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# RapidE: Rheumatic Fever

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**A systematic review of the literature on health literacy, overcrowding and rheumatic fever**



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# 1 Introduction

## 1.1 Background to the project

The Ministry of Health (the Ministry) is currently developing a Work Programme for Rheumatic Fever. The scope of the Ministry's programme is: the analysis of Rheumatic Fever data, cross agency work programme alignment, advice to cabinet on rheumatic fever, advice on targeting populations, targeted communications, awareness and support for individuals, whānau and primary health practitioners. To assist the Ministry in the development of this programme the New Zealand Guidelines Group (NZGG) has been asked to undertake a systematic review in two areas relating to the primordial prevention of Rheumatic Fever. These are: 1) the effectiveness of health literacy interventions, and 2) interventions to reducing overcrowding in households at higher risk of rheumatic fever. In addition, NZGG will provide the Ministry with information on current local activities and initiatives, which are designed to prevent rheumatic fever in high risk communities through health literacy interventions. This information will include an analysis of how current activities fit with what the literature indicates are the most effective components of such interventions.

## 1.2 Epidemiology

Acute rheumatic fever appears to have been virtually eradicated from most 'developed' countries yet globally there were an estimated 300,000 new cases identified annually and approximately 15.6 million people diagnosed with rheumatic heart disease (RHD) globally.<sup>1</sup>

Rates of rheumatic fever (rheumatic fever) in New Zealand have remained at about 200 cases per annum since 1980, corresponding to approximately 15 cases/100,000 children aged 5–15 years of age.<sup>2</sup> Data from the Ministry of Health's Annual Surveillance Report of notifiable disease rates has reported 100–150 cases annually over the last decade compared to the New Zealand Health and Information Service which reported 150–230 cases per year based on hospital admissions and ICD discharge codes.<sup>2</sup> The primary episode usually occurs in children aged between 5 to 15 years<sup>1</sup> and consequently interventions are usually targeted on this group.<sup>3</sup>

Table 1 illustrates the incidence of rheumatic fever and rheumatic heart disease as reported in a number of population based studies.<sup>1 2, 4, 5, 43</sup> The evidence suggests that the rates in New Zealand are comparable to developing rather than developed countries. With the exception of the New Zealand studies (Jaine 2010, Wilson 2010) the data is based on evidence collated up to 50 years ago. This is probably a reflection of the prevalence of the disease which has decreased in some of these countries over time.

**Table 1: Incidence of rheumatic fever and rheumatic heart disease  
(as per specified age group)<sup>1 2, 4, 5, 43</sup>**

Author/year	Study years	Country	Rheumatic fever per 100,000 population (of age group specified)	Age groups
Jaine 2010*	1996–2005	New Zealand	3.4	All age groups
Neutze 1988	1981–1985	Tonga	13.9	Not stated
	1982–1986	West Samoa	16.1	Not stated
	1980–1984	Fiji	15.3	5–39 years
Quinn 1967*	1963–1965	United States America	10.0	All age groups
Berrios 1984*	1976–1981	Chile	5.0	All age groups
Bach 1996*	1981–1992	Caribbean	8.0	< 20 years
Grover 1993*	1988–1991	India	51.0	5- 18 years
Talbot 1984*	1978–1982	New Zealand	22.0	< 30 years
Wilson 2010	Not specified	New Zealand	15.0	5-18 years
		Māori	31.9	
		Pacific	64.5	
		European	1.7	
Flight 1984	1969–1981	New Zealand (Northland)	116.0	Not stated
		Māori		
		Non-Māori		
Ekelund 1967*	1952–1961	Sweden	5.0	0–15 years
Stamek 1981*	1961–1972	Czechoslovakia	16.0	All age groups
Charagozloo 1976*	1971–1973	Iran	35.0	All age groups
Charagozloo 1976	1972–1974	Iran	80.0	Not stated
Majeed 1987*	1980–1983	Kuwait	18.0	<14 years
Majeed 1993*	1984–1988	Kuwait	23.0	5–14 years

\* Reported as first attack of rheumatic fever.

There are widening rates of disparity between Māori and Pacific peoples and other ethnic groups in New Zealand for rheumatic fever.<sup>3</sup> Māori rates are x22 that of New Zealand Europeans and Pacific peoples have rates x75 greater than New Zealand Europeans.<sup>3</sup> The increased rates among Māori and Pacific Islanders may be attributable to factors including overcrowding, poverty, increased rates of Group A Streptococcal (GAS) throat infections and decreased access to and utilisation of health care services.<sup>2</sup> Rates appear higher in the upper half of the North Island.<sup>3</sup> Sixty percent of cases of acute rheumatic fever are linked to urban settings in Auckland and South Auckland.<sup>2</sup>

The consequence of recurrent exposure to rheumatic fever is the development of rheumatic heart disease (RHD) which may include valvular disease and cardiac myopathy and sequelae such as heart failure, atrial fibrillation, systemic embolism, stroke, endocarditis and the requirement of cardiac surgery.<sup>6</sup>

### 1.3 Prevention

There are a number of points at which prevention is possible:

- Primordial prevention – this is usually in children in the absence of a history of GAS and involves improvements in socioeconomic variables and housing.<sup>1,6</sup>
- Primary prevention usually involves identifying and treating a preceding GAS throat infection<sup>6,7</sup> with treatment with antibiotics, although some children may be asymptomatic. Increased awareness and education about the potential impact of developing rheumatic fever and RHD.<sup>1</sup>
- Secondary prevention involves the long-term administration of antibiotics to prevent further recurrence of rheumatic fever and consequently rheumatic heart disease.<sup>6,7</sup>
- Tertiary prevention for those already with RHD and requiring additional medication, anticoagulation and/or surgery.<sup>6</sup>

### 1.4 Relevant New Zealand Guidelines

The New Zealand Heart Foundation has published a series of three clinical guidelines for the management, treatment and prevention of rheumatic fever. The first Heart Foundation guideline made recommendations for diagnosis, management and secondary prevention, and identified appropriate national standards of care in New Zealand.<sup>8</sup> The second guideline made recommendations for the diagnosis and management of Group A streptococcal sore throat in New Zealand.<sup>9</sup> The third guideline was a guideline for the primary prevention of rheumatic fever and rheumatic heart disease.<sup>10</sup>

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## 2 General Section – Methods

A systematic review of the literature was conducted by NZGG using the methodology described below to answer a number of research questions relating to:

1. health literacy /health education and rheumatic fever
2. overcrowding and rheumatic fever.

The systematic review of the literature was supplemented with illustrative examples of successful components of existing international programmes.

In addition, examples of New Zealand case studies in improving health literacy through health education in rheumatic fever were identified and summarised.

The systematic review is based on a review of the 1657 abstracts identified from the literature from 1980 to the present. The following section provides details on the methods used for study selection and appraisal (where appropriate) and the sources used to identify potential studies. Details of the search strategies can be found in Appendix 1.

### 2.1 Research questions

The project was undertaken to establish if:

- interventions to improve health literacy/health education reduced the incidence of Group A streptococcal infection and rheumatic fever
- interventions to reduce overcrowding and improving housing quality were effective in reducing rheumatic fever.

For the purpose of the review the following definitions were used:

- *'high risk'* was defined as children aged 5–15 years and for New Zealand specific questions as Māori and Pacific children aged 5–15.
- *Health literacy*: "health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions".<sup>11</sup>
- *Health education*: health education is directed towards improving health literacy. It is the process through which individuals learn about their health and how to improve it through skill and knowledge development. The format can vary through verbal, printed and electronic material, and should be educationally, culturally and linguistically appropriate. Health literacy is therefore a key outcome of health education.

It should be noted that health literacy and health education are equally applicable to health professionals and educators (teachers).

The specific research questions NZGG used to meet the objectives were as follows.

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### 2.1.1 Health literacy and health education

1. Do health education interventions to improve the health literacy of individuals/families/communities at high risk of rheumatic fever decrease the incidence of GAS throat infections/pharyngitis compared to no interventions or other types of interventions?
2. Do health education interventions to improve the health literacy of education providers in communities at high risk of rheumatic fever decrease the incidence of GAS throat infections/pharyngitis compared to no interventions or other types of interventions?
3. Do health education interventions to improve the health literacy of individuals/families/communities at high risk of rheumatic fever decrease the incidence of rheumatic fever compared to no interventions or other types of interventions?

### 2.1.2 Overcrowding and housing

1. Do interventions to reduce overcrowding in houses of families at high risk of rheumatic fever reduce the incidence of GAS throat infections/pharyngitis?
2. Do interventions to reduce overcrowding in houses of families at high risk of rheumatic fever reduce the incidence of rheumatic fever in children aged 5–15?
3. Do interventions to improve housing (reduced dampness, improved insulation) reduce the incidence of GAS throat infections/pharyngitis in houses of families at high risk of rheumatic fever?
4. Do interventions to improve housing (reduced dampness, improved insulation) of families at high risk of rheumatic fever reduce the incidence of rheumatic fever in children aged 5–15?

## 2.2 Included studies

Systematic reviews often are designed to only include high level evidence from randomised controlled trials (RCTs). However, in some subject areas there are unlikely to be such trials conducted because ethically randomised controlled trials are not appropriate. Rheumatic fever is one such area where it would be unethical to attempt a prevention programme in one group of a high risk population and do nothing in the control group. The majority of the data is likely to emerge from observational/non-comparative and epidemiological studies and large scale population based randomised trials are not anticipated. Due to the lack of randomised controlled trials, as explained above, NZGG included other study designs in order to provide an informative and useful summary based on the available evidence. Therefore, studies meeting the National Health and Medical Research Council (NHMRC) hierarchy of evidence I-IV (systematic reviews, meta-analysis, randomised controlled trials, cohort, case-control and cross-sectional studies) were included (refer to Appendix 2) if they reported on health literacy or health education interventions to reduce the incidence of rheumatic fever and ultimately rheumatic heart disease in children aged 5–15 years. Studies reporting on the epidemiology of overcrowding and housing in relation to rheumatic fever and interventions to address this were also included.

Those studies already included within a published systematic review will not be individually appraised in the current report unless they are felt to be a sentinel paper that requires further detailed reporting.

Some topics such as primordial prevention and health literacy are relevant to the public health strategies of governmental and non-governmental agencies and organisations. In order to maximise the identification of information the search was extended to include examples from these additional resources, in particular from the UK, Australia and the World Health Organization.

## **2.3 Excluded studies**

Case reports (individual patient data), editorials, letters, theses and books were excluded as sources. Documents published in languages other than English were excluded. Studies reporting on secondary prophylaxis, school screening programmes, poverty, and skin infection were also excluded.

## **2.4 Electronic databases**

The search strategy used for Medline and Embase can be referred to in Appendix 1. These search strategies were modified as required for the other electronic databases.

The following electronic databases were systematically searched from 1980 to the present:

- Medline
- Embase
- PubMed
- Cinahl
- all EBM resources on Ovid – this includes the Cochrane Database
- ERIC (Education)
- PsychInfo
- Web of Science
- CCTR
- Sociological Abstracts
- APAIS

## **2.5 Other sources**

Additional sources were searched as the evidence within them was unlikely to appear in the electronic databases searched:

- Ministry of Health – New Zealand
- Te Puna
- World Health Organization
- Commonwealth Department of Health and Ageing – Australia
- Heart Foundation

- Kenyan-Heart National Foundation
- Google Scholar
- World Heart Federation
- TRiP
- Guidelines International Network
- National Guideline Clearing House
- KRIS
- Index New Zealand via Knowledge Basket
- Australian New Zealand Reference Centre
- ESR

## 2.6 Appraisal

Relevant guidelines were assessed using the AGREE II instrument<sup>12</sup> for which the three outcome categories are: recommends guidelines, recommends with modifications, or does not recommend. Following NZGG policy, NZGG used adapted checklists from the Graphic Appraisal Tool for Epidemiology (GATE) framework to evaluate the quality of level I–IV studies (systematic reviews, meta-analysis, randomised controlled trials, cohort, case-control and cross-sectional studies). These can be provided upon request to NZGG, the original tools can be accessed at <http://www.fmhs.auckland.ac.nz/soph/depts/epi/epiq/ebp.aspx>.

The quality scores from the critical appraisal process using the GATE framework indicate whether each quality criterion has been met, is unmet, whether there is insufficient information to make a judgment, or minor flaws. Each checklist evaluates three domains (internal validity, precision, and applicability) and an overall assessment of the study quality (based on a synthesis of the scores for the three domains). This overall assessment includes the reporting of any major flaws that could affect the validity of the findings and the relevance to clinical practice. The overall quality ratings assigned to each study, for this review are:

- *'good quality'*: with low risk of bias or measurement error (+)
- *'mixed quality'*: not well reported, missing data or minor flaws (?)
- *'poor quality'*: significant methodological flaws (X).

Case series, surveys and observational studies are summarised in evidence tables but were not appraised using a critical appraisal checklist. However, the quality of population based studies can be ascertained through a number of components that include: use of population based ascertainment of incidence of disease using multiple sources, active case finding, diagnostic criteria used, clear inclusion and exclusion criteria, methods of case verification detailed, definitions of target population described, demographics of target population, discussion of confounding variables, precision estimates provided.<sup>5</sup> Surveys are considered to be of higher quality if they used validated instruments and have considered internal and external reliability.

## 3 Health Literacy and Education

### 3.1 Background

The results of the 2006 Adult Literacy and Life Skills Survey indicated that New Zealanders have limited health literacy to make 'informed and appropriate health decisions'.<sup>11</sup> This was particularly so for Māori compared with non-Māori. Seventy five to eighty percent of Māori have poor health literacy skills.<sup>11</sup> Those with poor health literacy are known to be less likely to utilise preventative services, be less informed about their disease, management and treatment, be less likely to adequately manage their disease or condition, are more likely to be hospitalised due to a chronic condition, be more likely to attend emergency services and be more likely to be the victim of workplace injuries.<sup>11</sup>

### 3.2 Body of evidence for health literacy and education

- One clinical guideline was identified – National South African guideline<sup>13</sup> (AGREE score – not recommended).
- Three randomised controlled trials were identified – Segador (2005) was considered to be of good quality;<sup>14</sup> Urien (2004),<sup>15</sup> and Colcher (1972)<sup>16</sup> were considered to be of mixed quality.
- One cohort study was identified – Arya (1992)<sup>17</sup> was considered to be of poor quality.
- One case control study was identified – Harre (2000)<sup>18</sup> which was considered to be of mixed quality.
- Four surveys were identified – Kasmaei (2008) was considered to be of mixed quality,<sup>19</sup> Bukachi (2008) was considered to be of poor quality<sup>20</sup> and Bengner (2005)<sup>21</sup> and Mincham (2003)<sup>22</sup> reported on qualitative interviews.
- One non-controlled intervention was identified which was reported in two papers and was considered to be of good quality – Lyengar (1992)<sup>23</sup>, Lyengar (1991).<sup>24</sup>
- Three longitudinal observational studies were identified – World Health Organization (1992),<sup>25</sup> Bach (1996),<sup>26</sup> Nordet (2008).<sup>27</sup> They were not considered to be of good quality.

### 3.3 Summary of findings

#### 3.3.1 Rheumatic fever prevention programmes – education

The South African national guidelines on primary prevention and prophylaxis of rheumatic and rheumatic heart disease for health professionals at primary level<sup>13</sup> is more akin to a guidance document than a clinical guideline. There was no evidence of supporting literature or appraisal of quality of the evidence on which the recommendations were based. The guideline suggested health education, dissemination of information and training directed at all school aged children, patients, parents, teachers, child-minders, health workers (including medical and nursing staff) and anyone involved with children. The suggested programme comprised inter-sectoral and inter-organisational collaborations between primary and secondary care, and education and housing. There was no evidence of a process of evaluation.

In a New Zealand study, Harre (2000) evaluated three communication methods for providing information on rheumatic fever and sore throats to high school students in low socio-economic schools in South Auckland.<sup>18</sup> The majority of the students in this case-control study were of Pacific or Māori background and were considered to be at 'high risk' of rheumatic fever. The control school (n=93), which was matched on decile and pupil demographics received no intervention. The communication methods for the intervention group (n=167) included assemblies conducted by health professionals and community workers. These year group assemblies provided information on the rationale for sore throat clinics and basic information on rheumatic fever and sore throats. Overheads and charts were used to convey the information and opportunities were provided for questions. The second mode of communication was via a lesson conducted by a life skills teacher, and included the use of video material on rheumatic fever and the sore throat project (a screening programme for Group A streptococcal throat infection), and written information on the aetiology and prevention of rheumatic fever. Written information was also provided as a third mode of communication for the students to take home about rheumatic fever and the sore throat clinics.

A questionnaire to assess the knowledge about rheumatic fever and sore throats was administered at baseline and after a four week interval to both schools. The mean number of correctly answered questions in the intervention group increased from  $3.62 \pm 1.56$  to  $5.27 \pm 1.74$  compared with a mean pre-test score of  $2.68 \pm 1.35$  and a mean post-test score of  $2.32 \pm 1.14$  for the control school. There was a significant improvement in the knowledge of the intervention students, and a significant difference between the intervention and control schools ( $P < 0.0005$ ). The intervention school demonstrated an increased knowledge on all questions and increased their knowledge on the link between streptococcal throat infection and rheumatic fever, penicillin as the prescribed treatment, and the association between rheumatic fever and damage to the heart. Feedback from the intervention group students indicated that the mode of communication of least value was the written information that was taken home of which only 35% had read. Year group assemblies appeared to be the most effective mode of communication. The study however did not evaluate the effect of the intervention on any changes in the incidence of rheumatic fever in the population observed.<sup>18</sup>

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In a longitudinal study, Nordet (2008) reported observational/cross sectional data from Cuba.<sup>27</sup> The aim of the study was to develop and implement a practical strategy for the prevention and control of rheumatic fever and rheumatic heart disease. The study included all 5–25-year-olds with permanent residence between 1986 to 1996 and 1997 to 2001. There was a service orientated plan that was implemented through the primary health care system and supported by the national health care system and education system of Cuba. It involved the co-ordinated involvement of hospitals, schools, teachers, patients and their families and the general public. The areas that were targeted by the prevention programme were limitations in expertise of health professionals, lack of public knowledge and awareness of rheumatic fever and rheumatic heart disease and adherence to antibiotic prophylaxis.<sup>27</sup>

There was a training programme for health personnel regarding primary and secondary prevention, surveillance, and a health education programme which involved provision of information and involvement of the wider community.<sup>27</sup> Training of health workers was conducted through workshops, seminars and continuing education programmes. Educational brochures and posters were readily available and distributed initially in English and subsequently World Health Organization resources were translated into Spanish for distribution. The health education activities were directed at the general public and school children and their families. There were provincial broadcasts on the television and radio two to four times a year in which the importance of identifying streptococcal throat infections and the consequent prophylaxis was emphasised. As a consequence of this coordinated programme there was a steady decline in the incidence of newly diagnosed cases of rheumatic fever in 5–15-year-olds from 23.4/100000 in 1986 to 1.9/100000 in 2002.<sup>27</sup> In addition, there appeared to be more timely identification and treatment of streptococcal sore throat. The study illustrates a long-term observational follow-up. However there was no control group to confirm that the intervention resulted in the decreased incidence or if this was due to some other confounding factor.

In another highly cited study, Bach (1996) evaluated the effect of an educational programme on the reduction of rheumatic fever in two Caribbean islands (Martinique and Guadeloupe).<sup>26</sup> The target groups were the public, social and educational professionals, health workers, general practitioners, paediatricians and cardiologists.<sup>26</sup> The materials used included pamphlets that detailed the clinical signs of cardiac complications of rheumatic fever; posters in native language and a 30-minute film. These were distributed by health workers, doctors and teachers to parents of school children and patients attending hospital clinics. As with the Cuban study<sup>27</sup> messages were also regularly broadcast on public and private radio and television. The main point of these messages was to emphasise the contrast between the benign sore throat and the serious cardiac complications. Newsletters were also distributed to doctors around the islands and workshops were held in small villages and communities for general practitioners to attend. The enhanced awareness resulted in an increased number of detected cases in the initial months. The overall programme was associated with a gradual decline (78% in Martinique and 74% in Guadeloupe) in the cases of rheumatic fever. Education was only one component of the prevention programme and Bach (1996) was unable to identify if there was a single component that was responsible for the decline, concluding that it was probably a combination of them all.<sup>26</sup> Bach (1996) reported that there was initial lack of motivation from medical staff and as complete eradication was not achieved there was a need for continued vigilance.<sup>26</sup> It was also noted that there was a decline in reported cases of rheumatic fever in some areas even in the absence of improved socioeconomic circumstances.<sup>26</sup>

The World Health Organization conducted an observational study of an implementation plan for the prevention of rheumatic fever and rheumatic heart disease implemented in 16 countries.<sup>25</sup> The programme constituted a service oriented activity through primary health care and the national health care delivery system of those countries involved. One component of the programme was 'personnel training and health education'. This involved the training of teachers and health personnel to educate 'healthy' children, their families and the general public about rheumatic fever. The health education message was primarily distributed to schools and health centres and was communicated through pamphlets, posters, brochures and radio and television broadcasts and, newspaper articles. The materials were specifically adapted to the locale, cultural and linguistic requirements. In total 24,398 health personnel and teachers were trained to carry out health education and other technical aspects of the programme. Teachers comprised two thirds (67.5%) of those trained. Although training and education varied between the countries involved any improvements led to increased case detection and secondary prophylaxis coverage.<sup>25</sup> There was no raw data provided on changes in case detection after the introduction of the programme.

In the Indian district of Varanasi an evaluation of an educational intervention programme was reported on.<sup>17</sup> The educational programme was delivered by workers in primary health care, rural health care and social workers and used multiple audio-visual medias to convey the message. The content of the programme was not clear. Knowledge about the symptoms of sore throat significantly increased after the health education programme. Those unaware of the causes of sore throat decreased significantly from 15% to 3% ( $P < 0.001$ ) and there was a significant increase in the awareness of the consequences of a sore throat including rheumatic fever (58% to 69%) after the intervention. After the programme those not aware of the symptoms of rheumatic fever fell from 38% to 14% ( $P < 0.001$ ). Awareness of consequences including rheumatic heart disease also increased significantly from 11% to 49% ( $P < 0.001$ ).<sup>17</sup>

Bukachi (2008) reported on an evaluation of an educational programme that had been implemented in Nairobi, Kenya under the auspices of the Kenya Heart National Foundation.<sup>20</sup> The evaluation was conducted using a survey method and there was no evidence of an attempt to link reported cases of rheumatic fever and rheumatic heart disease with the instigation of the education programme. The programme involved training teachers, pupils, health care workers and community groups and the establishment of 'Heart Clubs' in schools and 'Talking walls' (pictorial representations of the heart, and symptoms of rheumatic fever painted on prominent walls of the school or community). Overall, those interviewed felt that the training had improved their knowledge of rheumatic fever, rheumatic heart disease and of sore throat management although there was evidence of a lack of knowledge about the link to heart damage. Only a quarter of those interviewed were aware that children aged 5–15 years were at highest risk and a quarter thought that children under the age of 5 were at highest risk of rheumatic fever. Those who had not been trained were not as well informed about signs and symptoms and the link between sore throat, rheumatic fever and rheumatic heart disease. The study lacked any statistical analysis of the data.<sup>20</sup>

An educational programme was introduced into a rural area of North India and compared with a non-contiguous control block.<sup>23, 24</sup> The programme involved collaboration with the state health and education departments and involved training health care workers and teachers who then subsequently trained their pupils to identify rheumatic fever and rheumatic heart disease, and to motivate compliance with prophylaxis for those diagnosed. A total of 74 health workers, 773 school teachers and 12,500 pupils aged between 10–15 years in the intervention block were trained. The pupils were trained to suspect rheumatic fever not only in themselves but also in the non-school attendee members of their village. They then informed their teacher or a health care worker who referred the suspect case to the nearest health centre.

The training material comprised colour wall charts, posters, pamphlets and acrylic heart models (produced in Hindi) to convey the messages that:

- “rheumatic fever is a serious, life threatening disease that damages the heart thereby permanently crippling the individual
- if at any time between the ages of 5–15 years a person has fever, joint pain or swelling, or breathlessness or fatigue, or has had automatic face and limb movements, one must suspect rheumatic fever
- early recognition and treatment limits damage to the heart and controls the disease. Persons suspected of having rheumatic fever should be promptly referred for diagnosis and long term management. Every patient requires repeated injections on a regular basis failing which the disease may progress.”

In the two years preceding the study the case detection rate was 3.6/100000 population/year in the control block and 7.8/100000/year in the intervention block where the programme was initiated. During the two-year study there were 4.4 cases /1000000/year in the control block and 27.5/100000/year in the intervention block. Of the 140 children referred by school pupils and teachers only 22% of them were considered to be diagnosed with rheumatic fever or rheumatic heart disease. Likewise only 14% of those referred by health workers were subsequently registered. After cardiologist review 21% of the cases that had been registered were removed as they did not fit the strict criteria.<sup>24</sup> This suggests that there may be an additional burden on medical staff and cardiologists to correctly confirm potential cases and ensure that prophylaxis is administered to those with a correct diagnosis.

Following the programme, there was heightened awareness of the disease entity ‘rheumatic fever’ in the intervention block (100% for teachers and health workers and 99% for pupils), but to a lesser extent in the control block (42% for health workers and 7% for teachers and 3% for pupils in the control block)  $P < 0.001$ .<sup>23</sup> Only in the intervention block was there awareness that those aged 5–15 years were at high risk ( $P < 0.001$ ). A significant proportion of teachers and pupils considered babies and toddlers to be most vulnerable ( $P < 0.05$ ). In the intervention area the respondents acknowledged the heart to be the organ at risk of damage ( $P < 0.001$ ) compared with the control block. However, a significantly greater number of respondents in the intervention area also believed the disease to be curable as well as controllable.<sup>23</sup> When asked to list the signs of rheumatic fever, health care workers in both areas, intervention (68%) more than control (4%), were aware of fever and joint pain and swelling (85% versus 27% respectively),  $P < 0.001$ . Knowledge of breathlessness or fatigue and chorea was negligible in the control block (0%) and partial in the intervention block (58% versus 43% respectively). Five percent of control pupils and 9% of intervention pupils were

aware of fever, 0% of controls and 46% of intervention block pupils were aware of joint pain and swelling. Control block pupils were not aware of breathlessness or fatigue (0%) or chorea (0%) whereas the results were 14% and 41% respectively for the intervention block. Following training 11% of pupils and 13% of intervention block teachers compared with 0% and 2% respectively from the control block had encountered a potential case of rheumatic fever, at least half of these were based on signs learned in the training.

An evaluation of the value of a video for increasing knowledge of rheumatic fever/rheumatic heart disease was undertaken in a sample of indigenous Aborigines in Australia (Benger, 2005).<sup>21</sup> The video featured the signs and symptoms of rheumatic fever and rheumatic heart disease and addressed secondary prevention. It was widely used by health centres and shown to new patients, their families and Aboriginal health workers. Ninety percent of the 42 health centres that responded to the survey felt that the video was a 'very valuable' or 'moderately valuable' educational tool. The important features were that the video was culturally appropriate with regards to the 'cast' and that the video was available in local languages.<sup>21</sup>

In planning a primary prevention programme it is important to be aware of where the knowledge gaps exist, if at all, and how best these can be addressed and through which media. The level of knowledge on all aspects of rheumatic fever (epidemiology, symptoms, route of infection, prevention and complications) with the exception of treatment was considered to be poor or moderate in a survey of maternal knowledge by Kasmaei (2008).<sup>19</sup> Kasmaei (2008) suggested that providing information to expectant mothers and in the post-partum period as well as regular information through the media may be useful.<sup>19</sup>

In a qualitative interview study of people in the Kimberly region of Australia with a diagnosis of rheumatic fever or rheumatic heart disease there was a varied understanding of either disease and its management. Although the study was mainly about secondary prophylaxis it highlighted the need for culturally appropriate access to information about the disease and the support of community and clinic health workers.<sup>22</sup> This may equally apply in the prevention of rheumatic fever and Group A streptococcal throat infection prevention.

### 3.3.2 Health literacy and primary prophylaxis with antibiotics

Studies were included that used health literacy or health education interventions to increase adherence/compliance in antibiotic regimens for tonsillitis/pharyngitis. While not specified in the original project brief this area of study was included in this review as NZGG felt components indicating effectiveness in relation to health literacy could be utilised in primordial prevention programmes.

For those diagnosed with a streptococcal throat infection a course of oral antibiotics is recommended in order to prevent rheumatic fever. Compliance for up to 10 days of antibiotics can be difficult and often doses are omitted or there is premature discontinuation.<sup>14</sup> Compliance, or adherence, may be particularly difficult for those with low health literacy. Segador (2005)<sup>14</sup> compared a combination of written and verbal instructions with verbal instructions alone, in adults, on the adherence to antibiotic therapy for tonsillitis of possible bacterial or infectious aetiology (n=158). The written information, which was provided at the time of initial consultation emphasised: 1) the importance of completing the course of antibiotics, 2) of maintaining the intervals between doses and 3) the problems

related to an early dropout. The ability to comprehend was assessed by asking the patient to read and repeat those instructions out loud. The control group was given verbal information only. Compliance in the intervention group was 65.8% compared to 54.4% in the control group ( $P < 0.0008$ ). Over one-third (39.2%) of the control group were under-compliant. For those who did stop taking medication the main reason was resolution of symptoms followed by oversight. The authors concluded that written instructions, in combination with verbal instructions, significantly improve compliance with antibiotic treatment in tonsillitis in comparison with verbal instructions alone. Although this study represents an indirect comparison group compliance with children is likely to be based on the instructions given to, and the understanding, of the primary caregiver.

Urien (2004) utilised telephone support in conjunction with educational information versus educational information alone to promote adherence to antibiotic treatment for tonsillitis/pharyngitis ( $n=121$ ).<sup>15</sup> Good compliance, defined as 80–110% compliance, was significantly greater in intervention compared to control patients ( $P=0.005$ ). As with Segador (2005) the main reasons for non-compliance were clinical improvement and oversight.<sup>15</sup> Similarly, this was an indirect comparison with adults as the target population.

Wu (2008)<sup>28</sup> conducted a systematic review of interventions to increase adherence for medication in otitis media and GAS throat infections in children. The interventions were educational, behavioural and organisational. Only one of the 12 trials identified (10 randomised and two non-randomised) reported on children with GAS pharyngitis (Colcher 1972).<sup>28</sup> Colcher (1972) provided additional oral and written information to the parents of 1–15-year-olds with confirmed streptococcal pharyngitis receiving oral antibiotics compared to no additional information or intramuscular penicillin. There was no difference between groups for treatment failure (positive throat swabs at day 9), however there was a significant difference in the relapse rate which was 24% in the oral antibiotic treatment with no additional information compared with intramuscular penicillin (11%) and oral antibiotic treatment with additional information (8%). The rates of compliance were also significantly lower ( $P < 0.001$ ) in the oral group with no additional information compared with either of the other groups. The study did not ask about reasons for non-compliance. Wu (2008) reported that a combined intervention with educational and behavioural components appeared to be the most effective and that education alone as an intervention had significantly lower adherence than controls receiving usual care.<sup>28</sup>

### 3.4 Discussion

The studies identified ranged in their quality and due to their design NZGG were unable to formally appraise the quality of some. The studies generally described primary intervention strategies to improve the health education or health literacy of the target population (5–15-year-olds) or their parents and teachers. There is a consistent lack of evaluation of these interventions in the identified literature.

The World Health Organization<sup>29</sup> recommends a collaboration between health and education policies to be involved in the control of suspected outbreaks of Group A streptococcal throat infection. The World Health Organization<sup>29</sup> also recommends health education and training of health care providers. Health education should be organised by medical and nursing staff and teachers and should emphasise: i) the importance of recognising 'sore throats', ii) preventing the spread of Group A streptococcal throat infection, iii) the importance of adherence to antibiotic prophylaxis. Health education campaigns in schools are seen as effective by the World Health Organization in increasing awareness of rheumatic fever in schoolchildren and their parents and of the role of children in influencing their parents.<sup>29</sup> The types of media promoted by the World Health Organization are radio, television, newsletters and posters.<sup>29</sup> The important role of public health nurses in the implementation of primary prevention programmes was also emphasised.<sup>29</sup> The World Health Organization continually emphasised in their report the unprecedented role that is played by schools in the spread of Group A streptococcal throat infection and thus of the sentinel role also played in its prevention.<sup>29</sup>

Wilson (2010) suggests that public health campaigns are a requirement to ensure that Māori, whānau and communities are aware of Group A streptococcal throat infections, rheumatic fever and rheumatic heart disease. This should incorporate information about symptoms but should also be vigilant not to provide confused messages about sore throat management. This highlighted information is also relevant to health professionals working in particular communities.<sup>2</sup>

Telephone interventions to increase compliance are relatively inexpensive and can be potentially be carried out by doctors, nurses, pharmacists or other health care workers.<sup>15</sup> The timing of the call is essential and should be adapted to the habits of the country. Calls can be via land lines or mobile telephones.<sup>15</sup> Verbal information supported with written material appears to be effective in increasing antibiotic compliance in those diagnosed with GAS throat infection.<sup>14, 16</sup>

Other authors have suggested increasing the role of nurses and pharmacists in alerting individuals of the potential seriousness of streptococcal sore throat and rheumatic fever.<sup>30</sup> Kaul (1983) also noted that when introducing a health education programme it is important to be aware of traditional health practices and beliefs and to place consideration on the social structure, leadership, family structure and religious beliefs of the target population.<sup>30</sup> Integration of the primary health care system is vital for such a programme to be effective and should involve the training of midwives, nurses, general practitioners and school health service personnel in the recognition of rheumatic fever.

In the studies identified in this systematic review, the main media that appear to be used to inform the target population are

- television and radio
- video/DVD
- written (booklets)
- pictorial (images, posters)
- telephone interventions
- meetings and assemblies.

Only one of the studies identified (Harre 2000)<sup>18</sup> evaluated which media was the most effective in communicating to the target population.

Although secondary prevention of rheumatic fever was not within the scope of this report, it is important to note that those interventions suggested for primary prevention are probably also applicable and should be used in both scenarios.

### 3.5 Conclusion and key messages on health literacy interventions

The evidence has highlighted a lack of systematic evaluation of effectiveness of health literacy intervention programmes for rheumatic fever. The level of evidence of the trials was mainly observational and this is unlikely to change. Only five of the 10 included intervention studies reported a decline in rheumatic fever as a consequence of the intervention.<sup>23-27</sup>

As reported by Lyengar (1991, 1992)<sup>23,24</sup> the subsequent increase in case detection due to increased awareness may produce false positive results and may increase the burden on medical staff and cardiologists if there are increased referrals from the 'community'. Similar initial increases in case detection were reported by Bach (1996).<sup>26</sup>

In a primary prevention programme for rheumatic fever a number of key factors that have emerged from the literature:

- It would appear that multimodal approaches to conveying information are most effective from the evidence synthesised in this review of the literature.<sup>14-17, 31, 32</sup>
- The programme requires inter-sectoral collaboration between ministries of health and education.<sup>13, 18, 23-27</sup>
- The content of the information should clearly portray the risk of the link between a sore throat and heart disease and those most at risk.<sup>20, 23, 24</sup>
- The role of the school in getting the message across is important as those at risk are of school age.<sup>18, 20, 23-27, 33</sup>
- The role of the school and of the peer group in identifying those with a sore throat is also important.<sup>23, 24</sup>
- There is a need to identify the barriers to why children with sore throats in certain high risk areas of New Zealand are not seen by health professionals.
- Information needs to be culturally appropriate and in local languages<sup>21-27</sup> and those delivering the information should therefore ideally come from, or be clearly supported by, the community, church and educational leaders and lay health workers.

## 4 International Rheumatic Fever Prevention Programmes

The following information was identified while undertaking the systematic review reported above, but did not meet the inclusion criteria. Due to the limited nature of the published data reported in the systematic review this additional information was included as it may be useful to programme planners by providing illustrative examples of initiatives that have been used to prevent rheumatic fever, the information covers:

- existing international rheumatic fever prevention programmes
- effective components of health literacy programmes
- local (ie, New Zealand) programmes (this includes an analysis of the quality of local rheumatic fever health literacy programmes).

### 4.1 Existing international rheumatic fever prevention programmes

Three prevention programmes were identified which are currently in use and for which there are details available. There does not appear to have been any formal evaluation through rigorous research methods. However the details of the programmes may be of interest to those exploring the use of such programmes within New Zealand.

#### 4.1.1 The Awareness, Surveillance, Advocacy and Prevention (ASAP) programme<sup>7</sup>

This prevention programme was developed for the control of rheumatic fever and rheumatic heart disease at the 1st All Africa Workshop which was attended by representatives of 39 countries. It is a project initiated by the Pan African Society for Cardiology (PASCAR) and the World Heart Federation. The components of the programme are:

- *Awareness raising* – this focuses on increasing case detection within a community which requires that all key members of the community be aware and alert to risks and signs of both Group A streptococcal throat infection and rheumatic fever. The importance of the involvement of caregivers, teachers and health care workers was noted, especially for those who act as the primary contact point with the health care system. Low levels of awareness may be attributed to the increased priority of other disease-control programmes. There may also be a lack of understanding about the disease, progression and importance of adherence to prophylaxis. It is also important that healthcare workers are aware of the importance of treating Group A streptococcal throat infections and case reporting.
- *Surveillance* – registries of new and existing cases.
- *Advocacy campaign* – as rheumatic fever declines in the developed world, its global effects are somewhat de-emphasised. Advocacy is needed to reverse this trend and highlight the long term effects on children globally. The main barriers are that other conditions are viewed as having greater priority, a lack of reliable epidemiological data, a

lack of public demand to increase prioritisation due to lack of public awareness and a decreased prioritisation on the international health agenda.

- *Prevention programme* – this can be achieved through primary and secondary prevention. The main barriers to primary prevention are lack of public awareness and awareness of health care workers regarding the link between Group A streptococcal throat infections and rheumatic fever, lack of policy on antibiotic administration and sub-clinical Group A streptococcal infection. The role of education is therefore sentinel to the programme.

#### 4.1.2 PREFERE programme – Brazil

(<http://www.world-heart-federation.org> accessed 051110)

Brazil runs a programme referred to as PREFERE (Programma de Prevencao a Febre Reumatica).<sup>34</sup> This programme started in schools and was piloted for six months in Niteroi, Rio de Janeiro. The aim was to build a network for information, training and action to prevent rheumatic fever. The approach allowed children and teachers to come up with their own ideas on how to get the message across. The project organised trainer training for 33 teachers in 30 primary schools, these teachers then trained another 850 teachers who in turn reached 16,000 pupils in interactive projects including events, songs and plays. Brazil also uses the resources from the World Heart Federation database which it is adapted and translated into Portuguese.

The main aim of the PREFERE programme was to build an information/formation/action network about tonsillitis and rheumatic fever from school in order to disseminate and socialise knowledge about this illness and its prevention. The types of projects designed by the pupils to increase awareness included building an information network; key teacher training, happy heart events; song presentations about rheumatic heart fever prevention; theatre play about rheumatic heart fever prevention.

The programme authors conclude that health education currently should not be based only upon giving information about the disease and its consequences as it is not sufficient to promote behaviour changes leading to a healthier lifestyle. The pedagogic approach enabled school communities to develop concepts, to elaborate strategies, to consider situations and to make decisions that potentially produce changes in attitude of children and their relatives regarding the prevention of rheumatic fever.

#### 4.1.3 Samoa

The Samoan Ministry of Health and National Health Services instigate regular health promotion messaging on rheumatic fever and its prevention. These messages appear through national media and regular school visits to promote dental hygiene and medical checks as part of the “keeping schools healthy campaign”. The Samoan Ministry of Health and Ministry of Education work together to train teachers to identify school children with sore throats which ensures prompt referrals to appropriate health professionals. District nurses are also involved in the identification of Group A streptococcal infections and prescribe oral penicillin. A New Zealand Agency for International Development (NZAID) project was used to train health promoters focusing on the primary care training of nurses ensuring rheumatic fever becomes an integral part of the health promotion curriculum.<sup>35</sup>

## 4.2 Effective components of health literacy programmes

NZGG also explored the effective components of more general health literacy programmes to provide useful background information for programme developers.

Sudore (2009) has reported on the literature for interventions to improve care for those with limited health literacy.<sup>32</sup> Pignone (2005) and de Walt (2009) conducted systematic reviews of the literature on health outcomes for patients with low literacy. The systematic reviews were well conducted, searching appropriate databases and describing methodology and quality appraisal of included studies.<sup>31, 36</sup> Pignone (2005) found that although the 'knowledge' increased there was no improvement in literacy.

Sudore (2009) identified three different levels at which information was presented: clinician–patient, system–patient, and community–patient levels.

### Clinician –patient level

Patients are often overwhelmed with information and may leave the consultation without understanding the instructions provided.<sup>32</sup> Sudore (2009) recommended that clinicians employ: i) patient-centred communication to assess patient knowledge; ii) clear health communication as clarity and lack of ambiguity are essential, iii) confirmation of understanding by requesting the patient to restate the information<sup>31, 32</sup> iv) reinforcement through pictorial or graphic representations<sup>31, 32, 36</sup> and combined written and verbal media.<sup>37</sup> The importance of the style of writing, font size and 'reading level' have been emphasised.<sup>32</sup> Some studies reported increased understanding when information was supported with visual aids,<sup>32, 36</sup> video,<sup>32, 36</sup> or interactive video disc.<sup>31</sup> The value of these materials are that they can be viewed at the individuals' pace on multiple occasions and shared with other family members. Bengner (2005)<sup>21</sup> noted the value of video material but emphasised that it must be culturally appropriate including culturally appropriate actors and local languages.<sup>21</sup> Reinforcement by pharmacists, social workers, other family members, caretakers and support networks has also been suggested of value.<sup>32</sup> Those with low health literacy often have some difficulty in interpreting 'risk'. This would be an important component of health literacy for rheumatic fever.

Sudore (2009) summarised a number of approaches that have been demonstrated as being of use in conveying risk:

- use of multiple formats including verbal, written, numeric, pictorial and graphical
- use of a consistent understandable denominator such as 1 out of 100
- use of relevant time frames such as 5 or 10 years instead of lifetime
- use of relative risks rather than absolute risks (ie, risk would be reduced from 10% to 5% rather than a 'reduction of 50%')
- use of frequencies related to people rather than percentages
- use of both positive and negative framing of risk together rather than preferring one over the other.<sup>32</sup>

Adherence to medication can be achieved by using the lowest number of tablets or doses required per day and scheduling these to suit the individual. Visual reminders<sup>32</sup> and telephone back-up<sup>15</sup> have been found to be useful also.

### **System–patient level**

At the system–patient level there is a need to provide easy-to-read materials.<sup>32</sup> The New Zealand literature suggests that this type of material may be better directed to parents and is less likely to be read by the students themselves.<sup>18</sup> There are numerous resources available to evaluate the appropriateness and readability of the language used in educational material.<sup>32</sup>

Involvement of the target population in the development of materials has been shown to increase acceptability, ownership and understanding. The literature lacks evidence to support the long-term effectiveness of written material on ‘outcomes’.<sup>32</sup> Disease management programmes tend to use multi-modal approaches to improve health literacy and often use face to face sessions to reinforce written material.<sup>31, 32</sup> The importance of empowering the environment has also been demonstrated as effective in increasing health literacy, providing opportunities to ask questions and understand relevance.<sup>32</sup>

### **Community–patient level**

Sudore (2009) reported on the immense value, effectiveness and cost effectiveness of lay health workers and health navigators in decreasing disparities in health literacy.<sup>32</sup> These individuals are able to communicate in the local languages, are of the same cultural background, are able to communicate at an appropriate literacy level and are usually respected within their community.

# 5 Case Studies of Rheumatic Fever Prevention Programmes for High-risk Groups in New Zealand

## 5.1 Introduction

This section describes selected case studies of programmes that aim to improve health literacy and prevent rheumatic fever (rheumatic fever) among high-risk groups in New Zealand. Its purpose is to assess how New Zealand-based projects have attempted primordial prevention of rheumatic fever through health literacy interventions, and the extent to which the programmes and activities align with best practices, as outlined in the systematic review. The document closes with recommendations for the future development of health literacy programmes and education activities that aim to prevent rheumatic fever in high-risk communities, particularly Māori and Pacific communities.

Separately, the Ministry has been provided with a list compiling all of the rheumatic fever awareness-raising resources identified within the case studies for consumes which could be adapted for use/re-use in future rheumatic fever prevention activities.

Definitions of 'health literacy'<sup>1</sup> and 'health education' used here are as outlined on page 5 of the systematic review. For the purposes of the case study research, 'high-risk' groups are defined as Māori and Pacific children between the ages of 5 and 15 years.

Health literacy is a relatively recent concept in the New Zealand health sector. Because the concept is still emerging and being defined in different ways throughout the health sector, only one of the programmes identified throughout the research process for this section explicitly sought to prevent rheumatic fever by taking health literacy, as well as general literacy, into consideration (see case study 4). However, most DHBs and PHUs with high-risk populations, are either implementing, or in the process of making plans to implement, health education initiatives and activities that raise awareness of rheumatic fever among communities.

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<sup>1</sup> Health literacy is defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Ministry of Health 2010). Health education is a process through which individuals learn about their health, and how to improve it through skills and knowledge development (ie, improving health literacy is a key outcome of health education).

## 5.2 Methods

This evidence from this section was gathered from two sources:

1. A review of the grey literature for information on current programmes that aim to improve health literacy, and prevent rheumatic fever in New Zealand. This included searching for information on local health education programmes which may have contributed to improving health literacy, though not explicitly aimed to improve it.
2. Semi-structured interviews with programme providers, coordinators, regional Public Health Unit (PHU) representatives, and District Health Board (DHB) representatives.

The literature review and the interviews were restricted to those DHB regions with the highest Rheumatic fever incidence rates. These included: Waikato, Lakes, Bay of Plenty, Hawkes Bay, Counties Manukau, Waitemata, Auckland, Tairāwhiti, Capital & Coast, and Northland DHBs. Sources of grey literature reviewed included: Ministry of Health and Ministry of Education websites; DHB websites; regional Public Health Unit websites; Paediatric Society of NZ; Starship Foundation; Google; and Best Practice Journal NZ.

A list of rheumatic fever prevention programmes for investigation, were identified from a recent stock-take of rheumatic fever prevention programmes in New Zealand (Miller 2010). From this list, rheumatic fever prevention programmes were selected to present as case studies, based on the availability of grey literature on each programme, as well as the availability of programme representatives for interviews. Some of the rheumatic fever prevention health literacy and education programmes which were not selected as case studies, or were more in their developing stages, are presented in Appendix 1.

Snowballing techniques were used to identify more recent interventions and activities that aimed to prevent rheumatic fever by improving health literacy, or through health education. Interviews with programme coordinators, providers and representatives were structured around, and guided by, key best practices, as identified from the preceding systematic review.

The results of this data gathering are presented under the following headings:

- Location and target population
- Project background
- Health literacy or health education intervention
- Messengers
- Other components of the intervention
- Stakeholders involved and their role
- Perceived successes and weaknesses
- Alignment with evidence from the systematic review of literature.

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## 5.3 Case studies of rheumatic fever prevention

### 5.3.1 Case study 1: The Whangaroa Programme

#### Location and target population

The Whangaroa project was located in Whangaroa, Northland.

The target population was Whangaroa Māori communities, including school-aged children and their parents.

#### Project background

The Whangaroa project is an ongoing school-based Rheumatic fever primary prevention programme that was first implemented in February 2002. The programme was developed in collaboration with a local Māori Health Trust, and used a 'mixed' approach, combining school-based interventions with a community-wide health promotion campaign. In 2008, new versions of the school-based programme were launched in Kawakawa, Kaeo, and Kaikohe, with mixed success (BPJ 2008; Te Runanga O Whaingaroa 2009). These programmes used combinations of community awareness raising, both through local media (eg, Māori radio) and throughout the course of school-based throat swabbing and treatment activities.

Recently, Northland has started planning for an integrated approach to rheumatic fever prevention that draws on planning expertise and knowledge across the health sector (Miller 2010). The aim of the integrated approach is to collate, and spread innovations and key learnings, from rheumatic fever prevention programmes in high risk communities. A hui will be convened in early June, bringing together discussions and sharing key learnings from rheumatic fever prevention project co-ordinators and stakeholders in high-incidence communities across New Zealand.

#### Health literacy or health education intervention

For the community campaign, the 'Sore Throats Matter' messages were promoted to raise awareness of the importance of seeking medical treatment for sore throats (Loring 2008). The Whangaroa project and other Northland DHB rheumatic fever prevention campaigns use simple messages appearing in brochures, posters, flipcharts and local media advertorials. These messages inform Māori communities about sore throats and rheumatic fever. Key messages emphasise the link between sore throats and rheumatic fever. Key messages used include:

- Rheumatic fever is a serious disease that can damage the heart.
- Rheumatic fever usually starts with a sore throat, so take sore throats seriously.
- If your child has a sore throat take them to the doctor and ask for a throat swab.
- If the swab shows a strep A bug, the doctor will prescribe a 10-day course of antibiotics.
- It is very important to take all the antibiotics to prevent rheumatic fever developing.

Text and pictorial flipcharts, as well as a video of bacteria attacking the throat, originally developed by a local Māori community organisation for the first Whangaroa programme, are still useful modes of conveying the messages to school children in the current Whangaroa programme. The flipcharts contain 10–15 slides that are accompanied by basic messages on what rheumatic fever is, and how it is linked to untreated sore throats caused by strep A.

Local community health workers went into six local schools (five primary schools, one high school), once every school term, and gave presentations in classrooms using the flipchart and video resources. After each presentation, children participated in an interactive question and answer discussion with community health worker. Posters were also put up in these schools.

A four-week 'Health Kids' programme was also run for a two-year period, beginning in 2005. The Health Kids programme was a package of educational resources and presentations teaching local primary school children how to take care of themselves and stay healthy. As part of the programme, local community health workers gave activities and presentations on when to seek treatment for sore throats, to avoid developing acute rheumatic fever.

Activities to raise awareness of sore throats and rheumatic fever were also been channelled through radio advertorials, and local community events. More recently, resources have also been developed (information booklets, articles, t-shirts) and distributed in packages to attendees at a Kawakawa local Health Expo. Three main messages have been promoted; these are: "sore throats matter", "cover your coughs", and "if you have a sore throat, go to your GP and ask for a throat swab" (Te Runanga O Whaingaroa 2009, p.10).

Other activities, such as an inter-school colouring competition during Matariki, have also been useful for helping raise awareness of rheumatic fever among students in Kawakawa (Te Runanga O Whaingaroa 2009). In 2009, students at local schools were given "rheumatic fever promotion bags", containing information (as well as consent forms for a school-based throat swabbing initiative).

New information brochures have currently been developed by Northland DHB, in consultation with Māori stakeholders (Ngati Hine and Māori Health providers). Diagrams on the new brochure show an algorithm which shows the link between untreated sore throats and damage to the heart. Banners, promotional bags, and locally-designed rheumatic fever logo have also been developed to help maintain the presence of the messages in Māori communities.

### **Messengers**

Local Māori community health workers (*kaimahi*) delivered the educational messages, which were checked for consistency and monitored by a public health nurse. Local *kaimahi* continue to provide ongoing school-based presentations of the educational materials to maintain awareness the messages in Whangaroa.

### Other components of the intervention

For the school-based throat swabbing intervention, a local health worker visited the school three times per week, taking throat swabs of children reporting a sore throat. Local health workers described the throat swabbing process, as well as how to take the medicine if the throat swab is positive for strep A. Those children testing positive for group A streptococcal (GAS) throat infections were prescribed, and treated with a 10-day course of antibiotics (BPJ 2008). The community health workers facilitated these processes and also monitored antibiotic adherence with those children testing positive. There was no cost to the parents of children testing positive for GAS infection; this was covered by programme funds managed by the community health worker.

### Stakeholders involved and their role

The programme was initially driven from Māori communities and local health workers' concerns, and was guided by a Māori community paediatrician. It was delivered in a well-defined high incidence area, by local primary care providers, and continues to be co-ordinated by a single provider (Te Runanga O Whaingaroa), representing 15 local marae who whakapapa to the Iwi Ngapuhi, Ngatikahu ki Whangarua. Te Runanga O Whaingaroa collaborates with the Northland regional PHU in developing and implementing the programmes that raise public awareness of rheumatic fever.

Decision-making is shared by Te Runanga and local Māori primary health care providers (Loring 2008). Local community members have continually been drawn upon for developing campaigns to raise awareness in other high-risk areas. All six local schools participated in the programme (Public Health Media Release 2004).

### Perceived successes and weaknesses

The Whangarua programme is one of the more widely cited successful rheumatic fever prevention programmes reported in New Zealand. Whangarua formerly had one of the highest rates of rheumatic fever in New Zealand, and all the cases were Māori. The last new case of rheumatic fever was reported eight days after the programme started (BPJ 2008; Loring 2008).

The Whangarua programme is reported to have been built using a 'bottom-up' community-partnership approach, with partnerships between local Māori health providers, schools, and the community. These partnerships, as well as Māori leadership over the programme, have been implicated as key factors contributing to its success (BPJ 2008).

Other programmes, such as the Kaikohe programme, have been less successful than the Whangarua programme for a number of reasons, including:

- inadequate management capabilities and understanding of the health issues associated with rheumatic fever
- under-funding of resource development and production for programmes, such as Kaikohe, which have a much larger Māori community compared to Whangarua
- lack of funds to adequately train enough local Māori community health workers (*kaimahi*) on how to deliver the messages appropriately to schools.

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### Alignment with evidence from the systematic review of literature

Many of the studies identified in preceding systematic review sections of this report found that multi-modal approaches to conveying information were most effective. For the Whangaroa programme, a wide variety of communication modes, including brochures, posters, flipcharts and local media advertorials, were used to disseminate messages to school children and the community. As identified in some of the studies in the systematic review, the content of the information should clearly portray the link between a sore throat and heart disease, and those most at risk. In the Whangaroa programme, information resources developed emphasise the link between sore throats, the strep A bug, and rheumatic fever. The resources also provided messages about the importance of preventing rheumatic fever through adherence to the full course of antibiotics prescribed by a GP.

One study in the review suggested that written modes of communication (eg, take-home information pamphlets) were less effective modes of transmitting messages, compared to interactive presentations and discussions at school group assemblies, conducted by health professionals and local community health workers (Harre 2000). For the Whangaroa programme and other Northland DHB rheumatic fever prevention programmes, community health workers used non-written resources, such as the video and the presentations with pictorial flipcharts, in combination with written modes of communication, such as pamphlets.

Studies identified in the systematic review also highlight the important role played by school-based interventions, particularly in getting messages across to children (and their parents) most at risk from developing rheumatic fever. The World Health Organization recommends, and a number of other studies identified in the systematic review also suggest, that successful school-based interventions are involve inter-sectoral collaborations health and education sectors.

The systematic review identifies a need for collaboration between the health and education sectors. Intuitively, for a successful local prevention programme, collaborations must also occur at a local level. This appears to have been strongly present in the Whangaroa programme, which relied largely on collaborations between the Northland DHB, key local Māori stakeholders, and local schools in the district. This local and regional collaboration between health and education sector workers reflects the more community-driven, 'bottom-up', nature of the programme (ie, as opposed to being driven by policies and personnel at a national/ministry level). However, intersectoral collaborations provide opportunities to pool together funding, planning, and management resources, which may have been useful for the less successful programmes in the Northland region (eg, Kawerau).

Qualitative evidence presented in the systematic review, highlights the need for information to be culturally appropriate, and available in local languages; and that those delivering the information should ideally come from, or be supported by the community, church and educational leaders and lay community health workers. The development and provision of culturally appropriate resources was a particular strength of the Whangaroa programme. This was due largely to Māori having leadership of the project, including leadership over the development of resources, in consultation with their existing networks of local Māori communities. Local community health workers in Whangaroa, and a public health nurse, supported the delivery of the information to schools.

### 5.3.2 Case study 2: Bay of Plenty rheumatic fever awareness-raising campaign

Both case studies 2 and 3 are related programmes run by Te Toi Ora Public Health Service, the Public Health Unit (PHU) that co-ordinates services for both the Bay of Plenty (BoP) and the Lakes DHB regions. Community engagement, collaborative partnerships with local providers, maintenance of appropriate funding, and knowledge sharing, occurs regularly between stakeholders, both within, and across, these two DHB regions.

A BoP/Lakes Rheumatic Fever Steering Group meets regularly and takes a collaborative approach to developing and implementing primary prevention initiatives and awareness raising campaigns across the regions. The Steering Group also collaborates to ensure appropriate systems are in place for the monitoring and management of rheumatic fever (Bay of Plenty Health Promotion Workforce Development Group (BoPHPWDG) 2010). These collaborative processes are coordinated by a rheumatic fever co-ordinator at Te Toi Ora; whereas, the rheumatic fever programmes being delivered in the BoP and Lakes DHBs each have separate programme co-ordinators.

#### Location and target population

The Bay of Plenty (BoP) Rheumatic Fever Awareness-raising Campaign used a combination of:

1. general awareness raising in communities across the BoP region
2. targeted raising of awareness among high-risk communities (eg. Māori tamariki, whānau, iwi, and hapū)
3. awareness-raising among local GPs and health professionals.

#### Project background

Prior to the BoP campaign, Toi Te Ora had previously run an awareness campaign in the Lakes DHB. This campaign aimed to reduce rheumatic fever by promoting a number of messages about the preventable nature of rheumatic fever (see case study 3). These same messages are being promoted in a programme currently being implemented in the Bay of Plenty DHB region (Toi Te Ora 2009).

The underlying premise of the BoP campaign is that early diagnosis and treatment of strep throat will reduce the incidence of acute rheumatic fever (Lowe 2010). Almost all of the rheumatic fever cases (90% of all cases) in the Bay of Plenty region occur among Māori children aged 5–14 years (BoPHPWDG 2010; Lowe 2010). The campaign had three main aims for each of the three target populations:

1. General awareness-raising: to increase community awareness and knowledge of rheumatic fever across the Bay of Plenty.
2. Targeted awareness-raising: to increase awareness and understanding of rheumatic fever in high incidence communities (ie, Māori tamariki, whānau, iwi, and hapū).
3. GPs and health professionals: to promote the use of the Heart Foundation Rheumatic Fever Guidelines particularly Algorithm 4 – Guide for sore throat management.

The campaign incorporates a combination of a mass-media community awareness raising campaign, promoting messages about sore throats and rheumatic fever, as well as education and raising awareness of rheumatic fever and sore throats among local GPs and health professionals (BoPHPWDG 2010).

Campaign and educational resources were developed in collaboration with local Māori health providers and community organisations. Alongside the awareness raising campaign, local school-based throat swabbing projects were implemented in primary schools in high-incidence Māori communities, such as Opotiki, Murupara, and Kawerau. Presentations and written pamphlets were given by local community health workers, educating students and teachers about sore throats and rheumatic fever.

A total of 498 random public face to face surveys were conducted in Tauranga, Kawerau and Whakatane. Surveys were administered before, during and after the awareness campaign. Results showed increased knowledge of rheumatic fever and increased awareness of sore throats, which were still higher than pre-campaign levels in the months after the awareness campaign had finished. The public surveys also revealed a knowledge gap in the 15–24-year-old age group, even following the awareness raising campaign. A key challenge for future campaigns will be to develop innovative and creative approaches, capable of reaching the younger generations, many of whom will be the parents of the next generation of children (Lowe 2010).

#### **Health literacy or health education intervention**

The BoP rheumatic fever Awareness-Raising Campaign aimed to increase knowledge and awareness about sore throats and rheumatic fever. The campaign drew from a wide variety of resources which were developed locally, including:

- display kits, which included Bay of Plenty specific pamphlets (with some in te reo), posters, pull up banners, and a general rheumatic fever/sore throat information kit
- a rheumatic fever information book, which can be downloaded from the Te Toi Ora website at: [http://www.toiteorapublichealth.govt.nz/rf\\_resources](http://www.toiteorapublichealth.govt.nz/rf_resources)
- articles for school newsletters
- a large model of the heart, used to help children to understand how rheumatic fever can affect the heart (Lowe 2010).

Written pamphlets and information in te reo Māori have also been developed by local iwi in Opotiki, to raise awareness among kohanga reo, kura kaupapa, and Māori health providers (BoPHPWDG 2010). Educational resources were developed based on adapting existing resources (eg, brochures shared from Northland programmes) in consultation with local Māori community networks.

Many of these resources were part of the information and education provided to school children and teachers in school-based throat swabbing campaign that ran alongside the four month mass media campaign. These resources, and the mass-media awareness raising campaign, promoted the ‘sore throats matter’ and ‘sore throats can break a heart’ messages’. The multi media campaign, launched in March 2010, delivered the messages through:

- local newspaper press releases, advertorials and full page commissioned articles
- radio advertisements promoting the 'sore throats matter' and 'sore throats can break a heart' messages on eight stations across the Bay of Plenty
- Rheumatic fever information was shared with school communities and articles featured in 'Health Promoting Schools' and school newsletters (Lowe 2010).

The key messages promoted in the Bay of Plenty campaign were:

- Rheumatic fever is preventable
- an untreated sore throat ('strep throat') can lead to rheumatic fever
- if a child complains of a sore throat make sure they are checked by a doctor
- if a 'strep throat' is diagnosed, the doctor will usually prescribe a 10-day course of antibiotics
- it is important to complete the whole 10-day course to prevent rheumatic fever from developing
- by taking sore throats seriously, we can help prevent life long illness and suffering for our tamariki. Sore throats matter – get them checked (Lowe 2011, personal communication).

In 2011, additional funding has already been set aside for a further three-month radio campaign which will run from April to June, and reinforce the messages from the 2010 mass media campaign.

Raising awareness of rheumatic fever among GPs and local health professionals was delivered as part of a package of Continuing Professional Development (CPD). The package developed included:

- a rheumatic fever web page developed for GPs and health professionals:  
[http://www.toiteorapublichealth.govt.nz/Rheumatic\\_Fever\\_GP](http://www.toiteorapublichealth.govt.nz/Rheumatic_Fever_GP)
- CPD sessions for GPs, practice nurses, public health and district nurses, and hospital paediatric staff, based on the National Heart Foundation guidelines<sup>2</sup> for the treatment of sore throats and the diagnosis, treatment, and management of acute rheumatic fever
- evening CME meetings with GPs in Whakatane and Tauranga, and several presentations made to clinical staff at both Whakatane and Tauranga hospitals
- Rheumatic fever education sessions for public health nurses who, in turn, passed information on rheumatic fever and sore throats to school staff
- Rheumatic fever presentations to nursing students, public health and B4 school nurses
- relationships have been strengthened local laboratories, other public health units, and local paediatricians (Shoemack 2010).

Resource development for the mass media campaign was funded by BoP DHB. Resources created for each of the school-based swabbing campaigns were supported by a combination of funding from local Māori organisations and the BoP DHB:

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<sup>2</sup> <http://www.heartfoundation.org.nz/index.asp?pageID=2145881465>

- in Opotiki, Te Ao Hou PHO, and Whakatohea Iwi Social and Health (WISH) services provide funding, with support from BoP DHB and Toi Te Ora
- in Kawerau, Eastern Bay PHA (EBPHA) are leading the project, funded by BoP DHB, and supported by Toi Te Ora
- in Murupara, Te Ika Whenua Hauora (TIWH), and Toi Te Ora are funding the project until July 2011, which will thereafter be fully funded by BoP DHB.

### Messengers

The messages for the mass media campaign were delivered to the general community through pamphlets, and radio and newspaper advertisements. Local networks of community workers delivered messages through various resources developed for the campaign, including rheumatic fever pamphlets, meetings, and information books. *Kaimahi* (Māori community health workers) gave presentations on rheumatic fever and sore throats at local schools taking part in the school-based throat swabbing campaigns. The *Kaimahi* promoted the 'sore throats matter' message and disseminated the resources developed specifically for the community.

The rheumatic fever messages were also communicated through the following channels:

- Opotiki radio advertisements (with a te reo mihi and words spoken by local Opotiki community member)
- Māori TV covered the Opotiki project in the Native Affairs documentary on rheumatic fever
- promotional items, including t-shirts, drink bottles, red heart-shaped erasers
- Rheumatic fever information kiosks were set up at Mataatua regional kapa haka and Muriwai tournament hapū challenge
- *Kanohi ki te kanohi* – face to face meetings with local whānau, hapū and iwi
- *Panui*, newsletters in local schools
- newspaper articles as part of media awareness campaign.

### Other components of the intervention

As part of the package of rheumatic fever prevention initiatives in the Bay of Plenty region, school-based throat swabbing campaigns key BoP have been developed and implemented in Māori communities with high incidence of rheumatic fever. The first school-based throat swabbing initiative trialled in the Bay of Plenty region was the Opotiki Rheumatic Fever Prevention Project. This pilot project was modelled on an early South Auckland school-based throat swabbing trial and the Northland school-based throat swabbing campaign in Whangaroa (see case study 1). Te Ao Hou, a local Māori PHO, committed to setting the objectives, leading, and implementing the initiative, with support from Whakatohea Iwi Social and Health Services (WISH), and local iwi.

The Opotiki sore throat programme, aimed at Māori children, whānau, iwi, and hapū in the Opotiki district, was piloted and rolled out across Opotiki schools in 2009.

As part of the Opotiki school-based throat swabbing campaign, a WISH *kaimahi* visited each classroom twice a week, offering a throat swab to any child with a sore throat. If the swab tested positive for the group A streptococcus (GAS) bacterium, the child was prescribed a ten day course of penicillin by their GP. Over the first 12 months 1708 Opotiki school children had throat swabs taken, with 168 children (10%) testing positive for GAS bacteria (Shoemack 2010).

Key learnings identified from the Opotiki project are being used to inform the planning for similar school-based projects in other high-incidence Māori communities in the Bay of Plenty. Projects began in Kawerau in the first term of 2011, and in Murupara in the second term of 2011 (BoPHPWDG, 2010). In Kawerau, awareness raising is also planned for five local kohanga reo.

### Stakeholders involved and their role

The Bay of Plenty Rheumatic Fever Awareness Campaign was coordinated by Te Toi Ora and a rheumatic fever co-ordinator based at Bay of Plenty DHB. As of December 2010, a clinical rheumatic fever co-ordinator from Eastern Bay Primary Health Alliance (EPBHA) was brought on to oversee the co-ordination of the school-based programmes in Kawerau and Murupara.

The campaign maintained involvement of stakeholders through:

- quarterly BoP/Lakes steering group meetings
- separate meetings between the providers/programme leaders and the clinical rheumatic fever co-ordinator, as well as with the Toi Te Ora rheumatic fever co-ordinator once each term
- regular consultations with Māori communities (iwi, whānau, and hapū) and Māori health organisations.

Te Ao Hou, WISH and Te Toi Ora worked in partnership to develop rheumatic fever resources including: posters, pamphlets, pull up banners and information booklet. A pamphlet was developed by local iwi in Opotiki, including in one in te reo Māori, and this is endorsed by local Māori health providers in BoP district.

Modelled closely on the Whangaroa school-based throat swabbing campaign, the Opotiki programme incorporated extensive involvement of Māori community groups, Māori community leaders, Māori service providers and Māori health workers, throughout the development and delivery of the programme. Initial project plans and setting of objectives for the school-based intervention in Opotiki were developed with advice from the Ngati Hine Health Trust (a Māori health organisation previously involved with the Whangaroa project), and with funding from BoP DHB. Māori service providers (WISH in Opotiki, and Te Ika Whenua Hauora, TIWH, in Murupara), community health workers, and recognised community leaders, had existing iwi–hapū–whānau networks with Māori communities which were important for developing culturally appropriate messages, and disseminating them effectively.

## Perceived successes and weaknesses

Key perceived successes of the BoP Rheumatic Fever Awareness-raising Campaign were that:

1. The campaign was based on extensive leadership from local Māori communities and organisations. Local Māori networks were used in each of the school-based programmes to successfully develop and maintain relationships which were vital for disseminating prevention messages on rheumatic fever and sore throats. In Opotiki, managers from Māori service providers WISH and Te Ao Hou took senior leadership over the programme. Local doctors and Māori community leaders openly endorsed the programme at local events (eg, kapa haka) and the programme's messages maintained a strong presence in the local media. Local *Kaimahi* utilised a range of existing partnerships and networks with other local Māori agencies and kura kaupapa to help disseminate the messages.

The campaign maintained a commitment to Whanau Ora, and Māori models of health (eg, Whare Tapa Wha), which helped ensure the cultural appropriateness of the messages promoted. Resources were developed which were specific to the local communities. Each information brochure for the campaigns in Opotiki, Murupara, and Kawerau, for example, depicted a local child with acute rheumatic fever. A te reo pamphlet was also developed by WISH (in the Opotiki school based throat swabbing project). Toi Te Ora is currently seeking opportunities to distribute the te reo pamphlets to kura kaupapa schools, kohanga reos, Māori providers and the wider community across the Bay of Plenty. Involving more Māori and Pacific providers as well as community organisations that can reach Māori and Pacific populations is a main aim for the 2011 campaign.

2. Running the mass media awareness-raising campaign concurrently with the school-based throat swabbing programmes in high-incidence areas, ensured the messages maintained a presence and were reinforced among the community. The school-based throat swabbing programmes was seen as being complementary to the mass-media campaign as it also raised the profile of rheumatic fever prevention and, in many cases, incorporated presentations and written resources developed for the communities.
3. BoP DHB Planning and Funding have specifically ear-marked funds for the Bay of Plenty rheumatic fever prevention programmes since 2008. This ongoing financial support, as well as the prioritisation of rheumatic fever as a health issue has ensured the continual refining of programme resources and raising awareness through the media.

## Alignment with evidence from the systematic review of literature

Consistent with the evidence from the systematic review, the BoP Rheumatic Fever Awareness-raising Campaign used multi-modal approaches, in written and graphic forms, to convey information. The campaign used a broad range of communication modes to disseminate messages in brochures, posters, newspaper articles, radio advertorials, school newsletters, and through local Māori iwi networks.

Also consistent with the systematic review, the messages promoted in the campaign provided information about the link between sore throats ('strep throat') and rheumatic fever, and these messages were also targeted to those most at risk in the region (Māori families). The messages also promoted the importance of preventing rheumatic fever also by adhering to the full antibiotic treatment course for 'strep throat', prescribed by the GP.

In alignment with the literature, the important role of the school in getting messages across to those most at risk was recognised in the Bay of Plenty campaign. Alongside the Bay of Plenty mass media awareness-raising campaign, a school-based throat swabbing campaign in Opotiki (a high-risk area), also provided an avenue for disseminating messages about rheumatic fever. Further school-based campaigns are currently underway in other high risk regions (Murupara and Kawerau).

The Bay of Plenty awareness-raising campaign is slightly broader than the Whangaroa campaign, as it incorporates a health education initiative aimed at raising awareness of rheumatic fever among GPs and local health professionals. This health education initiative was delivered as part of a package of continuing professional development (CPD).

As with the Whangaroa programme, funding and planning expertise for the Bay of Plenty campaign were sourced locally and regionally, from Māori health providers, Māori community organisations, and the DHB. This more local and regional collaborative approach was ideal because existing Māori community networks, particularly those from Māori community health workers, were highly valuable for disseminating the messages and resources, thereby helping ensure the messages were endorsed throughout local Māori communities. This local-regional collaborative approach, also allowed Māori stakeholders to lead the development of culturally appropriate resources (including a pamphlet in te reo) for each of the targeted Māori communities.

### **5.3.3 Case study 3: Lakes DHB rheumatic fever awareness campaign (RFAC)**

#### **Location and target population**

The target population for the rheumatic fever awareness campaign (RFAC) was all Māori people in the Lakes DHB region.

#### **Project background**

The Lakes DHB RFAC was implemented between September and December 2009. The RFAC was a preliminary step in part of a broader rheumatic fever prevention project that now aims to reduce rates using a co-ordinated primary prevention and secondary management approach (Emery 2009). The RFAC had two main objectives:

1. to increase the awareness and knowledge of rheumatic fever amongst Māori people in the Lakes DHB
2. to increase the awareness and knowledge of 'Sore Throats Matter' amongst Māori communities in the Lakes DHB (Emery 2009).

To address both objectives, a number of local resources, such as pamphlets, posters, and education packages, were developed by the BoP/Lakes Rheumatic Fever Steering Group, a Rheumatic Fever Campaign Working Group, and various Māori stakeholders included in the steering and working groups.

The Lakes RFAC was supported by the Ministry of Health's 'Reducing Inequalities' funding programme. The campaign was also supported by direct funding from Lakes DHB, Te Kete Hauora and the Public Health Group at the Ministry of Health (Emery 2009).

### **Health literacy or health education intervention**

Much like the BoP rheumatic fever prevention initiatives, the Lakes DHB RFAC utilised a broad variety of avenues for disseminating key messages, both to the public and to GPs and health professionals. Key modes of communication included:

- pamphlets and posters
- Māori and Pacific radio advertorials
- press releases Rotorua/Taupo/Mangakino
- disseminating information through local iwi networks, and bulletins
- puppet show for Sunset primary school children was developed by local nursing students from the Wairiki Institute of Technology. The show was presented at was accompanied by a 'rheumatic fever education package' which included a story book, with supporting written information and a DVD for parents (Emery 2009). Children participated in a question and answer session at end of show
- community association newsletter/ Rotorua
- GP practice newsletters in Rotorua, Taupo, Turangi, and Mangakino
- a rheumatic fever website developed for GPs and health professionals
- PHN newsletters
- school newsletters and presentations
- an interview Rotorua TV
- an interview Radio Te Arawa
- intranet publications Lakes DHB
- Rheumatic fever project information on the Lakes DHB website, available for access by staff and the general public (Emery 2009).

The campaign messages were also developed into resources for various community promotional events, such as a Health Expo, the National Manu Korero Speech Contest, and a Pasifika Cultural Event (Emery 2009).

Campaign messages emphasised the link between rheumatic fever and heart damage, advising parents to take children with sore throats to GPs for a throat swab. The messages also emphasised the importance of taking all the medication to effectively treat the strep throat. The key campaign messages were:

- Rheumatic fever is a serious disease that can cause heart damage
- if your child has a sore throat take them to the doctor for a throat swab
- Māori children aged 5–14 years are particularly at risk
- it is very important that you take all your medicine as prescribed so that all the Group A strep bugs are killed (Emery 2009).

Local pamphlets and a poster delivering the ‘sore throats matter’ message were developed in te reo Māori and in English. Pamphlet and poster development were led by the Lakes DHB project co-ordinator, the Rheumatic Fever Campaign Working Group and a Lakes/BoP communication team.

The pamphlets were piloted by Korowai Aroha Health Services, a Māori primary care provider in the Rotorua and wider Lakes district. A project co-ordinator led a poster and pamphlet drop, distributing them to a wide range of local Māori community organisations, such as:

- Māori health providers, Rotorua and Lake Taupo PHOs, and GP clinics in high incidence areas
- primary schools, school clinics, and Kura Kaupapa in high-incidence areas (eg, Kaingaroa primary school, Sunset primary school, Te Kura Kaupapa Māori o Hurunga Te Rangi)
- Plunket and Well Child centres
- a health expo for Year 1 nursing students
- Tuwharetoa Health Services
- Mangakino Hauora Kokiri.

Rheumatic fever knowledge and awareness workshop/presentations were developed by the rheumatic fever project co-ordinator, and were delivered to a wider range of community and public organisations, including:

- Korowai Aroha Health Services
- Māori Nurses Forum, including staff from Ngati Pikiao Services
- hospital staff
- Tipu Ora, including Family Start/Parents as first Teachers
- Hunga manaaki Lakes DHB
- public health nurses
- Plunket nurses
- local Te Kura Kaupapa Māori schools
- Rotorua with clinical manager and secondary school-based nurses
- Health Rotorua PHO staff
- a training programme promoting knowledge and awareness of rheumatic fever, given to local GPs in Rotorua, Taupo, and Turangi (Emery 2009).

A rheumatic fever awareness *waiata* was also composed, and this held a regular spot in a weekly Kohanga Reo programme on a Māori radio station (Te Reo Irirangi o Te Arawa) from March to July 2010, as well as being played in an interview in November 2009.

A recent evaluation survey conducted after 12 workshop/presentations, asked respondents to self-rate their knowledge of rheumatic fever and sore throats, and found there was an average increase in rheumatic fever knowledge and awareness of 58% (across all questions and respondents) (Emery 2009).

### **Messengers**

Locally developed pamphlets, posters and flipcharts were developed distributed by local Māori health organisations, including Korowai Aroha Health Services, a local Māori sports foundation and health education provider (Te Papa Takaro o Te Arawa), Lake Taupo PHO, as well as the regional area public health service (Te Toi Ora).

Presentations and education workshops were given by:

- *kaimahi* (Māori community health workers) from Korowai Aroha Health Services
- Te Papa Takaro o Te Arawa
- Lakes Taupo PHO (including Turangi and Mangakino)
- School Principal's Association
- School Staff at Sunset, Aorangi and Western Heights Primary schools, Kaitao Intermediate, and Western Heights High School health clinic staff.

### **Other components of the intervention**

Alongside the three-month awareness raising campaign, a throat swabbing campaign was trialled in outreach clinics in the outreach clinic Fordlands and City clinic, to enhance awareness of sore throats and seeking treatment to prevent rheumatic fever.

### **Stakeholders involved and their role**

Key internal stakeholders included:

- Rheumatic Fever Project Co-ordinator
- Rheumatic Fever Campaign Working Group
- Rheumatic Fever Project Lakes Steering Group Communication Team
- Population Health Analyst
- GM Māori Health
- Portfolio Manager for Reducing Public Health and Reducing Inequalities
- Portfolio Manager for Personal Health.

Key external stakeholders included:

- Māori Health Providers (MHP) Rotorua/Taupo
- Te Papa Takaro o Te Arawa
- Māori communities
- whānau, hapū, iwi

- Pacific Island community
- Tuwharetoa Health Services
- Māori Women's Welfare League
- local schools and school staff
- child health providers (eg, Plunket)
- Lake Taupo PHO
- outreach nurses
- district nurses
- RAPHS
- RGPG Rotorua/Taupo.

The Lakes/BoP Rheumatic Fever Steering Group maintained oversight of the project, and the rheumatic fever Campaign Working Group assisted in the development of the campaign resources, as well as their delivery to local Māori communities.

The Steering Group and Rheumatic Fever Campaign Working Group members included representatives from Korowai Aroha Health Services, Te Papa Tākaro o Te Arawa, Lake Taupo PHO, Rotorua Area Primary Health Services, Lakes DHB, Bay of Plenty DHB and the Waiariki Institute of Technology School of Nursing (Emery 2009). A recent evaluation of the Lakes RFAC found many of the respondents highlighted the inclusive and participatory development processes established within the membership of the working and steering groups.

### **Perceived successes and weaknesses**

A key perceived success of the Lakes DHB Rheumatic Fever Awareness-raising Campaign, is that it was based on kaupapa Māori philosophies, which promote Māori self-determination. Planning, development, and implementation of the campaign was led by a local Māori health professional, with collaborative support from key (non-Māori) health professionals and organisations in the Lakes DHB sector.

Māori health providers and community organisation members guided the decision-making processes of the campaign, and these strong working relationships with Māori stakeholders, enabled them to give and receive critical feedback, and reach a consensus on the resources developed for the campaign. By participating in the development of resources, local Māori stakeholders were able to ensure they were culturally appropriate for target Māori communities.

Māori members of the BoP/Lakes Steering Group and the Campaign Working Group also had strong links with local whānau, iwi and hapū, which were vital for building relationships needed to effectively engage with Māori communities and disseminate the campaign messages.

The main weakness of the Lakes RFAC was that low levels of funding committed for rheumatic fever prevention projects constrained the ability to achieve the campaign objectives. In particular, lack of funding limited the range of resources that could be more effective for specific age, gender, and cultural groups.

### Alignment with evidence from the systematic review of literature

In alignment with the evidence from the systematic review, the Lakes Rheumatic Fever Awareness-raising Campaign (RFAC) used multi-modal approaches, in both written and pictorial forms to transmit information. The Lakes campaign used a wide range of communication modes to disseminate messages, although, lack of available funds seems to have constrained the range of resources developed slightly. Resources developed in the Lakes region include: pamphlets, posters, flipcharts newspaper articles, radio advertorials, school newsletters, on a website created for rheumatic fever resources, and through local Māori iwi networks.

Also in alignment with the literature, the messages in the campaign provided information about the link between sore throats ('strep bugs'), and rheumatic fever. These messages also identified who was most at risk in the region (Māori families), and promoted the importance of preventing rheumatic fever also by adhering to the full antibiotic treatment course for 'strep throat', prescribed by the GP.

Consistent with the systematic review, and similar to the other rheumatic fever prevention initiatives identified in the case studies presented here, the Lakes DHB campaign recognised the important role of the school in getting messages across to high risk communities. Alongside the Lakes awareness raising campaign, school-based dissemination of the campaign messages occurred through group presentations given by local Māori community health workers (*kaimahi*) to students and school teachers.

As with the Whangaroa and BoP programmes, the Lakes RFAC funding and planning expertise were sourced locally and regionally (from Māori health providers, Māori community organisations, and the DHB), with some funding coming directly from the Ministry of Health (Reducing Inequalities funding).

As previously mentioned, and in common with the success of the other projects, this more local community collaborative approach was ideal because existing Māori community networks, particularly those from *kaimahi*, were highly valuable for disseminating the messages and resources, and ensuring the messages were endorsed among local Māori communities. This local community collaborative approach, also allowed Māori stakeholders to lead the development of culturally appropriate resources specifically for Māori communities.

#### 5.3.4 Case study 4: The Bro'town Project

##### Location and target population

The rheumatic fever Bro'town<sup>3</sup> Project is an awareness raising programme targeted at Māori and Pacific children and youth. The programme is currently being trialled in children low decile South Auckland schools, and youth in the Waikato DHB region. Adults and parents of the children are a secondary audience for the project.

<sup>3</sup> Bro'town is a popular New Zealand television cartoon series about the lives of Māori and Pacific children characters in South Auckland.

## Project background

The Bro'town Project is the only project presented in this selection of case studies that specifically took children's health literacy, as well as general literacy, into consideration when developing resources for use in high-risk Māori and Pacific communities. The Bro'town project involved the development of three comic resources on:

1. Comic 1: 'Sore throats – preventing rheumatic fever'
2. Comic 2: 'The hospital journey' (targeted at children and youth admitted to hospital with suspected ARF)
3. Comic 3: 'How to prevent another attack of rheumatic fever' (ie, secondary prevention, targeted at children and youth diagnosed with rheumatic fever).

Of these resources, the Comic 1 is relevant to the series of case studies presented in this section. The comic resources are a graphic rheumatic fever information tool, developed specifically for children and youth in high-incidence communities. This pictorial approach to providing health education messages about rheumatic fever, takes into account the health literacy of the target age group, and is one of the few tools in New Zealand which has been primarily targeted towards school children.

## Health literacy or health education intervention

The Bro'town comics are traditional hard copy comics, presented in the style the Bro'town cartoon television series. Comic 1 ('Sore throats – preventing rheumatic fever') contains a few basic key messages presented by various characters from the cartoon.

The main aim of Comic 1 was to educate Māori and Pacific children and youth (and their parents) about what to do when they have a sore throat, and why they are important. Key messages included in Comic 1 are:

- If you are a Māori or Pacific child, tell an adult (parent, whānau member, teacher, school nurse) when you have a sore throat, as sore throats are important and can lead to heart damage.
- For adults, when a (Māori/Pacific) child tells you they have a sore throat, take them to the GP or nurse to get it checked.
- The GP/nurse will look in your mouth, take a throat swab for 'strep throat' and take your temperature.
- If the GP/nurse gives you antibiotic pills – take them for 10 days as prescribed, to get rid of the bug. People often stop them earlier as they feel better, but they shouldn't stop until the full course is finished.
- Stay off school until you have had a day of antibiotics.
- Tell an adult (eg, parent, whānau member, teacher or school nurse) if you have one or more swollen joints, short of breath, have a fever or are fidgety (bumping into things, dropping things).
- To stop bugs spreading, wash your hands and cover your mouth when coughing and sneezing around others (Liddel 2010a).

Comic 1 has recently finished being pre-tested in a decile 1 school in South Auckland and a youth group in Waikato. Further resources, including a teaching unit, are currently being developed for piloting in other high-incidence Māori and Pacific children in New Zealand, including the Waikato DHB. The teaching unit contains a package of information handouts, overhead slides, a poster and a memory stick with rheumatic fever information on it. These teaching units are being pre-tested in junior and senior students at a Papakura Intermediate.

Comic 1 is due to be launched on a nationwide 'Jump Rope for Heart' tour, led by the National Heart Foundation. The launch will be a small presentation on the rheumatic fever comics given to teachers and students. Teachers will also receive information about the teaching units which are due to reach final stages of development in the next two months.

### **Messengers**

The Bro'town comic on preventing rheumatic fever (Comic 1) is a 'tool' that will be made available for use in high-risk communities in New Zealand. The tool was developed specifically for other organisations in high-risk areas to be able to access, and adapt, for use in their local community (ie, the Bro'town comic is a rheumatic fever prevention/health education *resource*, which can be used in programmes that aim to prevent rheumatic fever by increasing awareness and knowledge of sore throats and rheumatic fever).

### **Other components of the intervention**

Comics 2 and 3 are almost at the end of development stages, and will soon be ready for pre-testing in schools across the CMDHB and Waikato DHB regions. Comic 2 aims to educate children admitted to hospital with suspected ARF about why they are in hospital, what rheumatic fever is, and what rheumatic heart disease is. Comic 3 provides key behavioural messages about how to prevent a second attack of rheumatic fever (eg, monthly penicillin injections) to children and youth who have had rheumatic fever.

### **Stakeholders involved and their role**

The development of the comic resources was led by a team at the National Heart Foundation (NHF), and informed by prior research and project members with expertise in health literacy. The Bro'town concept was originally presented to the Heart Foundation by a group of nurses from the Counties Manukau District Health Board (CMDHB).

Key stakeholders and their roles included:

- academic and research support from Professor Diana Lennon (University of Auckland)
- public health nurses from Counties Manukau, Waikato and Bay of Plenty DHBs. PHNs were involved with disseminating resources to their key stakeholders for consultation
- school principals in the CMDHB region
- Pacific Heartbeat managers, who were consulted during the comics' development
- Pharmac
- a paediatric cardiologist, who helped inform the comics' content development.

### Perceived successes and weaknesses

The Bro'town comics are still in their early stages, and are yet to be rolled out across a larger number of schools in South Auckland. Thus far, perceived successes of the project are:

- Its concept design, which uses a culturally relevant TV cartoon (Bro'town) to communicate messages to the target population (Māori and Pacific children and youths). The original idea for the concept was devised from a group of Pacific nurses who work with Pacific and Māori communities in CMDHB.
- The wide and extensive consultation processes that informed the programme's development. Numerous consultations with key stakeholders took place during concept development, the development of key messages, and the design of the comics.
- The programme was informed by the NHF's involvement with research on health literacy over a number of years leading up to the Bro'town project.

### Alignment with evidence from the systematic review of literature

Although still in its early stages, consistent with the evidence from the systematic review, the Bro'town programme is taking a multi-modal approach to conveying information on sore throats and preventing rheumatic fever. In addition to the Comic 1, messages are conveyed through a teaching unit containing overheads, a poster, information handouts and a data stick with rheumatic fever information resources.

As discussed in the systematic review, the school plays an important role at getting messages across to those most at risk, and collaborations between the health and education sectors are important for transmitting messages to children effectively. The Bro'town resources were specifically designed, pre-tested and are in the process of being piloted, in schools in high incidence areas of South Auckland and Waikato. These processes required extensive collaborations between the education and health sectors, although, unlike the previous three case studies, a national-level organisation (the NHF) led the Bro'town project.

Also consistent with the evidence in the systematic review, the information content describes the link between sore throats ('strep throat') and rheumatic fever. In addition to messages about what to do when they have a sore throat, the information includes a message about antibiotic adherence, and preventing the spread of bugs. This information is presented in a culturally relevant format, using characters from a recognised TV programme, popular among Māori and Pacific children and youths.

## 5.4 Lessons learned from case studies and recommendations

### 5.4.1 Summary of alignment of case studies with evidence from the systematic review

The case studies presented in this section aligned closely with many of the key factors that emerged from the literature included in the systematic review (p.15). These key factors are:

- multimodal approaches to conveying information are most effective
- the programme requires inter-sectoral collaboration between health and education sectors
- the content of the information should clearly portray the risk of the link between a sore throat and heart disease and those most at risk
- the role of the school in getting the message across is important, as those at risk are of school age
- the role of the school and of the peer group in identifying those with a sore throat is also important
- there is a need to identify the barriers to why children with sore throats in certain high risk areas of New Zealand are not seen by health professionals
- information needs to be culturally appropriate and in local languages and those delivering the information should, therefore, ideally come from, or be supported by, the community, church and educational leaders and lay health workers.

In alignment with the evidence presented in the systematic review, all of the case studies of rheumatic fever prevention programmes in high risk communities used multi-modal approaches to convey information. These programmes promoted messages about sore throats and rheumatic fever across a wide range of written and non-written channels, including: local media (newspapers and radio stations); promotion at community events; and resources developed for use in schools (posters, flipcharts and brochures).

Of the three programmes in Whangaroa, Lakes and BoP DHBs, the BoP awareness raising campaign was the most comprehensive as it also incorporated a health education initiative aimed at raising awareness of rheumatic fever and sore throats among GPs and local health professionals.

Funding and planning expertise for the Whangaroa, BoP, and Lakes programmes were largely sourced locally and regionally (from Māori health providers, Māori community organisations, and the DHBs), with some funding obtained directly from the Ministry of Health (eg, Reducing Inequalities funding). This more local collaborative approach was effective because existing Māori community networks, particularly those from *kaimahi* (Māori community health workers), were useful for disseminating the messages. These networks also gave rise to wide endorsement of the messages among local Māori organisations and communities.

In keeping with kaupapa Māori principles, this local collaborative approach, also allowed Māori stakeholders to own, and lead, the development of culturally appropriate education resources for their communities. This included developing information brochures in te reo Māori.

As identified best practice from the systematic review, all of the case studies use school-based education methods to disseminate information resources to children and their parents. In some instances a school-based throat swabbing campaign ran alongside the health education campaign.

In alignment with the systematic review, messages in the programme clearly convey the link between sore throats or strep A, and how to prevent rheumatic fever by seeking a throat swab and treatment by a GP. All of the three DHB programmes also included an educational message about the importance of preventing rheumatic fever through antibiotic adherence. In addition to these messages, the Bro'town comic on sore throats and preventing rheumatic fever, presented messages about the importance of preventing the spread of the strep A bug through hygiene, covering coughs, and staying at home from school until better.

It is important to note that conveying a message does not overcome the barriers that make it difficult for Māori and Pacific children (and their parents) to access GPs and primary health care. Although discussion of the complementary role of the school-based throat swabbing initiatives (running **alongside** mass media campaigns) is beyond the scope of this review, it is noted that some community health workers and public health nurses provided a link between the GP and the child with strep A. In many of the school-based throat swabbing campaigns, those testing positive for strep A, were prescribed a full course of antibiotics by their GP, in a process coordinated by the community health worker. In Whangaroa, this process occurred (and still occurs today) at no cost to the parents of the child with strep A.

#### 5.4.2 Conclusions and recommendations for developing health literacy and education programmes for high-risk groups in New Zealand

Based on best practices as outlined in the preceding systematic review sections of this report, and information gathered on rheumatic fever education activity in New Zealand, the following conclusions are drawn:

1. Māori (and Pacific) leadership is important for ensuring the programme and its messages are endorsed and accepted by community members.
2. Local Māori and Pacific community networks are important for ensuring the culturally appropriateness of health literacy and health education resources developed. These local networks are also valuable for disseminating the resources and messages to the community.
3. Sharing resources across programmes developed in high-risk communities reduces time and costs associated with developing the resources from scratch.
4. School-based education and awareness raising activities which are run alongside mass media campaigns can help establish and maintain a presence for the messages in the community.
5. School-based throat swabbing campaigns can also help prevent rheumatic fever in high-risk Māori and Pacific communities by diagnosing strep A in a process facilitated by community health workers. Community health workers, in turn, provide those children testing positive for strep A with medication prescribed by their GP. This overcomes the range barriers that Māori and Pacific experience when accessing primary health care.

Productive but feasible options for improving the consistency and quality of rheumatic fever health education and prevention include:

1. The Ministries of Health and Education explore intersectoral collaborative funding mechanisms to increase the pool of funds available for programmes. A larger pool of funds is needed to provide training resources in high risk areas where expertise in rheumatic fever prevention is apparently less developed (eg, Kaikohe and other less successful Northland programmes).
2. A national overview of health literacy is communicated to rheumatic fever prevention programme providers and stakeholders, to ensure that the increasingly used concept is understood consistently across New Zealand.
3. Processes and structures are established that allow programme providers and stakeholders to consolidate and share resources, innovations, and key learnings.

## 6 Overcrowding and Rheumatic Fever: Systematic Review

There is a range of definitions used in the literature regarding 'overcrowding', which appear primarily to be based upon judgements about the adequacy of personal space within the accommodation, or 'crowding' which is more often defined as the number of people per room in a dwelling. In summarising the included literature both of these terms have been used and definitions provided when available. The definition currently used in New Zealand can be referred to in Appendix 3.

The Ministry of Social Development document on 'Children and young people: Indicators of wellbeing in New Zealand, 2008'<sup>38</sup> reported that in 2006, 17% of children younger than 15 years old (n=136,563) lived in crowded conditions – where one or more additional bedrooms was required. With regards to ethnic differences Pacific children were the most likely to be living in crowded households. In 2006, 46% of Pacific children younger than 15 years old lived in crowded households compared with 28% of Māori and 8% of European children. The data indicated that over the previous two decades there had been evidence of decreased crowding in these ethnic groups and that this had been most pronounced for Māori children. The highest levels of overcrowding were reported in areas of South Auckland, Opotiki and the Far North.<sup>38</sup>

### 6.1 Body of evidence

- Two clinical guidelines were identified – The Heart Foundation – New Zealand (2009)<sup>10</sup> (AGREE score – Recommend with provisos or alterations; )The South African national guidelines<sup>13</sup> (AGREE score – Not recommend).
- Two systematic reviews were identified – Steer (2002),<sup>39</sup> Kerdelmidis (2010)<sup>40</sup> considered to be of poor quality due to there being no evidence that an assessment of quality of the included studies was undertaken.
- One case control study was identified – Kurahara (2006)<sup>41</sup> considered to be of good quality.
- One case series study was identified – Westlake (1990).<sup>42</sup>
- Three ecological/observational studies were identified – Jaine (2010)<sup>43</sup> was considered to be of mixed quality, McDonald (2010)<sup>44</sup> and Bach (1996)<sup>26</sup> were considered to be of poor quality.
- Two surveys were identified – Both Thakur (1996)<sup>45</sup> and Bukachi (2008)<sup>20</sup> were considered to be of poor quality.

## 6.2 Summary of findings

The South African national guidelines on primary prevention and prophylaxis of rheumatic fever and rheumatic heart disease for health professionals at primary level<sup>13</sup> is more akin to a policy document than a clinical guideline. There is no evidence of supporting literature or appraisal of quality of the evidence on which the recommendations are based. The guideline suggested primary prevention in tackling overcrowding in schools and homes and improved living conditions. There was no evidence of a process of evaluation and no supporting research evidence.<sup>13</sup>

Jaine (2010) recently reported on ecological data identifying an association between crowding and rheumatic fever.<sup>43</sup> The study reported on 1249 new cases of rheumatic fever identified between 1996 and 2005. The data appeared to be based on hospitalisation coding only and there are no details as to why the specific decade was selected. The average annual rate of rheumatic fever was 3.4/100,000 (age standardised to the 2001 New Zealand population). Rheumatic fever rates increased with increasing quintiles of household crowding. The rate for the most crowded quintile was 23 times the rate of the least crowded quintile (RR 23.1, 95%CI 15.0–35.6). The association was independent of age or ethnicity. Similarly the rate of the most deprived quintile was over 17 times greater than the least deprived quintile (RR17.5, 95%CI 12.7–24.3).

The effect of household crowding remained even when socioeconomic status and proportion of children aged 5–14 years was taken into account. The incidence rate ratio (IRR) was 1.065 (95%CI 1.052–1.079 P<0.000. For example for every 1% increase in crowding in a census area unit there would be a 6.5% expected increase in the acute rheumatic fever count assuming constancy of other variables. If the least crowded quintile was used as a reference (median crowding 0.77%) the expected acute rheumatic fever count in the most crowded quintile (median crowding 12.03%) would be expected to be up to 88% higher. Jaine (2010) suggested that policy initiatives such as increased social housing and subsidised rental costs may reduce rates of rheumatic fever as well as other communicable diseases.<sup>43</sup>

In a recent systematic review (Heart Foundation clinical guideline) 24 studies were identified that had reported on crowding and rheumatic fever and/or Group A streptococcal throat infection and 10 studies reported on issues related to housing and rheumatic fever.<sup>10, 40</sup> The included studies appeared to be primarily case series, survey or cross sectional studies and as such there was no report of quality appraisal. The evidence suggested a link between crowding and rheumatic fever and between housing quality and rheumatic fever although definitions varied between individual studies.<sup>10, 40</sup> There was contradictory evidence regarding the number of people sharing a bedroom and the incidence of rheumatic fever.<sup>10, 40</sup> A summary of the studies identified in the Heart Foundation systematic review can be found in Appendix 4.

The clinical question in The Heart Foundation guideline asked if reducing crowding reduced the incidence of rheumatic fever. The guideline and the systematic review behind it<sup>10, 40</sup> were unable to answer the question. They only reported on the evidence to substantiate the causal link between overcrowding and rheumatic fever and did not discuss if interventions to reduce overcrowding were effective in reducing rheumatic fever. It is interesting to note that although the overall conclusion of the systematic review and guideline<sup>10, 40</sup> was that a link between

crowding and rheumatic fever existed, those studies providing statistical data generally demonstrated wide confidence intervals suggesting a lack of precision. Drawing conclusions from studies in the lower levels of the hierarchy of evidence and also having concerns with the precision of the data means conclusions should be interpreted with caution.

With regards to housing quality Kerdemelidis (2010)<sup>10, 40</sup> noted that three of 11 included studies reported that dampness was significantly related to the incidence of rheumatic fever. Three studies reported on a positive relationship between rheumatic fever and deteriorated dwelling or environmental pollution and three studies reported no relationship.

In addition to the systematic review by Kerdemelidis (2010)<sup>10, 40</sup> several additional studies were identified that reported on the outcome of crowding or overcrowding and rheumatic fever incidence.

Kurahara (2006) reported on socioeconomic variables of individuals with rheumatic fever compared to non-rheumatic fever heart conditions (mainly congenital) in Hawaii.<sup>41</sup> The study reported that there were significantly ( $P=0.01$ ) greater household size in cases (mean 7.3) compared with controls (mean 5.5); the average household size for Hawaii being 2.9 people (census data 2000), and in the number of children per house which was 4.1 for cases and 3.0 for controls ( $P=0.03$ ). There were no statistical differences in the number of individuals sharing the subjects' bedroom or in the educational level of either parent. Kurahara (2006) reported that it was the number of children in the household that appeared to be the crucial factor in the risk of developing rheumatic fever and therefore other factors such as hygiene standards may play a role in the spread of respiratory diseases.<sup>41</sup>

One poor quality review of prevalence studies reported a link between overcrowding and rheumatic fever with one prevalence study reporting a four fold increase in risk of rheumatic fever in households of eight or more people.<sup>1</sup> Increased urbanisation was suggested as a factor associated with overcrowding as individuals move from rural areas for the purpose of seeking work. However, overcrowding was also identified as a contributory factor in semi-urban areas. For example, the prevalence of rheumatic heart disease in Kinshasa was found to be 22.2/1000 people in semi-urban areas compared to 4/1000 people in urban areas. Over 80% of the population in the semi-urban areas lived in houses with more than eight people.<sup>39</sup> Similarly, in a study in northern India, the prevalence of rheumatic heart disease was 3.8 per 1000 in rural areas and 1.3 in urban areas. 73.3% of cases lived in 'poor conditions' where there was 'considerable overcrowding'.<sup>39</sup>

In an ecological study of indigenous Australian Aborigines, a group also considered at high risk of rheumatic fever/rheumatic heart disease, overcrowding and environmental contamination were identified as risk factors for the spread of childhood infections.<sup>44</sup> In the households surveyed the average number of people sharing a three-bedroom house was nine (4.8 adults, 4.2 children). The adults interviewed or participating in focus groups appeared to be aware of the methods of spreading disease but when they were asked in more detail the responses were often contradictory. McDonald (2010) concluded that there was a need for a multifaceted approach that included the development of culturally appropriate health promotion programmes regarding hygiene practices and also improved infrastructure and housing projects that required governmental support.<sup>46</sup>

In the observational study by Bach (1996) a rheumatic fever prevention programme was introduced to two Caribbean islands.<sup>26</sup> This has been discussed in more detail in the previous chapter. The authors reported that 53% of evaluated children in Martinique were in families of at least five children compared with 5% in the general population ( $P < 0.001$ ). The average number of children in these families was 5.6 compared with the national average of 3.7. The average number of rooms in the houses of those with rheumatic fever was 2.8 and 15% of those houses did not have adequate mains water, toilets or electricity. The authors noted that the prevention programme appeared to decrease cases of rheumatic fever in both islands by over 70% despite no improvements in socio-economic standards.<sup>26</sup>

In a cross sectional survey of school children in Northern India<sup>45</sup> there was evidence of overcrowding (not defined) or poor housing in 73.3% of the cases of rheumatic fever/ rheumatic heart disease identified. Prevalence was higher in rural areas compared with urban areas ( $P < 0.05$ ) and in rural schools compared with convent schools ( $P < 0.05$ ). There was no significant difference in the socioeconomic status of the children.<sup>45</sup> The study did not provide any control data to support the findings on overcrowding.

Westlake (1990) also suggested a link existed between overcrowding and acute rheumatic fever during an outbreak in the 1980s in Tennessee. The family size (4.5 versus 3.2) and the number of people per sleeping room (1.6 versus 0.97) was higher in the rheumatic fever patients ( $n = 26$ ) compared with the expected average for Tennessee respectively.<sup>42</sup> This was a small case series study with no statistical analysis of the data. In another American study reporting on an outbreak of rheumatic fever in 1985–1986 in Utah<sup>47</sup> the average family size of patients was found to be twice that (6.5) of the expected state average (3.2). Sixty-five percent of the patients also reported sharing a bedroom with one or more family members. Both of these studies only reported on the hospitalised patients and did not screen the population for additional cases.<sup>47</sup>

As part of an evaluation of an educational programme in Kenya for the prevention of rheumatic heart disease, Bukachi (2008)<sup>20</sup> also described high levels of crowding within the target community. The median family size was four and median number of children was four (range 2 to 13.) Sharing bedrooms was common ranging from 2–15 children per room and 82.6% of the children interviewed shared a bedroom with siblings in groups of 2–6 per room.<sup>20</sup>

### 6.3 Conclusions and implications of overcrowding review

The evidence summarised in this systematic review does appear to indicate an association between rheumatic fever and overcrowding although the link with shared bedrooms is under debate.

Wilson (2010)<sup>2</sup> has suggested that improving the socioeconomic and living conditions of Māori would decrease the risk of Group A streptococcal throat infections and therefore rheumatic fever. The evidence from the systematic review by Kerdemelidis (2010) suggested that crowding was a factor for increased incidence of rheumatic fever, whereas the quality of the housing in terms of infrastructure and facilities were more controversial.<sup>40</sup>

Baillie (2010) explored relationships between other common childhood diseases such as scabies, diarrhoea and vomiting, respiratory and ear infections and the housing and social circumstances of remote Australian Aboriginal communities.<sup>46</sup> There was no direct reference to rheumatic fever or rheumatic heart disease. However, indirect evidence indicated that poor housing infrastructure was associated with scabies and ear infections.<sup>46</sup> Baillie (2010) suggested that improvements to housing infrastructure in conjunction with behavioural and social interventions may improve health.<sup>46</sup>

In a systematic review by Thomson (2009) housing improvements (insulation and improved heating) were associated with improved health. The systematic review did not identify any studies of rheumatic fever, however it did include studies of respiratory illnesses and identified significant improvements in health as a result of retrofitting from two large randomised controlled trials conducted in New Zealand<sup>48</sup> by Phillipa Howden-Chapman from the He Kainga Oranga, Housing and Health Research Programme, University of Otago.

Similarly, projects being run in Australia to improve housing and infrastructure of indigenous Aborigines, especially in the Northern Territories can also be viewed by referring to [www.healthinfonet.ecu.edu.au/health-resources/programs-and-projects](http://www.healthinfonet.ecu.edu.au/health-resources/programs-and-projects)

There is insufficient evidence to confirm an association between decreased crowding, or improved housing and a reduction in the incidence of rheumatic fever, although evidence does suggest that there is improved health and well-being generally with improved quality of housing.

The spread of communicable diseases such as rheumatic fever, and indeed more recently of pandemic influenza, can probably be ameliorated to some degree by good hygiene practices and early identification and treatment.

([www.moh.govt.nz/moh.nsf/indexmh/pandemicinfluenza-fags](http://www.moh.govt.nz/moh.nsf/indexmh/pandemicinfluenza-fags))

# 7 Initiatives for Reducing Overcrowding

The following information was identified while undertaking the systematic review. While it did not meet the criteria for inclusion, this additional information may be useful to programme planners as it provides illustrative examples of initiatives that have been used to tackle overcrowding. As this was outside the scope of the report and evidence is based on summaries of ongoing projects there has been no critical appraisal of the evidence. Two examples are included of ongoing initiatives, one in New Zealand and one in the UK.

## 7.1 Examples of initiatives for reducing overcrowding

### 7.1.1 Healthy Housing New Zealand ([www.hnzc.co.nz](http://www.hnzc.co.nz))

Healthy Housing is a collaborative project between Housing New Zealand and New Zealand District Health Boards (DHBs) and target selected Housing New Zealand tenants in parts of the Hutt Valley, Otara, Glenn Innes and Mangere.

The aim of the programme is to:

- raise awareness of communicable diseases including rheumatic fever
- improve access to health and social services
- reduce the risk of housing-related health problems
- reduce overcrowding.

In conjunction with the DHBs the most appropriate target sites for Healthy Housing are identified by looking at hospital admissions for infectious diseases, and the numbers of state houses in areas of high social deprivation. Tenants are interviewed by Housing New Zealand and public health nurses and housing and health issues are reviewed and issues addressed. By June 2009, the programme has completed 11979 Healthy Housing interventions and assisted 6582 house holds with a housing solution.

Housing improvements included:

- design alterations
- extending homes for larger families
- installing insulation
- ventilation and heating systems
- building and buying new homes
- transferring households or part households to more appropriate accommodation
- helping families move to private accommodation.

An evaluation of the programme found that the programme had significantly reduced the risk and rate of housing related disease and injuries including rheumatic fever. However the report does not provide any statistical evidence to support this statement nor is there any specific data for rheumatic fever.<sup>49</sup>

### 7.1.2 Tackling overcrowding – UK

In 2007/2008 five London boroughs in the UK piloted studies to improve the wellbeing of overcrowded families and develop options to alleviate the impact of their overcrowding.<sup>50</sup> A number of key initiatives were implemented that included:

- **Securing better deals with the private rented sector** – pilot work identified that many larger households would choose to move to the private sector if it meant a better standard of living for their family. Making better use of an accredited landlord scheme and options for longer leases would potentially help provide greater security for these families.
- **Making better use of the allocations framework to give greater priority to under-occupiers** – local authorities had adequate flexibility within their allocations framework to prioritise tenants who were under-occupying properties enabling them to move to a property more suitable to their current needs in a more timely fashion. As a consequence larger property was freed up earlier than might otherwise be expected for an overcrowded household.
- **Targeted support for under-occupiers** – under-occupiers may need to be targeted and made aware of their options for moving. Older tenants were likely to need support and assistance through the move process.
- **Cash incentives for under-occupiers** – many local authorities already offer a cash-incentive for under-occupiers to downsize, eg, a cash payment per bedroom given up.
- **Supporting adult children of overcrowded households** – overcrowding can be caused by more than one generation living together as one household. Where some family members wish to move to their own tenancy, local authorities can offer support by for example providing rent deposits to move to the private sector, giving them greater priority for bedsits and one-beds or advice on low-cost home ownership.<sup>50</sup>

#### Examples:

**Camden** adopted an approach to lessening the impacts of overcrowding on local families by developing packages of tailored interventions around space management, health, education, play and parenting and attempts to help families continue to stay where they are by improving their quality of life or move by providing high quality housing advice.

**Kingston upon Thames** procured 30 large family sized units in the private sector on long leases to offer overcrowded Council tenants some “breathing space” whilst they bid for appropriately sized social housing or rental property. Tenants can remain in their Breathing Space home for up to 4.5 years and Kingston are seeking to increase the proportion of large family homes on new developments to offer to these families.

In **Hackney** greater priority has been given to under-occupiers. Financial support is offered to cover the costs of moving, whilst amenities in the new home are upgraded. An additional bedroom is also on offer, if required. A bespoke ‘handholding’ service is provided for elderly tenants throughout the move process. The number of transfers for under-occupiers has increased by 50% in a year as a result, with the family homes freed-up through this process ring-fenced for overcrowded families.

**Tower Hamlets** offered enhanced grants to under-occupying tenants in properties with three or more bedrooms. A dedicated support officer was available for these households and there is a packing and removal service for vulnerable tenants. As part of this initiative they also provide intensive support for overcrowded tenants with specific health needs; offering these households appropriate advice and information on their housing options, so that they may secure a move to alternative suitable accommodation.<sup>50</sup>

The results of the pilot projects highlighted that there needed to be a fundamental understanding of the 'scale and severity' of overcrowding in order to develop a strategy to try and address the issue. Several strategies were identified as being effective in reducing overcrowding.<sup>51</sup>

- Freeing up under occupied properties remains an effective way of providing larger properties into which overcrowded households can move, but it is not the only strategy. Enabling an overcrowded household to stay in the same property by making modifications to property and engaging family members with relevant support services can reduce the adverse impacts of overcrowding.
- Moving from an under occupied property is a voluntary decision, and so deploying the right incentives is essential. Cash incentives appear to have little impact when used in isolation; providing effective personal support with the move is a key success factor.
- A case management approach to both overcrowding and under occupation moves, with ample personal targeted advice, has proved to be effective. For overcrowding moves this may take the form of advice on how to find a private sector tenancy or how to bid within a choice-based lettings scheme. For under occupation moves, additional reassurance and handholding leading up to and during the move process, is an essential part of the overall incentive to tenants to move.
- Given the right encouragements, tenants will take increased responsibility for improving their own housing conditions rather than passive reliance on the authority, this may include changing room layouts or producing rosters for room use at different times.
- Adding to the total stock available by entering into arrangements with registered social landlords (RSLs) – for example by including them in under occupation schemes – and by leasing from the private rented sector is a valuable option for those authorities able to access those sectors. Partnership with RSLs is valuable but requires an investment of effort to develop it. Authorities can find themselves in competition for private rented accommodation.

## 8 Overall Summary

The evidence for increasing health literacy and awareness of sore throat, rheumatic fever and rheumatic heart disease is clearer than the evidence for decreasing overcrowding as an intervention. Improvement of health literacy, decreasing overcrowding or improvement of housing infrastructure as interventions in isolation are unlikely to be as effective as if they were components of an integrated programme.

Multimodal approaches to improving health literacy through verbal and written information presented by culturally acceptable individuals and provided in the local languages is likely to be most effective.

In New Zealand, Māori and Pacific leadership is important for ensuring the programme and its messages are endorsed and accepted by community members.

In New Zealand, local Māori and Pacific community networks are important for ensuring the culturally appropriateness of health literacy and health education resources developed. These local networks are also valuable for disseminating the resources and messages to the community

Productive but feasible options for improving the consistency and quality of rheumatic fever health education and prevention include:

- The Ministries of Health and Education exploring intersectoral collaborative funding mechanisms to increase the pool of funds available for programmes. A larger pool of funds is needed to provide training resources for community health workers in high risk areas where expertise in rheumatic fever prevention is apparently less developed (eg, Kaikohe and other less successful Northland programmes).
- A national overview of health literacy being communicated to rheumatic fever prevention programme providers and stakeholders, to ensure that the increasingly used concept is understood consistently across New Zealand.
- Processes and structures being established that allow programme providers and stakeholders to consolidate and share resources, innovations, and key learnings.
- Decreasing overcrowding by improving housing stock is ultimately likely to improve health in general and quality of life, and as a consequence is likely to facilitate the decrease of rheumatic fever. It is possible that even in the absence of improved housing conditions there is a substantial impact on rheumatic fever through health literacy and education programmes in terms of increased public awareness and case detection.
- It should be noted that improvements in health literacy and primordial prevention in the form of decreased overcrowding and improved housing quality will only be effective within a wider prevention programme that includes case detection and registration and effective primary and secondary prophylaxis.

## 9 References

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