Advice for the Ministry of Health for Best Practice for Rheumatic Fever Control

Summary of International Workshop on Rheumatic Fever/Rheumatic Heart Disease Control in New Zealand

Funders: Ministry of Health
National Heart Foundation of New Zealand
AGREED AIM OF WORKSHOP:
To outline process to ensure the reduction of acute rheumatic fever rates in Maori and Pacific young people (5-14 years) to European/other levels by 2020.

Overarching Conclusion:
Published evidence supports that rheumatic fever in high risk populations in New Zealand can be reduced to that of low risk populations by 2020.
PURPLE HEART
When he was 14, Andrew Fiu was diagnosed with “flu” when in fact he had rheumatic fever. This is a disease endemic in Pacific Island (and Maori) communities that can lead to severe heart damage. Since that time he has had a record six open-heart surgeries, spending so much time in hospital that he virtually grew up there. This book is his story.

It is also the story of growing up Samoan in Auckland in the 1970’s and 1980’s.

A young mother with one child with rheumatic fever energised a small community. They had had 14 cases of rheumatic fever in 9 years. Sore throat clinics have abolished rheumatic fever in that community.

Helen Herbert
Whangaroa, Northland

In Starship Cardiology ward – 1 week in July 2009:

- Five children aged 11-15 years of age, all previously healthy
- All Maori and Pacific
- All for serious consideration of cardiac surgery
- None will have a normal life expectancy
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WHY RHEUMATIC FEVER AND RHEUMATIC HEART DISEASE MATTER

- One third of New Zealand children have a 1 in 250 chance of a damaged heart by the end of school though this is preventable.

- Two thirds of New Zealand had this scale of risk in 1920 – the risk is now negligible.

- Once diagnosed with rheumatic fever, more than 1,000 children and young people in New Zealand will receive a very painful injection every month for at least 10 years to prevent more heart damage.

- Their life span is reduced.

- Cardiac surgery may be necessary.

- Strokes, heart failure and heart arrhythmias are likely. Sequelae of rheumatic heart disease in adult life.
EXECUTIVE SUMMARY

RHEUMATIC FEVER (RF) CONTROL IN NEW ZEALAND: ABOLITION BY 2020 IS POSSIBLE

Background

Rheumatic heart disease (RHD) is one of the few preventable chronic diseases[1]. In most developed countries it has become extraordinarily rare. New Zealand sustains high rates of acute rheumatic fever in Maori and Pacific young people. This leads to chronic rheumatic heart disease in adult life. Maori adults (25-44y) are 8 times more likely to die of RHD. One in 5 patients with RHD need cardiac surgery.

Rheumatic fever in an urban school-aged population of mostly European origin in the 1920’s is recorded as ~65/100,000[2].

Over the past decades, proven pathways to progress the control of this disease have emerged.

An international workshop co-sponsored by the National Heart Foundation of New Zealand and the New Zealand Ministry of Health charged to provide Best Practice Advice for the New Zealand Ministry of Health was held in Auckland in June 2009.

The following conclusions were arrived at:

- **Primordial reasons for RF rates:**
  
  Household crowding is a critical factor for the development of ARF[3, 4].

  **Continued support for programmes such as Healthy Housing, which addresses crowding, is vital in high risk populations.**
This programme has been shown to reduce hospitalisations in CMDHB by 26% in 5-45 year olds for contagious diseases which includes RF[5].

- **Implement school/community-based clinics in all high risk schools in New Zealand as indicated in the guidelines for primary prevention.** This would include Auckland where **50-60% of the cases reside.** Funding is awaited for initiatives in high risk schools in Flaxmere, Hawkes Bay; Opotiki (now funded mid 2009), Kawerau and Murupara, Bay of Plenty with a short term initiative in Keneperu, Wellington. Scoping work is in progress in Tairawhiti and the Auckland region. A new initiative has started up in Kaikohe. There have been no cases of RF in Kaeo, Whangaroa in Northland over 8 years since. The sore throat clinics started in 2002.

Special emphasis should be placed on progressing RF control in schools of medium risk, where sore throat clinics per se are not supportable. Waikato DHB is well advanced in this regard with community and professional education.

- **Progress the proposed initiative for a New Zealand web-based rheumatic fever register**

All patients diagnosed with RF are recommended for monthly penicillin injections. Young people moving between DHB’s currently get lost to follow-up. Such a register could improve penicillin delivery to prevent second attacks with worsening heart disease. The register would also enable the effectiveness of school clinic programmes across the northern North Island to be evaluated by aggregating data (i.e. reduction of RF cases and group A streptococcal pharyngitis data) from each centre into a meta-analysis.
The workshop applauded the new approach of RHD detection by echocardiography as a screening test, supporting ongoing national and international research to define the position of this approach in the armamentarium of tools to control RF/RHD. 3,500 children will have undergone echocardiography by the third school term of 2010 in the DHB’s of Counties Manukau, Tairawhiti, Bay of Plenty, Northland and Waitemata.

The workshop identified the need for a comprehensive health promotion plan for RF/RHD. This challenge was taken up by the National Heart Foundation with a meeting in February 2010.

Inaugurate a National Steering Group to advise the Ministry of Health for control/abolition of ARF/RHD by 2020 in New Zealand, including oversight of the National RF register (first national meeting to advise the register and the need for a Steering Group held at the National Heart Foundation 8th December 2009).

Promote ARF/RHD as a sensitive indicator of child/youth health inequalities.

Published evidence supports that rheumatic fever in the high risk populations such as in New Zealand can be reduced to that of the low risk populations by 2020, i.e. eradicated in New Zealand.
National and International Workshop for the control ARF/RHD in New Zealand was held in June 2009 with national and international participation to explore implementation of the Guidelines and explore new initiatives. It was funded by the National Heart Foundation of New Zealand and the NZ Ministry of Health to provide best practice advice for control of RF/RHD in NZ. The proceedings and outcomes of this workshop are summarised below and in the Appendices.

The workshop endorsed the following:

1. Primordial reasons for RF rates:

The risk of RF is linked to high levels of deprivation using the NZ Dep Index which is based on household income, access to telephone and car, education level and housing[6]. Household crowding linked to RF is well supported by the literature. Work in the 1960’s in the USA showed that once variables such as ethnicity are controlled for, household crowding became a critical factor for the development of ARF[3, 4]. The Healthy Housing programme (refurbished Housing NZ houses appropriate for the size of the family with a health assessment in the highest risk areas) has been shown to reduce hospitalisations by 25% in 5-45 year olds for contagious diseases which includes RF[5].

Recommendations:

- Continued support for programmes such as Healthy Housing, which addresses crowding, are vital in high risk populations.

- The workshop strongly supported planning for and acceleration of implementation of improved housing for those at high risk of ARF/RHD, being a critical marker of inequality.
2. Primary Prevention in Very High Risk Schools:

This initiative, now critically supported in the published literature and with a New Zealand example[7-9], requires implementation in all areas of need (see timeline attached).

Components to this intervention include community consultation and education, appropriate educational materials (see below), assessment of risk and development of primary prevention programme through clinics in very high risk schools, where the observed rates in 5-14 year olds are highest (50/100,000 or greater) as per Appendix 2B in Primary Prevention Guideline. A Manual of Operations for school clinics, developed with the Auckland project is available on the National Heart Foundation website (www.heartfoundation.org.nz). Considerable experience has also been had in rural Northland.

Recommendation:

- The workshop applauded initiatives underway in several communities and DHB’s (Kaeo, Kaitaia, Opotiki, Kawerau) and urged planning to be initiated for all areas of high need especially Tairawhiti, and Auckland (where 50-60% of NZ cases occur), where no progress has been made to date.

- In addition, the development of a national web-based register was seen as critical for long term evaluation of sore throat clinics.

Footnote:

*Early planning underway for school clinics (March 2010) in Ngati Porou Hauora region. No funding as yet.

*Delivery of health care through schools is highly efficient (90% adherence to medication) and acceptable (80-90% consent rate: 5-13 year olds). A pilot programme is in the planning phase to test feasibility in one school of extending such a mode of healthcare to control of skin infections (including the large burden of hospital admissions).
3. Primary Prevention in Medium Risk Schools in a Region Where School Sore Throat Clinics are not Supportable:

Not all children at risk of developing RF attend schools with a rate of 50/100,000 or greater. An evidence-based internationally and nationally peer reviewed guideline is available at www.heartfoundation.org.nz and outlines a differential approach to those at high risk of rheumatic fever compared to those not at risk. The approach to the latter is to reduce overuse of antibiotics and the approach to the former is to prevent acute rheumatic fever wherever possible. Further promulgation to PHO’s and primary care practitioners is imperative. Most schools in NZ (>60%) will never have a student with RF.

Special emphasis should be placed on progressing RF prevention in areas with a lesser risk but still high need (5-14 year rates 20-50/100,000), and including those attending secondary schools in high risk areas. A programme involving the lay and professional communities needs to be evolved in consultation using the tool developed for sore throat management, recognising the risk or otherwise of RF following streptococcal pharyngitis (www.heartfoundation.org.nz [sore throat management][10]. Rates of RF in secondary schools, while outside the most at risk age group (5-14y), are often unacceptably high in high risk areas. For this reason the Auckland school-clinic study [8] involved secondary schools. On the basis of cases able to be prevented through this intensive whole school approach it was considered, when evolving the guidelines, that a less intensive approach may appropriate for this age group, at least in the urban environment where secondary schools are more likely to be stand alone. Many secondary schools have school nurses who could be involved in this process. Synergy with the AIM HIGH project is possible. An important consideration is the infectiousness within families of Group A Streptococcus
(GAS) where ages of siblings span primary and secondary school age groups. Contact tracing in families of index cases of GAS may be a way to ensure this is addressed.

Sore throat management in primary care is an important health care cost[11]. Data available in NZ suggests that antibiotic therapy is often misdirected without an assessment of risk of RF[12, 13] and those at highest risk do not attend. A previous audit was conducted ~10 years ago [14]. It was suggested that multiple ways in a primary care setting of improving knowledge and practice of sore throat management be explored. A report to the NZ Ministry of Health[15] suggested that primary care at that time was an inappropriate vehicle to control RF. This conclusion supported the decision to explore sore throat clinics in schools in high areas to improve health care access[8]. Innovative solutions for the control of RF in medium risk areas (20-50/100,000) deserve consideration.

**Recommendations:**

- The workshop recommended widespread promulgation of the Sore Throat Guideline, including discussions with PHARMAC regarding their blanket message on limiting antibiotic use (ongoing 2010), urging a different message in GAS pharyngitis in groups at high risk of RF
- An audit of the application of the sore throat management guideline in 2010 was recommended, including all deliverers of primary care (GP’s, nurse led clinics etc). A summary of advice to Public Health Units is available in the Medical Officers of Health Communicable Disease Manual.

4. Secondary Prevention to Abolish Recurrent Attacks of Rheumatic Fever which Further Damage the Heart
Ongoing support of the current secondary prevention programme is critical. This is running well in most areas[16] delivered by District Nurses in Auckland and Public Health Nurses in other areas of New Zealand for historical reasons. The need for a seamless child-adult delivery system, both for penicillin and for follow-up, was recognised as most patients continue on benzathine penicillin injections until 21 years of age, with more severely affected continuing until 30 years of age or for life. Some areas such as Counties Manukau District Health Board have a highly developed community support worker workforce working in partnership with their nursing colleagues, with a vital role in education, adherence to injections and facilitating clinic appointment attendance. This is a model which could be emulated in other areas. CMDHB has very high adherence rates for penicillin injections in all age groups [17].

An audit of recurrences of RF in the Auckland region highlighted that patients arriving in Auckland from other DHB’s or the Pacific are the most likely to be those who suffer a recurrence[18]. For socio-economic, housing or other reasons RF patients are very mobile. A national, preferably web-based, RF register to co-ordinate penicillin delivery, and to enable audits of penicillin adherence, recurrence rates, the primary prevention programme and RHD screening, is another important next step in RF/RHD control in NZ.

A stable supply of benzathine penicillin should be ensured by further seeking an alternative supplier. There has been ongoing correspondence with Pharmac on this matter and this dialogue needs to be continued.

Recommendations:

- The workshop supported the proposed initiative for a New Zealand web-based RF register (a scoping project was funded by the Ministry of Health in August 2009) and an ongoing dialogue with PHARMAC (see Appendix 5).
5. Development of Necessary Tools to Ensure Full Participation by Populations Most at Risk of ARF/RHD and for Health Professionals to Adhere to Published Guidelines:

Workshop participants produced documents/educational tools at the workshop and an audit/inventory is being undertaken by the National Heart Foundation of New Zealand to avoid repetition/unnecessary development and highlight the areas of need for the development of the necessary tools to control RF by 2020. Due consideration of the prose literacy skills was highlighted.

Recommendation:

- The need for a full day workshop was identified (covered 17th February 2010 at the National Heart Foundation). See full summary as Appendix 6.

6. Detection of Sub-Clinical Rheumatic Heart Disease by Echocardiography

Landmark progress in the detection of RHD using echocardiography[19] now been applied in a study in Auckland[20]. These and other studies have revealed a considerably higher rate of subclinical rheumatic heart disease than previously suspected or is detectable by clinical examination. This was particularly unexpected in an area where RF recurrence rates are rare and most (~80%) patients present with mild or moderate carditis[8]. Detail on the natural history of these findings is evolving.

The overarching question for discussion at this workshop was the possible future role of echo-doppler as a screening test for RHD in the light of the presently acknowledged role in clinical management. It was agreed:

1. **Standard criteria against which any screening approach can be assessed are necessary for echo-doppler.** Currently the methodology did not meet all criteria for a screening programme as the lower limit of certainty of RHD by echo is not defined. However as
research continues those found to have unequivocal RHD should be started on penicillin prophylaxis (2.5% of the 2007-8 South Auckland 10-13 year old decile 1-2 school. NZ deprivation index 9-10). Those with abnormal yet borderline, defined as possible RHD (1.5-2%), should be followed with current NZ consensus is for a 2 year time frame in the first instance. Unequivocal RHD for penicillin prophylaxis is defined by the Webb, Wilson study as changes to the mitral or aortic valve by echocardiography demonstrating any regurgitation (beyond physiologic) and any degree of valve structural changes, e.g. thickening, which is considered to be pathologic by consensus. Possible RHD in this study is defined as either any regurgitation or structural changes as above.

2. **The need for international standardisation was agreed.** This is being addressed by an international study to be undertaken by Dr Bo Remenyi who has been awarded a Heart Foundation Fellowship to work with Dr Nigel Wilson (Auckland) and Professor Jonathan Carapetis in Australia.

   - the work will produce a generic set of RHD echo studies that will be expert consensus standards for common patterns of RHD
   - protocols for RHD echo screening available to all countries with RHD control programs
   - Web access of the above. This will enable cardiologists who are involved with RHD screening to improve their accuracy for RHD and reduce over- and under-diagnosis.

3. A priority for future research was to **more clearly define progression of borderline cases compared with normal controls** for which the endpoints could be echo progression or ARF incidence. Power and sample size would obviously be determined by the choice of endpoints. Ideally this would be an RCT likely with NZ, Australian and/or South African
collaboration to increase the power of the study. It would be logical to start this phase of research as soon as the expert consensus/standardization (1. above) is agreed.

Success with such research would require a collaborative international approach with leadership from New Zealand. To this end a strong partnership between public health and clinical disciplines with appropriate funding is required.

Much of the discussion was centred on the possible cohesion that this imaging methodology could provide in bringing public health and clinical approaches together in partnership. It is already known that echocardiography is much more sensitive than auscultation to detect RHD. Portable echocardiograms make this possible in a school setting.

Various data sets from Auckland (Dr Rachel Webb), Australia (gECHO programme Dr Graeme Maguire) and Pacific (Dr Toa Fakakovi) experience were presented.

Technical discussion points arising included definitions of physiological and pathological appearances, the broad spectrum and variable time course of disease, distinguishing first from recurrent and chronic disease established RHD)

4. Cost and Cost Effectiveness for RHD Screening:

Preliminary costs for RHD screening from the 2007-8 South Auckland and 2009 Taraiwhiti DHB public health initiated and funded RHD echo screening programmes are shown here.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Cost – per person screened</th>
<th>Cost – per case diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical cancer1</td>
<td>$69</td>
<td>$7,000</td>
</tr>
<tr>
<td>Breast cancer2</td>
<td>$224</td>
<td>$37,965</td>
</tr>
<tr>
<td>Newborn hearing3</td>
<td>$25</td>
<td>$8,868</td>
</tr>
<tr>
<td>RHD echo screening</td>
<td>$230 South Auckland</td>
<td>Approx $3200</td>
</tr>
<tr>
<td></td>
<td>$60 East Coast</td>
<td>$1500</td>
</tr>
</tbody>
</table>

Cost effectiveness would include the relatively low cost of penicillin prophylaxis and high costs savings avoiding cardiac surgery and chronic RHD care.

**Update (2010):** Following the research funded CMDHB echocardiography screening in 2007-2008[21], other high prevalence RF regions have undertaken school echocardiography. Public Health Physicians and Paediatricians in the DHB’s of Tairawhiti, Bay of Plenty and Northland have funded and co-ordinated echocardiography in schools in their regions, in partnership with Dr Wilson and cardiology colleagues from Starship Children’s Hospital. Four hundred children were screened from a low prevalence RF region (Waitemata DHB) as a control group. Analysis of the 3,500 children scanned will help develop a potential model appropriate for RHD screening in NZ by age, region and school decile.

The workshop applauded this new approach. Ongoing national and international research will lead to defining the position of this approach in the armamentarium of tools to control RF/RHD.

7. **Formation of a National Steering Group**

**Recommendation:**

The workshop called for the **inauguration of a National Steering Group** to advise the **Ministry of Health on abolition/control of ARF/RHD** by 2020 in New Zealand, including oversight of the National Rheumatic Fever Register. The first meeting was held to consult (as part of the contract with the Ministry of Health) on the proposed register
document, requisitioned by the Ministry of Health in December 2009 (minutes attached) (see Appendix 5).

8. The workshop issued a strong call for ARF/RHD to be considered as a sensitive indicator of child/youth health inequalities. Important remediable factors are:

- Inadequate crowded housing
- Inadequate access to primary healthcare

Both lead to repeated untreated streptococcal pharyngitis and subsequent RF and heart damage.
**Addendum:**

Many infectious diseases including streptococcal pharyngitis are preventable and/or treatable. The marked discrepancies seen between Maóri and Pacific populations and the Pakeha population are potentially able to be abolished with known tools within a reasonable timeframe (World Dev Report 1993) as seen in Chile or the UK.

**Control of Infectious Diseases is Achievable**

**ECONOMIC PROGRESS: Death Rates (Female)**

![Graph showing economic progress in death rates (Female)](image)

Serious skin disease in children is an important numerical cause of hospitalisation (NZ ~3,000/year[6]) and RF though less common, persists into adult life with expensive cardiac sequelae. A combined approach for sore throats, skin infection and other common issues using the school clinic model to improve health access is to be studies (HRC Grant funded 2010). **It is estimated 10,000 hospitalisations per year in NZ could be avoided using available tools[22].**
Summary by Guest Speaker Professor Bongani Mayosi, Nuffield Fellow to Oxford University, Professor of Medicine, University of Capetown

“I would like to summarise my views on several issues that were raised during the sometimes robust discussions at the meeting. The first is to support the comprehensive approach taken in New Zealand to the prevention of rheumatic fever. The randomised evidence that you have gathered supports our contention that primary prevention is as important and effective as secondary prevention. The control of rheumatic fever by 2020 will require the implementation of these evidence-based measures in the context of an effective primary health care system. The incidence of rheumatic fever is an index of the penetration and effectiveness of primary health care services. The promotion of this idea will be an important contribution of the New Zealand Workshop to the strengthening of health care systems for affected communities all over the world.

The other issue is the readiness of echo screening is ready to be deployed widely in the health service. My pragmatic stand on this question is that screening for definite and clinically overt rheumatic heart disease must be recommended for uptake by ministries of health on the basis of the known cost-effectiveness of secondary prevention. Sub-clinical rheumatic heart disease, however, is a subject for research. We must set up large-scale multi-centre studies to address the uncertainty on natural history and the effectiveness of secondary prophylaxis. It will be crucial that our recommendations are based on reliable and generalisable evidence.”
TIMELINES:

1. Develop web-based rheumatic fever register to allow meta-analysis of outcomes of school clinic initiatives and improve secondary prophylaxis for students moving from DHB to DHB. **COMMENCED IN 2009**

2. Develop web-based rheumatic fever register to allow meta-analysis of outcomes of school clinic initiatives and improve secondary prophylaxis for students moving from DHB to DHB. **COMMENCED IN 2009**

3. Develop comprehensive set of health promotion materials for parents/child/health professionals for disease prevention and management. **INAUGURAL MEETING FEB 2010, NATIONAL HEART FOUNDATION**

4. Complete epidemiological assessment identifying all NZ high risk schools as per Appendix 32 of the Primary Prevention Guideline. **COMMENCED NOVEMBER, 2009 AS SUMMER STUDENTSHIP PROJECT, UNIVERSITY OF AUCKLAND IN COLLABORATION WITH TAIRAWHITI DHB and NGATI POROU HAUORA.**

5. Identify areas for sore throat clinics in schools. **WORK IN PROGRESS IN ALL DHB’S.**

6. Identify funding streams for instigation of school clinics and process. **FUNDING STREAMS NEED URGENT CLARIFICATION.**

7. Identify intermediate risk schools (20-50/100,000 in 5-14y) and selected secondary schools for focused delivery of sore throat management using current available structures (school nurses, PHO’s, GP’s).

AUCKLAND, a special case: More than 50% of RF cases occur in Auckland. Planning for **RF/RHD control** is retarded by lack of national leadership for DHB’s. Ministry of Health
urgently needs to assume leadership role indicating clearly to DHB’s that RF/RHD control is a national priority.

TIMELINE FOR AUCKLAND:

1. Region wide discussions (ADHB, WDHB, CMDHB and ARPH) AUGUST, 2009. Early planning underway in CMDHB and ADHB. A region-wide approach discussed linked with control of serious skin disease, a major cause of hospitalisations, and child pedestrian injury (see HRC application attached – Appendix 9). This approach is to be piloted, subject to funding in one school and area in south Auckland. **PLANNING UNDERWAY LATE 2009.**

2. ARPH ROLE: health promotion including best practice for sore throat management and family/whanau education through contract tracing around new RF cases. **ONGOING FROM 2009**

3. Community consultation and education: **ONGOING AND AS PART OF PLANNING FOR PILOT; 2009 ONWARDS**

4. Appropriate health promotion materials. **SEE ABOVE**

5. Assessment of disease burden by age, ethnicity, deprivation, school. **COMPLETED AND DISCUSSED REGION-WIDE 2009.**

6. Following successful funding and execution of the pilot above, roll-out of school-based clinics in schools with rates greater than 50/100,000 is envisaged in suburban clusters (Otara, Manurewa, Mangere and Mt Roskill) in a systemic fashion, subject to funding and town planning initiatives for traffic calming. **GAS control by suburban area is likely to augment the effect that school clinics can have on this very infectious disease, as many large households have children in multiple schools. If roll-out can occur in a graded and systematic fashion we envisage a robust evaluation could be**
put in place. **PLANNING UNDERWAY 2009 WITH CMDHB. ADHB ALSO**

**INVESTIGATING NEXT STEPS** (see Appendix 9).

7. Assessment plan. **SUBJECT TO HRC APPLICATION AND FUNDING FOLLOWING THE PILOT: 2010-2011**
<table>
<thead>
<tr>
<th>DHB</th>
<th>Assess Need as per Appendix 31/32</th>
<th>Assessing Document</th>
<th>Funding Applied for/Identified</th>
<th>School Clinic in Place</th>
<th>Community/ Professional Education in Place</th>
<th>Yearly Audit of Outcome in Place</th>
<th>Sustainability?</th>
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<td>Auckland DHB</td>
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<tr>
<td>Kaeo/Whangaroa</td>
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<td>Kaikohe</td>
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<tr>
<td>Waikato DHB</td>
<td>Yes – 2007</td>
<td>Attached</td>
<td></td>
<td></td>
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<td>Being addressed</td>
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<tr>
<td>Toitorea (Lakes/Bay of Plenty DHB’s)</td>
<td></td>
<td>Attached</td>
<td>Opotiki Yes Kawerau/Murapara planned</td>
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<tr>
<td>Hawkes Bay DHB</td>
<td></td>
<td>Attached</td>
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<td>Mid Central DHB</td>
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## Table 2: Actions to Control RF/RHD

<table>
<thead>
<tr>
<th>Who does what</th>
<th>Government</th>
<th>Communities</th>
<th>Schools</th>
<th>Ministry of Health</th>
<th>Relevant DHBs</th>
<th>PHOs/GPs</th>
<th>PHUs</th>
<th>Cardiology/paediatrics</th>
<th>National Heart Foundation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal 1: No new cases of ARF/RHD by 2020</strong></td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>Intersectoral collaboration eg housing</td>
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Appendix 1: EPIDEMIOLOGY OF RF/RHD

Historical Background

Rheumatic heart disease is one of the few preventable chronic diseases[1]. In most developed countries it has become extraordinarily rare [23]. New Zealand sustains high rates of acute rheumatic fever most likely as a result of inadequate low cost housing with overcrowding and, in addition, inequitable access to primary healthcare[24],

www.heartfoundation.org.nz/primaryprevention. Streptococcal pharyngitis, the precursor to acute rheumatic fever, is very contagious (20% of contacts of 43 new cases of acute rheumatic fever over a 6 month period in Auckland had throat swabs positive for group A streptococcus and thus required treatment themselves to prevent rheumatic fever)[25].

Rheumatic fever in an urban school-aged Pakeha population in the 1920’s is recorded as about 65/100,000 5-14 year olds[2]. Ninety years later ARF is now very rarely seen in the European population, which is similar to other countries in the OECD and best recorded in Denmark[23].

Extremely high rates of rheumatic fever were recorded on the East Coast of the North Island in the 1960’s[26] at 2,000/100,000 for mostly Maori school-aged children. These may be the highest ever recorded globally[23, 27, 28]. Definite progress was documented until the 1980’s with the overall rates for 5-14 year olds decreasing down to approximately 50/100,000[29]. Separate rates for Maori were not published.
Rates for New Zealand European and other ethnicities have been maintained in recent decades at <5/100,000 tracking down to <2/100,000 in the recent decade in Auckland. Maori and Pacific rates in childhood New Zealand wide persist at ~50-100/100,000[6, 30].

**CURRENT EPIDEMIOLOGY:**

Acute rheumatic fever (ARF), and its sequela rheumatic heart disease (RHD), are potentially life-limiting and life-threatening conditions and are preventable. Current rates in New Zealand Māori and Pacific populations are unacceptably high, mimicking those seen in Denmark in the 1940s, and are of developing world proportions.[6, 28, 31] In 1991, the annual cost of rheumatic fever to the Auckland District Health Board was estimated at $3.6 million.[32] While there was a reduction in disease burden during the 1970s and 1980s, the last decade has seen little progress. A nationally co-ordinated approach is likely to be the most cost-effective method for reducing the disease burden and societal costs of this disease.

ARF is a preventable disease that occurs in some people following a Group A Streptococcal (GAS) throat infection.[33] Sore throats are a frequent reason for presentation to primary health care accounting for 4-5% of all presentations in two New Zealand studies.[12, 13] Appropriate antibiotic treatment of sore throats in high risk populations will eradicate GAS in most cases[34], and prevent individual cases of ARF[35] and subsequent heart valve damage and chronic RHD. In addition, secondary prevention via regular penicillin prophylaxis reduces the risk of recurrent ARF, hospitalisation, surgery, and severe RHD and improves quality of life.[36] The World Health Organisation recommends register-based programmes as being the most effective at delivering secondary prophylaxis.[37]
In 2006, the first in a series of three evidence based New Zealand Guidelines for Rheumatic Fever was published focussing on diagnosis, management and secondary prevention of ARF.[36] This guideline summarises the medical evidence for the diagnosis, management and secondary prevention of ARF with the aim of preventing or minimising rheumatic heart disease (RHD).

ARF typically presents in children aged 5-14 years.[36] In contrast, RHD often occurs as a result of repeated episodes of ARF and may go undiagnosed for some time if ARF goes unrecognised, presenting most commonly in those aged 30-40 years.[36] In New Zealand, around 80% of ARF cases have some cardiac involvement, and in 20% of those the carditis is moderate-severe requiring cardiac surgery[38]. RHD carries significant risk of stroke, hypertension, and infective endocarditis, and remains a significant cause of premature death in New Zealand, accounting for approximately 140 deaths per year in 2000-2004.[36, 39].

**Burden of Acute Rheumatic Fever**

The New Zealand Rheumatic Fever guidelines recommend hospital admission of all those with suspected ARF.[36] This was first recommended at the earlier working party[40]. Rheumatic fever became a notifiable disease in 1986. Thus both notification and hospital admission data is available.

**Notifications of Acute Rheumatic Fever**

The Institute of Environmental Science and Research (ESR) operates the national notifiable disease surveillance database, EpiSurv, on behalf of the Ministry of Health.[41] EpiSurv collates
notifiable disease information on a real-time basis from public health units. Physicians making a
diagnosis of rheumatic fever are required to notify their local public health unit, who in turn upload data for cases that meet the case definition to EpiSurv using a standardised case report form. The Communicable Disease Control Manual, currently under revision, defines cases based on the 1992 updated Jones Criteria as possible or probable initial or a recurrent attacks[42]. Although the EpiSurv data collection forms suggest that it is a potentially rich source of diagnostic data, data published by the ESR in the annual surveillance reports and available from the Public Health Observatory is generally limited to estimates of rates of acute rheumatic fever disaggregated by demographic variables[43].

Whilst notification of rheumatic fever is a statutory requirement under the Health Act, several publications have identified under-reporting.[30, 44-46] Jaine and colleagues reported that during 1996-2005 there were 22% fewer notifications made than there were first hospital admissions for acute rheumatic fever.[30] Given that some notifications would have been for indolent rheumatic heart disease and not acute rheumatic fever, it is likely that this figure underestimates the degree of under-reporting. In comparing the number of cases by DHB in Jaine’s publication with EpiSurv data obtained from the Public Health Observatory it appears that under-reporting occurs in most regions (Table 1).[30, 41] A study of the epidemiology of ARF in the Waikato DHB (1998-2004) found that 10% of hospitalised ARF cases were not notified.[45] A similar study of ARF in the Bay of Plenty and Lakes DHBs (1999-2007) found that 50% of cases had not been notified.[44]
Notification data has further limitations. Episurv data reports on patients by year of notification and not year of diagnosis of ARF, thus it is more a reflection of the notification process than the true annual incidence of ARF each year. Publishing notification year results in spuriously high rates of disease in some calendar years, and spuriously low rates in other years because reporting is frequently sporadic and not always timely. For example, the doubling of the ARF rate in Lakes and the Bay of Plenty and the tripling of the rate in Waikato in 2008 observed in notification data occurred as a result of case-finding exercises and not a sudden spike in disease incidence (Table 1). Consequently, interpretation of notification time trends must be done with caution.

In addition, Episurv does not collect data on patients who are diagnosed with RHD in the absence of an acute episode of rheumatic fever and thus is unable to inform the epidemiology of RHD in New Zealand. RHD incidence is an important indicator of the success of primary and secondary prevention initiatives and is an under-researched entity.
### Table 1: Acute Rheumatic Fever Notifications by District Health Board, EpiSurv 1997-2008

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Source: Public Health Observatory.[41] Note: *Increase in notifications likely to be associated with case-finding exercises undertaken in these DHB’s.[44, 45]

### Hospital Admissions for Acute Rheumatic Fever

Most published New Zealand rheumatic fever epidemiology uses hospital admission data to estimate disease rates. Hospital admission data also has limitations. It will only capture patients with rheumatic fever that were admitted to hospital. Without revision of clinical notes, diagnosis and coding errors will not be detected. [47, 48] In addition, the methodology employed will affect the rates calculated, for example whether readmissions are excluded and...
whether evidence of rheumatic fever is sought beyond the primary diagnosis coding. A Waikato study (1998-2004) which identified patients discharged with a diagnosis of ARF among the primary and secondary diagnostic codes found that 25% did not fulfil ARF diagnostic criteria.\[45\] A Minnesota study in the 1970s of patients discharged from hospital with a diagnosis of ARF found the clinical record supported this diagnosis in only 15% of cases.\[48\] Without further investigation, it remains unclear how well hospitalisation data truly reflects the incidence of rheumatic fever in New Zealand. With these cautions in mind, the data presented in this section is limited to those with a primary diagnosis of rheumatic fever and where stated readmissions have not been excluded.

During 1996-2005 the age-standardised annual hospital admission rate for a first episode of ARF was 3.4 per 100,000, with the highest rates seen in 5-14 year olds (14.9/100,000) and 15-24 year olds (3.8/100,000) and the lowest rates in those aged over 24 years (0.7/100,000).\[30\] Rates were consistently higher for Māori and Pacific, and there was evidence that admission rates increased for Māori and Pacific during this time, whilst admission rates in NEW ZEALAND European/Other declined (Figure 1).\[30\]
In children and young people, ARF hospital admission rates declined during the 1970’s and early 1980’s and have essentially remained unchanged since (Figure 2). During 1996-2007, admission rates were highest in Pacific children and young people, followed by Māori, whilst European and Asian children and young people had the lowest admission rates (Figure 3). During 2003-2007, ARF admission rates were significantly higher in Pacific and Māori and those living in the most deprived areas (Figure 4). Hospital admissions for ARF are generally prolonged and during 2003-2007, the average admission duration for children and young people on the Auckland Rheumatic Fever Register was 22 days (median: 14 days; range: 1-392 days).
Figure 2: Acute Rheumatic Fever Admissions in 0-30 Year Olds and 0-24 Year Olds, New Zealand 1970-2007

Source: 0-30 Years: Ministry of Health[49]; 0-24 Years: NZCYES[22]. Note: 0-24 Years: Year pair data plotted i.e. data in 1991 is for 1990-91 and data in 2007 is for 2006-07. Neither data sources exclude readmissions.
Figure 3: Acute Rheumatic Fever Admissions in 0-24 Year Olds by Ethnicity, New Zealand 1990-2007

Source: New Zealand Child and Youth Epidemiology Service. [22] Note: Readmissions not excluded.
Hospital admission rates for ARF in 0-24 year olds are not evenly distributed amongst the DHBs (Figure 5). During 2002-2006, 57% of admissions occurred in the Auckland Region, 9% in Northland, 7% in the Bay of Plenty, and 6.4% in the Waikato DHB. During this time the highest admission rates were seen living in Counties Manukau (33.1/100,000), Northland (30.0/100,000), Auckland (20.5/100,000), the Bay of Plenty (19.8/100,000), Lakes (17.0/100,000), Tairawhiti (16.0/100,000), and the Hawkes Bay (13.8/100,000).
Figure 5: Acute Rheumatic Fever Hospital Admissions in 0-24 Year Olds by DHB, New Zealand 2002-2006

Source: New Zealand Child and Youth Epidemiology Service.[6] Note: Readmissions not excluded.
Burden of Rheumatic Heart Disease

Rheumatic heart disease is the most significant sequela of acute rheumatic fever and occurs in 60-80% of patients with ARF.[23, 38, 50-52] RHD typically manifests as damage to the heart valves, particularly the mitral and aortic valves, and can occur during an acute episode of ARF and persist once other signs the acute illness have resolved. Recurrent episodes of ARF increase the risk of developing or exacerbating existing RHD.[36] Once a person has developed RHD, they are at risk of complications including heart failure, atrial fibrillation, pulmonary hypertension, infective endocarditis, stroke, and premature death.[50, 51, 53-56] Approximately 20% of RHD is severe and likely to require surgical intervention including heart valve replacement.[56]

The introduction of secondary prevention programmes in New Zealand in the 1970s and 1980s has been credited with a reduction in the ARF recurrence rate and the incidence of RHD.[16] However, there is a paucity of detailed published New Zealand RHD epidemiology particularly for adults and Pacific peoples. RHD is not a notifiable disease in New Zealand.

Rheumatic Heart Disease Hospital Admissions and Related Morbidity

During the last two decades there has been little change in the annual number of hospital admissions due to RHD, with an annual average of approximately 550 admissions per year during 1997-2006 (Figure 6).[57] During 2003-2005, total population hospital admission rates for RHD were 25.2/100,000 and 5.5/100,000 in Māori and non-Māori respectively (Figure 7).[39] Thus, RHD admissions were 4.6 times higher in Māori when compared with non-Māori.
Comparable total population rates in Pacific are unknown. Whilst the diagnosis of RHD is most commonly made in 30-40 year olds[36], during the last decade there has been an increase in the RHD admission rate in 0-24 year olds and an average of 55 admissions per year (Figure 8).[22] In 0-24 year olds, the highest RHD admission rates were in Pacific followed by Māori (Figure 9).[22]

**Figure 6: Number of Hospital Admissions due to Rheumatic Heart Disease, New Zealand Total Population 1980-2006**

During 2003-2007, the heart valve replacement rate for RHD was 19.2 in Māori and 9.2 in non-Māori (Figure 7).[39] Valve replacement is associated with long-term health risks. In a 1994 review of 232 New Zealand women who underwent valve replacement at age 12-35 years in the period from 1972-1992, 75% were for RHD.[58] In total, 19.4% died within the study period and the relative risk of death was 8 times greater in Māori and 7 times greater in Pacific women.
when compared with European and Asian women. Endocarditis occurred in 10-22% depending on the type of valve used, 26% had a thrombo-embolic event, and 13% had an anti-coagulant related haemorrhage requiring hospital admission. By 10 years, 82% of bioprosthetic and 28-29% of homograft and mechanical valves required re-replacement. In addition, during 1988-2005 there were 11 heart transplants performed for RHD of which 82% were in Māori patients[59].

Figure 7: Admissions and Valve Replacements due to Rheumatic Heart Disease by Ethnicity, New Zealand 2003-2005

Source: Hauora: Māori Standards of Health IV. A study of the years 2000-2005[39]. Note: Rates are age-sex standardised to the 2001 Māori population
Figure 8: Rheumatic Heart Disease Admissions in 0-24 Year Olds, New Zealand 1990-2007

Source: New Zealand Child and Youth Epidemiology Service, 2008[22].
Figure 9: Rheumatic Heart Disease Admissions in 0-24 Year Olds by Ethnicity, New Zealand 1996-2007

Source: New Zealand Child and Youth Epidemiology Service, 2008[22].

Rheumatic Heart Disease Mortality

During 1980-2004, the number of deaths from RHD remained largely unchanged, and during 2000-2004 there was an average of 146 deaths per year (Figure 10).[39, 57] During this five year period the Māori RHD mortality rate (6.0/100,000) was five times greater than the non-Māori rate (0.8/100,000).[39] Comparable RHD mortality rates for Pacific were not found, however the 2004 Pacific Health Chart Book lists RHD as among the top five cases of death for Pacific males aged 0-44 and Pacific females aged 25-44 years.[60] Although RHD is more commonly diagnosed in adults, from 1990-2005 there were 40 deaths from rheumatic fever in children and young people aged 0-24 years.[22]
Adult mortality rates from RHD vary by age group which is likely to be due in part to access to secondary prevention programmes during childhood and adolescence for those in the youngest age group (Figure 11). [39] During 2000-2004, mortality rates were significantly higher in Māori than non-Māori in all age groups. [39]

Factors Contributing to the Persistence of Rheumatic Fever

The persistence of ARF and RHD in New Zealand is likely to be due to a combination of factors including poor health knowledge, under recognition and treatment of GAS pharyngitis in high risk populations, and under-diagnosis of ARF in the acute phase resulting in missed opportunities for secondary prevention, barriers to accessing primary health care, and crowded living conditions.
Figure 10: Number of Deaths due to Rheumatic Heart Disease, New Zealand Total Population 1980-2004

Source: M Baker (personal communication).[57]
In order for primary prevention of ARF to occur via the appropriate management of GAS pharyngitis, populations at high risk of ARF must recognise the importance of seeking medical attention for sore throats, and having sought care, must receive appropriate management. New Zealand Guidelines for Group A Streptococcal Sore Throat Management and Primary Prevention Programmes were published in 2009 in order to inform best practice in the prevention of ARF.[10, 61, 62] In addition, a New Zealand Guideline for the Diagnosis, Management and Secondary Prevention of rheumatic fever was published in 2006 to inform best practice in the recognition and management of ARF. The need for health promotion programmes to raise awareness of ARF, and the potential for prevention in high risk populations, has been emphasised in several publications.[61, 63, 64]
The New Zealand Rheumatic Fever Guidelines support a role for primary care in the primary prevention of rheumatic fever.[10, 61] This role is supported by ecological studies conducted in the Baltimore (1960s), Costa Rica (1970s-80s), and the French Caribbean (1980s) that suggest that improving access to primary health care is associated with a reduction in rheumatic fever incidence.[63, 65, 66] In addition, hospital admissions for both ARF and RHD have been identified as Ambulatory Sensitive Hospitalisations (hospital admissions which are potentially preventable via early access to primary care) in a new paediatric indicator adopted by the NEW ZEALAND Ministry of Health.[22] However, two recent New Zealand audits have shown that secondary prophylaxis is more successfully delivered by mobile nursing teams than general practice.[57, 67]

The New Zealand Health Survey shows improvements in access to primary health care in 2006 compared to earlier surveys conducted in 1996 and 2002 (Figure 12). [49, 68] In 2006, an unmet need for General Practitioner Services in the previous year was reported for 4.0% of children and 6.3% of adults.[68] In children aged 0-14 years, this unmet need was highest for male children and Māori children; however no differences were found by deprivation quintile. In adults, the unmet need was greatest in 15-44 year olds, Māori adults, and those living in the most deprived areas. [68] In addition, the Living Standards Surveys conducted in 2000 and 2004, found that families living in severe and significant hardship more frequently postponed a child’s doctors visit due to cost (Figure 13).[69, 70] Thus, access to primary health care remains unequally distributed with cost identified as a significant contributing factor for both children and adults.[68-70] This finding has implications for ARF and RHD rates as both occur more frequently in those living in the most deprived areas.[22]
Figure 12: Unmet Need for General Practitioner Services, New Zealand Health Survey 1996-2006

Source: Ministry of Health, New Zealand Health Survey. [49, 68] Note: Error bars indicate 95% confidence intervals.
In 1999, McNicholas analysed 9 studies involving ARF, including one New Zealand Study[71], and established a clear link between household crowding and rheumatic fever incidence independent of socio-economic variables.[72] In a community outbreak of rheumatic fever in the US in the 1980’s, cases were associated with large families but not with lower socio-economic status.[73] In New Zealand, household crowding increases with increasing deprivation and Pacific and Māori children are more likely to live in crowded households than European children.[6] This finding has implications for ARF and RHD control as both occur most frequently in populations at risk for household crowding.[6, 22, 71]
Effectiveness of Secondary Prevention

The risk of rheumatic fever following a GAS infection is much greater in those who have already experienced an episode of ARF than in the general population. In addition, recurrent GAS infections in those with carditis are likely to result in worse RHD. Thus, the rationale for secondary prevention is that prevention of GAS colonisation or re-infection will prevent recurrent episodes of rheumatic fever, thus reducing the risk of developing or worsening RHD. Secondary prevention of ARF is defined as the continuous administration of antibiotics to cases with previous ARF or well-documented RHD. In the 1960s Wood and colleagues demonstrated the superiority of intramuscular penicillin over oral penicillin in preventing streptococcal infections and recurrences of acute rheumatic fever in children and adolescents with a history of rheumatic fever. A recent Cochrane review confirmed this finding and concluded that penicillin given intramuscularly reduced the recurrence of GAS pharyngitis by 71-91% and ARF by 87-96%. Following intramuscular penicillin, serum penicillin levels peak at 12-24 hours and remain at an effective concentration for 3-4 weeks, resulting in more stable serum penicillin levels than when penicillin is taken orally. The duration of monthly penicillin injections for prophylaxis depends on a number of factors including age, presence and severity of carditis, risk of GAS infection, and time since last acute episode, however a minimum of 10 years is recommended and in some cases prophylaxis should continue until age 30.

Secondary prevention has a proven role in rheumatic fever management. It reduces the risk of recurrent ARF; developing or exacerbating RHD; hospitalisation, and reduces length of stay; surgical intervention for RHD; and death. The effectiveness of secondary prevention is associated with compliance, with the best outcomes observed in patients who receive 12
benzathine penicillin injections each year (Figure 14).[84] Several factors have been associated with suboptimal adherence including lack of patient/parent awareness of the implications of ARF/RHD; symptoms of illness; access to medical care; long-term continuity of care; and lack of active follow-up by health professional exacerbated in mobile populations[85-89]. Compliance to secondary prevention is enhanced by an active surveillance and reminder system and dedicated staff administering penicillin.[50]
Secondary prevention programmes have the potential for significant cost savings and have been found to be a cost effective in reducing rheumatic fever mortality and morbidity.[32, 50, 90, 91] Auckland, the introduction of a secondary prevention programme using intramuscular penicillin reduced proportion of ARF admissions that were for recurrent disease from 22% in the 1970s to 4.5% in the 1990s.[32, 92] Even with this reduction in disease the annual cost of rheumatic fever to the Auckland District Health Board in 1991 was estimated at $3.6 million, with the management of RHD accounting for 70%. [32] Of the total cost, only 13% was spent on secondary prevention. The World Health Organisation recommends register-based programmes as being the most effective for delivering secondary prophylaxis[77].
APPENDIX 2: NATIONAL HEART FOUNDATION SPONSORED GUIDELINES FOR RF/RHD CONTROL IN NEW ZEALAND

Guidelines peer reviewed and endorsed by key organisations lead the way to RF/RHD control.

The following is a summary of the three guidelines (www.heartfoundation.org.nz).

- Diagnosis, Management and Secondary Prevention (not summarised here)
- Sore Throat Management
- Proposed Primary Prevention Programme

2A Sore Throat Management Guideline

The diagnosis and management of group A streptococcal pharyngitis and surrounding issues are summarised in the sections below.

For a more in-depth discussion of GAS pharyngitis and related topics, refer to the full group A streptococcal sore throat management guideline, online at www.nhf.org.nz.

1. Diagnosing and Treating Group A Streptococcal Sore Throats and the Management Algorithm

Most sore throats are viral in origin. International studies have shown that approximately 10% of adult and 15 – 30% of paediatric sore throats presenting to doctors are estimated to be due to group A streptococcal pharyngitis[93] [94] [95] [96] [97] [98] [99].

Group A streptococcus is thought to be spread by droplets, saliva and nasal secretions, food preparation[100] and water[101]. It is more likely to be spread in crowded
settings [102]. GAS can also be spread through food preparation or water.

Sore throats, though mostly viral, need to be taken seriously in New Zealand, where a high rate of endemic rheumatic fever persists. As the sequelae of rheumatic fever are so serious (including permanent cardiac impairment or death), the small chance of a sore throat being caused by GAS, and potentially leading to rheumatic fever, cannot be overlooked in clinical decision-making.

The sore throat algorithm presented in this guideline takes into account the different risk of rheumatic fever in New Zealand populations. Nationally, those at highest risk are young and of Maori and Pacific ethnicity [41]. In 2003, of 142 cases of rheumatic fever, 70 were Maori, 58 Pacific [41]. Twenty-eight percent (n=82) were aged 10–14 years, 9.4 % ; (n=27) were aged 5–9 years, and 6.4 % (n=17) were 15–19 years old [41].

Areas of New Zealand with the highest incidences of rheumatic fever in recent years include lower socioeconomic regions of parts of the North Island: Northland, Auckland, Waikato, the Bay of Plenty/ Rotorua, Gisborne, Hawkes’ Bay, and the Wellington area.

Various risks factors for rheumatic fever in New Zealand were taken into account in developing the sore throat algorithm. Patients presenting with sore throats are first assessed for the presence of the following RF risk factors: whether they are living in lower socioeconomic parts of the North Island, whether they are Maori or Pacific peoples,
whether they are aged 3-45 years, and if they have a past history of acute rheumatic fever.

In the algorithm, having zero or one of the above risk factors means the patient is at low risk of contracting rheumatic fever, and the sore throat is then clinically assessed for whether it is likely to be group A streptococcal in origin, using the scoring system of McIsaac’s modified Centor criteria [103]. The modified Centor criteria factors in clinical signs and symptoms, and takes into account the age group at highest risk of GAS pharyngitis (3-14 year olds). The score from here determines whether a patient is at low, medium or high risk for having GAS pharyngitis present and what treatment is then appropriate.

Having two or more risk factors for GAS pharyngitis in the sore throat algorithm means the patient is already at risk of rheumatic fever. Following the algorithm, the sore throat is then assessed for the clinical likelihood of GAS, using Centor’s original clinical criteria for GAS pharyngitis [104]. The score from this will determine whether a patient is at medium or high risk of GAS and rheumatic fever.

Using the algorithm and scoring stratification, patients at low of GAS pharyngitis being present should have an alternative diagnosis sought. Those at medium risk should have a throat swab taken, and antibiotics given only if the throat swab is positive for group A streptococcus. Those at high risk of GAS pharyngitis should have a throat swab taken, but commencement of empiric antibiotics at this first consultation is recommended. Oral
penicillin V for 10 days is the first-line treatment for GAS pharyngitis (see table 1).

GAS pharyngitis is highly infectious. After a patient has been infected with group A streptococcal sore throat, the chance of another household member becoming infected in the ensuing month is up to one in three. Breese found 19% [105]; Lindbaek found 27% [106], and in Falck’s study 33% of family members became infected in the following month[107]. Poku estimated each household member had a 5-6% chance per month of contracting GAS pharyngitis from an index case within the household [108].

The infectious nature of GAS pharyngitis and its potentially dangerous sequelae mean that investigation of households may be useful, depending on rheumatic fever risk. To address this potential for ‘ping-ponging’ of infection, these guidelines recommend swabbing and treating the household if GAS positive (regardless of symptoms) if there are 3 or more cases of confirmed GAS pharyngitis within the household in a three month period (refer to www.nhf.org.nz). Notification of GAS 3 or more cases of pharyngitis to the Medical Officer of Health is being trialled in a pilot area), as a way of aiding this process.

Other issues relating to group A streptococcus have also been addressed in the guideline.

2. **Tests for Diagnosing Group A Streptococcal Pharyngitis**

The gold standard for GAS pharyngitis detection is a throat swab, carefully taken to avoid the tongue, and sent to the laboratory for culture on sheep blood agar plates. In general
swabs should be sent to the lab within 2 hours, but a delay of up to 24 hours is acceptable before processing[109]. Follow-up swabs are not usually indicated, the circumstances when they may be required are outlined in the guideline (see www.heartfoundation.org.nz) Rapid tests for diagnosing GAS pharyngitis vary in sensitivity and specificity in studies [110], and have not been assessed against laboratory cultures in randomised-controlled trials in the New Zealand setting. Pre-test probabilities for GAS also vary between populations. At this stage rapid tests are not able to be considered consistent enough to be relied on as the sole diagnostic test. In the United States, throat swab cultures are recommended back up, particularly for negative rapid strep tests [111] [112].

3. **Amoxycillin, Sore Throats and Drug Rashes**

Amoxycillin should not be used if infectious mononucleosis (Epstein-Barr virus (EBV) is suspected, as a rash may occur [113] [114, 115]. With EBV infection, the rate of a rash reaction to amoxycillin may be 70–100 %. Renn et al found real sensitisation to amoxycillin can occur in this setting [116]. If a rash to amoxycillin is non-puritic and maculopapular, and seen in a patient with infectious mononucleosis, then it is probable that subsequent penicillins are generally tolerated[117].

This type of rash is generally not IgE mediated, and although there may be a risk of recurrence of similar rash, and there is likely some other underlying immunologic mechanism, there is not an increased risk of severe allergic reaction to subsequent
courses. If there was an urticarial rash or other features suggesting an immunoglobulin (IgE) mediated mechanism then, even if a patient had infectious mononucleosis, evaluation for drug allergy should be undertaken prior to considering further courses of penicillin-based antibiotics.

4. **Should Patients with GAS Pharyngitis be Isolated (kept home from school/daycare)?**

Where a patient has a sore throat and GAS positive throat swab, the New Zealand Ministry of Health [118] [119] and American Academy of Paediatrics recommends keeping children of school and daycare for 24 hours after the initiation of appropriate antibiotic therapy. Snellman found that 36.2% of children with GAS pharyngitis still had a positive throat culture the morning after beginning antibiotic therapy [120].

Three or more GAS sore throats in three months are considered ‘recurrent’ in this guideline. The antibiotics recommended for recurrent cases are shown in table 2. Oral antibiotic choices include clindamycin, amoxycillin and clavulanic acid (Augmentin). IM benzathine penicilin G (with or without oral rifampicin) may be also considered.

Households where three or more cases of GAS pharyngitis occur within 3 months should be screened for GAS pharyngitis as discussed above and in the guideline, in the ‘Household Sore Throat Management’ algorithm (refer to [www.heartfoundation.org.nz](http://www.heartfoundation.org.nz)), and treated if GAS positive (regardless of symptoms).

5. **Recurrent Cases of GAS Pharyngitis: the role of seasonal prophylaxis and tonsillectomy**

Where patients have frequent sore throats, the issue of prophylactic antibiotic treatment
over winter has been debated, but there is currently insufficient evidence to recommend this course of action. Two randomised-controlled studies have shown some benefit for seasonal prophylaxis in circumscribed overseas communities[121, 122].

The role of tonsillectomy in recurrent pharyngitis has not been well investigated. There are three key randomised-controlled studies (RCTs) available on this topic, with total patients numbering only 665 children, all by Paradise [123-125]. One of the three RCTs remains in abstract form [125]. From this limited data there is insufficient evidence to form conclusions about tonsillectomy versus medical management in recurrent pharyngitis.

Conclusions

Most sore throats are viral, but in the GAS of untreated group A streptococcal throat infection, there is a chance this can lead to rheumatic fever and have potentially fatal consequences. New Zealand has a high rate of rheumatic fever by international standards, and the burden of disease rests unfairly on the disadvantaged sectors of the population.

Those most at risk of contracting rheumatic fever in New Zealand are young, Maori and Pacific peoples, living in lower-socioeconomic parts of the North Island, and may have a history of rheumatic fever. The sore throat guideline on which this article is based, and the algorithm reproduced here, takes into account this difference in risk among different patient groups. It takes the sore throats of these at-risk groups more seriously and advises on screening and
treatment for GAS pharyngitis. Ten days of oral penicillin V remains the first-line treatment for GAS sore throats.

GAS pharyngitis is highly infectious. After a patient has been infected with group A streptococcal sore throat, the chance of another household member becoming infected in the ensuing month is up to one in three.

The infectious nature of the illness and its potential sequelae mean that investigation of households may be useful, depending on rheumatic fever risk. If there are 3 or more cases of confirmed GAS pharyngitis within the household in a three month period, the entire household should be swabbed and treated if GAS positive (regardless of symptoms).

This guideline and algorithm have been developed for the New Zealand setting and reflects our unique situation. If appropriately applied, we hope the guideline and algorithm may lead to increased awareness about the importance of group A streptococcal sore throats and ultimately to a reduction in new cases of rheumatic fever – a preventable disease.

Based on McIssac JAMA 2004
2B Proposed Primary Prevention Programme Guideline

There are a number of possible factors influencing the development of RF and hence a number of possible interventions. These are examined in the questions below. Where possible recommendations were made.

For a more in-depth discussion of Primary Prevention strategies to control RF we refer the reader to the full Primary Prevention Guideline, online at www.heartfoundation.org.nz.

1. Socioeconomic Factors: poverty, crowding and housing

Although suggestive of a link between poverty and rheumatic fever, studies do not show a clear-cut association. Rheumatic fever patients tend to have lower incomes, as do many of the controls. Some studies found an association and some did not. Due to the differences in currencies and comparison groups, it is not possible to establish a definitive association or to draw any conclusions for New Zealand. Poverty may feed indirectly into other factors which may impact on rheumatic fever, such as crowding, housing, nutrition, parental unemployment and poor access to healthcare[3, 4, 52, 126-138].

Since the publication of the guideline, the New Zealand Child & Youth Epidemiology Service in their Indicator Handbook have linked the risk of rheumatic fever to high levels of deprivation using the New Zealand Deprivation Index (see above) which is based on household income, access to telephone and car, education level and housing[6].

Many published studies were found on the association between crowding and rheumatic
fever[3, 4, 71, 126, 129, 130, 132-135, 137-156]. There is evidence from comparative studies of a link between crowding in the home and rheumatic fever (Evidence Level 3-2). Information on household crowding is available by region in New Zealand with considerable geographic variation. In the Auckland region there are most people per bedroom (1.41) [157]. There is also good evidence in a study of Auckland children of a link between crowding and another infectious disease, meningococcal disease[158].

A link between quality of housing and rheumatic fever was also investigated[3, 4, 126, 129, 134, 136, 139, 141-143, 147, 151-153, 159, 160]. Some evidence was found for a link between poor quality housing and rheumatic fever, but definitions of housing quality vary between studies. It is impossible to generalise enough to make a recommendation for a minimum standard of housing at this stage in New Zealand.

2. **Biological Factors: approach to GAS pharyngitis diagnosis and management**

There is good evidence from randomised controlled trials that new cases of acute rheumatic fever can be prevented by treating group A streptococcal throat infections with antibiotics[35]. The majority of the original studies were carried out in the 1950’s and involved army recruits using injectable long-acting penicillin. The impressive 80% effect of long-acting penicillin found in a meta-analysis[35] was derived in the majority of studies from patients randomised to treatment or no treatment on the basis of clinically diagnosed exudative pharyngitis. Thus, a public health measure is available, supported by RCT evidence, to control rheumatic fever using long-acting injectable penicillin. The
unacceptability of this has led to the use of oral agents using eradication of GAS from the throat as the microbiological endpoint, as lack of eradication has been shown to equate with risk of developing rheumatic fever[161].

In most developed world settings, diagnosis of GAS pharyngitis is supported by laboratory culture with throat swabs as the ‘gold standard’, with the understanding that some patients may be carriers of the organism [162].

We have proposed (with extensive national and international peer review) an approach to sore throats in New Zealand which acknowledges that perhaps a third of the young population have a high pre-test probability of GAS pharyngitis leading to acute rheumatic fever and its serious cardiac sequelae. In an attempt to overcome this large disparity for rheumatic fever in New Zealand we developed a sore throat algorithm based on rheumatic fever risk factors include living in lower socioeconomic parts of the North Island, whether they are Maori or Pacific peoples, whether they are aged 3-45 years and if they have a past history of acute rheumatic fever as well as clinical criteria (www.heartfoundation.org.nz,[10]. In the algorithm the sore throat is then clinically assessed for the likelihood of GAS as the aetiology, using the scoring system of McIsaac’s modified Centor criteria[103, 104]. Using the algorithm and scoring stratification, those at highest risk of GAS pharyngitis (and its likelihood to lead to RF), e.g. a sore throat and one of tonsillar exudates or tender anterior cervical lymph nodes or temperature ≥38.5°C are recommended for a throat swab and commencement of empiric antibiotics at this first
consultation. Those with a lower number of epidemiological risks factors of RF (lower pre-test probability of RF) need to fulfil a higher number of clinical criteria to reach the threshold for empiric treatment.

- **What is the evidence for genetic susceptibility for rheumatic fever?**

  Clustering of cases of rheumatic fever in families has been documented for more than a century[163-165]. Familial clustering persists when socioeconomic factors and environment are controlled for [166, 167]. It remains unclear precisely what factor or factors render a person particularly susceptible to rheumatic fever. Currently, susceptibility to rheumatic fever can only be defined by contracting the disease. The imperative behind the search for a marker for genetic susceptibility is to identify susceptible persons before rheumatic fever occurs[168-170].

  The evidence for genetic susceptibility to rheumatic fever (grade IV-C) is conflicting. Effective antibiotic treatment of streptococcal throat infection may prevent the expression of susceptibility.

- **Do group A streptococcal skin infections (pyoderma/ impetigo) cause ARF? (Table 2)**

  Whether there is a causal link between skin streptococcal infections and acute rheumatic fever has been debated. A PubMed search for keywords skin and rheumatic fever was made (refer to
search strategy for details at www.heartfoundation.org.nz). Studies from this search were used
for the following questions. Key studies are shown in Table 2.

Recent research on a possible link between skin streptococcal infections and rheumatic fever
has come from Australia. McDonald has hypothesized that recurrent skin infections may
immunize against throat colonization and infection [171], although the link is not supported
with this research[172] Observations in Trinidad and Chile do not support this hypothesis[173,
174]. There is insufficient evidence that streptococcal skin infections cause ARF.

- **Lifestyle Factors**

  The question “does improving nutrition have a role in reducing rates of GAS or in rheumatic
  fever?” was addressed. Seven studies were found[132, 152-156, 175]. These studies addressed
  intake of various food items, particularly eggs[132, 152, 155, 173-175] and rheumatic fever, but
  the research is currently inconclusive. An association has been found between low body weight
  and/or thin arms and rheumatic fever in studies from Zaire, Bangladesh and Yugoslavia[132,
  153, 154]. These studies may not seem relevant in the New Zealand context at first, with
  obesity a growing problem in the local population, but it must be remembered that it is
  possible to have nutritional deficiencies despite a high body mass index (BMI).

- **Health Care Systems and Services**
In the past in New Zealand there has been no evidence that treating GAS pharyngitis in general practice made a difference to rheumatic fever rates[15]. However, as GAS pharyngitis can lead to rheumatic fever we examined the issues surrounding access to healthcare.

It is worth noting that if people do not consider sore throats important, or have the knowledge that they can lead to permanent heart damage, they will not seek medical help, creating a barrier in rheumatic fever prevention. We found one unpublished study conducted in a small rural community (~400 questionnaires) by Te Hotu Manawa Maori (a division of the NZ National Heart Foundation at the time) to evaluate RF awareness before an education programme was carried out[176]. Approximately fifty per cent of responders had never heard of RF and did not know how it was triggered, with ~4% ticking the response suggesting a sore throat or virus infection could be responsible. Other responses were a damp environment, coughing, a cold or ‘flu”, or cold weather. In the NZ school clinic study[8] with appropriate education about sore throats, GAS pharyngitis with appropriately increased streptococcal serology preceded development of 75% of RF cases enrolled in the programme at time of presentation.

Aspects of healthcare access were considered including background, access in socially disadvantaged groups and separately in Maori and Pacific peoples in New Zealand and ways to improve access to healthcare in New Zealand. There was evidence that primary healthcare reform in Maori and Pacific healthcare providers have improved access to healthcare providers. This approach does not address all barriers, such as transport and telephone access, which are encountered by those at risk of rheumatic fever.
With the **knowledge that penicillin can prevent rheumatic fever** and **access to healthcare for the highest risk groups likely to develop rheumatic fever in NZ was (and still is) inadequate**, **school-based sore throat clinics were devised to meet this need**. Community consultation seeking the most appropriate setting eg schools, marae or churches was first undertaken. The school clinic approach to reduce RF was evaluated in Auckland in a randomised controlled trial design[8]. The Auckland study led to a clinically significant reduction in rheumatic fever cases (~30%) in the intervention arm but in this underpowered study (>80,000 person years) this outcome was not statistically significant (p.0.27).

A meta-analysis of similar studies (see Fig 1)[7] was therefore conducted. Our search included terms for trials, before/after studies, and controlled trials with estimable risks relating to the treatment of sore throats with RF as an outcome. **A 60% reduction in rheumatic fever (relative risk 0.41 (95% CI: 0.23-0.70) p 0.001)** was demonstrated supporting community-based, in particular school-based, sore throat interventions. The limitations of this meta-analysis were that many studies were poor quality with only one randomised controlled trial[8]. This is the **best available evidence** in an area with imperfect information. Public health interventions may need to be undertaken in the absence of perfect information.

**Figure 1: Meta-analysis**
Of the analysable school and/or community studies found but rejected for the meta-analysis as lacking poolable data, the majority had significant results favouring the intervention[7].

The recommendation from available evidence supports community sore throat treatment interventions which could be expected to reduce the incidence of ARF by up to 60%.

In addition, historically significant non-RCT’s involving improved access for sore throat treatment for rheumatic fever prevention in low resource settings was summarised in this guideline. [63, 65, 66, 90]

Conclusions and Implementation of the Primary Prevention of Rheumatic Fever Guideline in New Zealand

Based on an evidence-based approach as summarised here, New Zealand can realistically expect to reduce RF rates of Maori and Pacific children and young people to those of other New Zealanders who have a much lower risk of developing RF, by 2020. A much poorer country, Cuba, has demonstrated this is possible in a similar timeframe. Already one small rural community has shown the way, with a significant reduction (p 0.002) in 8 years with a school
sore throat clinic programme[9]. Early signs of engagement at District Health Board and central government level are apparent, though there is much to be done.

Implementation of a guideline throws up many challenges (see www.heartfoundation.org.nz).

An estimate of the feasibility (see Table 1 in Timelines section) in each District Health Board where RF is a feature is underway. Variation of rates of RF by age has led to a differential approach, depending on the epidemiological risk, with school sore throat clinics only for primary and intermediate schools where most of the cases occur[8] and, arbitrarily only in schools with rates >50/100,000/year. This has not been assessed in an economic analysis to date. Medium risk schools/geographic areas (>20/100,000/y in 5-14 year olds) are recommended for appropriate GAS pharyngitis as a priority whether by a family practitioner or an enhanced school nurse service. Strategies to improve the socio-economic determinants of health such as housing are considered a priority in all areas at risk of RF.

Future Directions:

Possible future directions internationally in primary prevention may include further research into genetic susceptibility markers and vaccines against GAS infection. These may not benefit the developing world however, due to cost considerations. The puzzle of why some patients with rheumatic fever do not recall a preceding sore throat (10-33%) also needs to be addressed[177, 178]. Twenty-seven per cent of 60 patients with recurrent GAS pharyngitis of the same serotype had fewer symptoms and may be less likely to seek medical assistance. Avenues such as this provide tantalising possibilities of future directions in the fight against
rheumatic fever. We hope that in our lifetimes, further research will eradicate rheumatic fever and render it obsolete.

**Key Messages**

- Treating GAS throat infections reduces the subsequent rate of development of ARF.
- School, and mixed community and school-based GAS sore throat detection and treatment programmes are all effective in reducing rheumatic fever.
- Crowding in the household is associated with an increased risk of developing rheumatic fever.
- Some studies show a link between poverty and rheumatic fever, others do not.
- There is some evidence linking poor quality housing and rheumatic fever, but definitions vary between studies and it is impossible to make recommendations for minimum standards of housing at this stage.
- Maori and Pacific healthcare providers, school-based sore throat programmes and primary healthcare reforms have a role in improving access to healthcare for patients most at risk of rheumatic fever.
- There is no convincing evidence that rheumatic fever is caused by skin infections.
- There is no convincing evidence of a genetic cause of rheumatic fever and no reliable genetic markers of who is susceptible to the disease.
- The role of seasonal antibiotic prophylaxis for recurrent GAS sore throats has not been proven.
Separate guidelines in this series available to download from: [www.heartfoundation.org.nz](http://www.heartfoundation.org.nz), address the following:

- Group A streptococcal sore throat management, including diagnosis, management and a treatment algorithm.
- Rheumatic fever diagnosis, management and secondary prevention, including treatment algorithms.

In a population at high risk of RF, treatment of GAS pharyngitis should be strongly considered with sore throat plus one clinical sign/symptom only.

A project in Kaeo/Whangaroa in Northland which has now been running 8 years, has been able to demonstrate the disappearance of rheumatic fever in that small community from 1-2 cases per year to zero cases over the last 7 years[179](personal communication Jarman 2009). This school/community sore throat clinic model has been incorporated into a guideline for implementation in public health units and funding is awaited for initiatives in high risk schools in Flaxmere, Hawkes Bay and Opotiki, Kawerau and Murupara, Bay of Plenty. Scoping work is in progress in Tairawhiti and the Auckland region. A new initiative has started up in Kaitaia (see Timeline and Tables).
Algorithm Guide to Public Health Units

Are there well-defined communities within your region containing populations at high-risk for ARF i.e. Pacific people or Māori?

No

No further action is required as your ARF rates are very likely to be low

Yes

What are the annualised rates of ARF in children 5-14 yrs over the last 5 years in these communities?

<20 per 100,000

No further action as there are likely to be more important public health issues with these communities

≥20 per 100,000

Early detection and appropriate treatment of GAS pharyngitis strategies. Advocacy for strategies that address socioeconomic determinants of health such as housing

≥50 per 100,000

Assess the feasibility of implementing a primary prevention school-based programme using a “community partnership” approach
APPENDIX 3: SEVERE RHEUMATIC HEART DISEASE (RHD) FOR CARDIAC CARE IN STARSHIP WEEK OF 13TH JULY 2009

1. V-M T 12 year old. Cook Island ethnicity from West Auckland (WDHB)
   Admitted June 7 to orthopaedic ward and treated as “osteomyelitis” L foot, Also breathless, diagnosis “asthma” Weight 107 kg – all family very large framed so auscultation difficult. Diagnosis of Acute Rheumatic fever (ARF) made after 5days

   **Severe aortic regurgitation (AR) Moderate mitral regurgitation (MR) Very dilated heart**

2. Clinical problem: South African and NZ data shows if operate acutely the continued inflammation of ARF will persist putting the MV repair in jeopardy to deteriorate. Hence we wait (as her heart failure symptoms under control) until active inflammation improves. This can take 2-3 months usually but occasionally 6 months. In meantime if her left ventricular (LV) size deteriorates too much further her ventricular function will be worse post operatively and may not recover.
   Hence she is observed closely in hospital

   **Social:** Parents now separated, father back in Cook Islands. , VM is eldest of 4 siblings. Mother holds down Full time job in town, comes back and sleeps in ward by VM. Other relatives helping with transport and care of other siblings

3. TH 11 yr Maori girl from South Auckland (CMDHB)
   Admitted MAY 2009 **Severe AR mild MR.** Again, timing of operation problematic. Increasing cardiac dimensions despite rest and cardiac medications means operation cannot be deferred safely. Recommended 3 weeks ago but delays due to PICU bed and nursing shortage. Only positive feature is that the mitral regurgitation has remained mild and will not need surgery

   Father works nights, Mother stays sometimes but juggles 4 other children child care

4. JK 12 year Tongan boy from ADHB domicile
   Admitted May 09 **severe AR and MR.** Took 2 months for inflammation to settle
   Surgery 07/09 Aortic valve repair – very good repair left with mild AR this is radical surgery, 5 years ago rheumatic aortic valve repairs were unheard of and all needed replacement. Mitral valve repair – residual mild MR may or may not progress in coming years
   So far:
   60 days cost ward stay = 70K + operation 30K
   $100,000 minimum

   **Other problems:**
   Problem penicillin allergy. On oral ethryomycin. Unknown efficacy against recurrences.
5. **HP. 11 year old Maori girl from Bay of Plenty DHB**
   Father died aged 32 after 3 operations for RHD aged 19, 21 and 30.

   7 week history of lethargy, 3 weeks breathlessness. No acute symptoms of fever, arthritis. **Has severe MR and AR** and very dilated heart due to **rheumatic “indolent carditis”** Major risk of LV dysfunction.

   Likely preventable if we had a programme of RHD echo screening in high risk groups

6. **FT 15 yr South Auckland Severe AR and MR.** Congestive cardiac failure. Also had LLL collapse. Judged too ill to wait so operated within 1 week of transfer from KidzFirst.

   Homograft aortic valve replacement , Mitral valve repair

   Post op LLL collapse and bronchiectasis
   Family socially disadvantaged ++ Parents separated. Father has limited English. No school friends visit. Mother has own health problems

   A homograft aortic valve means she will not need warfarin but the longevity of the valve likely to be 10 - 15 years when she will need repeat valve surgery

   **In summary: 5 children, all previously healthy, all Maori or Polynesian.(by chance no Samoans in this group of 5)**

   **4 of 5 from Auckland DHBs who have the majority of ARF burden in NZ**

   **None have a normal life expectancy** due to the cumulative problems of valve failure, cardiac muscle failure, operative risk, endocarditis, re-operation, anticoagulation and thromboembolism, risks of pregnancy (disastrous for fetus and mother with prosthetic valves on warfarin)

   The hospital costs are enormous, for these 5 children likely 400-600 K.

   Failure to control RF in NZ ironically means our cardiac team and surgeons are among the most experienced in the world for rheumatic heart surgery and RF management in children.

   All these children are suffering from what is regarded in OECD countries as a preventable disease, rheumatic fever.
Acute Rheumatic Fever Could be Eliminated in New Zealand by 2020

Rheumatic fever causes long term heart damage. It occurs following a strep throat in school-aged children. If the strep throat is treated appropriately rheumatic fever is prevented. Lack of progress to date in New Zealand was summarised in a recent National Heart Foundation-sponsored workshop. Ways forward were identified:

- Sore throat clinics in schools in all high risk areas should be implemented. These are already in place in Kaeo, Kaitaia and Opotiki but these areas account for less than 5% of all RF cases.
- Echocardiographic screening to detect missed cases should be researched in detail.
- Improved community and professional knowledge should be addressed urgently.
- Delivery of healthcare through schools is highly efficient (90% adherence to medication) and acceptable (80-85% consent rate: 5-13 year olds). A pilot programme is in the planning phase to test feasibility in one school of extending such a mode of healthcare to control of skin infections (including the large burden of hospital admissions).
APPENDIX 5: NATIONAL RHEUMATIC FEVER REGISTER MEETING MINUTES

Tuesday, December 8th, National Heart Foundation, Ellerslie Auckland

**Purpose**

To progress the work of the June 2009 National Heart Foundation/Ministry of Health sponsored ARF and RHD workshop, specifically with respect to developing a National Rheumatic Fever Register.

The aim from this workshop was the reduction of ARF rates in Māori and Pacific young people to European/other levels by 2020; i.e. New Zealand/Aotearoa ARF free by 2020.

**Objectives**

- Formation of a National Steering Committee
- Specifications for a National Rheumatic Fever Register
  - Aims and objectives
  - Functions, reporting capacity, data collection forms

**Chair**

Professor Norman Sharpe, National Heart Foundation

**Attendance**

Catherine Jackson (Project Manager)
Kahu Livingstone (MOH), Anna Davidson (MOH)
Northland DHB  Corey Pia
Auckland DHB  Diana Lennon, Lesley Voss, Liz Wilson, Judy Haslemore, Jocelyn Curry
Counties Manukau  Karyn Sangster, Pip Anderson, Adrian Trenholme
ARPHS  Brigid O’Brien
Waikato DHB  Michelle Hooker
Lakes DHB  Johan Morreau, Neil Poskitt
Bay of Plenty DHB  Jim Miller, Lindsay Lowe
Hawkes Bay DHB  Janine Mardani, Helen Tobin (Teleconf)
Whanganui DHB  David Montgomery
Wellington Region  Margot McLean, Sarah Grey (Teleconf)
Richard Jaine (Pharmac - Teleconf)
Clair Mills (University of Auckland)

**Apologies**

Northland DHB  Jonathan Jarman
Auckland DHB  Nigel Wilson
Counties Manukau  Catherine Atkinson, Ross Nicholson, Briar Peat
ARPHS  Brad Novak, Julia Peters,
Waikato DHB  David Graham, Polly Atatoa-Carr, Anita Bell
Bay of Plenty DHB  John Malcolm
Tairawhiti DHB  Mary Stonehouse, Kim Quartermaine, Geoffrey Cramp
Minutes

1 Meeting Formalities
Norman Sharpe welcomed attendees to the meeting and thanked them for their time. Introductions were made and apologies accepted.

2 Background
Catherine Jackson briefly presented some rheumatic fever epidemiology, highlighting the disparities in disease burden and presented some of the evidence for optimising secondary prevention.

Diana Lennon discussed the outcomes of the June 2009 National Heart Foundation/Ministry of Health sponsored ARF and RHD workshop that was held in Auckland with New Zealand and international experts attending. This workshop identified the need for a nationally coordinated approach in order to achieve the aim of a reduction of ARF/RHD rates in Māori and Pacific young people to European/other levels by 2020. Six key tools were identified as necessary for achieving this aim: secondary prevention, primary prevention, health promotion, guidelines, a national steering committee, and a web-based national rheumatic fever register. This group was charged by Brendan Grey, Public Health Physician at the MOH at that time, with providing advice to the MOH.

Catherine Jackson presented an overview of the national rheumatic fever register scoping project, its aims and objectives, an overview of the current system of regional registers and the proposed national register, and a list of issues raised during the consultation phase of the project.

3 Rheumatic Fever Control Programme
There was strong support for the following:

- That a national programme for rheumatic fever control be developed with strong national leadership and consistency but with local flexibility recognising the differences in rheumatic fever epidemiology and secondary prevention delivery between the regions.
- That a national rheumatic fever register be considered a necessary but not sufficient component of a national rheumatic fever control programme.
- That a steering group be formed to provide governance for this programme.

Rheumatic Fever Control Programme
The following discussion points contribute to the development a rheumatic fever control programme.
**Aim**
The reduction of ARF/RHD rates in Māori and Pacific young people to European/other levels by 2020

**Components**
- Steering Group
- Primary prevention programmes
- Secondary prevention programmes
- Health Promotion
- Rheumatic Fever Evidence Based Guidelines and National Standards
- Web-based National Rheumatic Fever Register
- Comprehensive ARF and RHD epidemiology

**Additional Comments**
Although this MOH funded project was developed for the purpose of scoping a national register, the focus should move towards the development of a comprehensive rheumatic fever control programme, of which a register is only one component.

The scope of this rheumatic fever control programme needs to move from being regionally to nationally coordinated whilst capitalising on the expertise and experiences accrued to date by those running excellent regional programmes developed locally with a bottom-up approach.

A comprehensive, coordinated and consistent national approach is required to eliminate duplication of effort and the potential for mixed messages. However, there is agreement that local flexibility is also required.

One way to achieve this is via the translation of guidelines into standards/specifications to which DHBs are bound to comply with thresholds set for levels of service provision for rheumatic fever depending on the local epidemiology. Therefore the provision of a specific component of the control programme, e.g. the type of primary prevention programme, can vary between DHBs depending local disease patterns as long as it is within the parameters defined in the specifications. For example, these specifications may require programmes to be evidence based, have defined and measurable outcomes, and include an evaluation component.

Much of the current rheumatic fever workload is funded by DHBs. It would be appropriate for DHBs to be expected by the MOH to implement rheumatic fever control initiatives to a level determined by their epidemiology and also for the MOH to fund and support the provision of this level of care.

Several regions have well functioning secondary prevention programmes and others need additional resources and support. It is essential that current systems that are functioning well are not compromised.

A better understanding of the epidemiology of ARF/RHD than is possible from existing
data sources is required to inform decision making and programme design. In addition, an economic evaluation would greatly support this work and inform funding decisions. An economic evaluation has been commenced by Richard Milne however needs funding for completion.

A key aspect of the provision of secondary care is the secure supply of benzathine penicillin. There have been periodic interruptions in the benzathine supply. There is no national body responsible for responding to supply issues as they occur resulting in considerable stress on those involved in having to ensure continuous delivery of secondary prevention. Currently there is a sole supplier of Benzathine and is supply breaks down there is no alternative. This issue has been raised with Pharmac in the past with the suggestion made that benzathine be sourced from more than one supplier.

Concerns were raised about the devolution of the provision of benzathine prophylaxis to from DHBs public health/district nurses to primary care. The population served by secondary prevention programmes are typically difficult to reach patients, and are best served by mobile outreach delivery of benzathine. Evidence from the existing registers supports this and shows that adherence is greater with nursing delivered rather than primary care delivered benzathine, and that mobile outreach delivery ensures higher adherence than clinic-based delivery.

4 Rheumatic Fever Steering Group
Following discussion the following points were agreed:

- That a coordinated national approach to rheumatic fever control is necessary.
- That a Rheumatic Fever Steering Group (RFSG) be formed to develop a comprehensive rheumatic fever control programme.

Terms of Reference for the Rheumatic Fever Steering Group (RFSG)
The following discussion points contribute to the development of the terms of reference for this steering group.

Purpose
- To provide governance for a Rheumatic Fever Control Programme.

Functions
- National coordination of control efforts
- Clinical Leadership
- Clinical Networking
- Integration of primary, secondary and tertiary services
Oversight of additional working groups that would be responsible for each of the components of the rheumatic fever control programme e.g. the national register, health promotion, guidelines etc.

**Membership**
- Approximately 10 members.
- Inclusive of all of the following stakeholders: clinicians, public health, nursing (those involved in benzathine delivery), primary care, consumers, Māori/Pacific, Ministry of Health
- Members should have expertise in at least one of the identified components of a rheumatic fever control programme i.e. primary prevention, secondary prevention, RHD management, health promotion, guidelines, and registers.

**Funding**
- Funding for a secretariat and meetings be sought from the Ministry of Health

**Suggested Steering Group**
- Johan Morreau
- Diana Lennon
- Nigel Wilson
- Public Health Physician – Jim Miller, Jonathan Jarman, or Margot McLean
- Michelle Hooker
- Norman Sharpe
- Consumer representative
- Māori/Pacific representative
- Ministry of Health
- Primary Care
- Nursing representative

**Additional Discussion Points**
The steering group would oversee the work of additional working groups established to focus on the different aspects of the control programme as necessary. Each working would report to the steering group and would comprise experts from among the identified stakeholders and outside experts as appropriate. The terms of reference for each working group would be established by the steering group.

The steering group needs to be connected to and supported by the Ministry of Health with a clear mandate from the Ministry to providing rheumatic fever governance.

National Heart Foundation, as a charitable organisation, do not have the resources to financially support the steering group; however it is appropriate for a relationship to be maintained between the steering group and the NHF and that NHF expertise and advice be utilised as appropriate.
Kahu Livingstone described the recent formation of a Rheumatic Fever Control Team at the Ministry of Health consisting of Rebecca Blackmore (Manager Communicable Diseases, Population Health Protection Group), Kahu Livingstone (Senior Analyst, Māori Population Health Group), Darren Hunt (Deputy Director Public Health), Pat Tuohy (Chief Advisor - Child & Youth, Health & Disability Services Policy Group), Anna Davidson, and Libby Antoun. This was welcomed by the group as evidence of a Ministry commitment to rheumatic fever control.

5 National Register
Due to time constraints, discussion of the specifics of the proposed national register was limited. There was support for the direction of points raised in the draft document (summarised in the attached slides).

There was strong support for the following:

- That a web-based national rheumatic fever register be considered a necessary but not sufficient component of a national rheumatic fever control programme.
- That registers best work in conjunction with the other components of a control programme, especially adequate secondary prevention delivery systems.
- That the ultimate responsibility and ownership of a national register, and the data contained therein, rest with the Programme Steering Group, but that the governance for the register be provided by a Rheumatic Fever Working Group.
- That a Rheumatic Fever Working Group be responsible for the penultimate development of a national register and ensuring its ongoing security.

National Register Scoping Project
The following discussion points contribute to the project scoping the national register.

Governance
- Provided by a National Register Working Group overseen by a Rheumatic Fever Steering Group.
- This group would be responsible for ensuring the ongoing security of a National Register including the following aspects: funding, hosting, support, back-up, patient privacy, data access, upgrades etc.

Functions
- Confirm Diagnosis
- Ensure Secondary Prophylaxis Delivery
- Ensure Appropriate Management
  - May include a recall function
  - Should include records of clinical follow-up
- Inform epidemiology, strategic planning and programme evaluation
Allow for continuous quality improvement at a local and national level
- Ongoing evaluation of elements of the control programme is an essential function particularly evaluating the impact of initiatives e.g. primary prevention and health promotion
- Fulfil statutory obligations of notification to EpiSurv

Data Collection
- Data collected must inform action and support the functions of the register
- Need to include collection of outcome data i.e. cardiac status over time, deaths, ARF recurrences
- Consider the inclusion of risk factors in the data collected e.g. household crowding, smoking data, NZ Deprivation Index

Technical Issues
Data access protocols need to be developed. There was strong support for local access to local data. This is essential for meeting the aims and objectives of the register and ultimately of a rheumatic fever control programme. In addition, there was support for national level epidemiology from the register.

The development of this register should be kept as simple as possible, whilst allowing the specified functionality. The ability for this database to communicate directly with other health databases is very unlikely to be cost-beneficial. The additional benefits accrued by this ability are likely to be heavily outweighed by the additional development costs.

Potential hosts for the national register were listed including DHBNZ, a DHB, a PHU, the MOH, an independent service provider, a University.

Several individuals that have been involved via consultation have experience in the technical aspects of development and should be included in further work e.g. Neil Poskitt. In addition, further scoping around the costs of software development and hosting should involve an IT business analyst.

Register Staffing
There was support for the inclusion of Register Coordinators in each region to be primarily responsible for local register data collection etc. There was support for the potential roles of this position as described in the scoping document.

Additional Discussion Points
There is a continued statutory requirement to notify cases of ARF. This data is currently recorded on EpiSurv, which collects a set of variables at diagnosis similar to that proposed for the register. While there is some concern regarding duplication of effort, the ability for the register to report this information directly to EpiSurv should be further explored.

The role of a national NZ register in supporting Pacific Nations rheumatic fever control
efforts is not appropriate at this time. It could be considered in the future following the implementation of a national register in NZ.

The inclusion of data collection related to contact tracing should be considered as a function of the national register.

**Concerns Raised**
The governance and ownership of a national register, and the data contained therein, is of great concern for the DHB-based stakeholders involved in this consultation.

Most North Island regions already have functioning registers and have invested a significant amount of effort into the establishment and the maintenance of these. It is essential that the establishment of a national register be cognisant of regional needs and resources, and that current functioning systems not be compromised.

Registers have failed in some regions during times of health sector change due to lack of funding and support.

6  **Action Points**

**Steering Group**
- Convene a Meeting of the Steering Group within the First Quarter of 2010. The NHF offered their premises as a venue – either in Auckland or Wellington.
- Draft Terms of Reference for the Steering Group – Johan Morreau
- Meet with the Ministry of Health

**National Register**
- Establish a National Register Working Group to advance the work of this current project
- Continue the involvement of key stakeholders
These notes have been transcribed from the presentation given by Stewart Eadie on the feedback from the health promotion material workshop as part of the National (2 day) Workshop for the Control of RF/RHD in New Zealand.

**Attendees**

There were about 30 attendees in the Health Promotion session working in primary and secondary care, predominantly in the management of rheumatic fever. A few also worked in the prevention of rheumatic fever.

**Aim of the Health Promotion Session:**

1. To identify what novel communication approaches are needed to engage with those populations most at risk of RF/RHD.

2. To identify what the key messages are and actions required to reduce the incidence of RF/RHD and improve heart health outcomes.

**Introductory Presentation**

Stewart Eadie presented the following information to inform the workshop participants of current resource development issues:

Historically we have used traditional methods of delivering our messages to our target audience. Printed leaflets and booklets have been developed which have been underpinned by evidence based guidelines. However it has been recognised that Heart Foundation resources may not be appealing from a health literacy perspective for those who most need them. This may have inadvertently add to the inequalities.

The chart below shows the level of literacy within New Zealand

*Prose literacy* refers to the knowledge and skills needed to understand and use information from texts including newspaper and magazine articles, brochures and instruction manuals. The lowest level – Level 1, contains those people with the poorest literacy skills.
Health promotion literature demonstrates that to develop effective, targeted resources for populations with limited literacy it is not just a matter of simplifying the resource. The use of pictures is crucial. Pictorial/ graphic novels (comics) are popular as well as other media such as audiovisual, story telling and web-based interactive applications. Consumer focus groups undertaken on behalf of the NHF have identified that comics/illustrated journals that use plain, everyday language are popular and highly visual and can effectively communicate a high level of information on to the community.

Stewart then outlined the way forward for the workshop. Discussion in small groups and feedback was given on the following questions:

• Who is our target audience?
• What do we want our target audience to achieve?
• How will our target audience use this material?
• When will our target audience receive this information?

Stewart explained that as health professionals we are keen to give a lot of information on a topic to our target audience, when in reality four or five key messages are what the target audience need. So we need to consider what they “need to know” verses what is “nice to know”.

**Who is our target audience?**

Group feedback identified the following groups as our target audiences that required specific health promotion messages in order to reduce their risk of RF and RHD.

1. Communities and groups at risk of developing rheumatic fever - sore throat message.
2. People who have had an episode of acute rheumatic fever (ARF) i.e. secondary prevention
• 5-10 yrs and 11-14 yrs
• Adults
• Antenatal
• Families

3. Health care professionals

What do you want your target audience to achieve?

The feedback identified that the target audiences needed to understand the following and that the messages should be adjusted for age:
• Occurrence
• How RF/RHD could be prevented
• How the disease developed (pathophysiology)
• How to manage RF

Rather than give a lot of information we should provide ‘just enough’ information to keep themselves healthy – using the ‘need to know’ rather than the ‘nice to know’ principle.

The behaviour changes the group wanted the target audiences to achieve were:
• Increased uptake in attending clinic
• Increased compliance in treatment
• Communities actively engaged in prevention
• Increased community knowledge of the disease and its prevention

It was highlighted that trusting relationships needed to be developed between the healthcare professionals and the patient and their family/whanau which would help in encouraging change.

The group felt that health professionals should:
• Respect and understand each others’ roles
• Improve relationships between other health professionals
• Provide optimal management in sore throats, RF and assist in a global register

How will your target audience use this material?

The group discussed how the messages might be delivered to the target audiences. Multimedia resources such as visual and audio resources were believed to be the most appropriate. An interactive game, as has been developed in the past which could fit in with the school curriculum was also recommended.

Using groups to disseminated information and encourage change would be of benefit such as peer groups and parent support groups. Social networks such as Twitter and Facebook could also offer support and advice to people.
Healthcare professionals would also need education on RF/RHD and this includes unregistered healthcare workers, GPS and Practice Nurses. Discussion was had as to the development of an education package for practice nurses.

**When will your target audience receive this information?**

The group felt that the target audience would be most receptive in the more intensive acute care setting i.e. when someone is first diagnosed with RF/RHD. Whatever resource is produced, it needs to formally evaluated against current practice to see if it is effective.

**What is happening in NZ?**

Discussion was had from participants as to what resources are currently being used around the country. There was a strong desire to **not** reinvent resources, but to make nationally available resources being used in local programmes. If this was to occur, then they would need to have a national look and feel so as to be used in different areas.

The programme on sore throat management and reduction in RF rates in Northland was highlighted as an excellent example of good school and community engagement especially in sore throat management. They had a number of health promotion resources.

Resources from around the country included:

- Flip chart on sore throat management, a DVD of personalised stories and prevention leaflets from Northland Health
- Resources developed for Prof Diana Lennon’s study into sore throats in South Auckland were being used. The originals have been lost. Rachel to ask for copies
- The Heart Foundation has the ‘What is Rheumatic Fever? Booklet and Sore Throat Matters poster
- Leaflets from a local project on the East Coast were also distributed to the group

**Way Forward**

The way forward was discussed amongst the group and the following outcomes suggested:

- The NHF would collate the minutes from the workshop and email out to attendees to ensure accuracy
- The NHF would help to coordinate a working party to review and develop (where necessary) health promotion resources
- This working party would:
  1. Undertake a more formal review of national resources
  2. Develop a management plan
  3. Inclusive of advocacy doc
4. Identify funding sources
5. Consider summer students to work with a team to help develop culturally appropriate resources (need to work in group).

Minutes written by Rachel Liddel, National Heart Foundation of New Zealand
Facilitated by Stewart Eadie, National Heart Foundation of New Zealand
APPENDIX 7: DEVELOPING CLEAR CONSISTENT MESSAGING: WORKSHOP ON RF/RHD MINUTES – 17 FEBRUARY 2010

Attendees:
Tim Corbett (facilitator)  Kahu Livingstone
Rachel Liddel             Sue Dahl
Stewart Eadie             Helen Herbert
Louisa Ryan               Sussannah Dow
Michelle Hooker           Brad Novak
Diana Lennon              Andrew Lindsay
Lynette Southwick         Sue Cooper
Lindsay Lowe

Apologies
Andrew Fiu                     Jodi Botting
Elizabeth Farrell             Pat Tuohy
Marama Parore                 Helen Tobin

Proceedings:
A video interview by Dinny Lennon with Andrew Fiu was played. Andrew developed rheumatic fever as a child and he gave valuable insight into his experiences as a Samoan growing up in South Auckland and developing rheumatic fever and rheumatic heart disease and the impact on him and his family.

Unfortunately Andrew could not be here today as he is waiting for his sixth open heart surgery but asked that it was conveyed to the workshop the impact that this disease has had on his life. His book, Purple Heart, is now on the NCEA curriculum and that there is much that needs to be done with health promotion to prevent this disease.

Presentation on Current Health Promotion Resources
Rachel Liddel presented on the health promotion resources that were available in New Zealand. There are three guidelines and four algorithms for health professional guidance.

Most health promotion resources available at a local level are focused on sore throat management (Lakes, ARPHS, Northland) in leaflet format although Northland had a range of resources including posters, videos, flipchart and banners. The messaging around sore throats was aimed at parents, family and whanau and available in several languages.

Hawke's Bay had a leaflet that was given out to parents at school if a child there had been diagnosed with rheumatic fever advising what to do about sore throats.
Hawke's Bay and Whakatane DHB were using several resources on primary and secondary prevention in a number of languages which did not align with the current guidelines. The Heart Foundation currently has a resource on rheumatic fever and secondary prevention in English, Tongan and Samoan. Again these resources are aimed at parents, family and whanau. In review, there are current and regional resources being used, many of which are culturally specific and aimed at parents, family and whanau. However some of the messaging was either out-of-date or inaccurate. All resources were text heavy and did not address health literacy issues.

Future resource development by the Heart Foundation includes developing three Bro'Town comics on preventing rheumatic fever, the journey whilst in hospital and secondary prevention.

Feedback from the Rheumatic Fever workshop in June included the importance of encouraging behaviour change, the need to understanding each health professional’s role in prevention and management and identifying target audiences and potential health promotion activities. This included multimedia resources with a national look and feel, peer group support, social networks and educational packages for health professionals.

The health promotion activities in RF/RHD were talked about in relation to the Ottawa Charter. It was agreed that the way forward requires national leadership in health promotion.

**Workshop**

Focusing on the person (potential) affected by rheumatic fever we discussed; who are the key people we need to talk to. This ranged from the personal to the policy levels.

Where could we connect with the following groups?

**The child themselves**

- 5-11 - junior
- 11-14 - senior
1º prevention - well child
2º prevention with RHD

Primary Carer
Mum
Whanau
Big sister
Nan
Friends
Conduit is often the daughter
Decision maker
Kid’s movies
Happy moko
Ethnic
Church groups
$2 shops

Pak 'n' Save
Markets
Clubs
17-22 year olds
Music
Groups - athletics
You Tube
Blog/Facebook
Text
Mobile Phone

Events Manager

Crowd Conveners
Need to know about possible risks (or sore throat spreading) and their responsibility to look after the crowd.

-Informal -
Minister/ Minister's wife
Taumata

-Formal -
Teachers
PPTA (Principal PTA)

School carers
- Older students
Nurse
Secretary
Kapahaka coach

Issues and ideas discussed:
Ideally we should target hotspots, as we know that there are certain geographical areas affected and certain populations.
We need to get the message across that sore throats cause rheumatic fever and the connection between the two.
There are many hurdles for parents in actioning sore throats; time money, healthcare access.
Whilst health professionals are trying to rationalise antibiotic use, we are trying to promote it in certain groups.
We know there are foreign doctors who might not have come across this disease or know that it is an issue in New Zealand.
ARPHS have promoted to 'think differently about sore throats in different population groups'.
We also need to support GPs in becoming knowledgable in management of Rh Fever and sore throats.

Although we identified many areas where we could connect it was decided that we need to do some audience research. This could be done with MoH or HSC.

What Do We Need to Tell Them?
It was decided to focus on what do we need to tell people about prevention, treatment and management.

Prevention
The issue is complex. How do you convey that a sore throat can lead to a damaged heart - as there does not seem to be a logical process. Sore throats that lead to rheumatic fever are caused by a bug that enters the body.

Suggested ideas include:
Don’t spread
Cover mouth when coughing and sneezing
Keep it to yourself
Wash hand and dry
Don’t share
Any sore throat in Maori and Pacific needs attention (see ARPHS communiqué)
Sore throat and link to danged heart

The message(s) need to be personally relevant and emotive - Northland’s sore throats can break a heart is an excellent example of having an emotive tagline.

Michelle Hooker fed back on a youth survey done in Waikato by their district nurses. 76% of respondents were Maori.
On having a sore throat, they wanted to know:
- What does it mean to me?
- The expected pathway of care - what is normal e.g. going to GP?

On being hospitalised, they expressed fear of dying, being emotional and information being pitched above them. We need to remember that we are speaking to children, they wanted to know about the expectations for them in hospital and afterwards. Reinforce the importance of whanau and family pulling you through, about being strong. There was poor knowledge about follow up and why injections were important.
This is a valuable piece of work that Michelle presented and she was encouraged to present and write this up for publication. Analysis of survey to be distributed with these minutes.

Discussion was had on the disease process so that we could see how we could convey this using non-medical words that could be adapted in a visual format whilst focusing on the personal impact of the disease. This can be adapted to whanau, health professionals, youth, kids and carers.

Sequence of sore throat leading to a damaged heart:
About 30% of sore throats are caused by GAS.

**Treatment**
What do we want to tell people about treatment?
You will need an injection every 28 days. This can be delivered at home, clinic, school or workplace.

Need connection between broken hearts and dental hygiene.

We could take a social marketing approach looking at small groups or ethnic media. This could include 'how to' look after others and be delivered in 5 lots of 1-3 mins.

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* = can anyone explain what ‘misses’ refers to?
** = feedback from Stewart post Workshop: this seems to be an adult driven analogy – children do take comments literally, so ?appropriate?
GPs usual consultation is about 15 minutes, with about 7 minutes of this being quality time. They need the guidelines packaged in a user-friendly way, simply put and action orientated. We could utilise 'hive' website which health professionals use.

For those in hospital with rheumatic fever, they are there for a minimum of 2 weeks and so the information can be multi-layered, more in depth and focus on self-efficacy. We need to do some market research on:

- all sore throats count
- functional messaging e.g. if you have a sore throat in the family, tell others - sister, neighbours etc

**Health Professionals**

MOH is working on a framework for rheumatic fever. Sue Dahl has to deliver parameters on policy to MOH by the end of February as to how the MOH should be involved. As health professionals we can raise the profile of rheumatic fever through conferences (GP, IPAC, practice nurses). BPAC has some information on rheumatic fever and Jo Scott Jones has a CME which is web-based.
Health professionals need to raise intensity of sore throats and both diseases. We need to de-medicalise the terminology.

There is potential to develop a PMS module.

**Management**
Due to lack of time we did not cover this topic.

**Conclusion**

There are currently many health promotion resources being used nationally and at a local level. We were unable to go into the detail of messaging however taking a strategic approach enabled us to consider the broader implications around messaging when we then started focusing in on the three topics of prevention, treatment and management.

We need to do further work on demedicalising the sequence of sore throats leading to rheumatic fever. It was identified that we need to gain a greater understanding of our target audience in order to develop effective health promotion materials.

The Waikato survey has given us valuable insight into the person’s experience of RF?RHD in New Zealand and will be used to inform development of resources.

Written by: Rachel Liddel, National cardiac Information Co-ordinator, 18\textsuperscript{th} May 2010
APPENDIX 8: ATTENDEES OF JUNE 2009 NATIONAL & INTERNATIONAL WORKSHOP

Participants were:

Professor Diana Lennon (co-convenor), The University of Auckland, Dr Nigel Wilson (co-convenor), Starship Children’s Hospital, and invited New Zealand healthcare personnel including public health, primary care, paediatricians, physicians, nurses and community health workers and also representatives of the National Heart Foundation.

International guests were Prof Bongani Mayosi, Dr Liesl Zuhkle, Mark Engel from the University of Cape Town; Dr Graham Maguire, Dr Gavin Wheaton and nursing colleagues from Australia and Dr Toakase Fakakovi, paediatrician from Tonga.

Back Row Left to Right: Dr John Malcolm, Dr Melissa Kerdemelidis, Dr Polly Atatoa-Carr, Joanna Stewart, Dr Briar Peat, Dr Teuila Percival, Yvonne Hodder, Dr Toa Fakakovi (Tonga), Dr Sue Crengle, Dr Elizabeth Wilson
Middle Row Left to Right: Gavin Wheaton, Rebecca Blackmore (MOH), Martha Ngawaka, Samantha Colquhoun (Australia), Brendon Gray (MOH), Dr Johan Morreau, Dr John Stirling, Shaelynn Schaumkel, Dr Rachel Webb

Front Row Left to Right: Dr Ross Nicholson, Prof Norman Sharpe, Dr Nigel Wilson (co-convener), Dr Liesl Zuhlke (South Africa), Prof Bongani Mayosi (South Africa), Mark Engel (SouthAfrica), Dr Graeme Maguire (Australia), Prof Diana Lennon (co-convener), Henare Mason

Other Attendees:
Dr Adrian Trenholme, Andrea Calvin, Barbara Eddie, Bia Pham, Dr Brigid O’Brien, Catherine Atkinson, Christine Gemmell, Christina Edmonds, Claire McClintock, Dr Colin Tukuitonga, Crissie Hanover, Denise Booth, Gary Jackson, George Gray, Dr Gilli Sinclair, Dr Graeme Lear, Dr Hayley Bennett, Heather Spinetto, Helen Herbert, Jan Boyd, Jnet Paterson, Janine Mardani, Jaye Fuller, Jessica Vermonger, Lester Calder, Libby Haskell, Lizzie Farrell, Lois Walker, Lorraine Bailey, Lyn King, Margot McLean, Mary Cleland, Michelle Hooker, Dr Neil Poskitt, Dr Phil Shoemack, Dr Pip Anderson, Rachel Liddell, Robbie Atatoa, Dr Roger Tuck, Russell Corin, Rutu Maxwell Swinton, Sandra Ball, Sarah Gray, Dr Siniva Sinclair, Stewart Eadie, Sue Dow, Tania Crothall, Uputaua Goulter, Veronica Butterworth
RESOURCES AVAILABLE ON REQUEST:

- Email from Jonathan Jarman 20.10.09 – Medical Officers of Health Communicable Disease Manual 2009
- Transcripts, Henare Mason (Welcome), Te Aroha Teriaki, Bongani Mayosi, Diana Lennon, Nigel Wilson, Melissa Kerdemelidis, Hayley Bennett
- Email from Polly Atatoa-Carr (07.07.09) – notes on rheumatic fever Waikato
- Email from Pip Anderson (21.07.08) – Rheumatic Fever in the Bay of Plenty & Lakes District Health Boards. A review of the evidence and recommendations for action by Belinda Loring, Public Health Medicine Registrar
- Email from Margot McLean (24.06.09) – Report – Rheumatic Fever in the Wellington Region: A scoping paper identifying gaps in services and recommendations for action by Melanie Martin, Regional Public Health
- Email from Sandra Ball (16.07.09) – Funding Application for “The Development and Implementation of a Rheumatic Fever Prevention Programme for the Eastern Bay of Plenty”. Applicant: Te Ao Hou, Primary Health Organisation
- Hayley Bennett’s slideset – “How a Community Controlled the Streptococcus: Whangaroa school-based rheumatic fever primary prevention”
- Janine Mardani’s slideset – “Rheumatic Fever and the Kirikā Rūmātiki Sore Throat Programme in Flaxmere”
- Stewart Eadie’s slideset – “Health Promotion Materials Nationwide”
- Rachel Liddell’s email (04.09.09) – Notes on Health Promotion Materials from the Workshop
- Diana Lennon’s slideset – “A Preventable Disease with a Long Shadow: Rheumatic fever control in New Zealand”
- Nigel Wilson’s slideset – “Portable Echo for RHD: Can we prevent severe RHD?”
- Melissa Kerdemelidis’s slideset – “Three Evidence-Based Guidelines for Acute Rheumatic Fever Management and Control in New Zealand: Primary Prevention”
- Sue Crengle’s slideset – “New Zealand’s Approach to RHD Screening”
- Diana Lennon’s slideset – “Control of First Attacks of Rheumatic Fever in Auckland: School Clinics”
References:


120. Snellman LW, Stang HI, Stang JM, Johnson DR, Kaplan EL. Duration of positive throat cultures for group A streptococci after initiation of antibiotic therapy.[see comment]. Pediatrics 1993 June 1993;91(6):1166-70.


