Community Nurse)

The flexible, holistic, family centred model of care that the community nurses maintain was reported as another success factor by participants. Continuity and coordination were key factors to ensuring seamless and responsive services.

“Transfers, referrals, arrangements for scripts and discharge planning ...[are] managed by nurses in a seamless process”. (Interview 5 – Community Nurse)

“We just have a system in place ... for RHF. There is the system of filing and the system of paperwork to start off with for the general assessment, according to RHF and we have care plans, protocols for the injection, anaphylaxis, and standing orders”. (Interview 2 – Community Nurse)

Two participants shared the holistic approach taken by their community nurses to ensure that all aspects of well-being, both for the patient and their whanau, are assessed and addressed in an early

home assessment, and followed up with annual reviews. This provided an opportunity to ensure that no gaps arose from the inpatient and discharge processes regarding RHF care, and that the nurse, patient and family were kept up-to-date with current issues.

“What works really well is from getting them on our own register, as well as getting the case notes sent up, getting the assessment, their annual consent and all those processes started off and then working with the family throughout the year, and then revisiting that the next year. And one thing we’ve done, which is why I think it works well, we’ve timed all of that around the flu season. So, in March the expectation is that you do ... the annual consent ... consent for the flu vaccine... You’re going to want to be doing it in the school holidays so the mum’s there to look at the consent for the flu vaccine and did we ever get anywhere with that warm housing or whoever was giving up smoking and so although you might have talked about some of those things throughout the year, you are actually quite formally reassessing and rethinking what the most immediate things are for that family. And I suppose it’s a bit of a chance to refocus really, including whether they’ve been to the dentist or never did get to that appointment, or you know they need an echo for this reason. So I think that process and that yearly review is what helps with a lot of other things”. (Interview 6 – Community Nurse)

Participants can see the need for momentum behind all of these success factors to be supported by DHB’s to analyse the current picture, re-evaluate for the future and continue the momentum to see positive and sustainable outcomes. They also see the ease of moving that regional support to a national level due to the small RHF communities and small land mass that NZ has, making a national programme logistically much easier.

3. Opportunities and new initiatives.

Gaps in communications and between services were filled by a number of new initiatives. Participants shared examples of these, including: new IT programmes that had been instigated to support data management and ‘red flagging’ of RHF patients across services; initiation of new processes and checklists to improve consistency and completion of care plans; expansion of the referral processes to allow nurses to refer to clinics and GP’s; the availability and access to shared computer systems; and, the development of regional RHF groups to provide forums for updates, improve relationships and encourage coordination between services.

“Once diagnosed, computer systems alert clinicians that the patient has RHF, in whatever department they may be in”. (Interview 1 – Paediatrician)

“We have access whereby we can get [clinic letters] online, but they ... normally just appear in their notes”. (Interview 2 – Community Nurse)

“We have a new inpatient checklist to decrease gaps and inconsistencies. It’s a one page checklist which goes on the outside of each new case file. It has actions and responsibilities to be signed off, dated and completed prior to discharge”. (Interview 4 – RHF Coordinator)

“The nurse makes the referral [for discharge] using a referral form ... modified from our Tuberculosis form. It gives a summary of where they are at and what is required. We get direct feedback on the form, followed up by the clinic letter. It is a seamless process”. (Interview 5 – Community Nurse)

“We have regional team meetings with key representatives twice a year with updates, professional development and prioritising initiatives. We then form sub-groups to attack priority areas”. (Interview 4 – RHF Coordinator)

Initiatives have been instigated to address barriers and make services more accessible and acceptable to patient populations. Included in these initiatives have been; the holistic flexible nursing/kai awhina team approach that supports whanau in whatever way necessary to enable attendance for injections and clinics; delivery of programmes in settings suitable for the patient and whanau; and instigation of shared, concurrent and/or designated clinics to assist with transition between services and with the flow of communication.

“We are well known for transporting our patients to their appointments, ... just to make sure they get the care they need”. (Interview 3 – Community Nurse)

“It was a bottom up programme, we also at the same time were developing resources from funds we had got from the Ministry and we launched both of them together at the same time. And including some radio media stuff, and I think that by getting a small community on board, understanding their own impact, plus all the media stuff that went into it, the pamphlet and poster drops, there was a real indigenous population feel about it that went very well”. (Interview 3 – Community Nurse)

“We now have designated RHF clinics in both paediatrics and adult cardiology. It helps to increase communications between services enabling better clinical oversight and management and it enables [the community nurses] to work with patients to review and address any barriers to attending clinic”. (Interview 4 – RHF Coordinator)

Access to multiple services has been improved through the instigation of integrated, value laden, opportunistic programmes. An example of this was given whereby an echocardiography screening

programme was being planned into an integrated package of community awareness raising strategies.

“I think that if we can actually couple [the echocardiography screening] with a whole lot of resources and media and radio stuff into the community, I think we will have a really good vehicle for delivering a knowledgeable sore throats etc message to lots of families”. (Interview 3 – Community Nurse)

Another example came from several participants, following recognition of the multiple challenges patients faced when they had to come into tertiary hospitals for echocardiography and clinics.

“The thing that we do try and do with the patients [from outlying areas] is when they come to the clinic they have everything done at the same visit, like the echo, ECG, chest x-ray and us see them”. (Interview 1 – Paediatrician)

Additionally, participants identified multidisciplinary initiatives, and in some instances, a multi-departmental approach is needed to address the wider well being issues.

“Our Social Worker will certainly be involved, looking at transport and time off from work and those sorts of things. It is mainly the social issues, and perhaps some of the psychological issues of the child”. (Interview 1 – Paediatrician)

“We have Social Workers here too and we refer them because I mean we get kids living in garages who have just come out of cardiology after having major surgery. We can also give them information and they can self refer [to housing programmes]”. (Interview 2 – Community Nurse)

However, some healthy housing programmes were reported as being more focussed on warm housing than overcrowding, and some only focus on Housing New Zealand homes and have no impact on private rental properties.

“A lot of people in private rentals rather than Housing New Zealand rentals and my sort of experience, or our Social Workers’ experience, of trying to get those private rentals improved seems to be quite difficult”. (Interview 1 – Paediatrician)

In addition to these examples of initiatives to improve acceptability and accessibility of services, all of the participants shared new initiatives to address the barriers to accessing dental services. Interestingly, some areas found mobile dental services to be successful, others moved to stationary clinics to meet consistent high demand for dental services and one participant reported their DHB had

contracted services out to Maori providers. Having either school nurses or public health nurses available to ensure children were enrolled and had consent forms completed improved attendance at dental services.

“There are some Maori dental providers which are more accessible and affordable”. (Interview 5 – Community Nurse)

“A lot of the secondary schools have registered nurses and they are very responsible about getting the kids enrolled [with a dental provider] or sending home another form for the parent to sign because the first one went home and never came back”. (Interview 2 – Community Nurse)

Participants shared examples of new programmes and studies that have been initiated following audits of local RHF situations and a focus on continuous quality improvement. These include: community education sessions and awareness raising campaigns run by clinicians and nurses with family groups, health professionals and school groups in high risk communities; and, funding of a designated communications role within a Maori Provider to work on training local RHF champions. A youth focus group was formed to address the specific needs of young people with RHF.

“We’ve held a number of community based meetings. They included a session for GPs and practice nurses and then we had a session for the clients themselves (or parents of children with RHD) and that was last year and they both went really really well and the intention is that we will be doing that again on a regular basis”. (Interview 1 – Paediatrician)

“Her job is to move around lay people. She will train up champions to deliver her message, but they drop off of course, so she needs to continue doing that. And I know now that she is doing Maori radio in the [provincial areas] quite a bit”. (Interview 3 – Community Nurse)

“A youth focus group was created to develop youth friendly resources, review transition between services and source education for providers of care for youth identified needs”. (Interview 4 – RHF Coordinator)

Audits have been conducted of the RHF experience and patient satisfaction as planning tools for improvement of services and prevention of recurrences. Echocardiography screening has been conducted to identify undiagnosed cases of RHD and summer student research completed to provide local epidemiology.

“We are conducting a patient satisfaction survey of existing patients and services to be used as a planning tool for prioritising initiatives and review for 2011”. (Interview 4 – RHF Coordinator)

“We’ve done echo scanning, which I think proved what we sort of knew because we did it in two areas of high deprivation, very high Maori areas where we have a lot of people with diagnosed RHF. It showed that there were more children out there that were diagnosed with RHF, and some other conditions actually. So, in itself it was very worthwhile for those individuals because obviously they got treatment”. (Interview 6 – Community Nurse)

“There have been some summer students - which has again been excellent worthwhile work – and they’ve been looking into the background rates of RHF in the district, and RHD and associated conditions”. (Interview 6 – Community Nurse)

Yet, as highlighted by many participants, audit, research and guidance documents can be written and submitted to DHB’s and Ministry departments, but if they are not acted upon, they are unlikely to provide sustainable outcomes.

Discussion

The analysis of the interviews has shown that challenges in meeting the guidelines do exist due to complex environmental factors that programmes operate in. Participants have offered their perspectives on the challenges in meeting the guidelines, the success factors that have helped overcome some of these challenges, and new initiatives that have been put in place to improve the attainment of the standards and meet the needs of RHF populations. These examples offer opportunities for learning for other DHB’s who may not have considered some of these issues, and contribute to the wealth of knowledge and tools in the ‘kete’ of RHF approaches.

Out of the results presented, two core themes underline the challenges, success factors and new initiatives shared in the interviews. These were; cultural appropriateness and national leadership. These are addressed in the discussion below, along with comparisons to international and NZ literature.

1. Cultural appropriateness.

Maori and Pacific peoples have far greater rates of acute RHF, recurrent RHF and RHD than NZ Europeans (Jaine, et al., 2008). Clear links are seen between RHF and poverty, household overcrowding and inadequate access to healthcare (Atatoa-Carr, Bell, et al., 2008; Baker, et al., 2003; Best Practice, 2008; Christmas, 1984; G. Jackson, et al., 2009; Lennon, 2004; Neutze, 1988). When referring to ‘high risk RHF populations’, this usually means Maori and Pacific families from areas of high social deprivation, living in overcrowded homes with inadequate access to healthcare. Therefore, strategies and programmes need to be based on models of care that are appropriate to Maori and Pacific peoples.

In relation to the theme of cultural appropriateness, participants in the interviews identified challenges in meeting the guidelines due to the multitude of barriers and stresses faced by families from areas of high deprivation. These challenges were addressed within the context of holistic nurse-led community prophylaxis teams, assisted by kai awhina and administrative support. The participants of the interviews reiterated the importance of local community workers, or kai awhina, of similar ethnicity to the patient population. Their existing networks amongst the community, culturally appropriate approach, and support for the needs of individual families, enhanced the family's capacity to address the barriers to accessing services, and assisted nurses in the delivery of timely prophylactic injections. The services were provided in a manner and setting suitable to patient preference, tailored to address patient need, and supportive to enhance resilience.

Similarly, Australian studies (Harrington, et al., 2006; McDonald, Benger, Brown, Currie, & Carapetis, 2006) have highlighted the importance of appropriate approach, with success factors including pastoral care, close relationships, trust, respect, patience, persistence, clear roles and responsibilities, and familiarity with services. These factors have assisted in improving adherence to prophylaxis programmes in remote aboriginal communities.

Interview participants shared their new initiatives, which enhance these success factors in the provision of culturally appropriate services. These included; community based education sessions and awareness raising; designation of a community education role within a Maori Provider; formation of a working group focussing on the needs of young people; resourcing of dedicated key RHF workers; and, research identifying the patient experience and their perspectives on gaps and needs. These initiatives follow the recommendations given by other NZ audits, including: funding for designated mobile RHF nurses and community support workers; development of culturally appropriate resources in relevant language and media; and, raising community and health practitioner awareness of RHF (Grayson, et al., 2006; Martin, 2008).

Raising community awareness of RHF is a key component of most comprehensive RHF programmes and recommendations following audit and evaluation. Yet if community awareness raising is not conducted in an appropriate manner, approach, or language, the needs of Maori and Pacific communities may not be met and education campaigns may not raise awareness at all. Australian studies found low levels of RHF awareness amongst health professionals and communities; and a lack of appropriate personnel and resources, such as local indigenous community workers and culturally responsive services that consider alternative beliefs regarding disease and management (Harrington, et al., 2006; Stewart, et al., 2007). A NZ study found other conceptual barriers, including the inability to understand or accept the consequences of the illness, and differing cultural value systems and/or concepts of preventative health care (Martin, 2008).

Finally, the World Health Organisation (1992) highlighted the barrier of health literacy, which has major implications for health education of RHF populations in NZ. This was demonstrated in an early study in which parents of children with RHF were interviewed and data was gathered on their knowledge of RHF, beliefs and anxieties, and factors influencing their knowledge and beliefs (Kennell, 1969). The study found that regardless of the perceived quality of education that was given, the underlying fear of heart disease and death pervaded. This resulted in a low level of understanding of the disease, the purpose of prophylaxis and the long term effects of RHF.

These combined factors relating to culturally responsive services and consideration for alternative beliefs regarding disease and management, which were raised in these studies described above, require further investigation within the NZ RHF context. Examples of Maori experiences with other health contexts in NZ include the areas of mental health (Taitimu, 2007), asthma management (Crengle, 2008), and general health care interactions (Mauri Ora Associates, 2009). Such examples need to be emulated in the NZ RHF context to formulate a new understanding of the cultural considerations and beliefs under-pinning Maori and Pacific perceptions of health and well-being. These new understandings can then inform awareness raising campaigns to be delivered in culturally responsive approaches, utilising appropriate Maori and Pacific community workers in a partnership model with Maori and Pacific community leaders.

Such culturally appropriate approaches to RHF will then assist in achieving the Ministry of Health's goal of reducing health inequalities for Maori and Pacific Peoples (Minister of Health, 2006; Ministry of Health, 2001), and work towards the objective in the NZ guidelines for RHF of ensuring that high-risk populations receive the same standard of care as that available to other New Zealanders (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006).

2. National leadership.

The second theme arising from the interviews is the need for national leadership, direction, prioritisation and resourcing. Following the discussion above regarding culturally appropriate services, there are obvious resource implications for the funding and provision of appropriate personnel and resources, such as local indigenous community workers, a dedicated person to actively follow up and coordinate services, researchers to investigate the perspectives and needs of RHF populations, and reoriented health services to meet these identified needs. This requires government commitment and investment to support local providers and initiatives (Brown, et al., 2007; Brown, et al., 2003; Eissa, et al., 2005; Harrington, et al., 2006; Stewart, et al., 2007). The interview participants identified similar challenges in the lack of resources, support, leadership and direction from DHB's and National Ministries resulting in barriers such as inconsistent clinical practice, interrupted supply of Bicillin, and access issues relating to poverty.

NZ audit also showed that a lack of national and regional support of RHF services and activities had resulted in systems failures, such as the discontinuation of a local register and the subsequent coordination of secondary prevention (Atatoa-Carr, Bell, et al., 2008), interrupted supply of Bicillin with patients having to go onto oral medication or refusing prophylactic treatment completely, and lack of awareness amongst health professionals resulting in missed diagnoses (Martin, 2008). Each of these systems failures could be linked to increased recurrent rates. Participants from the interviews suggested such system failures could be minimised with appropriate recognition, support, leadership and direction at DHB and National levels.

International initiatives give examples of nationally driven, coordinated, multi-streamed approaches to RHF that have had successful outcomes. Downstream initiatives include comprehensive, nationally coordinated and long term programmes for control of RHF. These programmes assist in improving consistent practice, alignment with best practice standards, and integration between services and providers of care (Bach, et al., 1996; Brown, et al., 2003; Eisenberg, 1993; Mayosi, et al., 2006; McDonald, et al., 2005; McLaren, 1994; Robertson, et al., 2006; World Health Organisation, 1992).

Midstream initiatives include analysis of the structures, resources and capacity that are required within communities to successfully treat and sustainably manage RHF. This is followed through with appropriate funding, resourcing and regular evaluation (Brown, et al., 2003; Omokhodion, 2006).

Upstream interventions involve advocacy for improvements in the social determinants of health that span across various Ministries (Mayosi, et al., 2006; MBewu, 2006), particularly the Ministries of Health, Education, Housing and Social Development based on the clear links seen between RHF and poverty, household overcrowding and inadequate access to healthcare (Atatoa-Carr, Bell, et al., 2008; Baker, et al., 2003; Best Practice, 2008; Christmas, 1984; G. Jackson, et al., 2009; Lennon, 2004; Neutze, 1988). Collaboration amongst these Ministries would provide the platform to make an impact on the underlying factors that result in RHF, and many other illnesses of poverty and overcrowding.

To enable this to happen, RHF needs to feature on the agenda of Ministries, funders and policy makers (Robertson, et al., 2006), be supported by a steering committee of RHF experts and Maori and Pacific leaders (C. Jackson & Lennon, 2009; Lennon, 2009), and be founded on a culturally appropriate agenda driven by, and suited to the needs of, the Maori and Pacific RHF populations.

Strengths and Limitations

A high response rate from representative DHB's, the uniqueness of this research and the implications for practice were the strengths of this study. Obtaining participation from the six DHB's with higher rates of RHF and with a coordinated management approach to RHF care across the services has

ensured the data gathered has been meaningful and has captured a range of issues faced by clinicians when meeting the guidelines.

Although identification of barriers and facilitators in meeting best practice care had occurred throughout other NZ studies, there were none that had explored the full continuum of diagnosis, management and secondary prevention as this study has. Additionally, due to the relatively recent introduction of the NZ Guidelines for RHF in 2006, barriers and facilitators had not been explored directly against the guidelines, which this study achieves. Findings from these interviews provide in-depth perspectives of current issues in meeting the guidelines, with examples of new initiatives that may be used to help address the barriers described.

Practical evidenced-based recommendations will enable research utilisation to influence practice changes directly, and persuade decision makers to make changes in policies and practices that will assist in more focussed interventions (Polit & Beck, 2008). This research is justified in terms of its value and contribution to knowledge, and in terms of the robustness of the research process to produce quality research (Ministry of Health, 2006). The rigour and credibility of analysis was optimised by triangulating interview data with similar studies from NZ and Australia to check for outlier data and consistency in trends (Adami & Kiger, 2005; Harrington, et al., 2006; Polit & Beck, 2008).

Nurses are strongly involved with the care of RHF patients, from diagnosis and following through the years of nursing care that is given. The outcomes of this research will be of particular interest to such nurses throughout the continuum of secondary RHF care, and their multidisciplinary colleagues in the RHF community.

The limitations include the constrained interview sample and researcher bias. Ideally, interviews would have continued with as many participants as necessary to reach data saturation – whereby no new data emerges with further interviews (Polit & Beck, 2008). But due to time and resource limitations, six DHB's were purposively selected to participate, according to the criteria outlined in the recruitment letter (appendix two). It would have been beneficial to have at least had another two interviews to cover the perspectives of the spectrum of key health professionals, and have included a Cardiologist and a Medical Officer of Health.

An existing connection occurred between the researcher and some of the participants. This could have resulted in coercive recruitment and invalid data (Creswell, 2009). To minimise the risk of this occurring, strategies of validity were utilised to increase confidence in the findings (Creswell, 2009) This included requesting a third party – the DHB's MOoH or Paediatrician, to assist with the recruitment approach and participant selection.

Researcher reflexivity is required to ensure that the researcher has an awareness of their role in the interviews, and asks that they reflect on their behaviour and its consequential affect on the data (Polit & Beck, 2008). This was particularly pertinent as the researcher works in the RHF field and had connections with some of the participants. Member checking was undertaken with participants throughout the interviews to assist with credibility as it clarified that the researcher's interpretations reflected the participant's responses (Adami & Kiger, 2005; Polit & Beck, 2008). Care was taken in the analysis to represent the full range of responses and not just the general trend, as perceived by the researcher (Creswell, 2009).

Conclusion

The NZ Guideline for RHF provides best practice standards of diagnosis, management and secondary prevention. Yet the complex environmental factors that programmes operate within provide challenges to meeting these standards.

This research has presented rich stories to learn from. It has outlined some of the key barriers and facilitators the participants face in meeting the guidelines. The initiatives they have shared provide examples of what can be emulated in other local areas to assist in crossing the theory/practice divide to meet the needs of high risk populations. The discussion of the underlying themes has identified strategies to implement nationally led, culturally appropriate approaches to RHF. These could assist in achieving the Ministry of Health's goal of reducing health inequalities for Maori and Pacific peoples (Minister of Health, 2006; Ministry of Health, 2001), and ultimately help to improve the achievement of the standards of the guidelines and health outcomes for Maori and Pacific RHF populations.

5. Summary and Conclusions

'Crossing the Theory/Practice Divide'

Introduction

This research was conducted in two phases. The first phase presented District Health Board's (DHB's) attainment of the standards from the New Zealand (NZ) guidelines for Rheumatic Fever (RHF) (National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand, 2006), identifying those standards that have been achieved well and those that have proven challenging to achieve consistently. The second phase highlighted the barriers to, and success factors for, achieving the guidelines, and initiatives that have been instigated.

This chapter looks at the findings of the audit and brings meaning to it by reflecting on the stories shared in the interviews. Recommendations from the surveys, interviews and RHF literature are collated and summarised. This chapter also outlines the strengths and limitations of the portfolio and the unintended consequences of this research. It discusses implications for nursing practice, and concludes with a set of recommendations from this research and a proposed framework to help cross the theory/practice divide.

Summary of Findings

Quantitative audits.

Chapter three asked the question: **To what extent are District Health Board's meeting the 2006 New Zealand Guidelines for Rheumatic Fever?** The findings of this chapter showed that since the introduction of the guidelines in 2006, only 48% of all standards achieved mean scores over 75%, with considerable variance in attainment between DHB's and across the spectrum of services assessed.

As this was the first audit of practice against the 2006 guidelines, it is apparent that the guidelines are having good impact on practice in those standards from the diagnosis and management section, the provision of secondary prophylaxis and some of the register aspects of the secondary services section of the guidelines. Yet the guidelines have made little impact on practice relating to the lowest scoring standards of the guidelines primarily from the secondary services section.

Qualitative interviews.

Chapter four explored the following question: **What are clinician's perspectives on the barriers and facilitators to implementing the 2006 New Zealand Guidelines for Rheumatic Fever?**

Participants shared their insights into the challenges faced when meeting the standards within the guidelines; the success factors that made meeting standards easier; and, the opportunities and new initiatives that have been identified and implemented.

Two underlying themes arose from the interviews: cultural appropriateness and national leadership. These themes were compared and contrasted with international and NZ literature. The summary of the discussion showed that RHF needs to: feature on the agenda of Ministries, funders and policy makers (Robertson, et al., 2006); be supported by a steering committee of RHF experts alongside Maori and Pacific leaders (C. Jackson & Lennon, 2009; Lennon, 2009); and, be founded on a culturally appropriate agenda driven by, and suited to, the needs of Maori and Pacific RHF populations.

Participants were also asked in the interviews to give recommendations to address the challenges and gaps identified. These were not discussed in chapter four as it was outside the scope of investigating the barriers and facilitators to implementing the guidelines. Instead the recommendations from the interviews, surveys and RHF literature are summarised in this chapter.

Recommendations

The fourth interview question asked participants to make recommendations for targeted public health interventions to meet the needs of RHF patients in their area. As the interviews were only conducted with participants from six DHB's, these findings were cross-checked for consistency with both the RHF literature and the self-reported gaps in services that were provided by all of the survey participants from the 15 DHB's (appendix 8, question 17).

Combining the recommendations from the interviews, surveys and literature, five themes for recommended actions have been identified as: agenda for action, approach, accessibility, appropriateness, and awareness.

Agenda for action.

- Having RHF embedded in DHB and National agendas, led and coordinated strategically and driven by key experts
- Collaboration with non-health sectors to address the socio-economic determinants of health, particularly housing and household income

- Appropriately resourced, designated roles and services to provide holistic, responsive services, including designated RHF nurses and local community workers with existing key networks and administrative support
- Local activities, initiatives and existing processes and documentation need to be pulled together, standardised and driven by key experts for implementation throughout the country
- Securing a constant, uninterrupted supply of high quality Bicillin

Approach.

- RHF messages infiltrating existing processes and personnel
- Local team approach to review, coordination and management of RHF cases, led by identified local RHF experts and community leaders
- Experienced community nurses running secondary prophylaxis programmes, and having an oversight role in coordination between services to ensure all best practice standards are met, and the needs of the family are met within the holistic community team approach
- Continuity of care and trusting relationships with patients, their families and communities
- Consistent supportive messages across all secondary services

Accessibility.

- Removing the barriers to access by taking fully resourced services, such as mobile dental, outreach services, local wellness clinics with mobile echo, and secondary prophylaxis programmes, to communities of high need
- Making it easier for patients to get to clinics by supporting them with their physical needs such as transport; having multiple interventions in one visit; and, clear lines of communications
- Provision of free secondary services for RHF patients, including GP and dental services

Appropriateness.

- Asking patients and their families what they want and how that may be achieved
- Provision of integrated education in appropriate languages and media
- Utilising DVD/video/CD's and targeted media, such as Maori radio, for awareness raising
- Further investigation into specific cultural considerations for Maori and Pacific populations in their experience with RHF in NZ

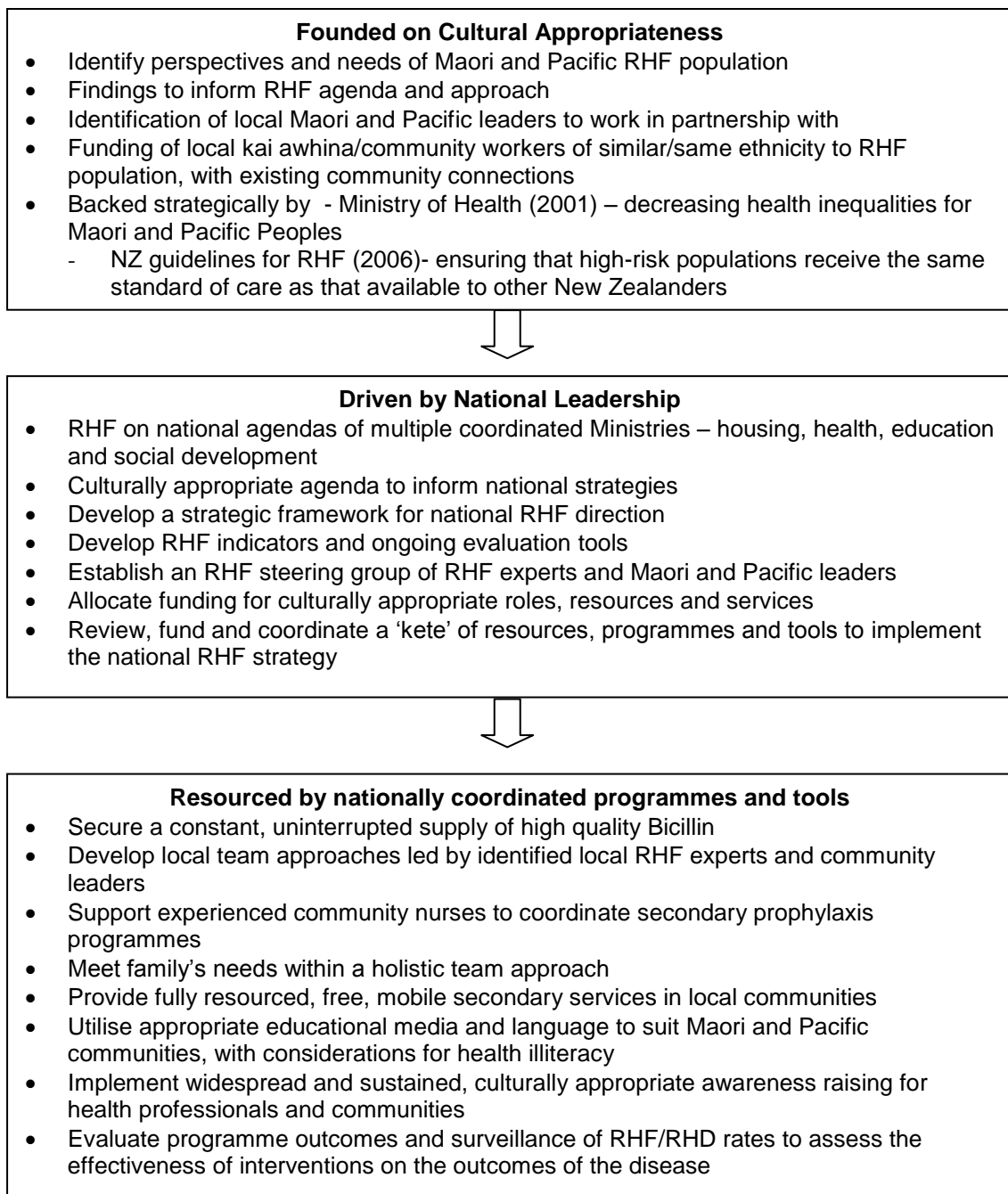
Awareness.

- Widespread RHF awareness campaigns, driven nationally, amongst health professionals and communities to improve understanding
- Increase contact points throughout communities to support families in RHF management and having everyone taking responsibility for RHF
- Including RHF in the school curriculum

- Constant evaluation of programme outcomes and surveillance of RHF/RHD rates to assess the effectiveness of interventions on the outcomes of the disease

This summary is consistent with the findings of the qualitative analysis, with the underlying themes of cultural appropriateness and national leadership; with an additional list of recommended interventions. As such, the following framework combines the findings, themes and recommendations to assist in crossing the theory/practice divide to make a sustainable impact on those areas of greatest need.

Nationally driven, culturally appropriate RHF actions



Strengths and Limitations of the Portfolio

The strengths of this research relate to the methods employed, the uniqueness of the study and the relevance of the findings to practice. The two phased approach to investigating the current standard of care being delivered in relation to the guidelines, enables both a description of the extent of the public health problem and an understanding of the complex reasoning behind it (Baum, 1995). This holistic approach extends the scope of implications and broadens the range of recommendations to include the contextual population and environmental considerations, making the findings more relevant to a wider audience.

Additionally, the two phased approach optimises the rigour and credibility of the analysis as the interview data was triangulated with both the survey findings and RHF literature to check for outlier data and consistency in trends (Adami & Kiger, 2005; Harrington, et al., 2006; Polit & Beck, 2008). This analysis showed that the findings of this research tended to fit with the existing literature.

What this research has added to the RHF literature is valuable local data, specific to the NZ guidelines and the contexts in which practice occurs. A benchmark of the North Island's attainment of the standards has been set, with the current challenges and success factors outlined. A framework of nationally driven, culturally appropriate RHF actions summarised the key themes and provides practical recommendations. With ongoing project evaluation and surveillance of RHF and RHD rates, similar research may be conducted in the future to assess improvements in the attainment of the guidelines, review emergent challenges and initiatives, and outline the impact of the guidelines on the outcomes of the disease.

The study has been confined by time and resource constraints, limiting the scope of research. As outlined in the limitations sections in chapters three and four, it would have been optimal to have included audits of clinical files, utilised hospital coded data, and conducted more interviews until data saturation had been reached. It would have been useful to complete the scope of RHF by including primary prevention in the research. However, this could constitute a research project of its own.

Unintended Consequences

Some unintended consequences have arisen during this research journey. Firstly, in the process of conducting the literature review, a repository of international and NZ literature has been collated, including some unpublished reports and audits. The literature matrix should prove to be a helpful tool for other researchers looking to gather similar literature.

Many participants reported that their involvement with the research had prompted internal review of their processes in light of the gaps identified in the survey. One had commented they had used the

completion of the survey as a joint activity with the objective of handing over their RHF oversight role to a new staff member.

The extended review of the Episurv data, and discussion regarding its limitations and incompleteness, has prompted both internal and national review. The Episurv data check that most participants conducted highlighted the gaps in their notification processes, and they were able to identify key points they would be rectifying in their processes. A brief summary of the findings regarding the incompleteness of Episurv data has contributed to an email discussion regarding national data sets for RHF. The email group has recently been developed amongst the wider RHF community in NZ, as a forum for sharing and discussion. Concerns were raised on this forum in light of the weight that is placed on this data set in planning and funding arenas, contributing to the discussion surrounding the use of hospital discharge data or a national register as an alternative.

Finally, valuable new connections with key RHF links in other DHB's have been made and maintained by intermittent email communications.

Influence of Research on Nursing Practice

This research has highlighted the crucial role that nurses have in management and coordination of secondary prevention programmes. Their expertise, knowledge, rapport, connections and holistic family-centred model of care provides the glue to hold together a very intricate web of services, with mobile, challenged and complex families. Hopefully nurses will find the outcomes of this research useful in their practice as they can identify key success factors, new initiatives and recommendations which would benefit their practice and patient population. Additionally, they may recognise similar challenges and barriers to their practice environment, and be able to identify suggestions to address barriers.

An important stage of this research, therefore, is the dissemination of information. Firstly, to report on how the guidelines are being implemented throughout NZ, secondly, to reflect on what gaps in RHF services exist, and finally, to share the lessons learnt in local communities when presented with challenges in meeting the standards set in the guidelines.

Opportunities to share this research will be sought in a variety of ways, including dissemination of the research report to the participants, a copy being sent to the New Zealand Nurses Organisation (NZNO) to be lodged in the NZNO library and the abstract being entered in the NZNO Nursing Research Section, Research database website. The research will be made available via the email group and circulated amongst the wider RHF community and to the National RHF Steering Committee that supports the Ministry of Health. Opportunities to present this research will be sought at grand

round presentations and at appropriate conferences in 2011. Additionally, submission for a journal publication is planned for 2011.

Conclusion

Throughout the past 20 to 30 years, many audits, research reports and national guidelines have highlighted high risk RHF populations, contributing factors, and the gaps, success factors and recommendations for improved service delivery and health outcomes for this population. This research has added valuable local data, specific to the NZ guidelines and the context in which practice occurs. It has illustrated the value of a two phased approach to such public health issues, by providing valuable, rich explanations for the current state of DHB's attainment of the standards within the guidelines. A benchmark of the North Island's attainment of the standards has been set, with current challenges and success factors outlined. A framework for nationally driven, culturally appropriate RHF actions has summarised the key themes and identified practical recommendations.

The outcomes of this research have the potential to have a wider impact on RHF management, beyond achieving the standards from the guidelines. They factor in the contextual environmental and population impacts to present strategies for crossing the theory/practice divide. The implementation of these strategies is expected to help improve the general attainment of the standards from the guidelines across all DHB's through the implementation of a responsive, holistic public health programme that is nationally driven, culturally appropriate, and based on the needs of Maori and Pacific RHF populations. Ultimately, the practical utilisation of these research recommendations will see more targeted RHF services aimed at reducing inequalities based on the at-risk populations and effective decreases in RHF related morbidity and mortality throughout NZ.

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7. Appendices

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Appendix 1: Literature Matrix

Reference	Theme 1 General International RHF	Theme 2 General NZ RHF	Theme 3 Int RHF Guide- lines	Theme 4 NZ RHF Guide- lines	Theme 5 Int RHF initia- tives	Theme 6 NZ RHF initia- tives	Theme 7 Int RHF Audit	Theme 8 NZ RHF audit	Notes/Methods
Arafa, M. A., Zaher, S. R., El-Dowaty, A. A., Moneeb, D. E., Arafa, M. A., Zaher, S. R., et al. (2008). Quality of life among parents of children with heart disease. <i>Health & Quality of Life Outcomes</i> , 6, 91							Yes		Patient impact audit - interviews cross referenced with clinical records in a comparative cross-sectional design. Impact of diagnosis on quality of children and parents lives. Implications for practice.
Atatoa-Carr, P., Bell, A., & Lennon, D. R. (2008). Acute rheumatic fever in the Waikato District Health Board region of New Zealand: 1998-2004. <i>New Zealand Medical Journal</i> , 121(1285), 96-105.		Yes						Yes	Audit of clinical notes 1998 - 2004, Waikato DHB region. Outlined epidemiology and clinical pathway of ARF in Waikato. Identified burden of disease. Recommendations for further study
Atatoa-Carr, P., Lennon, D., & Wilson, N. (2008). Rheumatic fever diagnosis, management, and secondary prevention: a New Zealand guideline. <i>New Zealand Medical Journal</i> , 121(1271), 59-69				Yes					Brief summary of the NZ guidelines for RHF
Bach, J. F., Chalons, S., Forier, E., Elana, G., Jouanelle, J., Kayemba, S., et al. (1996). 10-year educational programme aimed at rheumatic fever in two French Caribbean islands. <i>Lancet</i> , 347(9002), 644-648.					Yes				Summary of Eradication programmes, effect of interventions
Baker, M., & Chakraborty, M. (1996). Rheumatic fever in New Zealand in the 1990s: still cause for concern. <i>NZ Public Health Rep</i> , 3, 17-19.		Yes							Epidemiology of RHF in NZ
Best Practice. (2008). Why we still need to think of rheumatic fever. <i>Best Practice</i> (13), 25 - 28						Yes			Identified upstream determinants, success factors learnt from primary prevention initiatives
Brown, A., McDonald, M. I., & Calma, T. (2007). Rheumatic fever and social justice.[comment]. [Comment Editorial]. <i>Medical Journal of Australia</i> , 186(11), 557-558.							Yes		Adherence Audit - Success and failures of secondary prophylaxis programmes. Literature review

Brown, A., Purton, L., Schaeffer, G., Wheaton, G., & White, A. (2003). Central Australian Rheumatic Heart Disease Control Program A report to the Commonwealth November 2002. <i>The Northern Territory Disease Control Bulletin</i> , 10(1).							Yes		Programme audit - programme evaluation against the objectives of the Central Australian RHD programme
Carapetis, J. R., Brown, A., Wilson, N. J., & Edwards, K. N. (2007). An Australian guideline for rheumatic fever and rheumatic heart disease: an abridged outline. <i>The Medical Journal of Australia</i> , 186(11), 581 - 586.			Yes						Summary of Australian guidelines
Carapetis, J., McDonald, M., & Wilson, N. J. (2005). Acute rheumatic fever. [doi: DOI: 10.1016/S0140-6736(05)66874-2]. <i>The Lancet</i> , 366(9480), 155-168.				Yes					Guidance on the disease diagnosis, treatment and prevention
Christmas, B. W. (1984). Management of rheumatic fever: a review. <i>New Zealand Medical Journal</i> , 97(763), 598-600.		Yes					Yes		A review of NZ morbidity and mortality; control programmes; RHF as a health indicator; and, prevention measures. Highlights RHF audits conducted and resulting guidance.
Clur, S. A. (2006). Frequency and severity of rheumatic heart disease in the catchment area of Gauteng hospitals, 1993-1995. <i>South African Medical Journal</i> , 96(3 Pt 2), 233-237.					Yes				Gauteng Hospitals - identification of frequency and severity of RHF/RHD
Craig, L., Anderson, P., & Jackson, C. (2008). <i>The health status of children and young people in Counties Manukau</i> . Auckland: Child & Youth Epidemiology Service.		Yes							NZ RHF epidemiology, age, ethnicity and risk factors. Related documents
Department of Health. (1988). <i>Rheumatic fever secondary prophylaxis. Circular letter to medical practitioners</i> . Wellington: Department of Health				Yes					Guidance document with change from oral to injectable penicillin prophylaxis.
Eisenberg, M. J. (1993). Rheumatic heart disease in the developing world: prevalence, prevention and control. <i>European Heart Journal</i> , 14(1), 122-128			Yes						US guidelines within the context of the environment, the upstream determinants and challenges of meeting best practice guidelines

Eissa, S., Lee, R., Binns, P., Garstone, G., McDonald, M., Eissa, S., et al. (2005). Assessment of a register-based rheumatic heart disease secondary prevention program in an Australian Aboriginal community. <i>Australian & New Zealand Journal of Public Health</i> , 29(6), 521-525							Yes		Practice vs. guidelines review - register data compared with three other databases. Checking data relevance and accuracy. Review of specific indicators relating to register based prevention programme in remote Australian Aboriginal community against best practice guidelines
Eltohami, E. A., Hajar, H. A., & Folger, G. M., Jr. (1997). Acute rheumatic fever in an Arabian Gulf country--effect of climate, advantageous socio-economic conditions, and access to medical care. [Comparative Study]. <i>Angiology</i> , 48(6), 481-489	Yes								Report on 11 year study of incidence and consequences of ARF in an Arabian Gulf Country. Methods included clinical evaluation, lab studies, and echo. Comparison was conducted against other countries and communities to identify some contributing factors.
Flight, R. J. (1984). The Northland rheumatic fever register. <i>New Zealand Medical Journal</i> , 97(765), 671-673.								Yes	Retrospective quantitative audit of health report data – cross checking the register data against hospital and GP clinical records within the Northland region. Identified demographic details and clinical findings of RHF patients, reviewed recurrent cases and recommended strategies to prevent further recurrences.
Frankish, J. D. (1974). Rheumatic fever on the East Coast, North Island. <i>New Zealand Medical Journal</i> , 80(520), 48-51.		Yes							Comparative review of incidence rates of RHF between local hospital and other NZ and international studies. Reviewed use of Jones Criteria, manifestations, discussion of secondary and primary preventions strategies.
Frankish, J. D. (1984). Rheumatic fever prophylaxis: Gisborne experience. <i>New Zealand Medical Journal</i> , 97(765), 674-675.								Yes	A comparative group of RHF patients receiving injectable penicillin were followed to track recurrence rates in comparison to a retrospective review of case files for a group of patients on oral penicillin and their recurrence rates.
Frankish, J. D., Stanhope, J. M., Martin, D. R., Clarkson, P. M., Leslie, P. N., & Langley, R. B. (1978). Rheumatic fever and streptococci: the Wairoa College study. <i>New Zealand Medical Journal</i> , 87(604), 33-38.								Yes	Cross sectional survey of local secondary school in Wairoa to identify GAS prevalence, ASO Titres, prevalence of RHF and discriminating factors for RHF and GAS.

Gerber, M. A., Baltimore, R. S., Eaton, C. B., Gewitz, M., Rowley, A. H., Shulman, S. T., et al. (2009). Prevention of rheumatic fever and diagnosis and treatment of acute Streptococcal pharyngitis: a scientific statement from the American Heart Association Rheumatic Fever, Endocarditis, and Kawasaki Disease Committee of the Council on Cardiovascular Disease in the Young, the Interdisciplinary Council on Functional Genomics and Translational Biology, and the Interdisciplinary Council on Quality of Care and Outcomes Research: endorsed by the American Academy of Pediatrics. [Practice Guideline]. <i>Circulation</i> , 119(11), 1541-1551			Yes						US guidelines on appropriate diagnosis, treatment, secondary prevention follow up
Gordis, L. (1985). The Virtual Disappearance of Rheumatic Fever in the United States: Lessons in the Rise and Fall of Disease. <i>Circulation</i> , 72, 1155-1162.	Yes								Summary of studies into the rise and fall of RHF in the US and the possible interventions that have influenced them. Multi-factorial action of RHF therefore multi-factorial interventions required.
Gray, G. (2009, 8-9 October). <i>Epidemiology of Acute Rheumatic Fever in Lakes DHB 1998-2007</i> . Paper presented at the New Zealand Public Health Medicine Annual Scientific Meeting, Wellington.								Yes	Lakes DHB - epidemiology 1998 - 2007, recommendations for register, education to improve notifications, and surveillance to monitor impact and adherence rates
Grayson, S., Horsburgh, M., & Lennon, D. (2006). An Auckland regional audit of the nurse-led rheumatic fever secondary prophylaxis programme. <i>New Zealand Medical Journal</i> , 119(1243), U2255								Yes	Compliance audit of prophylaxis. 1998 and 2000 Auckland Register data. 79.9 - 100% compliance
Hanna, J. N., & Clark, M. F. (2010). Acute Rheumatic Fever in Indigenous people in North Queensland: some good news at last? <i>Medical Journal of Australia</i> , 192(10), 581 - 584.							Yes		Programme audit - routine surveillance, retrospective checking clinical records, and programme evaluation to ascertain if changing from enhanced to routine surveillance programme in North Queensland had any deleterious impacts

Harrington, Z., Thomas, D. P., Currie, B. J., & Bulkanhawuy, J. (2006B). Challenging perceptions of non-compliance with rheumatic fever prophylaxis in a remote Aboriginal community. [see comment]. <i>Medical Journal of Australia</i> , 184(10), 514-517.							Yes		Adherence Audit - patient interviews and audit of penicillin coverage in Australia. Identification of themes pertaining to uptake of secondary prophylaxis
Jackson, C., & Lennon, D. (2009). <i>Draft - Rheumatic Fever Register: Scoping the development of a national web-based rheumatic fever register</i> . Auckland: The University of Auckland.		Yes						Yes	Epidemiology of NZ RHF; Registers - history, overview of local registers, recommendations for national register
Jaine, R., Baker, M., & Venugopal, K. (2008). Epidemiology of acute rheumatic fever in New Zealand 1996– 2005. <i>Journal of Paediatrics and Child Health</i> , 44(10), 564-571		Yes							Epidemiology of NZ RHF. Ethnic disparities. Concentrated population
Jarman, J. (2007). How a community controlled the streptococcus: school-based rheumatic fever primary prevention in New Zealand. Retrieved August, 2009, from http://www.wecanmakeadifference.org.nz/ohml/downloads/6_Jonathan%20Jarman.pdf						Yes			Primary prevention - but identifies lessons learnt that could translate to other initiatives
Kaplan, E. (1981). Current Status of Rheumatic Fever Control Programs in the United States. <i>Public Health Reports</i> , 96(3), 267-268.	Yes								Review of US RHF control programmes - questionnaire sent to 29 state departments in 1979
Kelly, A. (2003). Top End Rheumatic Heart Disease Program. A report to the Commonwealth. <i>The Northern Territory Disease Control Bulletin</i> , 10(1), 9 - 11.							Yes		Programme audit - programme evaluation against the objectives of the Top End Australian RHD programme
Kennell, J. H., Soroker, E., Thomas, P., & Wasman, M. (1969). What Parents of Rheumatic Fever Patients Don't Understand about the Disease and its Prophylactic Management. <i>Pediatrics</i> , 43(2), 160-167.							Yes		Patient impact audit - interviews, review of clinical notes and databases, observation of people and processes. To gauge understanding of disease and beliefs relating to disease. Identified barriers to understanding and suggested implications for practice

Lee, J. L., Naguwa, S. M., Cheema, G. S., & Gershwin, M. E. (2009). Acute rheumatic fever and its consequences: A persistent threat to developing nations in the 21st century. <i>Autoimmunity Reviews</i> , 9(2), 117-123.	Yes								Summary of epidemiology and best practice guidance
Lennon, D. (2004). Acute rheumatic fever in children: recognition and treatment. <i>Paediatric Drugs</i> , 6(6), 363-373				Yes					Epidemiology of NZ RHF; investigations, management, secondary prevention, primary prevention
Lennon, D. (2009). Advice for the Ministry of Health for best practice for Rheumatic Fever Control. Unpublished Summary of International Workshop on Rheumatic Fever/Rheumatic Heart Disease Control in New Zealand. Ministry of Health and National Heart Foundation of New Zealand		Yes						Yes	Epidemiology of NZ RHF; workshop objectives, outputs and recommendations; timeframes
Loring, B., de Wit, N., Shoemack, P., & Hewison, C. (2008, 25-26 September). <i>Rheumatic Fever in the Bay of Plenty and Lakes DHBs - a Bigger Problem Than we Thought</i> . Paper presented at the New Zealand Public Health Medicine Annual Scientific Meeting, Auckland.								Yes	Bay of Plenty and Lakes DHB's, review of NZ guidelines, MOH documents and direction, recommendations for action
MacQueen, J. (1979). State Registries and the Control of Rheumatic Fever. <i>American Journal of Public Health</i> , 69(8), 761-762.	Yes								Editorial of the challenges of maintaining State registries
Maguire, G. P., & Nelson, C. (2006). Acute rheumatic fever and rheumatic heart disease: an insight into Aboriginal health disadvantage and remote Australia. <i>Medical Journal of Australia</i> , 184(10), 506.							Yes		Adherence audit - concepts of autonomy and paternalism in relation to Aboriginal health - editorial of issues
Marijon, E., Ou, P., Celermajer, D. S., Ferreira, B., Mocumbi, A. O., Sidi, D., et al. (2008). Echocardiographic screening for rheumatic heart disease. [Editorial]. <i>Bulletin of the World Health Organization</i> , 86(2), 84.	Yes								Editorial summarising use of echo rather than cardiac auscultation as screening tool

Martin, M. (2008). <i>Rheumatic fever in the Wellington Region: A scoping paper identifying gaps in services and recommendations for action</i> . Wellington: Regional Public Health								Yes	Wellington Region. Secondary prophylaxis mode for increased adherence, reasons for recurrent attacks, strategies to improve adherence
Mayosi, B. M. (2006). A proposal for the eradication of rheumatic fever in our lifetime. <i>South African Medical Journal</i> 96(3), 229 - 230.					Yes				Summary of Pan African Society of Cardiology conference
Mayosi, B., Robertson, K., Volmink, J., Adebo, W., Akinyore, K., Amoah, A., et al. (2006). The Drakensberg declaration on the control of rheumatic fever and rheumatic heart disease in Africa. <i>South African Medical Journal</i> , 96(3 Pt 2), 246					Yes				Determinants approach. Summary of A.S.A.P programme
MBewu, A. D. (2006). Welcome address: Rheumatic heart disease is a neglected disease of poverty requiring a multisectoral approach for control and eradication. <i>South African Medical Journal</i> , 96(3), 231 - 232.					Yes				Need for multi-sectorial action to address upstream, midstream and downstream determinant of disease
McDonald, M. I., Bengler, N., Brown, A., Currie, B. J., & Carapetis, J. R. (2006). Practical challenges of conducting research into rheumatic fever in remote Aboriginal communities. <i>Medical Journal of Australia</i> , 184(10), 511-513.							Yes		Adherence audit - summary of key success factors - summary of findings of epidemiological study
McDonald, M., Brown, A., Noonan, S., & Carapetis, J. R. (2005). Editorial - preventing recurrent rheumatic fever: the role of register based programmes. <i>Heart</i> , 91, 1131 - 1133							Yes		Practice vs. guidelines review - summary of functions of register based programmes
McLaren, M., Markowitz, M., & Gerber, M. (1994). Rheumatic Heart Disease in Developing Countries: The Consequence of Inadequate Prevention. <i>Annals of Internal Medicine</i> , 120(3), 243-245.	Yes								Editorial summarising challenges of preventing and managing RHF in developing countries

Meira, Z., Mota, C. C. C., Tonell, E., Nunan, E., Marques, A., Mitre, C., et al. (1993). Evaluation of Secondary Prophylactic Schemes, based on Benzathine Penicillin G, for Rheumatic Fever in Children. <i>The Journal of Pediatrics</i> , 123, 156-158.	Yes								Serum concentrations taken of children receiving BPG to ascertain best practice dosing and frequency
Mincham, C. M., Mak, D. B., & Plant, A. J. (2002). The quality of management of rheumatic fever/heart disease in the Kimberley. <i>Australian and New Zealand Journal of Public Health</i> , 26(5), 417-420.						Yes			Practice vs. Guidelines review - retrospective review of clinical notes of patients in Kimberly Region, Australia, 1982 - 1996. Attendance and adherence against best practice guidelines.
Minister of Health. (2006). <i>Implementing the New Zealand Health Strategy 2006: The Minister of Health's sixth report on progress on the New Zealand Health Strategy</i> . Wellington: Ministry of Health.				Yes					Link to infectious diseases that need addressing to decrease health inequalities
Ministry of Health. (2001). <i>An Integrated Approach to Infectious Disease. Priorities for action 2002 - 2006</i> . Wellington: Ministry of Health				Yes					Link to infectious diseases that need addressing to decrease health inequalities
Mota, C. (2003). Rheumatic fever in the 21st century. <i>Cardiology in the Young</i> , 13(6), 491-494.	Yes								Editorial summarising reasons for international decline in rates of RHF, factors influencing the declines, areas of resurgence, and responsibilities for the future
National Heart Foundation of Australia, & Cardiac Society of Australia and New Zealand. (2006). <i>Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia - an evidence-based review</i> . : National Heart Foundation of Australia.					Yes				Australian National Guideline
National Heart Foundation of New Zealand and Cardiac Society of Australia and New Zealand. (2006). <i>New Zealand Guidelines for Rheumatic Fever 1. Diagnosis, Management and Secondary Prevention</i> . Wellington: National Heart Foundation of New Zealand, Cardiac Society of Australia and New Zealand.									New Zealand National Guideline

Neutze, J. (1988). Rheumatic fever and rheumatic heart disease in the western Pacific region. <i>New Zealand Medical Journal</i> , 101(847 (part 2)), 404-406		Yes							Review of RHF and RHD incidence and prevalence, reasons for recurrences, financial cost of RHF/RHD, and summary of community programmes
Newman, J., Lennon, D., & Wong-Toi, W. (1984). Patients with rheumatic fever recurrences. <i>New Zealand Medical Journal</i> , 97(765), 678-680.							Yes		A retrospective review of clinical records to evaluate the effectiveness of follow up clinics in preventing RHF recurrences. Identified reasons for recurrences and possible solutions
Nkgudi, B., Robertson, K. A., Volmink, J., & Mayosi, B. M. (2006). Notification of rheumatic fever in South Africa -- evidence for underreporting by health care professionals and administrators. <i>South African Medical Journal</i> 96(3), 206-208.							Yes		Practice vs. guidelines review - audit of notification data captured at a West Cape, South African hospital, local health department, provincial Department of Health and national Department of Health to ascertain whether under-notification of RHF occurs, and if so, at which levels
Nordet, P., Lopez, R., Duenas, A., & Sarmiento, L. (2008). Prevention and control of rheumatic fever and rheumatic heart disease: the Cuban experience (1986-1996-2002). [Evaluation Studies]. <i>Cardiovascular Journal of Africa</i> , 19(3), 135-140.							Yes		Programme audit - programme evaluation against the objectives of the Cuban experience
North, D. A., Heynes, R. A., Lennon, D. R., & Neutze, J. (1993). Analysis of costs of acute rheumatic fever and rheumatic heart disease in Auckland. <i>New Zealand Medical Journal</i> , 106(964), 400-403.		Yes							Direct costs of RHF to Auckland Area Health Board, and direct and intangible costs to patients
Omokhodion, S. I. (2006). Management of patients with rheumatic fever and rheumatic heart disease in Nigeria - need for a national system of primary, secondary and tertiary prevention. <i>South African Medical Journal</i> , 96(3), 237 - 239.					Yes				Need for improvements in living standards, and funding for infrastructure required for effective primary, secondary and tertiary services
Paar, J. A., Berrios, N. M., Rose, J. D., Cáceres, M., Peña, R., Pérez, W., et al. (2010). Prevalence of Rheumatic Heart Disease in Children and Young Adults in Nicaragua. <i>The American Journal of Cardiology</i> , 105(12), 1809-1814.	Yes								Observational community-based study from 2006 to 2009 of children in Leon to identify the prevalence of RHD in children and young adults.

Purchas, S. H., Wabitsch, K. R., Taikato, M. R., & Miles, M. (1984). Rheumatic fever and rheumatic heart disease at the Rotorua Hospital 1971-1982. <i>New Zealand Medical Journal</i> , 97(765), 675-678		Yes							RHF and RHD in Rotorua hospital 1971 - 1982. Success and constraining factors
Rice, M., & Kaplan, E. (1979). Rheumatic Fever in Minnesota II: Evaluation of Hospitalised Patients and Utilization of a State Rheumatic Fever Registry. <i>American Journal of Public Health</i> , 69(8), 767-771.							Yes		Practice vs. guidelines review - Minnesota, US study of medical records from 1975 - 1976 to assess the use of the Jones criteria for diagnosis, and the reporting/notification processes
Robertson, K. A., & Mayosi, B. M. (2008). Rheumatic heart disease: Social and economic dimensions. [Editorial]. <i>South African Medical Journal</i> , 98(10), 780 - 781.	Yes								Editorial summarising the global picture of RHF, links to poverty and the need for multi-pronged primary, secondary and tertiary strategies
Robertson, K. A., Volmink, J. A., & Mayosi, B. M. (2005). Lack of adherence to the national guidelines on the prevention of rheumatic fever. <i>South African Medical Journal</i> , 95(1), 52-56							Yes		Practice vs. guidelines review - conducted interviews with patients/cases and physicians and gathered statistics from disease notification data in the Cape Metropole area of South Africa. Assessed data against the priority issues in the national guidelines
Robertson, K. A., Volmink, J. A., & Mayosi, B. M. (2006). Towards a uniform plan for the control of rheumatic fever and rheumatic heart disease in Africa - the Awareness Surveillance Advocacy Prevention (A.S.A.P.) Programme. <i>South African Medical Journal</i> , 96(3), 241 - 245.							Yes		Programme audit - programme evaluation against the objectives of the ASAP programme in South Africa
Sanyal, S., Berry, A., Duggal, S., Hooja, V., & Ghosh, S. (1982). Sequelae of the initial attack of acute rheumatic fever in children from north India. A prospective 5-year follow-up study. <i>Circulation</i> , 65(2), 375-379.	Yes								Prospective 5 year follow up study conducted in North India conducted to identify the sequelae of the initial attack of ARF
Spinetto, H., Lennon, D., & Horsburgh, M. Control of Rheumatic Fever Recurrences in Auckland, New Zealand: Questions Answered. <i>Journal of Paediatric and Child Health</i> , (in press).								Yes	Audit of recurrences in Auckland. Delivery of prophylaxis - challenges and solutions

Steer, A. C., Carapetis, J. R., Nolan, T. M., & Shann, F. (2002). Systematic review of rheumatic heart disease prevalence in children in developing countries: the role of environmental factors. [see comment]. <i>Journal of Paediatrics & Child Health</i> , 38(3), 229-234.	Yes								Systematic review of RHD prevalence. Identification of environmental factors.
Steer, A. C., Kado, J., Jenney, A. W., Batzloff, M., Waqatakirewa, L., Mulholland, E. K., et al. (2009). Acute rheumatic fever and rheumatic heart disease in Fiji: prospective surveillance, 2005-2007. [Research Support, N.I.H., Extramural]. <i>Medical Journal of Australia</i> , 190(3), 133-135.	Yes								Prospective enhanced surveillance study conducted in Suva, Fiji between 2005 and 2007 to determine incidence and clinical features of ARF and RHD
Stewart, T., McDonald, R., & Currie, B. (2005). Use of the Jones Criteria in the diagnosis of acute rheumatic fever in an Australian rural setting: [Outbreaks! diseases.]. <i>Australian and New Zealand Journal of Public Health</i> , 29(6), 526-529							Yes		Practice vs. guidelines review - use of Jones criteria. Retrospective review of discharge data in medical records from Katherine hospital between 2000 and 2004
Stewart, T., McDonald, R., & Currie, B. (2007). Acute rheumatic fever: adherence to secondary prophylaxis and follow up of Indigenous patients in the Katherine region of the Northern Territory. <i>Aust J Rural Health</i> , 15(4), 234-240.							Yes		Adherence Audit - injections and clinic attendance. Retrospective review of medical records in the Katherine District
Strasser, T. (1985). Cost-effective control of rheumatic fever in the community. <i>Health Policy</i> , 5, 159-164.							Yes		Financial analysis. Assessment of impact of socio-economic conditions, prevention strategies and hospitalisation costs
Talbot, R. G. (1984). Rheumatic fever and rheumatic heart disease in the Hamilton health district: II. Long term follow-up and secondary prophylaxis. <i>New Zealand Medical Journal</i> , 97(764), 634-637.				Yes				Yes	NZ RHF epidemiology, secondary prophylaxis and follow up in Hamilton Health District, reasons for recurrent attacks, need for differentiated approaches
Talbot, R. G. (1988). Rheumatic fever in the Hamilton health district: a nine year prospective study. <i>New Zealand Medical Journal</i> , 101(847 Pt 2), 406-408.		Yes						Yes	A nine year prospective study with current cases of RHF in the Hamilton District. Tracking of their demographics, reasons for recurrence, and suggestions for further study

Thornley, C., McNicholas, A., Baker, M., & Lennon, D. (2001). Rheumatic fever registers in New Zealand. <i>New Zealand Public Health Report</i> , 8(6), 41 - 44.				Yes				Yes	Report of 1995 - 2000 ARF rates in NZ. Survey of register-based prevention programmes in NZ. Best practice guidance on such programmes and effective evaluation
Tibazarwa, K. B., Volmink, J. A., & Mayosi, B. M. (2008). Incidence of acute rheumatic fever in the world: a systematic review of population-based studies. [Research Support, Non-U.S. Gov't Review]. <i>Heart</i> , 94(12), 1534-1540.	Yes								Systematic review incidence of ARF from 10 international studies. Identified need for further study, registers and population - based control programmes
Wabitsch, K. R., Prior, I. A., Stanley, D. G., & Pearce, N. (1984). New Zealand trends in acute rheumatic fever and chronic rheumatic heart disease 1971-1981. <i>New Zealand Medical Journal</i> , 97(763), 594-597.		Yes							Review of NZ Health statistics reports, hospital and morbidity data using ICD codes and demographic data to identify morbidity and mortality trends in NZ for acute RHF and chronic RHD.
White, H., Walsh, W., Brown, A., Riddell, T., Tonkin, A., Jeremy, R., et al. (2010). Rheumatic Heart Disease in Indigenous Populations. <i>Heart, Lung and Circulation</i> , 19(5-6), 273-281	Yes	Yes			Yes				Summary of Australian and NZ RHF programmes and tertiary treatment services. Challenges, barriers and success factors identified
Wilson, N. (2010). Rheumatic Heart Disease in Indigenous Populations- New Zealand Experience. <i>Heart, Lung and Circulation</i> , 19(5-6), 282-288.		Yes							Epidemiology; summary of primary prevention, secondary prevention, tertiary treatment and RHD screening
Working Group on Pediatric Acute Rheumatic Fever and Cardiology Chapter of Indian Academy of Pediatrics, Saxena, A., Kumar, R., Gera, R., Radhakrishnan, S., Mishra, S., et al. (2008). Consensus guidelines on pediatric acute rheumatic fever and rheumatic heart disease. <i>Indian Pediatrics</i> , 45(7), 565 - 573.			Yes						Indian guidelines - clinical guidelines on paediatric RHF and RHD
World Health Organisation. (1992). WHO programme for the prevention of rheumatic fever/rheumatic heart disease in 16 developing countries: report from Phase 1 (1986 - 90). <i>Bulletin of the World Health Organisation</i> , 70(2), 213 - 218.							Yes		Programme audit - programme evaluation against the objectives of the WHO programme Phase 1

World Health Organisation. (2004). <i>Rheumatic fever and rheumatic heart disease: report of a WHO expert consultation</i> . Geneva			Yes						Progress report since the last one in 1988. Updating epidemiology and evaluation of current programmes and at risk populations
World Health Organization. (2000). <i>The WHO Global Programme for the Prevention of Rheumatic Fever and Rheumatic Heart Disease: Report of a Consultation to Review Progress and Develop Future Activities 29 November-1 December 1999</i> . Geneva: World Health Organization							Yes		Programme audit - progress report against programme objectives, and recommendations for practice
World Health Organization. (2005). <i>A Review of the Technical Basis for the Control of Conditions Associated with Group A Streptococcal Infections</i> . Geneva: World Health Organization.							Yes		Practice vs. guideline review - review of best practice guidance for primary, secondary and tertiary prevention, against local initiatives

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THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

The University of Auckland
Private Bag 92019
Auckland

**Recruitment Letter for Rheumatic Fever
Research**

<Date>

To < >

Re: Assistance in identification and recruitment of staff to participate in Masters Research

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

My name is Michelle Hooker. I am a Registered Nurse completing a Masters of Health Sciences at the University of Auckland. I work for the Waikato District Health Board (DHB) as a Clinical Support Coordinator in Population Health. As part of my role, I coordinate the Rheumatic Fever (RHF) activities for Population Health, and the wider DHB.

The research I am conducting will follow a three phased process:

1. An audit of Episurv notification data for all 21 DHB's will be conducted against seven of the standards of the NZ guidelines for RHF
2. The remainder of the standards of the guidelines will be audited by a survey with RHF coordinators to identify the extent to which the NZ guidelines for RHF are being met throughout NZ and what gaps in services exist. This should take participants 30 – 60 minutes to complete.
3. Thirdly, qualitative interviews with a smaller sub-group of the participants will explore the challenges in meeting the guidelines and how they can be addressed in order to provide targetted services for the at-risk populations. This phase requires approximately 60 minutes of participants time to conduct the interview – either by phone or face-to-face.

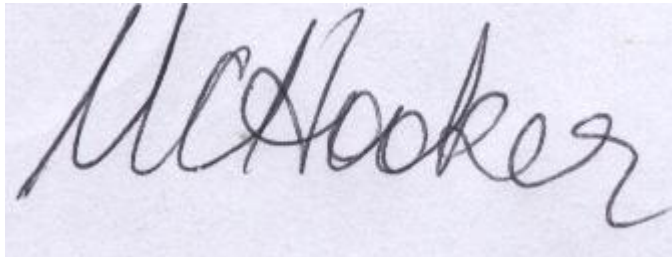
This letter is to ask for your assistance in this research by identifying the most appropriate person in your DHB to participate in this research. Naturally, if you have a Rheumatic Fever Co-ordinator, this person would be most appropriate. But if you do not, the potential participant should have a good overview of the rheumatic fever activities from the diagnosis of RHF to the long term community follow-up. They may need to rely on existing networks to assist if they do not span this continuum.

Upon identification of the potential participant, could you assist in recruitment by approaching this person and forwarding the attached information sheet, consent

form and letter of information for participant's manager/research body to them? I will contact all Medical Officers of Health within two weeks of this letter to follow up with the recruitment process.

If you have any questions or require further information regarding this research project, please contact me or my supervisors. An expedited ethics review was considered by the Chairperson of the Multi-region Ethics Committee and approved on 11/03/10. For a copy of the review, contact Michelle on the details below.

Thank you for your support in this research

A handwritten signature in black ink on a light-colored background. The signature is cursive and appears to read 'Michelle Hooker'.

Michelle Hooker
Registered Nurse
Clinical Support Coordinator
Population Health
Waikato DHB

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NEW ZEALAND

Information Sheet: Rheumatic Fever Coordinators

The University of Auckland
Private Bag 92019
Auckland

Research Student: My name is Michelle Hooker. I am a Registered Nurse carrying out a Masters of Health Sciences at the University of Auckland. I work for the Waikato District Health Board (DHB) as a Clinical Support Coordinator in Population Health. As part of my role, I coordinate the Rheumatic Fever (RHF) activities for Population Health, and the wider DHB.

Your <role eg MOH> was approached, and identified you as either the DHB's RHF coordinator or the most appropriate person to be able to participate in this study. I would like to invite you to be a part of this research project. This would involve completing a survey and for a smaller group, some will be asked to participate in an interview. These will be conducted between April and August 2010.

The Study and Participants

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

The aims of this study are:

- to audit current practice and services from local RHF programmes and initiatives within NZ's 21 DHB's against the NZ Guidelines for RHF
- to identify the challenges for clinicians in meeting the guidelines
- to make recommendations for highly targeted public health interventions to reduce inequalities based on the concentrated at-risk populations

In order to meet these aims, this research is in three parts. Firstly, an audit of Episurv notification data for all 21 DHB's will be conducted against seven of the standards of the NZ guidelines for RHF. Secondly, the remainder of the standards of the guidelines will be audited by surveying the RHF coordinators to identify the extent to which the NZ guidelines for RHF are being met throughout NZ and what gaps in services exist. Thirdly, interviews will explore the challenges in meeting the guidelines and how they can be addressed .

Your participation in this research will involve you firstly completing the survey. This should take 30 to 60 minutes to complete. You will be asked to rate your DHB's achievement of the standards set out in the New Zealand Guidelines for RHF and identify any resulting service gaps. It may require you forwarding specific questions to appropriate representatives to assist in answering any questions which you cannot answer as they relate to other services from your own.

Some participants will be re-interviewed to explore the challenges, barriers and opportunities faced when meeting the guidelines. The interview will take approximately an hour and will be tape recorded.

Benefits and Risks

Your participation in this study provides an opportunity for you and your DHB to share the lessons learnt in implementing the guidelines. In doing so, other DHB's can consider the potential to apply them to their DHB to provide optimal care and improved outcomes for their RHF community.

Ultimately, the practical utilisation of this research will see stronger ties amongst the RHF research community, further development of the evidence-based research collection, more targeted RHF services aimed at reducing inequalities based on the concentrated at-risk populations, and effective decreases in RHF related morbidity and mortality throughout New Zealand.

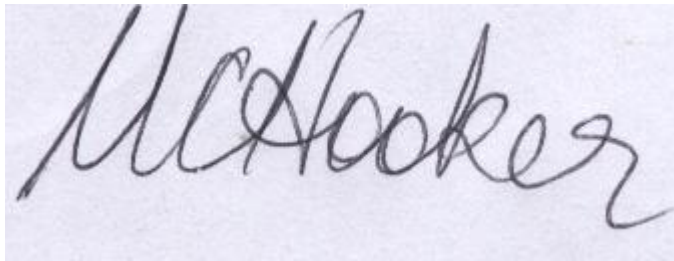
The main risk of participating in this study is the potential repercussions if participants report gaps in meeting the guidelines and service standards. Participants may feel threatened by those they are representing in their DHB, and they may feel judged by others in the wider RHF community throughout the country. This study is not being conducted to pass judgement or compare and contrast one DHB against another. Each DHB faces their own unique challenges, which this study looks to explore. The stories of these lessons learnt and the initiatives implemented will be shared amongst the RHF community and will inform recommendations for public health interventions which focus on the specific needs of the RHF communities throughout NZ.

Confidentiality

The identity of the participants and the name of the DHB will remain anonymous. Limited details of the general demographics of the DHB will need to be given, making the DHB potentially identifiable. This is done so that readers are able to assess the application of the learnings from similar DHB's in relation to their local situation.

The tapes used for the interviews will be stored, along with the completed surveys and the interview transcripts in a locked filing cabinet at the investigators place of work. The tapes, transcripts and surveys will be kept secured for six years in this location before destruction.

Thank you for considering this invitation to participate in this study. If you are happy to participate, please sign the consent form and return to Michelle via the contact details on the consent form. If you choose to consent, please feel free to forward the Letter of Information for Participant's Manager/Research Body to the appropriate personnel to explain your involvement in this research. Please contact me or my supervisors if you have any questions or require further information regarding this research project.



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Clinical Support Coordinator
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Ethical Approval: An expedited ethics review was considered by the Chairperson of the Multi-region Ethics Committee and approved on 11/03/10. For a copy of the review, contact Michelle on the details above.

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Consent to Participate

The University of Auckland
Private Bag 92019
Auckland

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

Research Student: Michelle Hooker, Masters Student and Registered Nurse, Clinical Support Coordinator, Population Health, Waikato District Health Board.

Please complete this consent form and return to Michelle Hooker either scanned by email: michelle.hooker@waikatodhb.health.nz, by post to PO Box 505 Hamilton or by fax to (07) 838 2389.

This consent form will be held in a secure place for six years before it is destroyed

- I have read and I understand the information sheet for volunteers taking part in this study
- I have had an opportunity to ask questions and have had them answered
- I understand that I am free to withdraw consent at any time during this project
- I will not have to give any reasons if I wish to withdraw
- I understand that the interview will be tape recorded
- I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study
- I understand that the name of my DHB will remain confidential, but limited demographic details will be reported, making it potentially identifiable

I consent to complete the survey Yes

I consent to participate in an interview (if required) Yes

Signed: _____

Date: _____

Name: _____
(Please print clearly)

Designation: _____

Contact Details: _____
(Please include work area and two phone contact numbers)

Ethical Approval: An expedited ethics review was considered by the Chairperson of the Multi-region Ethics Committee and approved on 11/03/10. For a copy of the review, contact Michelle on the details above.

SCHOOL OF NURSING

Faculty of Medical & Health Sciences



The University of Auckland
Private Bag 92019
Auckland

**Letter of Information for Participant's
Manager/Research Body**

<Date>

To Whom It May Concern

Re: Staff participation in Masters Research

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

My name is Michelle Hooker. I am a Registered Nurse completing a Masters of Health Sciences at the University of Auckland. I work for the Waikato District Health Board (DHB) as a Clinical Support Coordinator in Population Health. As part of my role, I coordinate the Rheumatic Fever (RHF) activities for Population Health, and the wider DHB.

I have approached your DHB's <role> to identify either your DHB's RHF coordinator or the most appropriate person to be able to participate in this study. This letter is to inform you of the nature and requirements of the study and to invite you to make any further inquiries into the research your staff member has been asked to participate in.

This research will follow a three phased process:

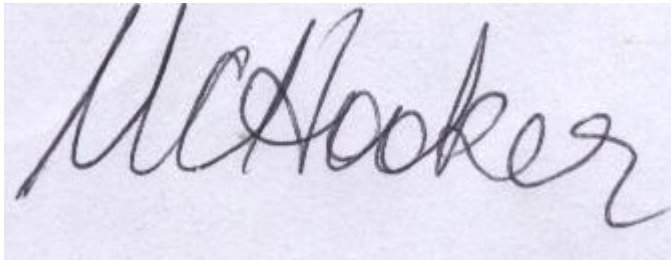
1. A quantitative audit of Episurv notification data for all 21 DHB's will be conducted against seven of the standards of the NZ guidelines for RHF
2. The remainder of the standards of the guidelines will be audited by a survey with RHF coordinators to identify the extent to which the NZ guidelines for RHF are being met throughout NZ and what gaps in services exist. This should take participants 30 – 60 minutes to complete.
3. Thirdly, interviews with a smaller sub-group of the participants will explore the challenges in meeting the guidelines and how they can be addressed in order to provide targetted services for the at-risk populations. This requires approximately 60 minutes of participants time to conduct the interview – either by phone or face-to-face.

The surveys and interviews will be conducted between April and August 2010.

Please contact me or my supervisors if you have any questions or require further information regarding this research project. If you would like to receive a copy of the participant information sheet, consent form, survey tool, interview schedule, the

research proposal or multi-region expedited ethics approval letter please contact me on the details below.

Thank you for your support in this research

A photograph of a handwritten signature in black ink on a light-colored background. The signature is cursive and reads "Michelle Hooker".

Michelle Hooker
Registered Nurse
Clinical Support Coordinator
Population Health
Waikato DHB

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HAMILTON
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(07) 838 2569 x2026
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Supervisors:

Robyn Dixon
Associate Professor
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Diana Lennon
Professor
School of Population Health

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Grafton
Auckland
Ph: (09) 923 7388
Email: r.dixon@auckland.ac.nz

Appendix 6: Standards and Scores

Standards and Scores (each standard rated out of 10)

Episurv Data:

- | | |
|--|------|
| 1. Diagnosis of ARF/recurrence according to Jones criteria | x/10 |
| 2. Distinction of recurrence or ARF | x/10 |
| 3. Admission to hospital | x/10 |
| 4. Case entered onto register | x/10 |
| 5. Arrangements made for delivery of prophylaxis | x/10 |
| 6. Case under specialist care | x/10 |
| 7. Case's dentist advised of condition | x/10 |

Register Data:

- | | |
|--|------|
| 8. Possession of a local register | x/10 |
| 9. Functions of the register | x/10 |
| 10. Allocation of dedicated register coordinator | x/10 |
| 11. Service that manages the register | x/10 |
| 12. Services that can access the register | x/10 |
| 13. Frequency of updating the register | x/10 |

Questionnaire:

- | | |
|--|------|
| 14. Contact tracing for household members of an acute case of RHF | x/10 |
| 15. Accurate distinction of RHD | x/10 |
| 16. Appropriate use of echocardiography for diagnosis and review | x/10 |
| 17. Ten day course of penicillin given upon diagnosis | x/10 |
| 18. First injection of penicillin administered in hospital | x/10 |
| 19. Notification to public health | x/10 |
| 20. Uninterrupted delivery of injections for ARF every 28 days | x/10 |
| 21. Uninterrupted delivery of injections for recurrent RHF every 21 days | x/10 |
| 22. Appropriate duration of prophylaxis | x/10 |
| 23. Regular and appropriate education conducted | x/10 |
| 24. Routine out-patient review | x/10 |
| 25. Opportunistic care provided | x/10 |
| 26. Medium to high risk patients receive appropriate vaccinations | x/10 |
| 27. Rheumatic heart disease patients have 6 monthly dental reviews | x/10 |
| 28. Process in place for transferring patients to another DHB | x/10 |
| 29. Case finding surveillance and screening activities | x/10 |
| 30. Gaps in services (listed) | x/10 |

Appendix 7: Register Data Check

SCHOOL OF NURSING
Faculty of Medical & Health Sciences



Data Check for Register Information

The University of Auckland
Private Bag 92019
Auckland

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

A recent report investigating a national register was drafted in December 2009 (C. Jackson & Lennon, 2009). As part of the consultation, each District Health Board was asked to respond to a set of questions regarding their local register (if one exists).

For the purposes of this research, data from that report was used to audit the following six standards of the New Zealand guidelines for Rheumatic Fever:

1. Possession of a local register
2. Functions of the register
3. Allocation of a dedicated register coordinator
4. The service that manages the register
5. The services that can access the register
6. Frequency of updating the register

The following tables reflect the data from that report for your DHB:

1. Does your DHB hold a regional register? Y/N	2. What is its function?	Data Storage Y/N	Prescription generation Y/N	Coordination of information between services Y/N	Coordination of community based prophylaxis delivery Y/N	Accumulation of data for evaluation Y/N	Other (list)	3. Is there a dedicated register coordinator? Y/N	3a. If yes, what is their designation? (tick one of the following)	Administrator	Nurse	Doctor	Other - please specify

4. What service manages the register?	Public Health Y/N	Primary Health Organisation Y/N	Hospital Based Y/N	Community Based Y/N	Other (list)	5. What RHF related services are coordinated from the register?	Out patient clinics - Y/N	Hospital inpatients - Y/N	Dental Services - Y/N	GP services - Y/N	Community provider of injections - Y/N	Public Health - Y/N	Other (please specify)

6. How often is it updated? (tick or specify)	biannually	annually	no set timeframe	other (specify)

Do you consider this to be an accurate account of your DHB's register? Y N

If no, please explain why not or make changes on the tables:

Appendix 8: Questionnaire

SCHOOL OF NURSING
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The University of Auckland
Private Bag 92019
Auckland

Survey of Practice

Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

Instructions for completing this survey

Please complete all questions on both sides of each page. Each question has instructions on whether to tick one answer which best reflects your DHB's practice, or to tick as many answers as required.

When completed, please return your survey in the self-addressed envelope provided by 30 April 2010. If you have any issues with completing the survey, please contact Michelle Hooker on the details in the information sheet.

Overview of Services and Processes

A. In your DHB who makes the diagnosis of acute rheumatic fever/recurrence? (please select as many as required)

- GP
- Emergency Department Physician
- General Medical Physician
- Paediatrician
- Cardiologist
- Other (please specify below)

In the hospital setting, please specify what level of physician makes that diagnosis: (please select as many as required):

- Consultant
- Registrar
- House Surgeon
- Other (please specify below)

B. In your DHB who makes the notification of acute rheumatic fever/recurrence to public health? (please select as many as required)

- GP
- Emergency Department Physician
- General Medical Physician
- Paediatrician
- Cardiologist
- Nurse
- Receptionist
- Other (please specify below)

In the hospital setting, please specify what level of physician or nurse makes that notification: (please select as many as required):

- Consultant
- Registrar
- House Surgeon
- Clinical Nurse Manager
- Clinical Nurse Specialist
- Staff Nurse
- Other (please specify below)

C. In your DHB who makes the referral for community prophylaxis? (please select as many as required)

- GP
- Emergency Department Physician
- General Medical Physician
- Paediatrician
- Cardiologist
- Register Coordinator
- Nurse
- Receptionist
- Other (please specify below)

In the hospital setting, please specify what level of physician or nurse makes that referral: (please select as many as required)

- Consultant
- Registrar
- House Surgeon
- Clinical Nurse Manager
- Clinical Nurse Specialist
- Staff Nurse
- Other (please specify below)

D. In your DHB, who generally delivers the community prophylaxis programme: (please select as many as required)

- GP
- District Nurse
- Public Health Nurse
- Other (please specify below)

E. In your DHB, what service conducts on-going out-patient clinical review? (please select as many as required)

- GP
- Hospital based out-patient paediatric/cardiology clinics
- Hospital based designated rheumatic fever out-patient clinics
- Other (please specify below)

Survey of Practice

1. Contact Tracing

1a. Is contact tracing for household members of an acute case of rheumatic fever conducted in your DHB?

- Yes (please answer questions 1b, 1c and 1d)
- No (continue to question 2a)

1b. If yes, what is the process? (please select one)

- Contact tracing conducted by public health service, identifying all household contacts, swabbing and offering antibiotic treatment if positive.
- Contact tracing conducted by public health, offering all household contacts antibiotic treatment (no swabbing).

(continued over page)

- All household contacts referred to their GP for swabbing and appropriate treatment.
- Other (please specify below)

1c. If yes, in what percentage of all cases notified is this contact tracing process initiated? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

1d. Are antibiotics offered free to all contacts with a positive throat swab?

- Yes
- No

2. Accurate Distinction of Rheumatic Heart Disease (RHD)

2a. If a newly diagnosed case of RHF also presents with RHD, is their RHD status clearly documented in discharge letter/notification form/clinical notes? (please select one)

- Never Occasionally Sometimes Often Always

2b. If an existing case of RHF subsequently develops RHD is their RHD status clearly documented in clinic letter/clinical notes? (please select one)

- Never Occasionally Sometimes Often Always

3. Echocardiography

3a. Please read algorithm 2. According to this, is echocardiography used appropriately as a diagnostic tool in acute presentations of RHF? (please select one)

- Never Occasionally Sometimes Often Always

3b. For medium and high risk cases, are echocardiographs performed with every cardiologist/physician/paediatrician review? (please select one)

- Never Occasionally Sometimes Often Always

4. Ten Day Course of Oral Penicillin V

4a. Upon diagnosis of RHF, what percentage of cases receive a ten day course of oral penicillin V? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

5. First Injection Administered in Hospital

5a. In what percentage of all new cases of RHF is the first injection of Bicillin administered in hospital prior to discharge? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

6. Cases Notified to Public Health

6a. What percentage of the population of newly diagnosed patients would you estimate are not notified to public health? (please select one)

- 0 - 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

7. Injections Every 28 Days

7a. What proportion of your existing RHF patients would achieve the standard of receiving the appropriate dose of Bicillin injection every 28 days on an ongoing basis? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

8. Recurrent Cases Receiving BPG IM Every 21 Days

8a. What proportion of your existing patients who have confirmed recurrent RHF despite full adherence to 4-weekly prophylaxis, would achieve the standard of receiving the appropriate dose of Bicillin injection every 21 days on an ongoing basis? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

9. Appropriate duration of prophylaxis

9a. Please read algorithm 3. According to this, what percentage of your patients receive their prophylaxis for the appropriate duration of time? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

10. Education Sessions by Community Provider

10a. How often are education sessions conducted with patients? (please select one)

- Education sessions not conducted (continue to question 11)*
 No Specified Frequency
 Monthly
 Annually
 Other (please specify below)

10b. Who conducts the education sessions? (please select as many as required)

- DN
- PHN
- GP
- Clinic Physician
- Other (please specify below)

10c. What information is provided in education sessions? (please select as many as required)

- The cause and complications of RHF*
- The reason for secondary prophylaxis and the signs and symptoms of recurrence*
- The prevention of endocarditis and the differences between this and secondary prophylaxis of RHF*
- Sore throat management*
- The importance of medical and dental follow-up*
- How to contact the relevant people or agencies should they need further information or assistance*
- Other (please specify below)

10d. What proportion of patients receive regular education? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

11. Routine Review

11a. Does your DHB have a standard for routine RHF follow up? (please select one)

- Yes (please answer questions 11b, 11c and 11d)
- No (continue to question 11e)

11b. If yes, which standard best represents your out-patient services for low risk cases and how often does this occur? (please select one)

- | Outpatient Service Standard | Frequency of selected outpatient standard |
|--|--|
| <input type="radio"/> GP follow up with echocardiography | <input type="radio"/> Six monthly |
| <input type="radio"/> GP follow up without echocardiography | <input type="radio"/> Annually |
| <input type="radio"/> Clinic review with echocardiography | <input type="radio"/> Every two years |
| <input type="radio"/> Clinic review without echocardiography | <input type="radio"/> Other (please specify below) |
| <input type="radio"/> Other (please specify below) | |

11c. If yes, which standard best represents your out-patient services for medium/high risk cases and how often does this occur? (please select one)

Outpatient Service Standard

- GP follow up with echocardiography
- GP follow up without echocardiography
- Clinic review with echocardiography
- Clinic review without echocardiography
- Other (please specify below)

Frequency of selected outpatient standard

- Six monthly
- Annually
- Every two years
- Other (please specify below)

11d. For medium to high risk cases, what proportion are seen in out-patient services, with an echocardiograph every 2 years? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

11e. For those not seen, what are the reasons? (please select as many as required)

- Unknown*
- Did not attend
- Unavailability of clinic appointments
- Unavailability of echo
- Unavailability of clinicians
- Lost in transition from paediatric to adult services
- Other (please specify below)

12. Opportunistic Care

12a. In reference to p27 of the guidelines, is your DHB currently doing any opportunistic care either in inpatient or outpatient services? (please select one)

- Yes (please answer question 12b)
- No (please continue to question 13)

12b. If yes, what opportunistic care is offered? (please select as many as required)

- Promotion of a healthy diet
- Promotion of exercise
- Promotion of good hygiene
- Assistance with socio-economic stressors
- Opportunistic immunisation
- Other (please specify below)

13. Vaccinations

13a. For those medium to high risk patients, what proportion receive annual influenza vaccination? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

13b. For those medium to high risk patients, what proportion receive 5 yearly pneumococcal vaccination? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

14. Six Monthly Dental Review

14a. What percentage of patients with RHD are given six monthly dental reviews? (please select one)

- 0- 20% 21 - 40% 41 - 60% 61 - 80% 81 - 100%

15. Process for Transfer out of DHB

15a. What is your process for patients transferring out of your DHB? (please select as many as required)

- No existing process
 DN/PHN refers to new DN/PHN
 Clinic physician refers to new clinic physician/department/GP
 Referral letter given to patient to give to new hospital/GP
 Register to register referral
 Transfer via Episurv
 Other (please specify below)

16. Case Finding Surveillance and Screening Activities

16a. Does your DHB undertake any case finding surveillance? (please select one)

- Yes (please continue)*
 No (please continue to question 16c)

16b. If yes, what case finding surveillance occurs? (please select as many as required)

- Case finding surveillance by searching coded data*
 Case finding surveillance by reviewing echo reports
 Reviewing specialist correspondence
 Reviewing primary health care information
 Other (please specify below)

16c. Does your DHB undertake any screening activities? (please select one)

- Yes (please continue)*
- No (please continue to question 17)*

16d. If yes, what screening occurs? (please select as many as required)

- School based screening for RHD using cardiac auscultation*
- School based screening for RHD using echocardiography*
- Community screening programme for RHD using cardiac auscultation*
- Community screening programme for RHD using echocardiography*
- Other (please specify below)*

16e. If you find new cases, what is their pathway of care? (please select as many as required)

- No existing process*
- Notification to public health*
- Referral to GP*
- Referral to clinic physician*
- Admission to hospital*
- Other (please specify below)*

17. Gaps in Service

17a. Reflecting on these standards from the guidelines, what gaps in services do you think your DHB has? (please list below - this may be bullet pointed. Please use next page if required)

--

Participant Name:

Participant DHB:

These details will not be included in the research. They are for the researchers use only to contact and link to, if required, for qualitative interview.

Appendix 9: Scoring System

Survey of Practice

1. Contact tracing.

- a. Is contact tracing for household members of an acute case of rheumatic fever conducted in your DHB? Yes/No **1pt Yes**
- b. If yes, what is the process (please tick or comment):
 - Contact tracing conducted by public health service, identifying all household contacts, swabbing and offered antibiotic treatment if positive? **2pts**
 - Contact tracing conducted by public health, offering all household contacts antibiotic treatment (no swabbing)? **1pt**
 - All household contacts referred to their GP for swabbing and appropriate treatment? **1pt**
 - Other **1pt**
- c. If yes, is this contact tracing process initiated:
0– 20% **1** 21 – 40% **2** 41 – 60% **3** 61 – 80% **4** 81 – 100% **5** of all cases notified?
- d. Are antibiotics offered free to all contacts with a positive throat swab?
Yes/No **2 pts Yes**

2. Accurate distinction of Rheumatic Heart Disease (RHD)

- a. If a newly diagnosed case of RHF also presents with RHD, is their RHD status clearly documented in discharge letter/notification form/clinical notes:
Never **1**, seldom **2**, sometimes **3**, often **4**, always **5**
- b. If an existing case of RHF subsequently develops RHD, is their RHD status clearly documented in discharge letter/notification form/clinical notes:
Never **1**, seldom **2**, sometimes **3**, often **4**, always **5**

3. Echocardiography

- a. Please read algorithm 2. According to this, is echocardiography used appropriately as a diagnostic tool in acute presentations of RHF?
Never **1**, seldom **2**, sometimes **3**, often **4**, always **5**
- b. For medium and high risk cases, are echocardiographs performed with every cardiologist/physician/paediatrician review:
Never **1**, seldom **2**, sometimes **3**, often **4**, always **5**

4. 10 day course of oral penicillin V

- a. Upon diagnosis of RHF, what percentage of cases receive a ten day course of oral penicillin V?
0– 20% **2** 21 – 40% **4** 41 – 60% **6** 61 – 80% **8** 81 – 100% **10**

5. First injection administered in hospital

- a. In what percentage of all new cases of RHF is the first injection of Bicillin administered in hospital prior to discharge?
0– 20% **2** 21 – 40% **4** 41 – 60% **6** 61 – 80% **8** 81 – 100% **10**

6. Case notified to public health

- a. What percentage of the population of newly diagnosed patients would you estimate are not notified to public health:
0– 20% **10** 21 – 40% **8** 41 – 60% **6** 61 – 80% **4** 81 – 100% **2**

7. Injections every 28 days

- a. What proportion of your existing RHF patients would achieve the standard of receiving the appropriate dose of Bicillin injection every 28 days on an ongoing basis?
0– 20% **2** 21 – 40% **4** 41 – 60% **6** 61 – 80% **8** 81 – 100% **10**

8. Recurrent case receiving BPG IM every 21 days

- a. What proportion of your existing patients who have confirmed recurrent RHF despite full adherence to 4-weekly prophylaxis, would achieve the standard of receiving the appropriate dose of Bicillin injection every 21 days on an ongoing basis?
0– 20% **2** 21 – 40% **4** 41 – 60% **6** 61 – 80% **8** 81 – 100% **10**

9. Appropriate duration of prophylaxis

- a. Please read algorithm 3. According to this, what percentage of your patients receive their prophylaxis for the appropriate duration of time:
0– 20% **2** 21 – 40% **4** 41 – 60% **6** 61 – 80% **8** 81 – 100% **10**

10. Education sessions by community provider

- a. How often are education sessions conducted with patients?
(please select one)?

- Education sessions not conducted
- No specified frequency
- Monthly **1**
- Annually **1**
- Other

- b. Who conducts the education sessions? **1pt for selecting any provider(s)**
(please select as many as required)

- DN
- PHN
- GP
- Clinic Physician
- Other

- c. What information is provided in education sessions? **½ pt each tick - /3**

- The cause and complications of RHF
- The reason for secondary prophylaxis and the signs and symptoms of recurrence
- The prevention of endocarditis and the differences between this and secondary prophylaxis of RHF
- Sore throat management
- The importance of medical and dental follow-up
- How to contact the relevant people or agencies should they need further information or assistance
- Other

- d. What proportion of patients receive regular education
0– 20% **1** 21 – 40% **2** 41 – 60% **3** 61 – 80% **4** 81 – 100% **5**

11. Routine review

- a. Does your DHB have a standard for routine RHF follow up? Yes/No **1pt Yes**
b. If yes, which standard best represents your out-patient services for low risk cases and how often does this occur?

- GP follow up with echocardiography **1pt**
- GP follow up without echocardiography **1pt**
- Clinic review with echocardiography **1pt**
- Clinic review without echocardiography **1pt**
- Other (please specify)
Frequency **1 pt for anything selected under 5 yearly**
- Six monthly
- Annually
- Every two years
- Other (please specify):

- c. If yes, which standard best represents your out-patient services for medium/high risk cases and how often does this occur?
- GP follow up with echocardiography **1pt**
 - GP follow up without echocardiography **0pt**
 - Clinic review with echocardiography **1pt**
 - Clinic review without echocardiography **0pt**
 - Other (please specify)
- Frequency **1 pt for 6 – 24 mthly. 0 pts for anything over**
- Six monthly
 - Annually
 - Every two years
 - Other (please specify):
- d. For medium to high risk cases, what proportion are seen in out patient services, with an echocardiograph every two years?
0– 20% **1** 21 – 40% **2** 41 – 60% **3** 61 – 80% **4** 81 – 100% **5**
- e. For those not seen, what are the reasons:
(please tick appropriate box(s))
- Unknown
 - Did not attend
 - Unavailability of clinic appointments
 - Unavailability of echo
 - Unavailability of clinicians
 - Lost in transition from paediatric to adult services
 - Other (please list)

12. Opportunistic Care

- a. In reference to p27 of the guidelines, is your DHB currently doing any opportunistic care either in inpatient or outpatient services? Yes/No
- b. If yes, what opportunistic care is offered: **2 pts per tick /10**
- Promotion of a healthy diet
 - Promotion of exercise
 - Promotion of good hygiene
 - Assistance with socio-economic stressors
 - Opportunistic immunisation
 - Other (please list)

13. Vaccinations

- a. For those medium to high risk patients, what proportion receive annual influenza vaccination?
0– 20% **1** 21 – 40% **2** 41 – 60% **3** 61 – 80% **4** 81 – 100% **5**
- b. For those medium to high risk patients, what proportion receive 5 yearly pneumococcal vaccination?
0– 20% **1** 21 – 40% **2** 41 – 60% **3** 61 – 80% **4** 81 – 100% **5**

14. Six monthly dental review

- a. What percentage of patients with RHD are given six monthly dental reviews?
0– 20% **2** 21 – 40% **4** 41 – 60% **6** 61 – 80% **8** 81 – 100% **10**

15. Process for transfer out of DHB

- a. What is your process for patients transferring out of your DHB? **2pts per tick /10**
- No existing process **0pts**
 - DN/PHN refers to new DN/PHN
 - Clinic physician refers to new clinic physician/department/GP
 - Referral letter given to patient to give to new GP/Hospital
 - Register to register referral
 - Transfer via Episurv
 - Other (please list)

16. Case finding surveillance and screening activities

- a. Does your DHB undertake any current case finding surveillance? Yes/No **½ pt Y**
- b. If Yes, what case finding surveillance occurs? **1 pt per tick /4**
 - Case finding surveillance by searching coded data
 - Case finding surveillance by reviewing echo reports
 - Reviewing specialist correspondence
 - Reviewing primary health care information
 - Other (please describe)
- c. Does your DHB undertake any screening activities? Yes/No **½ pt Y**
- d. If Yes, what screening occurs: **1 pt per tick /4**
 - School based screening for RHD using cardiac auscultation
 - School based screening for RHD using echocardiography
 - Community screening programme for RHD using cardiac auscultation
 - Community screening programme for RHD using echocardiography
 - Other (please describe)
- e. If you find new cases, what is their pathway of care? **1pt if indicates pathway exists**
 - No existing process **0 pts**
 - Notification to public health
 - Referral to GP
 - Referral to clinic physician
 - Admission to hospital
 - Other

Register Scoring

1. Does your DHB hold a regional register? Y/N	Y = 10 pts
2. What is its function?	max 10pts
Data storage Y/N	Y = 2 pts
Prescription generation Y/N	Y = 2 pts
Coordinate information between services Y/N	Y = 2 pts
Coordinate community based prophylaxis delivery Y/N	Y = 2 pts
Accumulate data for evaluation Y/N	Y = 2 pts
Other (list)	
3. Is there a dedicated register coordinator? Y/N	Y = 10 pts
4. What service manages the register?	10 pts noting a service
5. What RHF related services are coordinated from the register?	x/10 2 pts per service
6. How often is it updated? (tick or specify)	10 pts if set timeframe indicated

Episurv Scoring

1. Accurate diagnosis	
Meets Jones criteria - Y x%	x/10
2. Distinction of recurrence or ARF	
Specified ARF or recurrence x%	x/5
Completion of Recurrence history x%	1/2 pts /2.5
Completion of recurrence protective factors x%	1/2 pts /2.5
3. Admission to hospital - Y x%	x/10
4. Entered onto register	
Recurrence - case on register - Y x%	x/5
ARF - placed on register - Y x%	x/5
5. Arrangements for prophylaxis - Y x%	x/10
6. Under specialist care - Y x%	x/10
7. Dentist advised - Y x%	x/10

SCHOOL OF NURSING
Faculty of Medical & Health Sciences



The University of Auckland
Private Bag 92019
Auckland

Participant Letter

12 May 2010

Dear

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

Thank you for volunteering to be part of my masters research.

Your participation in this research will involve you firstly completing the enclosed survey. This should take 30 to 40 minutes to complete. It asks you to rate your DHB's achievement of the standards set out in the New Zealand Guidelines for RHF and identify any resulting service gaps. It may require you forwarding specific questions to appropriate representatives to assist in answering any questions which you cannot answer as they relate to other services from your own.

The enclosed form entitled "Data Check for Register Information" presents six standards regarding local RHF registers that has been compiled for your DHB. Please read this form, check it for accuracy, make any necessary changes and return it with the completed survey in the stamped self-addressed envelope.

Once again, thank you for your participation in this research. Please do not hesitate to contact me with any queries.

Yours sincerely

A handwritten signature in black ink that reads 'Michelle Hooker'.

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Appendix 11: Episurv Data Check

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Data Check for Episurv Information

Research Title: Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide

Notification data was gathered from the Institute of Environmental Science and Research (ESR) for each of the 21 District Health Boards (DHB) for 2007, 2008 and 2009. It audits each DHB on the following seven standards in the Zealand guidelines for Rheumatic Fever (RHF):

4. Diagnosis of acute RHF/recurrence according to Jones Criteria
5. Arrangements made for delivery of prophylaxis (and to which occupation group)
6. Distinction of recurrence or acute RHF
6. Case under specialist care
6. Admission to hospital
7. Case's dentist advised of condition
7. Case entered onto register

The following tables reflect the data from your DHB:

Total Number of ARF cases (2007 – 2009)	Total Number of Recurrent Cases (2007 – 2009)	1. Accurate diagnosis	Meets Jones criteria Y x%	Incomplete field x%	2. Distinction of recurrence or ARF	Specified ARF or recurrence Y x%	Incomplete field x%	Completion of Recurrence history Y x%	Completion of recurrence protective factors Y x%

3. Admission to hospital Y x%	Incomplete field x%	4. Entered onto register	Recurrence - case on register Y x%	Incomplete field x%	ARF - placed on register Y x%	Incomplete field x%	5. Arrangements for prophylaxis Y x%	Incomplete field x%

Occupation group - PHN x%	Occupation group – Hospital based Nurse x%	Occupation group - other - specify x%	Occupation group not selected x%	6. Under specialist care - Y x%	Incomplete field x%	7. Dentist advised - Y x%	Incomplete field x%

As this data only reflects those cases notified on Episurv and may contain incomplete fields, do you consider this data to be an accurate reflection of your DHB's attainment of these seven standards of the guidelines? Y / N

If no, please circle the percentage range that better reflects your DHB's attainment of these standards:

Meets Jones criteria - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Specified ARF or recurrence - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Completion of Recurrence history - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Completion of recurrence protective factors -Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Admission to hospital - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Recurrence - case on register - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
ARF - placed on register - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Arrangements made for prophylaxis - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Occupation group - PHN - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Occupation group – Hospital based Nurse - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Occupation group - other - specify	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Under specialist care - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%
Dentist advised - Y	0 – 20%	21 – 40%	41 – 60%	61 – 80%	81 – 100%



Qualitative Interview Schedule

The following questions are to be asked in the interview with responses being recorded on tape and notes taken by interviewer.

1. What standards of the guidelines have been hard to meet?
2. Why do you think they have been hard to meet?
3. What standards of the guidelines have been easy to meet?
4. What has made them easy to meet?
5. What new initiatives has your DHB implemented to meet the standards of the guidelines and the needs of your populations?
6. What have been the key success factors of these initiatives?
7. If you were to offer a list of critical recommendations for targeted public health interventions to meet the needs of rheumatic fever patients in this area, what would it include?

Appendix 13: Thematic Matrix of Interview Findings

Themes	CONTEXTS OF PRACTICE AND POPULATION					
	Inpatient experience	Secondary prophylaxis	Clinics	Secondary services	Coordination between services	DHB/ national support
1. Challenges	<ol style="list-style-type: none"> 1. Inconsistent practice 2. Unfamiliarity with disease/guidelines 3. No consistent person with general oversight 4. Backtracking and constant education 	<ol style="list-style-type: none"> 1. Adult population – referrals between services, breaking continuity of care, access barriers 2. Mobile population – time consuming chasing – school leavers and adults 3. Interrupted supply of Bicillin 	<ol style="list-style-type: none"> 1. Inconsistent practice between clinicians 2. Unsupportive environments 3. Poverty related DNA's 4. Resource constraints 	<ol style="list-style-type: none"> 1. Access barriers to private practice – dental and GP 2. Funding/ resource limitations 3. Keeping up with new practice standards – no designated responsibility to oversee and translate into documents and processes 	<ol style="list-style-type: none"> 1. No key worker to coordinate between services 2. Lack of IT systems to pull together multiple data sources 	<ol style="list-style-type: none"> 1. Lack of DHB funding and prioritisation 2. Isolated pockets of activities 3. Duplication between DHB's 4. Lack of national leadership, coordination and direction
2. Success factors	<ol style="list-style-type: none"> 1. Familiarity 2. Clear processes & documents 3. Networks and communications between services 4. Experienced lead clinician 5. Team review 6. Smaller teams 7. Innate practice 	<ol style="list-style-type: none"> 1. Transition – community nurse visit in hospital 2. Small teams of experienced community nurses 3. Continuity of care 4. Relationships and networks 5. Home assessment on discharge then 	<ol style="list-style-type: none"> 1. Clinics held at local bases 2. Phone and text reminders by admin 3. Reminders by community support and nurses 4. Clinic nurse follow up after DNA to find out 	<ol style="list-style-type: none"> 1. Enthusiastic, experienced staff 2. Mobile, local services 3. Community projects led by community champions 4. Clear processes and connected communications 	<ol style="list-style-type: none"> 1. Actively managed by nurses 2. Team approach 3. Appropriate IT 4. Small size of teams within DHBs and specialists between DHB's for ease of referrals and communications 	<ol style="list-style-type: none"> 1. Historical DHB support developed by key champion 2. Consequential support and resourcing for new initiatives 3. Small numbers of RHF patients in NZ and small land mass to logistically coordinate a

		<p>annual review</p> <ol style="list-style-type: none"> 6. Nurse management and coordination between services 7. Delivered in appropriate environments 8. Flexible, holistic, responsive service 9. Team including local community workers of same ethnicity, and admin support 	<p>why and rebook</p> <ol style="list-style-type: none"> 5. Flexible appointment times 6. Joint/shared clinics 7. Multiple services in one visit 8. Clinic letters with clear plan and distributed to all carers 9. Supportive environments to foster family resilience 			national response
3. Opportunities & new initiatives	<ol style="list-style-type: none"> 1. Use of echo for all diagnoses 2. IT patient alerts 3. Regular paediatric team meetings 4. Inpatient and discharge checklist 	<ol style="list-style-type: none"> 1. Earlier planning and follow up to ensure injection given by 28 days 2. Recruitment of local community workers of similar ethnicity to patient population 3. Programme delivered in appropriate community settings 4. Family centred care, and team approach 5. automatic/nurse managed process for obtaining timely scripts 6. Dedicated, 	<ol style="list-style-type: none"> 1. Nurse, community worker and administrative reminders, including use of phone and text 2. Providing transport or linking into existing transport providers 3. Local clinics 4. Collaboration between services to enable one visit and multiple services 5. Shared/ concurrent/ designated/ clinics 	<ol style="list-style-type: none"> 1. Mobile dental services 2. Stationary dental clinic in low decile schools 3. School or public health nurses following up dental appointments 4. Formal dental processes, referrals and documentation 5. Echo screening programmes integrated with community awareness programmes 	<ol style="list-style-type: none"> 1. Collaboration with healthy housing projects 2. Opening up referral pathways and computer access to nurses 3. Instigation of regional RHF groups with key representatives 	<ol style="list-style-type: none"> 1. Provision of evidenced based reports for planning and funding 2. Lobbying DHB's

		<p>smaller, experienced team of nurses for continuity and expertise in delivery of injections</p> <p>7. Annual review conducted pre-winter for holistic assessment</p> <p>8. Annual team review of nurse/patient mix, challenges and learnings</p>				
4. Recommendations			<ol style="list-style-type: none"> 1. Provision of incentives/ petrol vouchers 2. Mobile echo for local clinics 3. More opportunistic services available for one clinic visit 	<ol style="list-style-type: none"> 1. Free dental and GP services 2. Free sustainable oral health programmes and resources 3. National media and communication programmes 4. Resourced education packages for health professionals and communities 5. Translated resources in appropriate media 6. Use of DVD/video and Maori Radio 7. Inclusion of RHF 	<ol style="list-style-type: none"> 1. Inter-ministry links to be made to address socio-economic determinants of health, particularly housing and household income 	<ol style="list-style-type: none"> 1. RHF onto DHB and Ministry agendas for action 2. Leadership and mandate to decrease inequalities, reduce barriers and provide measurable targets 3. National programme (like meningo) with package of resources, reporting targets and national media 4. Coordination of local activities,

				<p>in school curriculum</p> <p>8. Appropriately resourced and funded services</p> <p>9. Surveying Patients and families for their perspectives and suggestions</p>		<p>initiatives and processes at National level for standardisation, sharing an to reduce duplication</p> <p>5. Utilising existing structures, processes and personnel for widespread effect</p>
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