National surveillance of rheumatic fever in Australia, and continuous quality improvement of rheumatic heart disease in Fiji: contemporary models for identification and management.

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A thesis submitted for the degree of Master of Science, Institute of Advanced Studies, Charles Darwin University.

February 2014
Declaration

I hereby declare that the work herein, now submitted as a thesis for the degree of Master by Research of the Charles Darwin University, is the result of my own investigations, and all references to ideas and work of other researchers have been specifically acknowledged. I hereby certify that the work embodied in this thesis has not already been accepted in substance for any degree, and is not being currently submitted in candidature for any other degree.

Signed        Date    24 February 2014
Acknowledgements

My association with rheumatic heart disease has been long and diverse. This thesis brings together some of the things I have learned; none of which would be possible without the ongoing support and direction provided by others.

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## Acronyms and Abbreviations

<table>
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<th>Acronym</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>ABCD</td>
<td>Audit and Best Practice of Chronic Disease</td>
</tr>
<tr>
<td>ACIC</td>
<td>Assessment of Chronic Illness Care</td>
</tr>
<tr>
<td>ADNB</td>
<td>Anti-deoxyribonuclease B</td>
</tr>
<tr>
<td>APSU</td>
<td>Australian Paediatric Surveillance Unit</td>
</tr>
<tr>
<td>ARF</td>
<td>Acute rheumatic fever</td>
</tr>
<tr>
<td>ASOT</td>
<td>Anti-streptolysin-O</td>
</tr>
<tr>
<td>BPG</td>
<td>Benzathine penicillin G</td>
</tr>
<tr>
<td>CCM</td>
<td>Chronic care model</td>
</tr>
<tr>
<td>CQI</td>
<td>Continuous quality improvement</td>
</tr>
<tr>
<td>CRP</td>
<td>C-reactive protein</td>
</tr>
<tr>
<td>CWM</td>
<td>Colonial War Memorial (Hospital)</td>
</tr>
<tr>
<td>ECG</td>
<td>Electrocardiogram</td>
</tr>
<tr>
<td>ESR</td>
<td>Erythrocyte sedimentation rate</td>
</tr>
<tr>
<td>GAS</td>
<td>Group A streptococcus</td>
</tr>
<tr>
<td>INR</td>
<td>International normalised ratio</td>
</tr>
<tr>
<td>PAR</td>
<td>Participatory action research</td>
</tr>
<tr>
<td>RHD</td>
<td>Rheumatic heart disease</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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</table>
Acute rheumatic fever (ARF) is an autoimmune response following an untreated streptococcal infection. The devastating effect of ARF is residual damage to the heart valves; a condition called rheumatic heart disease (RHD).

Diagnosis and management of these conditions is complex. The most important yet most difficult element of treatment is delivery of regular intramuscular injections to prevent recurrence of ARF and worsening of RHD.

Two contemporary models were employed to investigate current approaches to diagnosis and management and whether they could be improved.

Diagnosis of ARF in Australian children was monitored through an existing national surveillance system over a 3 year period (2007 to 2010). One hundred and fifty-one cases were identified, with joint symptoms, fever and carditis being the most common features. There were delays in presentation of children to primary care services, and referral by medical officers to higher-level care across both urban and remote areas. Results of ARF in low risk children suggest that subtle presentations of ARF in this group are being missed.

Management of ARF and RHD was analysed at three sites in Fiji over a two and a half year period (2009 to 2011). A process of continuous quality improvement (CQI) was applied to determine what impact such an intervention might have on key aspects of service delivery and client health outcomes.

The study produced mixed results. Overall, the quality of clinical documentation improved; however there was not a consistently positive impact on the delivery of intramuscular injections despite reported improvements in clinical delivery systems.

Based on the experience of using CQI in Fiji it is not a valid tool in its current form. Modification of the CQI tool and a higher level of technical and financial support for CQI activities should be considered prior to any future research.
**Prologue**

During a recent visit to support the RHD program in Nauru I was witness to the desperate screaming of a 5-year old boy with rheumatic heart disease. He was begging his mother not to make him have another painful injection – 4ml of thick fluid into the buttock – which he required every 28 days to help prevent a recurrence of acute rheumatic fever. The boy’s mother was crying and the nurse preparing the injection was also visibly upset.

Even after 15 years working in this field I took myself outside and had a little cry; and I asked myself “why do little kids like this still have this horrible disease?”

He had the injection (again) into his skinny little bum, and will possibly continue to do so for at least another 20 years.
1.1 **Background to acute rheumatic fever and rheumatic heart disease**

1.1.1 **Streptococcal infections and acute rheumatic fever**

*Streptococcal infections in humans*

Humans are exposed to a wide range of pathogens in our environment. One of the most prolific is the *β*-haemolytic *Group A streptococcus* bacterium that is responsible for a wide range of diseases in humans throughout the world. (1) Group A streptococcus (GAS) is responsible for a number of severe diseases including among others; acute rheumatic fever, post-streptococcal glomerulonephritis, sepsis and necrotising fasciitis. These conditions often progress quickly and severely, and are readily treated with effective medicines including penicillin. (2) However, streptococcal infections can also present more superficially as painful but otherwise benign throat infections (pharyngitis) or skin infections (pyoderma). (3) Unlike the more severe forms of streptococcal disease, these superficial forms are generally resolved by the body’s normal immune response with no long-lasting effects unless rare auto-immune complications occur.

*Acute rheumatic fever*

Acute rheumatic fever is known to be a self-limiting, autoimmune response following an untreated streptococcal infection. The preceding infection is generally believed to occur in the throat, however research from the Northern Territory hypothesises that skin infections may also play a role in the development of ARF, particularly among populations living in tropical climates. (4)

A number of areas of the body can be affected with ARF including the heart, skin, joints and central nervous system. The combinations of different signs and symptoms associated with ARF can vary between individuals, and between episodes in the same person.

Diagnosis of ARF is based on clinical assessment of presenting signs and symptoms together with evidence of a recent streptococcal infection. To guide diagnosis of ARF a set of criteria
was developed by US Physician T Duckett Jones in 1944. At this time, Jones wrote “(rheumatic fever) remains one of the important soluble medical problems of our day.” (5)

Jones divided the criteria for diagnosis into major and minor manifestations. Major manifestations include symptoms directly associated with the areas of the body affected. They include carditis (heart), arthritis (joints), Sydenham’s chorea (central nervous system), and erythema marginatum, and subcutaneous nodules (skin). Minor manifestations are those which are less specific to ARF but, if present, can be used to support the major manifestations. The minor manifestations include fever, and raised erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) - (inflammatory markers), arthralgia (joints), and prolonged PR interval on electrocardiogram, which may indicate heart involvement.

The Jones criteria have undergone a number of modifications since their inception, (6) and have been further modified in Australia to reflect presentations in certain populations considered at high risk of disease, including Indigenous Australians. (7)

First episodes of ARF most commonly occur between the ages of five and 15 years, and recurrences can occur up to, and rarely beyond the fourth decade of life. The illness is occasionally seen in children as young as three, and recurrences have been observed in adults aged over 40 years, however this is rare. (8-10)

Heart involvement is the most serious presenting feature of ARF since it is the one feature that may not fully resolve. Carditis refers to inflammation of the heart; usually of the heart valves and their supporting structures, but may also include the heart muscle and the protective membranes which surround the heart. Carditis may be detected as a heart murmur heard through a stethoscope or as physical changes to the heart seen on an echocardiogram. In the event that a murmur is not detected using a stethoscope and where echocardiography is not available, evidence of a prolonged interval between the P and R waves on electrocardiogram may be an indication of cardiac involvement with ARF, although this feature alone is not diagnostic. (11)
Joint involvement is one of the more common features seen in up to 80% of all ARF cases. (7, 12) Symptoms may include pain, redness and swelling (arthritis) or generalised pain without objective evidence of inflammation (arthralgia). One or more joints may be involved, and, assuming no additional trauma has been experienced during the acute phase, symptoms eventually resolve without treatment; however this may take many weeks. The large joints are most commonly affected including the knees, ankles, elbows and wrists; however other joints such as the shoulders, hips and fingers can also be affected.

Skin involvement is less common, (13) however if present, skin features are highly specific for ARF. The nodules are small, round painless lumps which occur in crops over the elbows, wrists, knees, ankles and spine. Erythema marginatum presents as patterned discolouration of the skin – often referred to as a rash – which occurs on the trunk and limbs. It is neither itchy nor painful and typically blanches when pressure is applied. Erythema marginatum can be difficult to see on people with dark skin.

Sydenham’s chorea is a movement disorder resulting from involvement of the central nervous system during ARF. This manifestation may occur later – up to 7 months after the initial streptococcal infection – and is more common in adolescents and females. (7, 14, 15) Chorea presents as uncontrollable movements of the face, tongue, hands and/or legs which occur on one or both sides of the body. The term used to describe chorea manifesting on one side of the body is ‘hemichorea’. There are a number of specific signs which help to identify Sydenham’s chorea including milkmaid’s grip (a rhythmic squeezing motion of the hand when trying to grasp something), spooning (flexion of the wrists and extension of the fingers when the hands are extended), and the pronator sign (turning outwards of the arms and palms when held above the head and the inability to maintain protrusion of the tongue). (7) While mental function is not affected, people with chorea may display disturbances in behaviour attributed to the physical limitations experienced during chorea, and embarrassment and frustrations at having the condition. (16) Due to the potential for chorea to present some
months after the other signs and symptoms have resolved, confirmed Sydenham’s chorea – in the absence of all other criteria - is sufficient for a diagnosis of ARF.

With the exception of chorea and indolent carditis, evidence of a recent streptococcal infection is also required to link the presenting illness to the specific autoimmune response that is ARF and confirm the diagnosis. *Streptococcus* may be observed directly from a throat or skin swab, or may be detected as an elevated or rising anti-streptolysin-O (ASO) or anti-deoxyribonuclease B (Anti DNase B) titre.

Typically, not all manifestations associated with ARF are present during the acute illness. A combination of major and minor manifestations is required to confirm the diagnosis. The World Health Organisation published a modified version of the Jones criteria in 2003 (Table 1) and guidelines for minimum number of criteria required for diagnosis. (6)

Of particular note is that the WHO Criteria for the first time provided specific guidance about the different requirements for diagnosis of primary episodes compared to recurrences. Fewer criteria are required to confirm subsequent ARF episodes in an individual, since previous ARF indicates that the risk of subsequent ARF is increased, and therefore an illness appearing to be ARF is more likely to be so.

There are some considerations when applying the Jones criteria; for example, if arthritis is included as a major manifestation, arthralgia cannot also be considered as a minor manifestation because both indicate joint involvement. Similarly, if carditis is considered as a major manifestation, prolonged PR interval cannot be considered as a minor manifestation because both indicate cardiac involvement.
Table 1. 2002–2003 WHO criteria for the diagnosis of rheumatic fever and rheumatic heart disease

<table>
<thead>
<tr>
<th>Condition</th>
<th>Guidelines</th>
</tr>
</thead>
</table>
| Major manifestations | • Carditis  
• Polyarthritis  
• Sydenham’s chorea  
• Erythema marginatum  
• Subcutaneous nodules |
| Minor manifestations | Clinical:  
• Fever  
• Arthralgia  
Laboratory: elevated acute phase reactants (erythrocyte sedimentation rate or leukocyte count or C-reactive protein)  
Supporting evidence of a streptococcal infection within the preceding 45 days  
Elevated or rising antistreptolysin-O or other streptococcal antibody, or a positive throat culture or rapid antigen test for group A streptococci, or recent scarlet fever. |
| Primary episode of ARF (for an individual) | Two major or one major and two minor manifestations plus evidence of a preceding group A streptococcal infection |
| Recurrent episode of ARF in an individual without established rheumatic heart disease. | Two major or one major and two minor manifestations plus evidence of a preceding group A streptococcal infection. |
| Recurrent episode of ARF in a patient with established rheumatic heart disease. | Two minor manifestations plus evidence of a preceding group A streptococcal infection. |


1.1.2 Rheumatic heart disease

Pathophysiology

The most devastating result of recurring ARF is accumulated heart valve damage caused by repeated inflammation of the heart valves with carditis; this is called rheumatic heart disease.

The four valves of the heart are the mitral, aortic, pulmonary and tricuspid valves. In rheumatic heart disease one or more valves is chronically deficient due to specific problems resulting from changes in structure and function; almost always the mitral and aortic valves. Valve leaflets may become thickened; and movement becomes restricted leading to blood
leaking back over the incompetent valve, this is referred to as *regurgitation*. The valve may also become scarred causing narrowing and obstruction of blood flow through the valve. This is referred to as *stenosis*.

A history of ARF does not automatically imply development of RHD. Indeed, it is estimated that 60% of people who have ARF will subsequently develop RHD. (17) The risk of developing RHD is greater for individuals who have carditis with ARF where the valves and supporting structures are scarred.

*Signs and symptoms*

Despite its chronic nature, RHD can progress unnoticed for many years. A diagnosis is often only made when symptoms develop or worsen; such as when the level of valve damage increases, particularly following recurrent ARF, or if an additional burden is placed on the damaged heart; as in pregnancy. Asymptomatic RHD can be identified through targeted screening, (18, 19) or inadvertently during clinical assessment of a concurrent illness.

Diagnosis of RHD is based on the particular valve affected, and the type and severity of the damage. Symptoms vary due to the position of valve damage in the heart, and the impact that the particular type of damage has on blood flow. For example, moderate or severe aortic regurgitation may remain asymptomatic for some time. As regurgitation worsens, breathing will become difficult with exertion and when lying down flat. With stenosis, the valve area narrows with progressive thickness and scarring, the heart works harder to ensure blood flow through the restricted valve space, and symptoms of heart failure develop.

1.1.3 The pre-penicillin era

Rheumatic fever was common in affluent countries up until the 1950s. For example, Dr John Parkinson from the Cardiac Department of the London Hospital reported in 1945 that rheumatic fever was the main source of heart disease in people aged up to 40 years, and that it exceeded Tuberculosis as a cause of death in people aged less than 20 years. Further, he suggested that up to one-tenth of young men were rejected for active war service on account
of having RHD. Poverty and overcrowding were identified at this time as the major causes of ARF and RHD, and ARF was rare among the ‘well-to-do’. (20)

Convalescent homes provided long-term accommodation for large numbers of children recovering from the effects of ARF. One such facility was Irvington House in New York, USA. In 1951, Anderson wrote from Irvington House (21):

*Rheumatic fever is one of the most important of all the diseases in childhood and adolescence. The acute phase of the disease is generally short-lived, but often minor clinical or laboratory evidences of the infection remain for weeks, months, or in exceptional cases, years. Convalescence may be said to begin when all or almost all of the signs of rheumatic activity have passed away, and it only ends when the child is restored to that degree of activity which is compatible with the degree of cardiac damage which he has sustained. For some, this may be complete, unrestricted activity; for others this may mean virtual bed rest.*

A study by Bland and Jones (22) describes 1000 children with ARF and RHD hospitalised in Boston between 1921 and 1931 for periods ranging from a few months to a few years. Recurrences of ARF occurred in approximately one fifth of children during the first five years after first episode, and in a tenth during the next five years. Almost a third of the children died during the ensuing two decades, and for those with ‘grossly enlarged hearts’ it was rare to live beyond the age of 30 years.

1.1.4 A disease of poverty

Since the early to mid-20th Century, ARF and RHD have become relatively uncommon in developed countries, primarily due to improvements in the quality of housing, reduced domestic crowding and the availability of penicillin to treat and prevent streptococcal infections. (23) Socioeconomic and environmental factors such as overcrowding and poor housing can promote the spread of streptococcal disease and result in higher rates of
pharyngitis and ARF. (4) Health system factors including poorly-resourced or poor quality health care, inadequate clinical expertise and low levels of awareness among the community can impact on timeliness of diagnosis and initiation of treatment, which in turn impact on the severity of disease in the community and client outcomes (Table 2). (6)

Table 2. Direct and indirect results of environmental and health-system determinants on ARF/RHD

<table>
<thead>
<tr>
<th>Determinants</th>
<th>Effects</th>
<th>Impact on ARF &amp; RHD burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socioeconomic &amp; environmental factors</td>
<td>Rapid spread of group A streptococcal strains.</td>
<td>Higher incidence of acute streptococcal-pharyngitis and suppurative complications</td>
</tr>
<tr>
<td>(poverty, under-nutrition, overcrowding,</td>
<td>Difficulties accessing health care.</td>
<td>Higher incidence of ARF</td>
</tr>
<tr>
<td>poor housing)</td>
<td></td>
<td>Higher rates of recurrent ARF.</td>
</tr>
<tr>
<td>▪ shortage of resources for health care</td>
<td>Misdiagnosis or late diagnosis of ARF.</td>
<td>Patients unaware of the first ARF episode.</td>
</tr>
<tr>
<td>providers</td>
<td></td>
<td>Untimely initiation or lack of secondary prophylaxis.</td>
</tr>
<tr>
<td>▪ low level of awareness of the disease</td>
<td></td>
<td>Higher rates of recurrent ARF with more frequent and severe heart valve involvement, and</td>
</tr>
<tr>
<td>in the community.</td>
<td></td>
<td>higher rates of repeated hospital admissions and expensive surgical interventions.</td>
</tr>
</tbody>
</table>


1.2 Epidemiology

1.2.1 International data

Detailed data on ARF is restricted to countries where control programs have been developed and disease registers established. However, geographical studies have provided useful information about ARF, with estimates of incidence varying between countries and between population groups within countries. For instance, a study of ARF in New Zealand children
between 1982 and 1997 found an incidence of 40-80 per 100,000 per year among New Zealand Maori, 80-100 among other Pacific Islanders, and less than 10 per 100,000 per year in children of European descent. (24)

Traditionally, RHD was diagnosed with a reported history of ARF and a characteristic murmur identified on auscultation. Echocardiography has been found to be a much more sensitive tool and is more accurate for identifying cases, particularly during screening for RHD, than auscultation alone. (25, 26) Rheumatic heart disease diagnosed using echocardiography in the absence of a noticeable murmur or history of ARF is referred to as ‘subclinical RHD’.

Table 3 includes examples of RHD prevalence from recent studies where reported high prevalence is consistent with echocardiographic diagnosis of RHD.

### Table 3. Selected prevalence of RHD

<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Prevalence per 1000</th>
<th>Age group (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>Mozambique (25)</td>
<td>30.4</td>
<td>6-17</td>
</tr>
<tr>
<td>2007</td>
<td>Cambodia (25)</td>
<td>21.5</td>
<td>6-17</td>
</tr>
<tr>
<td>2008</td>
<td>India (27)</td>
<td>51</td>
<td>6-17</td>
</tr>
<tr>
<td>2008</td>
<td>Tonga (18)</td>
<td>33.2</td>
<td>10-15</td>
</tr>
<tr>
<td>2011</td>
<td>Fiji (26)</td>
<td>55.2</td>
<td>5-14</td>
</tr>
<tr>
<td>2011</td>
<td>New Zealand (28)</td>
<td>26</td>
<td>10-13</td>
</tr>
</tbody>
</table>

Based on the methodology and results of these and other studies over the past decade, a World Heart Federation working group published specific criteria for diagnosis of RHD by echocardiogram. (29) Of particular note is the inclusion of a ‘borderline RHD’ classification which is applied to cases aged less than 20 years to increase sensitivity in this age group which is most likely to benefit from early detection and intervention. Future RHD surveys will be able to test the accuracy of their results against the WHF criteria and standardise classification of cases.

Encouragingly, some regions have reported a decrease in RHD prevalence in recent years. For example, following a comprehensive, 10-year control initiative in Cuba the prevalence among
children decreased from 2.27 per 1000 in 1986 to 0.24 per 1000 in 1996. (30) A decline in United States is credited with improved living conditions, decreased scarlet fever and increased preventative use of penicillin for streptococcal infections despite streptococcal throat infections remaining common. (31) India has seen a reduction in RHD in some regions and attributes this to improved access to health care and the availability of antibiotics. (32, 33)

1.2.2 Australian Data

In Australia, the Northern Territory, Queensland and Western Australia have developed a better understanding of the burden of disease following establishment of register-based control programs, starting with the Northern Territory program in 1997. There is a marked disparity in the prevalence between Indigenous and non-Indigenous Australians. Aboriginal and Torres Strait Islander children in these areas still have unacceptably high rates of ARF. (10, 34) The most accurate data come from the Northern Territory where the prevalence of RHD among Indigenous Australians is 100 times higher than the non-Indigenous population. (35)

The average incidence of ARF in Aboriginal children in the Northern Territory between 2002 and 2008 was 240 per 100,000, and during this period recurrent ARF made up an average of 25% of all ARF notifications. (10)

High rates of ARF have also been found in Far North Queensland and northern West Australia. (34, 36) However almost 44% of Australia’s Indigenous population lives in jurisdictions (37) which are beyond the scope of current control efforts, and little is known about the burden or pattern of ARF and RHD in these areas. Approximately 30% of Australia’s Aboriginal population lives in New South Wales, (38) and it is conceivable that these people may also be at increased risk of ARF and RHD.

Nationally, Indigenous Australians aged less than 65 years are 8 times more likely to be hospitalised for RHD than non-Indigenous Australians in this age group, and they are four times more likely to die from RHD. (35)
1.2.3 Fijian data

The population of Fiji was estimated to be almost 840,000 at the 2007 census. (39) Indigenous Fijians made up almost 57% of the population, Indo-Fijians represented 37% and other ethnic groups represented the remaining 6%. Over the preceding 10 years the Indian population decreased steadily due to a decline in the birth rate and ongoing emigration. Almost half the population, predominantly Indigenous Fijians, lives in the rural area.

Data on ARF and RHD in Fiji were not routinely recorded until the establishment of a national RHD Register in 2005. Since this time, activity around RHD has increased and a number of studies have provided an insight into the burden of disease in Fiji. A study by Reeves et al (26) reports a prevalence of RHD in children of 55.2 per 1000, the highest ever documented. This high rate is questionable given Steer’s result of 8.4 per 1000 in Fijian children, which includes definite and probable RHD. (19)

An audit by Parks et al (40) found that the incidence of first episodes of ARF in children and young adults to be almost 25 per 100,000, and an autopsy audit by Singh et al (41) found that death from RHD is common (2.4% of cases audited); that young people die from RHD in Fiji (mean age 38 years); that Indigenous Fijians are more likely to have RHD than Indo-Fijians, and that RHD-related death identified on autopsy is increasing.

1.3 Problems associated with diagnosis of acute rheumatic fever

Frequently, ARF is under-diagnosed. (6, 34, 40, 42) Individuals with symptoms may not present to health services for assessment, and clinical staff may not be aware of the symptoms, or symptoms may be resolving and difficult to identify when they do present. If the initial episode of ARF in an individual is missed or if diagnosis is delayed, prevention strategies will not be initiated to prevent a recurrence. Further, the individual, if not previously diagnosed, may not have reason or concern to seek prompt treatment for future sore throats or to recognise symptoms of recurrence, and monitoring to detect the development or worsening of RHD is not established.
Accurate and timely diagnosis of ARF is important. Over-diagnosis may require individuals to undergo unwarranted treatment for many years, placing unnecessary demands on both the individual and the health service. Under-diagnosis may result in the individual developing RHD without preventative intervention, resulting in life-long disease and risk of premature death.

A review of confirmed and suspected ARF cases in Australia’s Northern Territory up to the late 1990s found joint symptoms to be less severe among Indigenous people; particularly the presence of monoarthritis with low-grade fever. (43) To increase diagnostic sensitivity in this population, the diagnostic criteria for ARF have been adapted. Specific changes include increasing options to identify carditis by including evidence of subclinical carditis on echocardiogram, moving aseptic monoarthritis and polyarthralgia from the minor to the major category, (7) and including monoarthralgia as a minor manifestation. (11) These changes only apply to Aboriginal and Torres Strait Islanders and other similar high risk groups, and all other individuals are assessed on the international Jones criteria.

It is estimated that about 43% of Aboriginal clients with ARF or RHD in Australia’s Northern Territory first present to health services with established RHD; usually because they have become symptomatic. (44, 45) Individuals living in remote areas where RHD is common may have difficulties accessing medical care services due to distance to the health centre or lack of reliable transport or family. A study of perceptions around uptake of long term treatment in one remote Northern Territory community found that clients were more likely to attend the health centre if they were comfortable in their relationship with the health staff. (46) In this instance, improving relationships between the health centre and the community was a key factor associated with improved client attendance.

When individuals with symptoms of ARF do present to the health service, misdiagnosis can occur. (40) The signs and symptoms of ARF are numerous and may present in a variety of combinations. The combination of joint pain and fever, particularly in children, can be associated with a wide range of conditions other than ARF, particularly if the joint pain is
mild. (11, 12) Khriesat and Najada (47) suggest that some flexibility of the modified Jones criteria may be needed to capture cases that present atypically or less severely than expected. Parks et al (40) found in Fiji, “patients presenting with potential features of ARF seldom had a diagnostic evaluation sufficient to exclude its diagnosis” suggesting that clinical staff working in high incidence settings may not be familiar with the symptoms of ARF.

For example, if no murmur is heard on auscultation or if auscultation is not performed, a diagnosis of ARF or RHD may be dismissed. Similarly, if there is no presenting joint involvement with ARF, a diagnosis can be dismissed. (48) This suggests a heavy reliance on cardiac and joint symptoms without due consideration of other symptoms.

1.4 Control of rheumatic heart disease

Acute rheumatic fever and RHD are specific conditions that present differently and at various stages along a continuum (Figure 1). There are a number of opportunities for intervention to change the course, progression and severity of the later outcome, which is RHD. Preventing the first occurrence of ARF, either through changes to the environment to reduce streptococcal infections or prompt treatment of acquired infections, removes the risk of developing RHD (primordial/primary prevention). Once ARF has occurred, preventing ARF from recurring can greatly reduce the potential for RHD (secondary prevention). If RHD is established, management focuses on preventing, or at least delaying the need for heart valve surgery for as long as possible (tertiary prevention).

1.4.1 Primordial and primary prevention of acute rheumatic fever

Primordial and primary prevention refer to the prevention of disease by reducing risk factors. In the case of ARF, this involves reducing the incidence and impact of streptococcal infections.

Primordial prevention relates to reducing external risk factors. Improved living and environmental conditions have been shown throughout history to decrease the burden of ARF and RHD. (49-52) However, and despite the continuing high rate of RHD among Indigenous
Australians and some Pacific Islander populations, many of these populations still live in socio-economic conditions associated with high rates of ARF. (53, 54)

Primary prevention of ARF involves prompt treatment of streptococcal infections with antibiotics to interrupt the body’s auto-immune response to the bacteria and reduce the risk of developing ARF. The World Health Organisation defines this as “the adequate antibiotic therapy of group A streptococcal upper respiratory tract infections to prevent an initial attack of acute RF”. (6) In remote northern Australia, the incidence of streptococcal pharyngitis was been found to be low despite high rates of ARF. (4, 55) People with streptococcal infections may not have ready access to health services or may not be inclined to present for treatment. In these instances the opportunity for primary prevention is lost.

While primary prevention can be beneficial at an individual level, (56) this approach has shown to be largely impractical on a population level. (57) A meta-analysis conducted in New Zealand reported a potential reduction of ARF in children by up to 60% if primary prevention was conducted in schools of community clinics. (58) However, a randomised control trial of primary prevention of ARF also in New Zealand schools failed to demonstrate a significant reduction in ARF incidence, (59) so this 60% reduction estimate is questionable. A study in Africa found that antibiotic regimens for primary prevention of ARF were not adhered to. (60)

1.4.2 Secondary prevention of acute rheumatic fever

People who have already developed ARF are easier to identify than those who might be at risk. These individuals who have had an ARF diagnosis are also at high risk of experiencing a recurrence of ARF following future untreated streptococcal infections. (6) The focus of management in an individual known or highly suspected to have had ARF is to prevent recurrent episodes of the illness. Currently, this involves delivery of regular, long-term antibiotics to prevent subsequent streptococcal infections, removing the potential for ARF. Since this treatment aims to prevent recurrent or secondary episodes of ARF it is called secondary prevention or secondary prophylaxis. These terms are used interchangeably. This
secondary prevention approach is currently the recommended international benchmark of RHD control. (6)

Secondary prophylaxis (treatment) is most commonly administered as three- or four-weekly intramuscular benzathine penicillin G (BPG) injections commenced as soon as possible after the initial episode of ARF has been identified. Oral penicillin is an alternative to intramuscular preparations, and alternative oral antibiotics are suitable in the event of documented penicillin allergy. Intramuscular injections are considered to be superior in terms of preventing streptococcal infections and subsequent ARF than oral preparations. (61)

The World Health Organisation has established an international standard for treatment doses and duration (Table 4) which has been modified by a number of countries. Differences focus on the weight at which the dose should be increased in children. (7, 62, 63)

Regional variations also exist regarding the frequency of injections. In the Fiji Islands, the recommendation for children aged up to 15 years is to receive three-weekly injections, and all persons over 15 years are recommended to receive four-weekly injections. (62) In Australia, four-weekly is recommended as the standard frequency and three-weekly as considered for those who receive all prescribed injections and still develop recurrent ARF.

Due to difficulties monitoring regular use of oral medication, oral penicillin is recommended for individuals in whom injections are contraindicated due to excessive bleeding or other complication. (6)

Table 4. Antibiotics used in secondary prophylaxis of rheumatic fever

<table>
<thead>
<tr>
<th>Antibiotic</th>
<th>Mode of Administration</th>
<th>Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benzathine penicillin G</td>
<td>Single intramuscular injection every 3-4 weeks</td>
<td>For adults and children ≥30kg in weight: 1,200,000 units. For children &lt;30kg in weight: 600,000 units</td>
</tr>
<tr>
<td>Penicillin V</td>
<td>Oral</td>
<td>250mg twice daily</td>
</tr>
<tr>
<td>Sulfonamide</td>
<td>Oral</td>
<td>For adults and children ≥30kg in weight: 1 gram daily. For children &lt;30kg in weight: 500mg daily</td>
</tr>
<tr>
<td>Erythromycin</td>
<td>Oral</td>
<td>250mg twice daily</td>
</tr>
</tbody>
</table>

Secondary prevention is indicated for people who have ARF or RHD, but it is also recommended where the diagnosis is not confirmed, but highly suspected. For example, the Australian guidelines recommend that secondary prevention should be given in suspected cases, and ceased if the diagnosis is ruled out. (11) It is also important that if indicated for age, secondary prevention should continue after heart valve surgery. While surgery corrects the blood flow within the heart; it does not have any impact on the ongoing risk of ARF.

The decision to cease secondary prophylaxis should be based around two main factors: the risk of developing recurrent ARF (which reduces with age, and with time since the last ARF episode); and the potential for a catastrophic outcome should a recurrence occur (i.e. in someone with established severe RHD the risk of death after recurrent ARF will be much higher than in someone with no, or minimal RHD). Based on a number of factors including progression of disease and ongoing environmental risk, the WHO established a recommended minimum duration of secondary prevention treatment. An individual with ARF and no cardiac damage should receive treatment for at least 5 years after the most recent ARF illness, and an individual with RHD should receive treatment for at least 10 years (Table 5). These recommendations are intended as a guide to support clinical judgement based on the individual circumstances. Again, the standard has been modified by others to cater for high risk populations. (6)

Table 5. Recommended Secondary Prophylaxis Regimens

<table>
<thead>
<tr>
<th>Disease Classification</th>
<th>Duration of Secondary Prophylaxis</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARF (No proven carditis)</td>
<td>▪ Minimum of 5 years after last ARF, or</td>
</tr>
<tr>
<td></td>
<td>▪ Until age 18 years (whichever is longer)</td>
</tr>
<tr>
<td>Mild-moderate RHD (or healed carditis)</td>
<td>▪ Minimum 10 years after last ARF, or</td>
</tr>
<tr>
<td></td>
<td>▪ Until age 25 years (whichever is longer)</td>
</tr>
<tr>
<td>Severe RHD and following Cardiac Surgery for RHD</td>
<td>Lifelong</td>
</tr>
</tbody>
</table>

A sustained level of antibiotic in the blood is required to prevent subsequent development of streptococcal infections and ARF. Injection delivery can be monitored by identifying clients who are late for a scheduled injection or who regularly fail to receive injections. Adherence to twice daily tablets is difficult to determine, however oral treatment can be monitored more broadly by identifying people who regularly fail to renew medication supplies.

The Australian guidelines propose that 80% or more of injections per year is considered a reasonable benchmark in terms of service delivery. (7) While receiving 100% of evenly-spaced injections is expected to provide optimal protection against streptococcal infections, 80% allows for one or two injections being received later than planned. Based on a 4-weekly injection regimen, this equates to receiving at least 11 injections in a calendar year or 17 injections if on a 3-weekly regimen. The proportion of injections received by an individual is determined by dividing the number of injections received by the number of injections proposed, and multiplying by 100.

For example: *If an individual is prescribed 4-weekly injections, 13 are required in a full year.*

*If 9 are received: 9/13x100 = 69% of injections were received in the full year.*

Other benchmarks can be used to measure patterns in service delivery. For example, demonstrating an increase in the proportion of people who receive 50% or more of injections each year can be used as a marker of program success. This can be determined by dividing the number of people who reviewed 50% or more by the total number of people indicated for injections and multiplying by 100.

For example: *If 10 from a total of 25 people receive 50% or more of injection in the year: 10/25x100 = 40% received fifty percent or more of injections.*

Delivery of secondary prophylaxis is challenging. Delivery of regular intramuscular injections requires a lengthy, invasive regimen which places an ongoing demand on individuals and sets up challenges for the health system.
A number of barriers to secondary prophylaxis delivery have been proposed by health staff and clients in Australia and Pacific Island countries.

For some people living in remote areas, isolation from health facilities is major factor determining the uptake of services such as regular injections. (64) High staff turnover can also impact on the continuation of care and support provided to clients. The holistic nature of services provided to clients, as well as attitude of staff can also have an impact on the uptake of secondary prevention. (46)

Some programs have developed strategies to help improve uptake of secondary prophylaxis.

A New Zealand initiative based in the Auckland area has had marked success with a community nurse-led secondary prophylaxis program. (65) A rheumatic fever register was set up in 1981 to generate BPG prescriptions for people with a history of ARF who were being treated with penicillin tablets. Nurses working with the program provide comprehensive outreach services, delivering injections in homes, work places and schools. An audit of the register for the period 1998 to 2000 found injection delivery rates increased from 79.9% to 100% across three District Health Boards. Program nurses reported that the presence of health workers actively involved in the program impacted positively on the overall outcomes. These strategies dramatically reduced hospitalized ARF recurrences from 20% to 6% of the total ARF cases. Lessons can be learned from the Auckland experience; however such an approach requires a high level of dedication, reliable staff and resources.

In Central Australia, a full moon calendar was introduced to Indigenous communities by the Northern Territory RHD program to help standardise timing of BPG injections. Health staff and clients were encouraged to use the full moon as a prompt for injections every 28 days. The calendar was supported by an educational flipchart, promotional posters in clinic waiting areas, and regular radio broadcasts a few days before and after the full moon date each month. Analysis of the strategy found that while uptake of secondary prophylaxis improved, improvements did not coincide directly with the full moon. (66)
In July 2007 a mobile phone text message reminder service was established by the Fiji RHD program in conjunction with Fiji Vodafone. A total of 55 people received a text message every three and a half weeks reminding them to attend their health facility for a BPG injection. An audit conducted early in 2008 found that only 20% of the intended recipients were receiving the message. The low message delivery rate was due to mobile phones and sim cards being replaced or given to friends or family members, and messages being diverted to other numbers. (K. Prasad, personal communication, August 2008)

Recall systems and standardisation of timing for injections, such as with the Full Moon strategy are designed to remind those who forget, and outreach services will primarily benefit populations in rural and remote areas where access to health services is a factor. However, if individuals are not aware of the importance of secondary prevention and what it means for them personally, these strategies may not have an impact. Adopting a standard or regional approach to improving secondary prophylaxis delivery does not seem reasonable given the variety of proposed barriers. Ultimately, health staff need to work with their clients to identify the local barriers to secondary prevention delivery and develop targeted strategies within the capacity of the local health service.

Regular dental assessment is an essential element of RHD management. (11) Dental caries may be associated with an increased risk of bacterial endocarditis in the presence of RHD and clients should be checked regularly to ensure that teeth are intact. (6) This is particularly important prior to cardiac surgery, where the risk of complications due to endocarditis is increased.

1.4.3 Management of rheumatic heart disease in Australia and Fiji

The World Health Organisation recommends that countries with a high prevalence of RHD implement dedicated, register-based control programs that focus efforts on secondary prevention of ARF. (6) The term ‘register-based’, indicates that people with ARF and RHD are identified and included on a register, and the information is used to coordinate care and monitor disease in the population. A number of programs have been established in line with
the WHO recommended components of a national control program. As such, programs endeavour to undertake the following:

- Identify and register people who are known or suspected of having ARF and RHD
- Standardise, monitor and improve delivery of secondary prophylaxis treatment to prevent recurrent ARF in people who are known to be at risk
- Standardise diagnosis of ARF and RHD
- Support improved clinical management of ARF and RHD (including clinical follow-up, dental care and regular echocardiogram)
- Provide training and support for the health workforce, particularly those working with populations at high risk
- Support health staff to provide education and support to clients, and support education of the wider community
- Report on the program progress including client outcomes and rates of disease.

Rheumatic heart disease control in the Australia/Pacific region has been building momentum since the late 1990s with establishment of control programs in a number of countries with high disease burden.

**RHD control in Australia**

The inaugural Australian program was established in line with WHO recommendations in the Top End of the Northern Territory in 1997. (67, 68) A program focusing on registration of cases and education for health staff was established in Far North Queensland in 2006; (34) however it was not until the formation of the National Rheumatic Fever Strategy by the Commonwealth Government in 2009 that a national approach to tackling RHD was formed. A national coordination unit, **RHDAustralia**, was established as part of the Rheumatic Fever Strategy in 2009 to provide national support and direction for RHD control. (11) RHDAustralia was charged with updating national guidelines, developing a national ARF and
RHD data collection and reporting system, developing quality education and training materials and providing technical support to the activities of the state-based programs.

Funding was also allocated to jurisdictions that could demonstrate a burden of RHD. The Northern Territory program received funding to strengthen and progress existing activity; the Queensland program expanded to become a state-wide initiative and a new program was established in Western Australia. These programs are based on the WHO’s secondary prevention model (6) with separate registers in each jurisdiction. Each program has developed specific strategies and goals based on local populations, issues and requirements.

**RHD control in Fiji**

To help Ministries of Health with control of RHD in the Pacific region, the World Heart Federation supported establishment of RHD control programs in Samoa and the Fiji Islands commencing in 2005. Demonstration projects (69) were established in line with register-based secondary prevention principles. The focus of these programs was:

- Identification and registration of individuals known or highly suspected to have ARF or RHD
- Standardisation of clinical diagnosis and management of ARF and RHD
- Improved delivery of secondary prophylaxis
- Increased awareness among of health professionals
- Echocardiographic screening for undetected RHD cases
- Increased community awareness of ARF/ RHD

The Fiji program was established in the country capital Suva; the program initially focused on disease control activities and building capacity within the health system within the Central Division. Over the next two years the program was expanded nationally and as of January 2008, over 1300 people with ARF and RHD were registered on the national database. (70) Over half of the cases (61%) at this time were identified from the Central/Eastern Division.
Individuals known to the health system were identified from existing clinical and public health records including the hospital information system, the echocardiogram clinic log book at the Colonial War Memorial (CWM) Hospital in Suva, and cardiac surgery records. A purpose-build electronic register was developed to store and report client information. This information included personal details, relevant medical and surgery history, secondary prophylaxis details and information about death. The register’s reporting function included number of cases registered at each health facility, number of surgeries and deaths within specified periods, and BPG injection delivery for individuals and groups over time. A recall function was included to identify clients due or overdue for recommended services such as echocardiogram, clinical review or cardiac surgery.

Prior to the establishment of the RHD program, processes for diagnosis and management of ARF and RHD in Fiji were driven by the knowledge and perceptions of individual clinicians. Of particular note was the variation in regular BPG injection doses administered to prevent ARF. The internationally recommended dose for adults is 1.2 international units. However, at some health facilities doses up to 3.7IU were administered to obese clients because it was assumed that a higher dose would be more effective in preventing ARF in larger people.

Diagnosis and management guidelines from Australia (7) and New Zealand (71) were developed in 2006 with consideration of the burden of disease among Pacific Islander populations. These documents were used as the basis for standardising practice in Fiji.

Additional cases were identified through screening for unknown cases of RHD in the community. From 2006 to 2008, 97 children were found to have RHD through screening activities in the Central and Western Divisions. Only four of these children had been identified and registered previously.

A two-day workshop module to train health workers in diagnosis and management of ARF and RHD was developed through the World Heart Federation Pacific RHD Program. Workshops using this model are now regularly conducted for medical and nursing staff working in Fiji. Workshop content included detailed analysis of the diagnostic criteria for
ARF, recommendations for secondary prophylaxis, discussion around diagnosis of RHD and activities to raise awareness of the importance of accurate diagnosis, education and follow-up. By late 2012, approximately 390 staff from the Central, Western and Northern Divisions had attended workshops.

Recording and monitoring of BPG injections was standardised in the form of Benzathine Books, which were established in all health facilities. It was anticipated that this would assist primary care staff to identify clients who had missed injections, and facilitate regular reporting of BPG injection delivery to the national RHD register. However, reporting of injections to the register did not improve significantly; in 2007 injection delivery had been recorded for only 36% of all clients registered to receive injections. From the data available, it appeared that injection delivery was increasing only slightly. Review of the Fiji RHD register found that in 2006 and 2007 32% of recipients were receiving 80% or more of injections, up from 27% in 2004 and 2005. These results suggested that two thirds of people at risk of recurrent ARF were not adequately protected.

Twenty-four hospitals, 84 health centres and a number of nursing stations across Fiji had the capacity to administer BPG. However, most clients travelled to central locations and only a few isolated nursing stations were required to manage secondary prophylaxis. The majority of centres did not have access to transport to provide outreach. Further, communication between the hospitals and health centres and the central RHD register was complicated by poor technological infrastructure and difficulties for program staff to provide direct support.

Of particular concern was the increased prescribing of oral medication for ARF prevention. In December 2008, 101 adults at one health facility had been prescribed penicillin tablets twice daily. However, clinic staff were not able to determine why tablets were recommended instead of BPG injections, nor were they able to determine whether tablets were being taken. Doctors and nurses attending the RHD training workshops reported a number of factors impacting on effective RHD control in Fiji. These include poor awareness of ARF and RHD
as a major factor in delayed presentation to medical care, delayed diagnosis and poor secondary prophylaxis follow-up. Other issues reported by health staff include poor documentation and communication between health facilities providing care, and lack of quality time spent with clients when they present for secondary prophylaxis injections.

Fiji demonstrated a number of significant advances in the management of people with ARF and RHD, particularly around standardisation of secondary prophylaxis delivery, building capacity in the workforce through targeted training, and undertaking community screening to detect unknown cases. However, secondary prophylaxis delivery and follow up of clients for clinical management was still below acceptable levels. This placed a large number of people at risk of recurrent ARF and development or worsening of RHD. A dedicated and targeted strategy was required to improve secondary prophylaxis delivery at primary health care level and improve day-to-day care delivered by primary care staff.

1.5 A case for further investigation

1.5.1 Surveillance for acute rheumatic fever in Australia

Rheumatic heart disease control in Australia has focused on areas with a known high burden of disease. However, about 47% of the Indigenous population lives in cities or large regional centres which are beyond the scope of current control efforts. (37) Little is known about the burden or pattern of ARF in these areas. Surveillance for ARF had never been conducted on a national basis; it was therefore not known if ARF occurred commonly in Indigenous groups outside central and northern Australia, and in other population groups.

Further, it was not known whether national recommendations developed for diagnosing and managing ARF, (7) would be appropriate for people with ARF living in other parts of the country, particularly in regard to Indigenous people for whom the diagnostic criteria have been adapted. More needed to be known about who is at risk of ARF and how it presents to guide future recommendations for diagnosis and management. Together with the Heart Foundation and the Australian Paediatric Surveillance Unit (APSU), Menzies School of
Health Research established a study of ARF in children at a national level. This study is discussed in Chapter Two.

1.5.2 Improving clinical services for rheumatic heart disease in Fiji

The issues around delivery of care for people with ARF and RHD across Fiji are complex. Some facilities are not able to maintain staff and other resources, there is diversity in understanding of ARF and RHD among staff and clients, and access to tertiary care and other support services is a problem for many remote and island health facilities.

Given the diversity of the issues, the national RHD program could not expect that the introduction of standard improvement approaches would be equally effective in all health settings across Fiji. An alternative approach was needed; one that would work with facilities to identify barriers to improving clinical services and support improvement based on local capacity. Investigation of clinical services in Fiji is discussed in Chapter Three.
2. Surveillance of acute rheumatic fever in Australian children
2.1 **Methods and Materials**

2.1.1 Aims of the study

The primary aims of this study were to determine the pattern of ARF presentations nationally, particularly in regions from which there were no data or only poor quality data; determine the proportion of all ARF episodes that are recurrences; identify populations, groups and regions at highest risk of ARF, and provide further information to guide future control efforts for the National Rheumatic Fever Strategy, which was launched in late 2009 by the Australian Government.

2.1.2 Research model

An existing surveillance mechanism was used to conduct prospective surveillance of ARF in Australian children. This mechanism was established by the APSU in 1993 to facilitate surveillance of uncommon childhood diseases in Australia. The primary aims of the APSU are to estimate the incidence, epidemiology, clinical features, current management and short-term outcomes of rare childhood conditions in Australia and to produce, and disseminate study results that will inform the health workforce, and support development of clinical guidelines and prevention strategies for these diseases. (72)

Information about children with ARF was supplied from a database of approximately 1350 paediatricians, paediatric cardiologists and other clinicians representing most regions of the country. Data collection was initiated through monthly prompts sent to each clinician on the database. Each month the clinicians received a report card from the APSU which they were asked to return whether or not they had seen any children with conditions of interest in the last month. If they reported that they had seen a child with a reportable condition, enhanced diagnostic, clinical and outcome data were collected.

People with ARF and RHD in Australia are more likely to live in rural and remote areas (12, 44) and therefore for this study, the existing APSU membership was expanded to include a
number of non-specialist clinicians working in regional hospitals where children with ARF were expected to be seen. Additional clinicians were added from a number of hospitals in regional towns in the Northern Territory including Tennant Creek, Nhulunbuy and Katherine, and Grafton and Moree in country New South Wales.

2.1.3 Data access and storage

Information was collected from clinicians who reported seeing children with ARF in their clinical practice. Once received, access to the information was restricted to the principal researcher and primary supervisor.

The reporting clinician’s name and contact information were collected so that they could be contacted for additional information or clarification if necessary. Identification of ARF cases included initials, date of birth and postcode so that duplicate reports could be identified. The information collected from questionnaires was entered into a Microsoft Access database version 2007 (Redmond, Washington USA) for storage and analysis.

2.1.4 Data collection tool

A questionnaire (Appendix A) was modelled on the questionnaire template used in other APSU studies. and included information about the child, family living situation, details of relevant medical history, specific information about the ARF diagnosis including presenting signs and symptoms, medical and surgical management of the acute episode, details of any barriers to making the diagnosis, and reasons for which recurrences occurred.

A separate questionnaire was developed to collect enhanced data on children presenting with Sydenham’s chorea (Appendix B). It included clinical details specific to chorea, the severity of symptoms and treatment provided. This optional questionnaire was forwarded to reporting clinicians to complete in the event that the child presented with Sydenham’s chorea.
### Definitions

**ARF case definition**

Children up to age 15 years were included in the study if they had an ARF diagnosis date between 1st October 2007 and 31st December 2010 that satisfied the 2006 Australian diagnostic criteria for ARF (Table 6). (7) Children in high-risk groups included Aboriginal and Torres Strait Islanders, Pacific Islanders and migrants from high risk countries. All other children were considered to be low risk. (7)

**Table 6.** 2006 Australian guidelines for the diagnosis of acute rheumatic fever

<table>
<thead>
<tr>
<th>Initial episode of ARF</th>
<th>High Risk Groups</th>
<th>All Other Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2 major or 1 major and 2 minor manifestations</td>
<td>2 major or 1 major and 2 minor or 3 minor manifestations</td>
</tr>
<tr>
<td><strong>Plus</strong></td>
<td>Evidence of a preceding GAS infection</td>
<td>Evidence of a preceding GAS infection</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recurrent attack of ARF in a patient with known past ARF or RHD</th>
<th>High Risk Groups</th>
<th>All Other Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 major or 1 major and 2 minor or 3 minor manifestations</td>
<td>Evidence of a preceding GAS infection</td>
<td></td>
</tr>
<tr>
<td><strong>Plus</strong></td>
<td>Evidence of a preceding GAS infection</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Major Manifestations</th>
<th>High Risk Groups</th>
<th>All Other Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carditis (including subclinical evidence of RHD on echocardiogram)</td>
<td>Carditis (including subclinical evidence of RHD on echocardiogram)</td>
<td></td>
</tr>
<tr>
<td>Polyarthritis or aseptic monarthritis or polyarthritis</td>
<td>Polyarthritis</td>
<td></td>
</tr>
<tr>
<td>Chorea</td>
<td>Chorea</td>
<td></td>
</tr>
<tr>
<td>Erythema marginatum</td>
<td>Erythema marginatum</td>
<td></td>
</tr>
<tr>
<td>Subcutaneous nodules</td>
<td>Subcutaneous nodules</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Minor manifestations</th>
<th>High Risk Groups</th>
<th>All Other Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fever</td>
<td>Fever</td>
<td></td>
</tr>
<tr>
<td>ESR ≥30 mm/hr or CPR ≥30 mg/l</td>
<td>Polyarthralgia or aseptic monarthritis</td>
<td></td>
</tr>
<tr>
<td>Prolonged P-R interval on ECG</td>
<td>ESR ≥30 mm/hr or CPR ≥30 mg/l</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evidence of a preceding GAS infection</th>
<th>High Risk Groups</th>
<th>All Other Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elevated or rising titre of anti-streptolysin O or other streptococcal antibody, or a positive throat culture or rapid antigen test for GAS. Upper limits of normal for streptococcal antibody titres in Australia:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AGE GROUP (years)</th>
<th>UPPER LIMIT OF NORMAL (IU/ML)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASO titre</td>
<td>Anti-DNase B titre</td>
</tr>
<tr>
<td>4–5</td>
<td>120</td>
</tr>
<tr>
<td>6–9</td>
<td>480</td>
</tr>
<tr>
<td>10–14</td>
<td>320</td>
</tr>
</tbody>
</table>

Reproduced with permission from *Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia. An evidenced based review.* © 2006 National Heart Foundation of Australia.
The APSU had a case classification for all cases notified to studies. These included confirmed cases which fully met the study criteria, duplicate cases of any previously reported case, other/error cases including those with key data missing or reported outside the study parameters and probable cases.

**Probable ARF**

Previous ARF studies have identified highly suspected or ‘probable ARF’ cases. Ralph *et al* (12) proposed definitions for probable and possible ARF which were based entirely on clients who present with joint problems, Spinetto *et al* (73) defined probable as *one major and two minor with the inclusion of evidence of a preceding GAS infection as a minor manifestation*, however these definitions were not considered broad enough to include all potential presentations of ARF. Despite an extensive search, a robust clinical definition for probable ARF was not found. For this study, probable ARF was defined as *a child in whom the most likely diagnosis was thought by the treating clinician to be ARF but which did not meet the case definition by virtue of missing either one major or one minor manifestation, or in the absence of raised streptococcal serology.*

**Classification of location**

To answer a key question around location of cases, postcode was collected for reported cases. Some postcodes include a large number of settlements and so identifying specific place of residence is not always possible. Recognising this limitation and using postcode, classification of location was based on the Australian Institute of Health and Welfare’s classification of Rural, Remote and Metropolitan Areas. (74) Cities and other large metropolitan areas (population >100,000) were classified as urban, centres with populations ranging from 10,000 to 99,000 and other rural centres with a population <10,000 we classified as rural, and small towns and communities with a population less than 5,000 were classified as remote. The ARF cases reported to reside in urban and rural locations were grouped and compared to those from remote areas where people have less access to multidisciplinary care and specialist services. (53)
**Barriers to diagnosis**

Delay in diagnosis was defined in terms of duration between onset of symptoms and first presentation of the child to health services, and duration from presentation to appropriate referral for confirmation of the diagnosis.

2.1.6 Data analysis

Reported cases were classified by the principal researcher and confirmed by the primary supervisor. Difficult cases were discussed in more detail with additional evidence, including echocardiogram results where available. Data analysis was done following development of a series of dummy tables based on simple and cross tab queries in the Microsoft Access database and by manually filtering data in the main table. Statistical calculations were done using SPSS v19 (IBM, Armonk, New York).

2.1.7 Ethics clearance

A research proposal was submitted to and approved by the Australian Human Research Ethics Committee of Northern Territory Department of Health and Families and the Menzies School of Health Research (AHEC Code No: EC00153).

2.1.8 Funding

An application for funding was submitted to the Heart Foundation of Australia. Ten thousand dollars was allocated to the study; $5,000 to the APSU to provide administrative support and $5,000 to the Menzies School of Health Research to facilitate the study in terms of consumables, communications and travel for the principal researcher. Otherwise this study was supported in kind using resources from the Menzies School of Health Research and APSU.
2.2 Results

2.2.1 Notified cases by classification

A total of 241 suspected episodes of ARF were reported to the study. Questionnaires were received for 223 (93% return rate) and of these, 151 were classified as confirmed ARF according to the study definition. The remainder were classified as probable ARF (17), multiple reporting of the same case by different clinicians (24), and cases not meeting the criteria were classified as errors (29). Examples of errors included cases that did not meet the study definition (e.g. age or diagnosis date outside study parameters), cases where there were core data missing preventing classification, and inadvertent reporting of the same case by the same clinician.

Seventeen cases were classified as ‘probable ARF’ according to our proposed definition (Table 7). All were in the high risk group and none had a reported history of ARF. Fifteen presented with joint symptoms including polyarthritis or aseptic monoarthritis and two presented with clinical carditis. Six presented with the required number of manifestations with insufficient evidence of recent streptococcal infection.

Table 7. Probable ARF presentations according to the proposed definition

<table>
<thead>
<tr>
<th>No evidence of recent streptococcal infection</th>
<th>Evidence of recent streptococcal infection</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 major manifestations</td>
<td>1 major and 2 minor manifestations</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Short by 1 major or 1 minor manifestation</td>
</tr>
<tr>
<td></td>
<td>11</td>
</tr>
</tbody>
</table>

2.2.2 Demographics of confirmed cases

The male to female ratio was 1.3 to 1. Eighty four were males and over half were in the 8-12 year age group (Figure 2). Aboriginal and Torres Strait Islanders represented 87% (n=131) of the 151 confirmed cases; however an African child, and a number of Pacific Islanders and non-Indigenous Australians were also identified (Figure 3). Over half of all children with ARF (96, 64%) were identified from Queensland (43%) and the Northern Territory (21%). One hundred children (66%), of whom 97 were Indigenous, were from remote areas. Of the
ten Caucasian children reported, seven were from urban or rural areas, predominantly in south eastern Australia. The majority of Pacific Islanders (six of eight) were reported from major urban centres along the east coast. Risk group for one child was unknown. The median age at diagnosis was 10.2 years (range 3.1–14.9).

Figure 1. Age at ARF diagnosis by gender.

Figure 2. Geographic distribution of confirmed ARF cases
Clinical presentation

The most common clinical features at presentation were joint symptoms (81%), fever (63%), and carditis (60%; 50% clinical and 10% ‘subclinical’ diagnosed by echocardiogram).

Polyarthritis was the most common joint manifestation representing 48% of all joint involvement. Aseptic monoarthritis as a major manifestation was common among children in the high risk group (19%) but only seen in one child as a minor manifestation in the low risk group. (Table 8)

Table 8. Manifestations of ARF in confirmed cases

<table>
<thead>
<tr>
<th>Manifestation</th>
<th>All cases (n=151)</th>
<th>Risk classification (n=150)*</th>
<th>Chorea classification</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>High risk (n=140)</td>
<td>Low risk (n=10)</td>
</tr>
<tr>
<td><strong>MAJOR MANIFESTATIONS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical carditis</td>
<td>76 (50%)</td>
<td>69 (49%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Subclinical carditis</td>
<td>14 (9%)</td>
<td>14 (10%)</td>
<td>n/a</td>
</tr>
<tr>
<td>(echocardiography)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>All carditis</strong></td>
<td>90 (60%)</td>
<td>83 (59%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Poly-arthritis</td>
<td>59 (39%)</td>
<td>56 (40%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Sydenham’s chorea</td>
<td>29 (19%)</td>
<td>26 (19%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Erythema marginatum</td>
<td>8 (5%)</td>
<td>4 (3%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Subcutaneous nodules</td>
<td>3 (2%)</td>
<td>2 (1%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Poly-arthralgia (HR)*</td>
<td>33 (22%)</td>
<td>33 (22%)</td>
<td>n/a</td>
</tr>
<tr>
<td>Aseptic monoarthritis (HR)*</td>
<td>26 (17%)</td>
<td>26 (17%)</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>MINOR MANIFESTATIONS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poly-arthralgia (LR)*</td>
<td>3 (2%)</td>
<td>n/a</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Aseptic monoarthritis (LR)*</td>
<td>2 (1%)</td>
<td>n/a</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Fever ≥39°C</td>
<td>96 (64%)</td>
<td>88 (63%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Raised ESR and/or CRP</td>
<td>122 (81%)</td>
<td>114 (81%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Prolonged PR interval</td>
<td>8 (5%)</td>
<td>8 (6%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Any joint manifestation</td>
<td>123 (81%)</td>
<td>115 (82%)</td>
<td>7 (70%)</td>
</tr>
</tbody>
</table>

* Risk classification unknown for 1 case. HR indicates high risk (Aboriginal and Torres Strait Islanders, Pacific Islanders, migrants from high risk countries); LR, low risk (all others).
The proportion of cases with cutaneous manifestations (erythema marginatum or subcutaneous nodules) and the proportion with raised inflammatory markers were higher in the group from urban and rural areas and in the low risk group (Table 9). Similarly the median streptococcal titres were higher in these groups. They were also higher in non-chorea than chorea cases.

Four of the eight children with erythema marginatum and all of those with subcutaneous nodules had rheumatic carditis.

Thirteen cases of ARF (8.6%) were reported to be recurrences. All were in the high risk group. Eight were from remote areas and nine were female. The median age for recurrent cases was 12 years (range 6–14). Two had two known previous episodes and two had three known previous episodes. Overwhelmingly, the reported reason stated for recurrence was failure of adherence to regular secondary prevention treatment. Family problems were also cited in a number of these cases. Carditis was more common among the recurrent cases (11, 85%) than the first episodes (65, 47%).

Table 9. Mean and median inflammatory markers and streptococcal titres by geographical area and risk group

<table>
<thead>
<tr>
<th>GEOGRAPHICAL AREA</th>
<th>RISK GROUP*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban/rural (n=51)</td>
<td>Remote (n=100)</td>
</tr>
<tr>
<td>ESR (mm/hr)</td>
<td>93 (m 95)</td>
</tr>
<tr>
<td>CRP (mg/L)</td>
<td>143 (m 150)</td>
</tr>
<tr>
<td>ASOT (IU/mL)</td>
<td>939 (m 704)</td>
</tr>
<tr>
<td>ADNB (IU/mL)</td>
<td>1333 (m 858)</td>
</tr>
</tbody>
</table>

* Risk classification unknown for 1 case. M indicates median; ESR, erythrocyte sedimentation rate; CRP, c-reactive protein; ASOT, anti-streptolysin O titre; ADNB, anti-DNase B titre

Of the 10 Caucasian children, the clinical features in seven were highly specific for ARF, including chorea, erythema marginatum, and/or subcutaneous nodules. In comparison, only 32 (23%) of the 140 high risk children presented with any of these features ($\chi^2= 10.80$, $p = 0.001$).
Chorea was reported in 29 (19%) of the confirmed cases – 26 (19%) of the high risk cases, and three (30%) of the low risk cases. Twenty-one (72%) were female and the median age at diagnosis was nine years (range 4–14). Thirteen (9%) of high risk and two (20%) of the low risk cases had carditis with chorea. Three (23%) children with recurrent ARF episodes presented with chorea; all were Indigenous females. Chorea was the only presenting manifestation in nine children (6%); eight of whom were from high risk groups. Chorea was more common among girls (21, 72%) and more common in children from remote areas (19, 66%). Delayed presentation was a factor in 21% (6) of the chorea cases with an average delay of 31.5 days (range 14–90).

A comparison was made of the inflammatory markers and streptococcal titres in the chorea and non-chorea groups. Fever, raised ESR or CRP and evidence of elevated streptococcal titres were all more common in the non-chorea group (Table 10), possibly because chorea was a late manifestation in the ARF illness and inflammatory markers had subsided at the time of diagnosis.

**Table 10.** Comparison of inflammatory markers and streptococcal titres in the chorea and non-chorea groups.

<table>
<thead>
<tr>
<th></th>
<th>CHOREA (n=29)</th>
<th>NO CHOREA (n=122)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elevated ESR or CRP</td>
<td>13 (45%)</td>
<td>97 (80%)</td>
</tr>
<tr>
<td>Fever (≥38°C)</td>
<td>7 (24%)</td>
<td>89 (73%)</td>
</tr>
<tr>
<td>Fever and elevated ESR/CRP</td>
<td>4 (3%)</td>
<td>83 (68%)</td>
</tr>
<tr>
<td>Elevated streptococcal titres</td>
<td>22 (76%)</td>
<td>119 (96%)</td>
</tr>
</tbody>
</table>

Additional information was collected for the 19 chorea cases; seven had mild, nine moderate, and three had severe movement disturbances. Females were more likely to have moderate to severe symptoms (9, 69%) than males (3, 50%). ‘Milkmaid’s grip’ was reported in 10 cases, the ‘pronator’ sign in six, darting tongue and explosive speech in five cases each, and writhing movements in six cases. Treatment was reported for five of the 12 moderate-severe cases; the most common therapy was sodium valproate, which was reported to reduce the severity of
movement disorders in all. None of the mild chorea cases received treatment. Duration of symptoms was reported for 14 cases; median 7 weeks (range 1–40).

2.2.4 Barriers to diagnosis

Questions relating to delay in presentation and delay of referral relied on the subjective view of the clinician. There was little difference in the proportion of delayed presentations and delayed referrals between urban/rural areas and remote area (Table 11). There was also little difference in the median time of delayed presentation between the two geographical locations, with median delays of 16 and 17 days. There was no difference noted in the median referral times (14 days).

Table 11. Number of cases of delayed presentation and referral

<table>
<thead>
<tr>
<th></th>
<th>Urban/Rural (n=51)</th>
<th>Remote (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No cases delayed</td>
<td>Time delayed</td>
</tr>
<tr>
<td>Delayed presentation</td>
<td>9 (20%)</td>
<td>Range 6-90 d m 16 d</td>
</tr>
<tr>
<td>Delayed referral</td>
<td>9 (18%)</td>
<td>Range 5-1156 d m 14 d</td>
</tr>
</tbody>
</table>

M, median; d, day(s)

Delayed presentation was mostly due to delayed recognition of symptoms or lack of awareness of the importance of symptoms by the child and/or family. Difficulties accessing the health service due to remoteness were also reported. Delayed referral was most commonly due to diagnostic uncertainty on the part of the clinician; usually because presenting symptoms were confused with other conditions such as osteomyelitis or septic arthritis. Several delayed referrals from remote areas were due to lack of available specialist services.

2.2.5 Risk factors

Information about the number of siblings with ARF was provided for 101 (67%) children. Nine (9%) children had siblings with ARF; eight had one sibling and one had two siblings with ARF.
The number of people per bedroom was reported in 39% (59) cases. Based on the accepted definition of overcrowding (more than two persons per bedroom), (75) 39 of these children (66%) lived in overcrowded housing. Fifty-five children with occupancy data were Indigenous, 38 of whom (69%) lived in overcrowded conditions, 33 from remote areas. A breakdown of household occupancy is provided in Table 12.

Table 12. Level of household crowding for children with confirmed ARF

<table>
<thead>
<tr>
<th>Number of occupants per house</th>
<th>Number of bedrooms per house</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 bedroom</td>
</tr>
<tr>
<td>1–4 occupants</td>
<td>1</td>
</tr>
<tr>
<td>5–9 occupants</td>
<td>--</td>
</tr>
<tr>
<td>&gt;9 occupants</td>
<td>--</td>
</tr>
</tbody>
</table>

Data were collected on reported sore throat or skin sores in the 3 weeks prior to onset of ARF symptoms. Fifty children (33%) were reported to have had a recent sore throat. Sore throat was more common among children from urban and rural (25/51) than children from remote areas (25/100 $\chi^2 = 8.80$, $p = 0.003$). For Indigenous children, recent sore throat was also more common among those living in urban and rural areas (15/34) compared with remote areas (24/97 $\chi^2 = 4.52$, $p = 0.033$). If a sore throat was reported, almost equal proportions of children sought treatment for their sore throat, regardless of location (13/25 and 12/25 respectively). Twenty-nine children (19%) reported skin sores prior to ARF diagnosis: nine of 51 (18%) from urban and rural areas and 20 of 100 (20%) from remote areas. Twenty-seven (93%) of the children with recent skin sores were Aboriginal or Torres Strait Islanders, with almost equal proportions of urban and rural compared to remote Aboriginal and Torres Strait Islander children reporting prior skin sores (Figure 4).
2.2.6 Completeness of case ascertainment

To determine the level of case ascertainment, reported cases were compared with the number of ARF cases in the under 15 year age group identified in jurisdictions with established notification systems. Comparison with ARF cases notified to the Northern Territory Notifiable Diseases System for 2008 showed that this study captured 63% of the cases locally notified. (M. Fittock, personal communication, July 2011). Comparison with Queensland Health data showed that the APSU surveillance method captured 62% of reported ARF cases for 2008–2010 (L. Lubbers, personal communication, July 2011).

2.2.7 Secondary prevention

All children classified as confirmed ARF were started on or continued with secondary prophylaxis following the reported episode. One hundred and thirty nine (92%) were prescribed intramuscular penicillin, 10 (7%) oral penicillin, and two (1%) erythromycin which can be used as an alternative method in the case of penicillin allergy. Four of the 10 children prescribed oral penicillin were in the low risk group (Figure 5). Two of the six children prescribed oral penicillin in the high risk group had a previous diagnosis of ARF, and were at

Figure 3. Reported sore throat and skin sores for Aboriginal and Torres Strait Islander cases \((n=131)\) by geographical location.
high risk of further recurrence. All children with ‘probable ARF’ were commenced on BPG injections.

![Figure 4](image)

**Figure 4.** Long-term secondary prophylaxis method prescribed for confirmed ARF cases by risk group.

2.3 **Discussion and recommendations**

2.3.1 **Clinical presentation and risk groups**

These are the first prospective clinical and epidemiological data collected on ARF in Australian children and at the time of writing, this was the only prospective surveillance study of ARF that has employed a model to collect data at a national level. Despite being an under-representation of the true number of ARF cases, the data highlight important aspects of clinical presentation and implications for diagnosis and treatment of ARF in children in Australia.

Twenty-three (18%) of the high risk cases were confirmed based on aseptic monoarthritis as a major manifestation. Monoarthritis was included as a major manifestation of ARF for high risk groups in the 2006 Australian guidelines (7) to increase sensitivity in populations at high risk of developing RHD. This change was made in response to reports that this manifestation
was common in ARF. (76, 77) The results of this study support the need to maintain monoarthritis as a major manifestation in high-risk individuals.

Not all of the reported cases presented typically. For example, there did not appear to be a common reason for the seventeen probable ARF cases not being confirmed; not specifically due to delayed diagnosis, lack of hospital admission or lack of clinical workup. These cases support the idea that the diagnostic guidelines for ARF need to retain some flexibility so that clinicians can interpret them according to the context for each presentation rather than rule out cases that do not fully comply.

One established deviation from the normal rule of requiring evidence of recent streptococcal infection is using Sydenham’s chorea alone to confirm ARF, because chorea can present long after the streptococcal infection and other signs and symptoms have resolved. Three of the children with chorea had delayed presentation (delay range 28-90 days) with anti-streptococcal titres remaining high. Other major and minor manifestations of ARF were more common in the absence rather than in the presence of chorea, which supports previous published data. (78) Despite this, carditis occurred in about half the children with chorea (52%), emphasising the importance of undertaking a baseline echocardiogram where possible to determine the presence and severity of carditis. Children presenting with chorea are at high risk of developing RHD and need careful monitoring and strict delivery of secondary prophylaxis medication to prevent ARF recurrences.

Erythema marginatum and subcutaneous nodules are rare presentations of ARF; and previously reported for up to 2% of Aboriginal and Torres Strait Islander cases in the Northern Territory. (76) Although these were also rare in this study, there were higher proportions of low-risk children with these manifestations. Forty percent of low risk cases had erythema marginatum. There are a number of possible explanations: high risk groups in Australia predominantly include people with dark skin and the erythema colouring may be harder to see on dark-skinned people, only the more overt cases may be diagnosed in low-risk children, or there may be a true difference in the manifestations of ARF between high-risk and low-risk
children in Australia. Furthermore, all of the children with subcutaneous nodules also had carditis which is consistent with previous findings. (79, 80)

A history of a recent sore throat was more common in this prospective study than has been found in previous retrospective studies in the Aboriginal and Torres Strait Islander population. Overall, 30% of Indigenous children had a reported prior sore throat, including 25% of those living in remote areas, compared to just 5.2% in a previous study from the Northern Territory. (55) It must be noted however that sore throat is a common complaint in children from all social backgrounds, and has not been shown to correlate with the incidence of streptococcal pharyngitis. (81)

Regardless of ethnicity, children in urban and rural areas more frequently had sore throat than those in remote areas (49% compared to 25%); supporting a previous finding that sore throat is relatively less common in remote-dwelling Aboriginal children. (55) These findings indicate that presentations of sore throat to health care should be encouraged (given that only half of the children with sore throat in this study sought medical care), and that health staff need to be aware of the potential for sore throat to be a precursor to ARF in high-risk children. But even if these measures are implemented, the majority of ARF cases are not likely to be prevented, highlighting the importance of primordial prevention (e.g. improved housing) to reduce exposure to group A streptococcal infection, and of ongoing research into developing a group A streptococcal vaccine. (82) The finding that 21% of Aboriginal and Torres Strait Islander cases reported recent skin sores supports current approaches to encourage better awareness, treatment and prevention of streptococcal impetigo and underlying scabies as a component of primary prevention, particularly in remote areas, even though a definitive link between skin infection and ARF remains unproven. (55)

Acute rheumatic fever continues to occur in low risk children. A hospital audit of childhood cases in the New Zealand Waikato district from 1998-2004 found 10% of the ARF cases to be European (low risk); however the rate in this group was found to be decreasing. (13)
Almost 7% of the cases in this study were Caucasian (low risk) predominantly from urban and rural settings and all from southern and eastern Australia. These children were much more likely to have highly specific features of ARF (chorea, erythema marginatum, subcutaneous nodules) than those from high-risk groups, and given that the clinical characteristics of ARF are relatively stable between different populations, this suggests that there are likely to be more ARF cases in low risk groups than are currently being diagnosed. This is further supported by the finding that average and median anti-streptococcal antibody titres were higher in low risk children and among those living in urban and rural areas. This suggests that, when children present with features of possible ARF in places (e.g. large urban centres) or from populations (e.g. non-Indigenous) not normally associated with a high risk of ARF, clinicians may only be diagnosing the most obvious cases and therefore are probably missing some milder or slightly atypical cases. If cases are not being correctly diagnosed, secondary prophylaxis will not be initiated, and children will be at risk of recurrent ARF and worsening RHD. Strategies may be needed to raise awareness of ARF among health professionals in populations and regions where the disease is less common, including low risk groups and large urban centres. A reasonable level of suspicion for ARF needs to extend to populations other than Indigenous Australians; in the case of low risk children in Australia, ARF still needs to be considered in the differential diagnosis of children with relevant signs and symptoms.

2.3.2 Secondary prevention of acute rheumatic fever

All children, including those classified as probable ARF, were commenced on or continued with secondary prophylaxis to prevent recurrent ARF. However there was an over-reliance on oral penicillin, particularly among the children from urban and rural settings (6, 12%) and among the low risk children (4, 40%). Two of the children prescribed oral penicillin were Aboriginal or Torres Strait Islanders from remote areas and had a recorded history of ARF. These children are at particularly high risk of ARF recurrence, for which the preventive medication of choice is intramuscular penicillin.
Uptake of long-term, prophylactic oral medication by children and adolescents has been found to be inadequate. Leistyna and Macauley (83) reported that more than 33% of children failed to receive the full 10-day course of oral penicillin to treat a streptococcal infection. This sets up poor expectations for children who require penicillin twice daily for at least 10 years following ARF. Mackner and Crandall (84) found that only about 50% of Caucasian adolescents with inflammatory bowel disease self-administered all prescribed long-term medication. Clinicians must be made aware of the practicalities of self-administering long-term oral medication, particularly by people who do not feel unwell.

2.3.3 Case ascertainment

The APSU surveillance methodology was voluntary and therefore under-ascertainment of the true number of cases in children was considered likely. A large proportion of the cases were reported from the Northern Territory and Queensland where ARF surveillance systems exist, and this was encouraging despite early concerns that double reporting would produce fewer notifications. High reporting rates might be attributed to an established culture of reporting of ARF in these areas. It is expected that under-ascertainment was also likely from other jurisdictions, and ARF could therefore be more common outside Indigenous populations of northern and central Australia than previously thought. This study has identified the potential for cases in other jurisdictions; however active surveillance in the form of mandated notification in other jurisdictions would help provide a more accurate description of ARF across Australia.

The proportion of recurrences (8.6%) is low compared to the most recent 3-year average reported from the Northern Territory of 24.4%. (10) Recurrences were possibly under-reported, and this might be due to the specialist clinician not having access to the complete medical history at the time of reporting.

First and recurrent episodes of ARF can be incorrectly recorded on disease registers if the individual has experienced a previous missed diagnosis, or if the complete medical history has not been sourced and recorded. In these instances, a recurrent illness may be identified as
‘ARF’ rather than ‘recurrent ARF’ in the client record, and future attempts to report the proportion of recurrent episodes may be difficult. ARF/RHD control programs should establish reliable notification systems and systematic recording practices so that complete medical histories are available, and recurrent ARF episodes are recorded accurately.

Delays in case presentation and health system referral existed across all geographical areas. This has implications for client and community education to increase self-awareness of the symptoms of ARF, and training for health staff to improve recognition of potential ARF when it does present, and to refer for specialist review and confirmation of the diagnosis as soon as possible.

Five children in this study were born overseas; four in the Pacific region and one in Africa. Immigration screening for permanent entry to Australia is limited to Tuberculosis, Hepatitis and HIV/AIDS, and obese persons may be further screened for diabetes, hypertensive heart disease and arthritis. Pre-departure screening for refugee and humanitarian groups includes tuberculosis check, malaria and parasite testing and a Measles/Mumps/Rubella vaccination for all people aged between nine months and 30 years. (85) The Australian health workforce needs to apply increased sensitivity for high burden populations who present with symptoms that could be ARF.

2.4 **Summary of recommendations**

It is anticipated that the results from this study will provide information about ARF in Australian children for jurisdiction-based control programs in their efforts to support local clinical and public health practice. Results will also assist the national coordination unit **RHDAustralia** as it supports further research into rheumatic fever and rheumatic heart disease in the Australian and immigrant population.

A number of recommendations have been made throughout the discussion; the following points are a summary of these recommendations.
1. Increase awareness and management of the risks of sore throat by health staff, particularly for high risk children

2. Standardise treatment and prevention of streptococcal impetigo and underlying scabies as an important intervention particularly in remote areas, even though its role in primary prevention is unproven

3. Develop and implement self-management strategies to improve client and community self-awareness of the symptoms of ARF and the need to present early for medical evaluation

4. Develop and improve structured and timely referral systems for managing children with ARF, particularly those from remote areas

5. Establish notification systems in jurisdictions with high Indigenous, Pacific Islander and migrant populations where systems do not currently exist, to identify true rates of ARF in these groups.

6. Highlight flexibility of diagnostic guidelines so that clinicians can interpret them according to the case context

7. Maintain monoarthritis as a major manifestation in high-risk individuals

8. Continue to recommend echocardiograms for all children presenting with Sydenham’s chorea to determine the presence and severity of carditis

9. Establish supportive notification systems and data entry rules for disease registers so that ARF episodes and episode type (first or recurrent) are accurately recorded.
3. Continuous quality improvement for the control and prevention of rheumatic heart disease in Fiji
The Fiji continuous quality improvement for RHD study was conceived within the parameters of the National Fiji RHD program. A number of national program objectives, primarily improved delivery of secondary prophylaxis, were difficult to achieve and maintain for the majority of health services. Given that health services across Fiji were seen to face unique challenges, the national RHD program considered a model of supporting health services to work towards improved service within their own capacity. Continuous quality improvement was considered; it is based on a model of management for chronic disease which originated as the Chronic Care Model.

3.1 **The Chronic Care Model**

The Chronic Care Model (CCM) (Figure 6) is an intervention framework developed in the United States in the 1990s to describe changes to healthcare that assist primary care settings to improve health outcomes for people with chronic disease. (86) It was developed by the MacColl Institute for Healthcare Innovation with a focus on efforts for improving diabetes care which up to that time had relied primarily on educating the health workforce. Prior to intervention with the CCM, and despite the development of management guidelines and some improvement in clinical practice; overall, critical client outcomes such as control of blood sugar and blood pressure had not improved. (87)

The CCM works on the principle of identifying and overcoming underlying deficiencies in the management of chronic disease. Deficiencies are considered to be lack of adherence to existing guidelines, inconsistent care coordination and follow up on the part of the health services, and lack of self-management capacity of the client population. The CCM architects realised that availability of guidelines alone does not ensure good practice or optimal client outcomes, rather, that best practice needs to be integrated into current practice through education and implementation with support from clinical experts.

Effective management of chronic disease should be seen as a partnership between the health system and the individual with disease, and treatment should be provided which is appropriate
to the client and within the framework of locally appropriate guidelines. Wagner et al (88) proposed that clients with chronic disease should be able to confidently self-manage their condition given that their interaction with health systems is usually episodic. However, the relationship between client and system is ongoing, and during health service-client interactions the health system should provide competent care to ensure the best possible health outcomes.

One of the essential elements of the CCM is a quality improvement-evaluation program which is founded on evidence-based guidelines for clinical care. Quality improvement works by health staff identifying areas of their practice that need improvement based on best practice management for the particular condition. The CCM architects suggested that effective health service intervention could be described by results from improvements in a number of components that make up the health service delivery system including the level of organisation of the health care, the appropriateness of the design of the health delivery system, access for clients to community-based resources, self-management support provided to clients, clinical decision support available to clinicians, and the availability and reliability of clinical information systems. (88)

![The Chronic Care Model](http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2)

**Figure 5.** The Chronic Care Model

* Taken from: [http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2](http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2)*
The CCM model expanded nationally into the Improved Chronic Illness Care program which was designed to assist health services to manage the chronically ill, particularly those servicing low-income population groups. (88) This initiative operated within the framework of three chronic conditions; diabetes, cardiovascular disease and asthma, and included hundreds of clients attending over one hundred organisations. Those organisations addressing management of diabetes demonstrated improved evidence-based practice and improved control of blood sugar, and approximately two-thirds of all organisations reported that the intervention for targeted chronic condition had a positive impact on clients with other chronic conditions. (88)

3.2 Australian ABCD Project

In 2002 an Audit and Best Practice of Chronic Disease (ABCD) project was established by the Menzies School of Health Research in the Top End of the Northern Territory. This project was based on the Chronic Care Model principles with the aim of improving management of chronic disease among Indigenous Australians living in remote communities. A study using the CCM to investigate management of chronic disease was conducted over 2002 to 2005 in Australia’s Northern Territory. The study included 12 community health centres that were different is governance, remoteness and size of population served. A number of chronic diseases were targeted including diabetes, mental health, vascular and metabolic disorders, maternal and child health and preventative services. (89) Information related to the components that make up a health service delivery system (mentioned above) was collected via mailed questionnaires and interviews with health staff. Data collected from each health centre was analysed in terms of strengths and weaknesses of the health service delivery system, taking into account opportunities and threats from external forces. Results were presented as a description of the structure and workforce flow of the health centres as well as a description of each of the system components. Results were mixed; however each facility demonstrated areas of strength and weakness in each of the components.
Between 2008 and 2010 the ABCD initiative was expanded to include RHD, for which clinical services and client health outcomes were audited at six remote community health centres. The RHD project had two aims; the first was to assess the level of adherence by the Northern Territory health system to the national guidelines for diagnosis and management of ARF and RHD which were published and distributed in 2006. (7) The second aim was to improve primary care for people with ARF and RHD using a quality improvement process to optimise use of best practice guidelines. One important product of the RHD project was the development of a clinical audit tool specific to ARF/RHD.

3.3 **Continuous Quality Improvement**

The ABCD RHD project was based on a model of continuous quality improvement (CQI). Continuous quality improvement is a cycle of improving health service delivery and health outcomes through audit, reporting, planning and action. (Figure 7) The process relies on local health care staff to determine the priorities for improving care within the local context through a process of self-evaluation. The research component measures evidence of practice as documented by the health centre and compares them to best practice standards, to identify priority areas for improvement.

The ABCD project utilised the CQI model within the framework of participatory action research (PAR). Minkler (90) suggests that action research is not a method itself, but an orientation to research that may employ any of a number of qualitative and quantitative methods. The success of such research depends largely on the attitudes of the research participants who employ a number of methods to build local capacity to improve systems in line with best practice. Action research is undertaken by local participants to benefit local individuals or communities. The researcher’s primary role is to support the research with the aim of analysing and improving the situation, as well as providing participants with an adequate appreciation of the process so that they can assume responsibility to continue into the future. Specifically, the researcher’s role is to develop the research tools, to provide training to participants in using the tools and assisting with auditing, to analyse the data and report results back to participants, to facilitate self-evaluation and
goal setting based on the results, and provide ongoing support to participants throughout the course of the study.

Figure 6. Continuous Quality Improvement cycle elements (91)

The ABCD project developed and employed a secure, internet-based database for storing and reporting the data. In January 2010 the database was transferred to the One21Seventy program website which continues to be maintained by the Menzies School of Health Research. (92) Data collected during the systems assessment and clinical audits were entered into the One21Seventy web-based information system (Figure 8).

Figure 7. One21Seventy database screen image

Taken from: information system audit page
Results were reported as aggregated data for the six study sites, as well as comparisons between the sites. Overall, both the quality of documentation and delivery of care showed trends of improvement, however documentation was more likely to be improved for those clients identified as having more severe disease, or being at higher risk of disease complications. When analysed separately there was a wide range in results between the sites. The key indicator of the proportion of clients who received 80% or more of BPG injections over the study period remained low. (7) While this in itself has implications for the health outcomes of individual clients, it is only one factor in the continuum of care for people with RHD.

In the final report on the ABCD project, Bailie et al (93) highlighted that there are many factors that impact on the results of such a study, including capacity of the health service and the level of on-going support provided to participants. Further, it was observed that results at individual sites could also be affected by changes to the makeup of the client group including movement of people into or out of the area, and disease progression. The authors made it clear that while the sites included in this study were not representative of all health facilities across the Northern Territory, they did provide an understanding of the diversity of the level of RHD care provided to clients.

3.4 Background to the Fiji study

3.4.1 Aims of the study

The aims of the Fiji study were to investigate the current approaches to secondary prophylaxis delivery and clinical care for people with ARF and RHD in different types of facilities, and determine their capacity to improve clinical practice and client health outcomes using CQI.

3.4.2 Methodology framework

The methodology used in the Fiji study draws strongly from that used for the ABCD project undertaken in Australian Indigenous primary health care environments. The Fiji study was an
investigation of the use of an adapted version of the ABCD model in a Pacific Island setting. The study was conducted using PAR which, through its design, is intended to develop equal relationships between the participants and researchers and empower individual communities to drive towards locally appropriate system and social change. (94) In the Fiji study, the principal researcher provided the research tools and instructed other researchers and participants in their use. The principal researcher also supported data collection, including facilitating group discussions on current clinical practice based on the findings from audits. It was therefore essential for the researcher to have an intimate understanding of the research topic so that support could be provided within the parameters of best practice.

In the absence of locally developed evidence-based guidelines, the Fiji Ministry of Health adopted the Australian Guidelines (7) which were developed for high risk groups including Indigenous Australians and Pacific Islander populations living in Australia.

**Research team**

This research was undertaken in collaboration between the Fiji Ministry of Health and the Menzies School of Health Research, and the study was undertaken through the activities of the Fiji national RHD program. The research team included the principal research and author of this thesis, the Fiji National RHD Program Officer and the Fiji Group A Streptococcal Project Research Nurse. The team worked with participating study sites to undertake data collection and support the sites during the research cycles.

**Signed agreement, Orientation and Training**

Prior to data collection the research team provided information about the study to participating sites through one or more orientation sessions for the participating site staff. When participating staff had a clear understanding of the research process and how it was to be conducted at the site, a participation agreement was signed by key researchers and site representatives. (91) This agreement consolidated a partnership between the research team and the study site based on common understanding of the CQI process and an agreed format.
by which to undertake the research. The participation agreement contained information about how the study was to be conducted; the method and objectives of the study, proposed roles and responsibilities of the researchers and the participants, and how the information collected in the study was to be stored and used.

*Audits and System Assessments*

Staff members from participating sites were invited to work with the research team at each audit to review medical records and record key information onto data collection forms. This process of auditing, in line with the CQI process used by the ABCD project in Australia, was intended to determine the level of care provided to people with ARF and RHD in relation to best practice.

Not all of the data elements included on the ABCD clinical audit tool suited the Fiji context. For example, the Australian ABCD tool included the option of recording documentation from both paper and computer records; however medical records in Fiji are in the form of paper. Therefore questions relating to use of computers were scored with ‘zero’ or ‘not applicable’ and omitted from the reports. The audit tool itself was modified only where changes to the value domains would support accurate data collection for the local context, such as ethnicity and geographical region. Data elements included on the Australian and Fiji audit tools are compared in Table 13.

Assessments of the current service delivery system (system assessments) were conducted to assess the development of health systems to support clinical care. Participants assessed their system by reviewing and scoring aspects about the methods by which they delivered care based on a pre-determined set of system factors.

The systems assessments included discussion about the current team structure and function, and capacity to address issues within the system. the level of clinical leadership and support, appointments and scheduling for clients, use of information systems and availability and accessibility of decision support (such as best practice guidelines), self-management support
provided to clients, the existence and process of links with other health services, and the quality of documentation of all of these elements. Following wider discussion the site teams agreed on a score for each element which most accurately corresponded to the self-determined level of service provision for each question.

This process of critical self-evaluation helped site staff and researchers to develop an understanding about how the health service worked; the strengths and weaknesses in service delivery practice and potential barriers to a system improvement process. Results from these discussions identified areas of service systems which may need improvement to achieve results that would be in line with best practice.
Table 13. Data elements and values: comparison between the ABCD audit tool and the Fiji audit tool.

<table>
<thead>
<tr>
<th>Question</th>
<th>Elements from ABCD Project *</th>
<th>Changes for the Fiji study</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Patient ID</td>
<td></td>
<td>A 6-digit number used to identify the health service and the client being audited. (e.g. 981-001, 981-002)</td>
<td></td>
</tr>
<tr>
<td>1.2 Medicare number recorded</td>
<td></td>
<td>Changed to National Health Number recorded</td>
<td></td>
</tr>
<tr>
<td>1.3 Date of birth</td>
<td></td>
<td>Every person who presents to a Government health facility is allocated a unique National Health Number which is used to identify them at all public hospitals and health facilities throughout the country.</td>
<td></td>
</tr>
<tr>
<td>1.4 Age at date of audit</td>
<td></td>
<td>Age calculated manually using date of birth and date of audit</td>
<td></td>
</tr>
<tr>
<td>1.5 Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.6 Ethnicity</td>
<td>Aboriginal Torres Strait Islander Both Neither Not stated</td>
<td>Fijian Indo-Fijian Other Not recorded</td>
<td>The alternative values represent the major population groups in Fiji</td>
</tr>
<tr>
<td>1.7 Auditor’s name and initial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.8 Audit date</td>
<td></td>
<td>For audits that took more than one day to complete, audit date was the date on which the audit commenced.</td>
<td></td>
</tr>
<tr>
<td>1.9 State/Territory of audit</td>
<td>ACT NSW NT QLD SA TAS VIC WA</td>
<td>Central Western Northern Eastern</td>
<td>These values represent the Divisions in Fiji by which populations are governed and measured.</td>
</tr>
</tbody>
</table>

SECTION TWO: Attendance at Health Centre

<table>
<thead>
<tr>
<th>Question</th>
<th>Elements from ABCD Project *</th>
<th>Changes for the Fiji study</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Date last attended</td>
<td></td>
<td>The date the client last attended the health service to receive any care. If</td>
<td></td>
</tr>
</tbody>
</table>
clients attended and left before being seen by health staff that date of attendance is not applicable.

Computers are not used in primary health care facilities in Fiji. The use of Benzathine books have been standardised throughout Fiji. They are the primary source of documentation of Benzathine penicillin G injections to prevent ARF in Fiji.

<table>
<thead>
<tr>
<th>2.2 Location of record of last date attended</th>
<th>Medical Record Computer</th>
<th>Medical Record Benzathine Book</th>
<th>These options were changed slightly to more accurately reflect the types of health presentations that are common in Fiji.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.3 Reason for last attendance</td>
<td>Acute care Benzathine penicillin injection Well person’s check Specialist review Other n/a</td>
<td>Acute care/trauma Benzathine penicillin injections Secondary prophylaxis (oral) RHD Specialist review Routine medical review Other</td>
<td></td>
</tr>
<tr>
<td>2.4 First seen by (staff member at the health facility)</td>
<td>Omitted from the audit tool</td>
<td>The ABCD model included this question to determine the category of staff providing the initial client health assessment at last presentation (e.g. Doctor, Nurse, Aboriginal Health Worker) Some facilities have a policy on which category of staff member should be the first to see clients and this was question was intended to see how well the policy was being implemented. The study sites in Fiji did not have any such policies, so this question was not relevant.</td>
<td></td>
</tr>
</tbody>
</table>

### SECTION THREE: Recording of key health information

<p>| 3.1 Record of diagnoses | Includes whether a diagnosis of definite first and recurrent ARF, suspected first and recurrent ARF and RHD, including date of diagnosis. |
| 3.2 Where in the client’s medical record/s is the client’s level of classification recorded? | Changed to <em>Is the Disease Classification recorded?</em> |
| 3.3 If recorded, what is the clients classification | Including High risk, Medium risk and Low risk |
| 3.4 If not recorded, what is the classification according to the Priority Level Algorithm? | |
| 3.5 Is there a current ARF/RHD management Plan? | A management plan is a comprehensive plan based on the care required for the |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.6 Is cigarette smoking status recorded?</td>
<td></td>
</tr>
<tr>
<td>3.7 What is the recorded smoking status?</td>
<td></td>
</tr>
<tr>
<td>3.8 What is the recorded alcohol use status?</td>
<td></td>
</tr>
<tr>
<td>3.9 If the Disease Classification is High Risk, is it recorded that this patient is waiting for cardiac surgery?</td>
<td></td>
</tr>
<tr>
<td>3.10 If the Disease Classification is High Risk or Medium Risk, is the patient currently prescribed Warfarin?</td>
<td></td>
</tr>
<tr>
<td>3.11 If Warfarin is prescribed, please record the two most recent INRs including results and dates of these tests.</td>
<td>Most recent INR and date of INR, or Not Applicable</td>
</tr>
</tbody>
</table>

**SECTION FOUR: Audit of penicillin use and acute rheumatic fever**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Is this patient receiving Benzathine penicillin injections?</td>
<td></td>
</tr>
<tr>
<td>4.2 Is the patient receiving <em>oral</em> antibiotic prophylaxis (Penicillin V or Erythromycin tabs)?</td>
<td><em>Not Applicable</em> if receiving injections (4.1)</td>
</tr>
<tr>
<td>4.3 Is there a <em>current</em> order for Benzathine penicillin injections?</td>
<td>An order that is correct for weight, age and frequency</td>
</tr>
<tr>
<td>4.4 Where is the planned frequency of injections recorded?</td>
<td></td>
</tr>
<tr>
<td>Current prescription</td>
<td></td>
</tr>
<tr>
<td>Non-current prescription</td>
<td></td>
</tr>
<tr>
<td>Elsewhere in medical record</td>
<td></td>
</tr>
<tr>
<td>Not recorded</td>
<td></td>
</tr>
<tr>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Current order</td>
<td></td>
</tr>
<tr>
<td>Elsewhere in medical record</td>
<td></td>
</tr>
<tr>
<td>Benzathine book</td>
<td></td>
</tr>
<tr>
<td>Medical record AND</td>
<td></td>
</tr>
<tr>
<td>Benzathine book</td>
<td></td>
</tr>
<tr>
<td>Not recorded</td>
<td></td>
</tr>
<tr>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>These options were changed slightly to more accurately reflect the way Benzathine penicillin G injections are documented at health facilities in Fiji.</td>
<td></td>
</tr>
<tr>
<td>4.5 If not consistent, which one is correct?</td>
<td></td>
</tr>
<tr>
<td>Medical record</td>
<td></td>
</tr>
<tr>
<td>Clinical Master chart</td>
<td></td>
</tr>
<tr>
<td>Medical record</td>
<td></td>
</tr>
<tr>
<td>Benzathine book</td>
<td></td>
</tr>
<tr>
<td>The Benzathine Book is considered to be the ‘master chart’ of people with ARF and RHD who require Benzathine penicillin G injections.</td>
<td></td>
</tr>
<tr>
<td>4.6 If recorded in both the client medical record and the clinic master chart, are the two records consistent?</td>
<td></td>
</tr>
<tr>
<td>Medical Record</td>
<td></td>
</tr>
<tr>
<td>Benzathine book</td>
<td></td>
</tr>
<tr>
<td>Changed to <em>If recorded in both the patient’s medical record and the Benzathine Book, are the two records the same?</em></td>
<td></td>
</tr>
<tr>
<td>4.7 If not the same, which</td>
<td></td>
</tr>
<tr>
<td>Medical Record</td>
<td></td>
</tr>
<tr>
<td>Medical record</td>
<td></td>
</tr>
<tr>
<td>The Benzathine Book has been standardised across Fiji for the recording of</td>
<td></td>
</tr>
<tr>
<td>one is currently used?</td>
<td>Clinical Master Chart</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td></td>
<td>Not Applicable</td>
</tr>
</tbody>
</table>

4.8 Frequency of injections planned

| Monthly (12 injections) | 4-weekly (13 injections) | 3-weekly (17 injections) | Other | No record | Not Applicable |

4.9 Number of injections given in last 12 months

4.10 If injections started within the last 12 months, record date of first injection

4.11 Calculate the percent (%) of planned injections that were received in the last 12 months (or since beginning BPG injections)?

4.12 If the client has received less than 80% of planned Benzathine penicillin injections, is there a record of:

- An attempt to contact the relevant health centre to Arrange for Benzathine penicillin injections to be given if the client is known to be out of the community?
- Advice about importance of preventing recurrent ARF?
- A family meeting?
- An action plan made?
- Other appropriate action?
- Details of other appropriate action:

4.13 Number of recorded episodes of recurrent rheumatic fever in the last 12 months:

*If one or more episodes of recurrent rheumatic fever recorded in the last 12 months despite good delivery of Benzathine penicillin (80% or more of scheduled),*

4.14 Is there a record of

- Change to more frequent Benzathine penicillin injections?
- Advice on the role of throat and skin infections in leading to ARF?
| Advice on the role of overcrowding in predisposing to ARF? |
| Action plan made? |
| Referral to support services (for example, environmental health services, housing services)? |
| Other appropriate action? |
| Details of other appropriate action: |

### SECTION FOUR: Audit of penicillin use and acute rheumatic fever

#### 5.1 Evidence of services

| Influenza vaccination (within 2 yrs.) Polysaccharide pneumococcal vaccination (Pneumovax 23) (within 5 yrs.) | Omitted from the audit tool | Neither seasonal influenza vaccine nor Polysaccharide pneumococcal vaccine was available in Fiji at the time of this study. |

#### 5.2 Education

| Watched DVD or video Given written materials | Education / Discussion Given written materials | Culturally appropriate DVDs and videos about ARF and RHD are not available to clients. |

#### 5.3 Brief intervention. Is there a record of brief intervention including the following risk factors having been provided?

| Smoking (adults aged >15yrs) Nutrition Alcohol (adults aged >15yrs) Physical activity |

* Based on v6.4: 11 September 2008
Data storage and reporting

Information was collected by accessing existing health records and from the Fiji National RHD database maintained by the Fiji Rheumatic Heart Disease Program, Fiji Ministry of Health.

Client data were de-identified and audit forms were marked with a number. During the audits a master list of client names with corresponding number was maintained from each site by the Fiji RHD program staff so that records could be re-accessed if data needed to be checked. These master lists were destroyed after data analysis. Similarly, sites were de-identified during analysis; sites were only identified in reports to the Fiji RHD program and during feedback to study supervisors. (95)

The One21Seventy database system provided pre-determined default alerts and mechanisms to ensure accurate data entry. Each site for this study was allocated a separate data area where system assessment results were stored, and where multiple audits were stored as individual client records. The One21Seventy database automatically collated, analysed and presented in graphs and tables, and the report produced after each audit cycle contained standard text that could be edited by the researcher.

Key audit results and outcomes of the systems assessment were then presented to staff at the study sites during a subsequent meeting. If two or more CQI cycles had been completed the report included comparative data from each audit cycle.

Participatory interpretation and action planning

The participating teams were assisted to develop an action plan based on the interpretations of audit and assessment results with guidance from the research team. The research team facilitated constructive discussion and assisted participants to set specific goals for improvements to service delivery and systems structure and function. Goal-setting at this stage was critical. The direction and pace of any changes needed to be considered carefully so
that goals were relevant to ARF and RHD, timely, and measurable. Most importantly, achieving goals needed to be possible with the available human and material resources. (7)

3.4.3 Ethics approval

A research proposal was submitted to two ethics committees for approval: the Fiji National Research Ethics Review Committee and the Human Research Ethics Committee of Northern Territory Department of Health and Families and the Menzies School of Health Research (HREC EC00153).

3.4.4 Language

English is the official language in Fiji, with Fijian and Fijian Hindi also commonly spoken. Fijian and/or Fiji Hindi are often used during medical and nursing consultation where staff and client speak the same language, however staff meetings, community-based health promotion, professional correspondence and medical records are routinely conducted in English. Communication and documentation for this study was therefore conducted in English.

3.5 Planning the intervention

3.5.1 Site selection

The Fiji Ministry of Health divides the country into three medical administrative divisions; Northern, Central/East, and Western. The Northern Division includes Vanua Levu, Rotuma and Taveuni, the Central/East Division includes the eastern side of Viti Levu, Kadavu, and the Lomaviti and Lau Island groups. The Western Division includes the western side of Viti Levu and the Yasawa group (Figure 9).

All health facilities in Fiji where primary health care services are delivered for clients with ARF and RHD were considered for inclusion in the study. However, selection of the study sites was based on two specific determinants. Firstly, sites needed to be reasonably accessible to the research team. Access to remote and island regions of Fiji is often complex, expensive and often unreliable due to weather extremes. The number of people with ARF and RHD
receiving regular care at a site was the second key consideration. Many rural and remote health facilities service only a small number of people living in and around a local village, so sites that provided care for larger client populations were targeted to ensure that as many clients as possible would be involved.

One study site was selected from each of the Northern, Central and Western Divisions. Each site differed in size, function and capacity.

![Figure 8. Map of Fiji](image)

3.5.2 Description of the audit sites

Site One

Site One was a regional community health centre that serviced a large rural population on the outskirts of the national capital Suva. The facility managed primary care services including a small maternity hospital, integrated maternal and child health program, and skin, respiratory, and diabetes services. Radiology (x-ray) facilities were available on site. A small emergency room was staffed 24 hours a day. Clients with a diagnosis of RHD received specialist medical care at the Colonial War Memorial (CWM) Hospital Specialist Outpatients Department in Suva over 20km to the south-west. Clients were responsible for their own travel and costs to CWM Hospital. Information about ongoing clinical review and assessment was retained in the
client’s CWM hospital record and not sent to the health centre. A number of people with ARF and RHD living in neighbouring communities attended this facility to receive BPG injections because it was located at a transport and commercial hub and was easily accessible for people commuting for work and school.

*Site Two*

Site Two was a paediatric ward within a regional hospital. The ward provided inpatient and outpatient services for children with ARF and RHD who lived in the township and surrounding area. Staff were experienced in paediatric care, and many had worked on the ward for a number of years. A regular Saturday morning BPG outpatient clinic had been established on the ward a number of years prior to the study. Saturday was market day and was well attended by the wider population; since the market was adjacent to the hospital Saturday was thought to be the most convenient time for the clinic.

Dental services were available on site. Routine echocardiography was performed by a Paediatric Specialist during irregular outreach visits from Suva. Urgent echocardiograms required referral to the CWM Hospital in Suva, and this involved travel by aircraft and a total travel time of at least 2 days.

*Site Three*

Site Three was a multi-disciplinary regional hospital with well-established leadership across departments and an established system for care and referral of clients with ARF and RHD. Independently managed paediatric and adult outpatient and inpatient services were available. Echocardiogram services and specialist clinics were available on site. This site also had a dedicated part-time RHD program nurse who was available to provide day-to-day support to the study. A list of all ARF/RHD clients attending the hospital was not maintained; however the Paediatric Department had a list of children who were being reviewed in the Children’s Outpatient Department. Benzathine penicillin G injections were provided for both adults and children through the adults’ outpatients department.
3.5.3 Study tools

A Resource Kit developed by the ABCD project was used to guide the data collection process, and data collection tools developed by the Australian ABCD RHD project were used in this study. (91) This included a tool for drawing a random sample of clients for audit, a systems assessment tool, and a clinical audit tool.

Sampling of medical records

All clients who were registered on the national Fiji RHD register to receive BPG injections at each study site (or registered to receive primary health care at the study site if regular injections were not indicated) were entered into an Excel spreadsheet in the order that they were generated from the RHD register (order of registration date) and a random sample list was generated using the random (RAND) function in Microsoft Excel. (96)

This study used the ABCD project recommendation to use “a random sample of thirty clients if the number on the disease register is greater than thirty.” (91) In the event that selected charts were not located or that a selected client was not attending the study site (or was found to be deceased), the next name on the random list was selected until the required number of eligible medical records was selected for auditing. The process of determining a random sample was repeated for each consecutive audit cycle using an updated list of people from each study site. This process ensured that random samples were drawn for each audit cycle; however the samples may have included some of the same clients.

Clinical audit tool

A clinical audit tool was used to support collection of data from client medical records. The tool included general information about the client including de-identified person attributes and demographic data (initials, date of birth, gender, and ethnicity), record of attendance at the health facility and the recording of key health information related to the current level of disease of the individual as documented. Information about secondary prophylaxis included evidence of a current and accurate prescription, the number of injections received over the
previous 12 months, and attempts to improve delivery of BPG injections where clinically indicated. The last section focused on the level of ongoing care, including medical officer and specialist reviews, dental reviews, and routine echocardiogram.

Medical documentation in the client record was deemed to be evidence of services provided; if documentation did not exist it was assumed, for the audit, that the service was not provided.

*System Assessment Tool*

The systems assessment tool is a practical tool to help organisations evaluate the strengths and weaknesses of their delivery of care for chronic illness. It is based on the Assessment of Chronic Illness Care (ACIC) scale (97) and consists of six system and service delivery components that are important targets of care for chronic illness: delivery system design, decision support, information systems, self-management support, community linkages, and organization of care. (98) Each of these components can reflect poor to optimal organization attributes. Participants discuss each component within their own context and agree on the most accurate appraisal and corresponding score. (99) The ACIC scale is based on the Chronic Care Model framework of promoting effective change in provider groups to support evidence-based clinical and quality improvement.

1. Delivery system design.

This component refers to the extent to which the health centre design, staff roles and responsibilities and quality of leadership, and work flow and clinical planning capitalise on the potential effectiveness of the centre.

2. Information systems and decision support.

This component refers to clinical and other information resources and processes to support the planning, delivery and coordination of care.

3. Self-management support
This component refers to established processes that support clients to take an active role in maintaining their own health and wellbeing, and managing health problems. This includes availability and accessibility of peer support services and the involvement of families in the self-management support process.

4. Links with the community, other health services and other services and resources

This component refers to the extent to which the health centre uses external organisations to link clients to relevant community resources, to which centre staff work in settings in the community, and to which the centre contributes to local planning and development.

5. Organisational influence and integration

This component refers to the capacity of the organization to influence a culture that is supportive and safe, and that promotes quality of care. It also refers to how well all the system components are integrated across the service.

Client questionnaire

A client questionnaire was developed for this study to determine from clients their understanding of the quality of clinical care provided by participating sites. (Appendix C). Clients were invited to complete the questionnaire when they presented for a regular BPG injection. Questionnaires were completed in English either by clients or by the research team who asked the questions in the client’s preferred language. The client group was not randomly selected; this group included clients who attended for BPG injection during the audit and were willing to complete a questionnaire. It was anticipated that at least 30 people from each site would complete a questionnaire at each audit.

The client questionnaire included questions related to age, gender and ethnicity, history of diagnosis and treatment, any changes to treatment over time and attitudes around the changes, acceptance (or non-acceptance) of treatment, health services provided by the health facility including follow-up, education and support as reported by the client.
3.6 **Method of analysis**

Due to the difference in size, structure and function of participating sites, results from the audits and systems assessments were analysed and reported for each site separately. Results were discussed in terms of goal setting and action planning by each site, and a descriptive analysis included changes observed in the quality of documentation in medical records, and changes in the level of evidence of care for clients. The following outcome measures are summarised in Table 14.

3.6.1 **Quality of Documentation**

Three key elements were measured; documented severity of disease, evidence of a written order for BPG injections (where indicated), and evidence of disease management planning.

Determining disease severity was measured by the direct recording of the severity of disease in the medical record, and if not recorded, by using an algorithm to interpret general information about the disease written in the medical record. The algorithm included options of ARF, and mild, moderate and severe RHD. The algorithm was developed by the Australian ABCD project and included a description for each option to standardise severity of disease classification by level of risk (see 3.7.1 Recording of risk classification).

Documented order for injection was analysed in terms of being both correct and incorrect frequency for age, as a proportion of the total audited population requiring injections. Incorrect frequency was highlighted because of its potential to impact on the results. For example, an adult prescribed three-weekly injection who receives 13 injections would have received 76% injections in a year. Based on the correct frequency for age of four-weekly injections (13 in a year), this person would have received 100% injections in that period.

Management plans were deemed to be present if they addressed immediate, short-term and long-term needs of the client, including plans for ongoing secondary prevention treatment and clinical and investigational follow-up requirements. A note in the medical record stating, for example, “Review in 6 months” was not considered to be a management plan.
3.6.2 Quality of client care

Three key areas of client care were audited including delivery of regular BPG injections, follow-up of clients who did not receive 80% or more of required injections in the 12 months prior to the audit, and elements of clinical and investigational care.

Delivery of injections was calculated on the documented frequency, regardless of whether correct for age, because it was the documented order which was applied by nursing staff when injections were administered. Follow-up of clients who received less than 80% of injections included a number of identified strategies aimed at improving uptake of injections. Specific actions that were measured included active recall of the client by phone or by person, convening a family meeting, arranging for injections to be given elsewhere if the client was travelling, ARF prevention counselling, and developing an action plan.

The benchmark for measuring clinical and investigational care was based on Australia’s guidelines for ongoing care requirements for people with ARF and RHD. (7) This included Medical Officer, Medical Specialist and dental review within the previous 2 years, and echocardiogram within the previous 3 years. These standards of care for clients with RHD had been promoted by the program through clinical workshops. The impact of change was reported as the proportion of clients who had evidence that these services were received within the recommended time frames prior to each audit.

3.6.3 Systems assessments

The systems assessments were analysed according to the participants’ evaluation of the site’s support to infrastructure and processes according to the six components. Within each component was a pre-defined list of options with the following parameters: limited or no support (e.g. no clinical leadership), basic support (e.g. clinical leadership emerging), good support (e.g. clinical leadership becoming established and recognised), and fully-developed support (clinical leadership fully established and recognised). Possible scores ranged from zero, indicating no support, to 11, demonstrating that support was well-established and
recognised by all staff. Results were considered to be significant if the subsequent scores were three or more points higher or lower than the initial score.

Table 14. Summary of main outcome measures

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Element</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of documentation</td>
<td>Documented severity of disease</td>
</tr>
<tr>
<td></td>
<td>Evidence of written order for BPG injections</td>
</tr>
<tr>
<td></td>
<td>Evidence of disease management planning</td>
</tr>
<tr>
<td>Quality of care</td>
<td>Delivery of regular BPG injections</td>
</tr>
<tr>
<td></td>
<td>Follow-up for clients who received less and 80% injections in previous 12 months</td>
</tr>
<tr>
<td></td>
<td>Elements of investigational care</td>
</tr>
<tr>
<td>Systems assessments</td>
<td>Delivery system design</td>
</tr>
<tr>
<td></td>
<td>Information systems and decision support</td>
</tr>
<tr>
<td></td>
<td>Self-management support</td>
</tr>
<tr>
<td></td>
<td>Links with community, other health services and other services and resources</td>
</tr>
<tr>
<td></td>
<td>Organisational influence and integration</td>
</tr>
</tbody>
</table>

Results from client questionnaires were included where they assisted interpretation of the audit and system assessment data, and the relationship between the system assessments and audit data was used in some instances to demonstrate supportive or conflicting results.

The reports generated by the One21Seventy information system included basic analysis of key performance indicators related to the management of ARF and RHD. The three key indicators in this study are listed here with a description of how categories were derived, how the data were structured, including any specific analytical techniques that were applied.

3.6.4 Recording of risk classification

Risk classification was derived from the severity of disease where identified from the medical record. There were 4 options in the audit for risk classification adopted from the ABCD audit tool: (100)

- **Low Risk** - a history of ARF with no evidence of, or trivial to mild valvular disease;
- **Medium Risk** - any moderate valve lesion in the absence of symptoms and with normal left ventricular function OR mechanical prosthetic valves;
- High Risk - severe valvular disease OR moderate/severe valvular lesion with symptoms OR tissue prosthetic valves and valve repairs;

- Unknown Risk – where the disease status is not documented, and where it cannot be determined from the medical notes.

Recording of risk classification in the medical record helped local health staff to identify the level of morbidity and plan appropriate long-term care.

3.6.5 Delivery of intramuscular penicillin

There were three critical elements for evaluation related to delivery of BPG injections in this study.

The first was evidence of a current and correct order for clients who had been prescribed regular injections. An order was considered current and correct if it stated the correct dose and frequency for age and weight. (62) The Benzathine Book is most commonly consulted by staff prior to BPG injection delivery and so the dose and frequency is expected to be documented in this book; however the order should also be documented by the medical officer in the medical notes as a prescription. This information was used to measure the quality of documentation and was calculated as the proportion of people requiring BPG injections who had documented evidence of a current and correct order.

The second element was BPG injection delivery: the proportion of injections delivered to each client in the 12 months prior to the audit based on documented frequency (3-weekly or 4-weekly).

The third element was evidence of intervention for clients who did not receive at least 80% of required injections in the previous 12 month period. Specific interventions included recalling the client for injection, coordinating with other health facilities to delivery injections, advising the client about the importance of injections, hosting a family meeting and developing an action plan.
3.6.6 Elements of clinical and investigational care

Four key elements of clinical and investigational care were measured in this study: evidence of medical officer review, specialist review, dental review, and evidence that an echocardiogram had been conducted where indicated. Results were presented as proportional change between the first and third audit for each site.

3.7 Results

3.7.1 Course of the intervention

Auditing commenced at Site One in March 2009 and was completed with the third audit at Site Three in April 2011. Two full audit cycles including clinical audits and systems assessment, and a third clinical audit for final evaluation was undertaken at each site.

A systems assessment was included during the first audit cycle to determine a baseline for how staff perceived their health delivery system design and function. The systems assessment included during the second cycle identified changes in self-assessed performance after the first intervention phase. The third cycle included only the clinical audit to determine changes in documentation and delivery of care outcomes over the course of the project. Due to problems coordinating the dissemination and return of client questionnaires, these were only completed by 15 clients from Site Two during the first audit and 21 clients at Site Three during the third audit. Table 15 outlines the process including dates and number of audits done at each site.

Table 15. Timelines and activities for each audit

<table>
<thead>
<tr>
<th>Audit date</th>
<th>Audit date</th>
<th>Audit date</th>
</tr>
</thead>
<tbody>
<tr>
<td>(№ records audited)</td>
<td>(№ records audited)</td>
<td>(№ records audited)</td>
</tr>
<tr>
<td>systems assessment</td>
<td>systems assessment</td>
<td>systems assessment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site One</th>
<th>Site Two</th>
<th>Site Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 Mar 2009 (23) yes</td>
<td>30 Mar 2009 (28) yes</td>
<td>3 Apr 2009 (27) yes</td>
</tr>
<tr>
<td>2 Feb 2010 (30) yes</td>
<td>26 Nov 2009 (29) yes</td>
<td>30 Nov 2009 (19) yes</td>
</tr>
<tr>
<td>24 Feb 2011 (30) no</td>
<td>12 Apr 2011 (30) no</td>
<td>29 Mar 2011 (30) no</td>
</tr>
</tbody>
</table>
3.7.2 Characteristics of the audited population

The total number of medical records audited during this study was 246: 78 at first audit, 78 at second audit and 90 at third audit. Overall, Fijians made up 46% (112), Indo-Fijians 52% (126) and clients classified as ‘other’ 2% (five) and there were slightly more males (51%) than females (49%). There was little difference in the proportion of Fijian and Indo-Fijian clients audited at sites one and three, however Indo-Fijians were somewhat higher at Site Two (64%). All ‘others’ were reported from Site Three.

Sixty-four percent of all clients audited were aged less than 15 years at the time of audit, which classifies them as children (T. Babitu, personal communication, March 2009). A breakdown of age for each site shows 43% were aged less than 15 years at the time of audit at Site One, 94% at Site Two and 46% at Site Three. Site Two was a paediatric facility which explains the higher number of children compared to other sites.

Eight high-risk clients were waiting for surgery at the time of audit. Seven of these were from Site Three and were aged between seven and 55 years; four of the seven were Fijian and five of the seven were male. The additional client, an eight year old Fijian female, was waiting for surgery at Site Two.

Reason for last attendance at the health facility at the initial audits was predominantly to receive regular BPG injections, however the proportion of people recently presenting for routine or specialist review (rather than for BPG injection) increased at all sites during subsequent audits.

3.7.3 Examples of team planning

Setting goals and planning strategies for improved service delivery was conducted by participating teams after the first and second audit and was based on audit findings. Not surprisingly, the key elements of the audits – benzathine injection delivery and coordination of clinical care – dictated priorities for improvement.
All sites focused on improving delivery of BPG injections after the first audit. Specific activities included appointing a staff member to oversee RHD activities at the facility and liaise with the national RHD program (Site One), and identifying clients indicated for injections, updating the Benzathine injection Book, and expanding support for clients through the outreach Zone Nurses (all sites). Site Three went further to propose that the national secondary prevention protocol (62) would be available to all staff administering injections, and planned for the establishment of a dedicated paediatric injection clinic for children with ARF and RHD within six months of the initial audit. All sites planned to incorporate check lists for coordinating care into their service, and all included regular communication of clients with the national RHD register into their planning. Site Two aimed to improve coordinated care for clients, specifically the coordination of dental care and increase documentation for echocardiograms done at the CWM Hospital in Suva.

A number of these goals set at Site One were not achieved, or only partly achieved. They were considered to be important and the second round of planning included completing or strengthening a number of the strategies developed during the first audit.

A number of goals set by Site Two were achieved or in progress at the time of the second audit. The second planning activity therefore, maintained some of the existing goals, and expanded to the introduction of appointment cards to help clients monitor their clinical care regimen. The team also planned to investigate prospects for a local clinician to be trained in echocardiography; capacity to do echocardiograms locally would enable to facility to provide all clinical care for clients with RHD locally.

The paediatric injection clinic at Site Three was established, and the second planning activity included broader strategies such as improving education for clients during clinical contact sessions, and ensuring guidelines for diagnosis and management could be accessed on all computers within the hospital.
3.7.4 Changes associated with the intervention at Site One

Changes observed in documentation

There was a small improvement in the ability to determine disease severity from the medical records at the second audit, however this improvement was not sustained and quality of documentation remained low at the third audit (Figure 10). Improvements in recording of BPG injection order were sustained; (Figure 11) however this included a slight increase in the proportion of records with incorrect injection frequency for age. Disease management planning was not routinely documented (Figure 12). There was no evidence of management planning found in medical records from the first audit; this increased to seven records each in the second and third audits.

Figure 9. Evidence of disease severity for Site One
Changes observed in delivery of care

The proportion of clients receiving 80% or more of scheduled injections decreased from 44% to 37%; however the number of clients in this group remained stable at 10-11 at each audit. This was due to a large increase in the proportion of clients receiving less than 50% of injections (30-57%) over the study period. The proportion of clients who received between 50 and 79% also decreased by 20%. (Figure 13)
One client in each of the first two audits had documented evidence that follow-up for missed injections was attempted, and four of 30 clients had evidence of attempted follow-up prior to the third audit. Multiple interventions were employed for some of these clients including an attempt to recall the client back to the health centre for injection (five instances), and arranging the injection at another clinic more convenient to the client (three instances). Arranging a meeting with the client’s family to discuss the issues and identifying support, and developing an action plan with the client were also recorded.

![Figure 12. Benzathine penicillin G injection delivery for Site One](image)

Systems assessment results

There were mixed results for evidence of clinical and investigational services. Documented evidence of echocardiograms increased from the first to third audit by one client, while evidence of Medical Officer review was stable at nine clients, and dental review increased from one client to three. Evidence of specialist reviews improved from one client in the first audit to 14 in the third audit.

*Systems assessment results*

System assessment component scores for Site One are listed in Table 16. The Specialist-generalist collaboration component identifies the strength and quality of communication between clinical specialists and local medical officers about the needs of the client. There was
deterioration in this area (10, 2). In light of this, and given the improvement in evidence of Specialist reviews, it was not clear whether an increased number of clients were being seen by a Specialist prior to the third audit, or whether documentation provided to the facility following Specialist review at the CWM Hospital had improved.

Table 16. Systems assessment results for Site One

<table>
<thead>
<tr>
<th>Component</th>
<th>Item</th>
<th>Audit 1 Score (0-11)</th>
<th>Audit 2 Score (0-11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivery system design</td>
<td>Team structure and function</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Clinical leadership</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Appointments and scheduling</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Care planning</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Systematic approach to follow up</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Continuity of care</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Client access/ cultural competence</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Physical infrastructure, supplies and equipment</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td><strong>Average score</strong></td>
<td><strong>3.4</strong></td>
<td><strong>8.2</strong></td>
</tr>
<tr>
<td>Information systems &amp; decision support</td>
<td>Maintenance and use of electronic client list</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Evidence based guidelines</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Specialist - generalist collaborations</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td><strong>Average score</strong></td>
<td><strong>3.3</strong></td>
<td><strong>2.7</strong></td>
</tr>
<tr>
<td>Self-management support</td>
<td>Assessment and documentation</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Self-management education and support, behaviour risk reduction and peer support</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td><strong>Average score</strong></td>
<td><strong>0.5</strong></td>
<td><strong>2.5</strong></td>
</tr>
<tr>
<td>Links with the community, other health services and other services and resources</td>
<td>Communication and cooperation on governance and operation of health centre and other community based organisations and programs</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Linking health service clients to outside resources</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Working out in the community</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Communication and cooperation on regional health planning and development of health resources</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td><strong>Average score</strong></td>
<td><strong>1.5</strong></td>
<td><strong>0.2</strong></td>
</tr>
<tr>
<td>Organisational influence and integration</td>
<td>Organisational commitment</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Quality improvement strategies</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Integration of health system components</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td><strong>Average score</strong></td>
<td><strong>5.7</strong></td>
<td><strong>2</strong></td>
</tr>
</tbody>
</table>
Overall, the systems assessment scores for the delivery system design component improved between the first and second systems assessment. Improvements in care planning (1, 7) and continuity of care (1, 5) were not reflected in the audit results. Scores for approach to appointments and scheduling also improved at the second systems assessment (4, 9) however the increase of only 4 clients receiving follow-up by the third audit did not support a significant improvement. Similarly, the score for self-management education and support improved (0, 4) but this did not coincide with an increase in BPG injection delivery.

The initial systems assessment component score for follow-up of clients was low and improved with follow-up becoming routine at the second audit (1, 7). Zone (community) Nurses attached to the study site provided an outreach service to support clients with a range of medical conditions, however there was minimal communication between site staff and Zone Nurses regarding follow-up of missed BPG injections, despite this partnership being established as a priority implementation goal following the first systems assessment.

The overall systems assessment component score for information systems and decision support remained low. Some staff had access to the national hospital information system, however site reports could not be viewed, and BPG injection data were not recorded on the system.

The score for quality improvement strategies deteriorated significantly (10, 0), possibly due to the change in the Senior Medical Officer following the first audit, and the central support that this position provided to the facility.

There was a reduction in the overall systems assessment score for organisational influence and integration component (5.7, 2). Staff did not feel they had adequate power to improve the system; “(we) can recommend changes to practice, but that does not guarantee change.”

Discussion

Participants’ perception of the quality of clinical leadership was strong at Site One. This was attributed to the ongoing support from the Senior Nurse. The Senior Medical Officer who had
been overseeing clinical services for a number of years transferred out of the facility between
the first and second audits and the new incumbent was yet to fully develop a working
relationship with external services.

Apart from the delivery of BPG injections, clients with ARF and RHD were managed by the
CWM Hospital. They did not receive consistent or holistic care for any element of RHD by
the local health service. Quality of medical documentation, therefore, relied on clinical
information being returned from the Specialist Outpatient Department at the CWM Hospital
in Suva. One staff member commented, “Referral (to the CWM Hospital) is usually okay, but
discharge summaries and echo reports are not always sent back to the local doctors here. So
we don’t always know what has happened to the patients in hospital.”

Despite a large investment of support by the local RHD program since 2005, Site One
struggled to manage BPG injection delivery. Based on 80% as a benchmark for adequate
injection delivery to prevent recurrent ARF (7), almost 40% of the clients audited at Site One
remain at risk of recurrent ARF. Injections were available to clients at any time during the day
or night through the outpatient area which was permanently staffed. However, there was no
dedicated clinic time, and clients attending during business hours regularly waited for long
periods when the outpatient area was busy. Waiting times were not addressed, and did not
change during the study period. Equipment and supplies, including BPG supplies frequently
“run out of stock” and staff reported that it was not unusual to borrow equipment and
supplies from other facilities. One staff nurse reported “when we run out of Benza (benzathine
penicillin G injections) we send the patients to other health centres for their injection.”

Client questionnaires were not offered to clients at Site One by the research team; this is
unfortunate because client responses to reasons for missed injections would have provided
valuable insight to aid planning for appropriate follow-up intervention.

It was noted during the study that blood, glucose and ultrasound tests were reported back
from the CWM Hospital routinely, and clients requiring intervention were followed up by the
Senior Staff Nurse and the treating Medical Officer. Medical conditions which were managed
directly by the facility, such as diabetes, had structured care planning, outreach and coordination of client care that was reported to run smoothly.

During the second audit feedback and planning meeting staff reported that their failure to improve performance in a number of key areas was partly due to circumstances which relied on external influences, such as off-site Specialist services, and partly due to the heavy day-to-day workload and turnover of staff at the facility. Implementation plans for improved care following the first audit were either forgotten or overlooked, and this could also be attributed to high work demands and the turnover of staff. The research team found it difficult to reorientate new staff to the study during site visits to provide ongoing support during the implementation phases; a number of staff were not aware of the CQI study during these visits.

3.7.5 Changes associated with the intervention at Site Two

*Changes observed in documentation*

Site Two demonstrated improvements in all measured elements of documentation. Determining disease severity from the medical records improved consistently throughout the study from 11% to 96% (Figure 14). There was no evidence of direct recording of disease severity in the first audit, however this improved to 83% by the third audit. There was also an increase in the proportion of medical records with a documented BPG injection order from 85% to 100% (Figure 15); this included an increased proportion of orders with correct frequency of injections for age (78% to 96%). Evidence of management planning improved overall by 36% (Figure 16).
Figure 13. Evidence of disease severity for Site Two

Figure 14. Documented order for Benzathine penicillin G injections at Site Two
Changes observed in delivery of care

The proportion of clients receiving 80% or more of injections remained stable at around 75% (Figure 16). There was a slight but steady increase in the proportion of clients receiving less than 50% of injections from 7% to 15%, with a corresponding slight decrease in the proportion receiving between 50% and 80% of injections (14% to 11%). This can be interpreted as an overall decrease in the number of BPG injections given each year.
Follow-up of clients receiving less than 80% of injections increased slightly during the study. There was no record of any intervention for the six clients who received less than 80% prior to first audit, and this corresponded with results from the client questionnaire in which two of 15 respondents who reported having missed injections reported there was no follow up by the health service. There was evidence that three of eight clients who received less than 80% of injections were followed up prior to the second audit, and three of seven prior to third audit. Again, multiple interventions were employed, including family meetings (six instances), action planning, active recall and disease prevention advice (3 instances each) and arranging an alternative site for injection (two instances). Two children who were classified as high risk and had not received 80% of injections had additional interventions put in place including financial and transport assistance and social welfare support.

Site Two also performed well in all measured aspects of clinical and investigational care. Evidence of Medical Officer review increased by 68%, dental review by 23% and echocardiograms by 59%. The proportion of clients reviewed by a Specialist did not register as a change because this was almost 100% at baseline: one-hundred percent of clients audited were seen by a Specialist prior to first audit, 99% prior to second audit and 100% prior to the third audit.

System assessment results

System assessment component scores for Site Two are listed in Table 17. Marked improvement was seen for the assessment and documentation component (5, 9), and this was reflected in the improvements across all areas of documentation (Figures 14-16). Clients diagnosed with RHD were subsequently managed through the Specialist Outpatient Clinic which was attached to the ward. One staff member commented that “Paediatric review appointments are part of routine practice here, and the system works very well.” Twelve of the 15 client questionnaire respondents reported having seen a Specialist within the previous 12 months.
There was an improved component score for clinical leadership (7, 10); indeed, many of the improvements during the study appeared to be attributed to the consistent efforts and support of the Senior Paediatrician.

There was also a significant improvement in the overall component of delivery system design (6.1, 9.4) which was reflected by improved care planning, continuity of care and client follow-up. Care planning was conducted almost exclusively by the Paediatric Specialist and the improvement was reflected in the higher proportion of management plans identified during the second and third audits (Figure 16).

There was also an improvement in the component of information systems and self-management support (4, 8.5). Site Two provided both in-patient and outpatient services for children with ARF and RHD and the senior Paediatrician actively encouraged self-management during consultation. Thirteen of the 15 client questionnaire respondents reported having received self-management support. Support was provided in the form of discussions about the importance of attending the health service for regular treatment to minimise the risk of recurrent ARF and optimise management of RHD, and education about how to balance the demands of the disease with activities of daily living.

Specific goals to improve BPG injection delivery and coordinated care were established following feedback from the first systems assessment. One nurse commented that “there is sometimes limited space on the ward (during Saturday BPG injection clinics) but we try and give the injections as quickly as possible so the children don’t have to wait long.” The Benzathine Book was reviewed to determine the status of clients who had not presented for BPG injections for some time, and clients who had difficulties attending for injections were to be identified and assisted. Another nurse noted that “the Benzathine book is well maintained and referred to routinely.” Despite this, injection delivery deteriorated slightly during the study.
Table 17. Systems assessment results for Site Two

<table>
<thead>
<tr>
<th>Component</th>
<th>Item</th>
<th>Audit 1 Score (0-11)</th>
<th>Audit 2 Score (0-11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivery system design</td>
<td>Team structure and function</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Clinical leadership</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Appointments and scheduling</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Care planning</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Systematic approach to follow up</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Continuity of care</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Client access/ cultural competence</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Physical infrastructure, supplies and equipment</td>
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</tr>
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<td></td>
<td><strong>6.1</strong></td>
<td><strong>9.4</strong></td>
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<td>Information systems &amp; decision support</td>
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<td>5</td>
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<tr>
<td></td>
<td>Evidence based guidelines</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Specialist - generalist collaborations</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td><strong>Average score</strong></td>
<td></td>
<td><strong>6</strong></td>
<td><strong>8</strong></td>
</tr>
<tr>
<td>Self-management support</td>
<td>Assessment and documentation</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Self-management education and support, behaviour risk reduction and peer support</td>
<td>3</td>
<td>8</td>
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<tr>
<td><strong>Average score</strong></td>
<td></td>
<td><strong>4</strong></td>
<td><strong>8.5</strong></td>
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<td>Links with the community, other health services and other services and resources</td>
<td>Communication and cooperation on governance and operation of health centre and other community based organisations and programs</td>
<td>0</td>
<td>4</td>
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<tr>
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<td>Linking health service clients to outside resources</td>
<td>0</td>
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<tr>
<td></td>
<td>Working out in the community</td>
<td>0</td>
<td>2</td>
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<tr>
<td></td>
<td>Communication and cooperation on regional health planning and development of health resources</td>
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<td>2</td>
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<td><strong>0.8</strong></td>
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<td>Organisational commitment</td>
<td>6</td>
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<tr>
<td></td>
<td>Quality improvement strategies</td>
<td>10</td>
<td>8</td>
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<tr>
<td></td>
<td>Integration of health system components</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td><strong>Average score</strong></td>
<td></td>
<td><strong>7.7</strong></td>
<td><strong>5.7</strong></td>
</tr>
</tbody>
</table>

Scores for appointments and scheduling (10, 9), and quality improvement strategies (10, 8) were consistently high. Senior staff provided competent and consistent support and consulted with ward staff on the day-to-day management of clients in the clinical setting. One nurse commented; “Care planning is done by (Specialist name) but all staff know what (care) is needed for the patients with RHD.” The team felt they had autonomy to make changes to processes and procedures in the ward environment; however this power did not extend outside the ward. Site Two was primarily an acute clinical service provider, and staff did not liaise
with external bodies other than with Zone nurses for outreach support. Further, there were no identified external resources to support clients with ARF and RHD in the local area.

**Discussion**

Site Two attained or maintained a high level of service delivery. Competent, long-term staff together with a well-organised clinical team structure contributed to this; however the structure appeared to be driven almost entirely by the Paediatric Specialist. The model of centralising inpatient and outpatient services for children with RHD and the Saturday morning BPG injection clinic were well designed to support children with RHD and their families. With basic infrastructure in place, Site Two was able to focus on enhancing their service during the study, including establishing a regular visiting echocardiogram service (from Suva) and making future plans to support training of a paediatric ultrasonographer to take over the echocardiogram service locally. Improved medical care coordination was an implementation goal set following the first systems assessment and the sustained high level of Specialist reviews together with improved evidence of dental reviews and echocardiograms was a positive outcome.

The proportion of clients receiving 80% or more of scheduled BPG injections at Site Two was high but did not improve during the study. All clients had been given a personal BPG card for recording injection due dates. Staff reported that “*children are not shy with nursing staff giving injections.*” Staff also posited that Indo-Fijian clients received more support from their families and were therefore more likely to attend for regular injections than Fijian clients. This was supported by the data in which 84% of audited Indo-Fijian clients received 80% or more of injections compared with 59% of the Fijian clients.

3.7.6 Changes associated with the intervention at Site Three

*Changes observed in documentation*

Overall, documentation in the client medical record improved at Site Three. Direct recording of disease severity improved from 33% at first audit to 97% in the third audit (Figure 17),
documented BPG order remained high but steady with a range of 85 to 91% (Figure 18), and evidence of management planning was found to have improved slightly at the second audit, with a slight reduction at the third audit; a rise of 17% (Figure 19).

A number of documented BPG injection frequencies were incorrect for age based on the Fiji BPG protocol, (62) with the most common error presenting as adults maintained on three-weekly injections when they should have received injections every four weeks. Incorrect order accounted for between 8% and 12% of clients with a documented frequency.

![Figure 17. Evidence of disease severity for Site Three](image17.png)

![Figure 18. Documented order for Benzathine penicillin G injections at Site Three](image18.png)
Changes observed in delivery of care

The proportion of clients receiving 80% or more of BPG injections increased from 36% to 58% (Figure 20). There was also a small increase in the proportion of clients receiving less than 50% of injections (24% to 38%) and a large decrease in the proportion receiving between 50 and 79% (40% to 4%). These changes indicate an overall improvement in BPG injection delivery. There was a greater improvement in injection delivery to children (41% to 80%) than adults (25% to 44%) over the study period.

Follow-up of clients who missed injections remained low. One client was provided with prevention advice prior to the second audit and three clients received interventions prior to the third audit including follow up through active recall (two instances), prevention advice, and family meetings (one instance each).

Figure 19. Evidence of management planning in the Medical Record at Site Three
There was improved evidence of clinical and investigational care through the course of the study. The greatest increase was Medical Officer review which increased from 19% to 93%. Evidence of echocardiograms increased from 59% to 90% and dental reviews increased from 4% to 43%. While Specialist reviews did not appear to increase significantly, the proportion of reviews conducted was sustained between 81% and 97% of records audited.

**System assessment results**

System assessment component scores for Site Three are listed in Table 18. Paediatric and adult services were managed independently at this facility. Staff from both service areas were involved in the CQI study, and scores for the systems assessments were the result of negotiation for the site as a whole service, rather than a reflection of performance in a particular area. To provide a deeper understanding on the impact of the study on each service area, some of the results are discussed separately for adult and paediatric services.

The overall score for the delivery system design component improved. Little change was observed in the agreed component score for care planning, however there were more children found to have a care plan (54%) than adults (27%). Appointments and scheduling improved significantly (6, 10), as did continuity of care (4, 9). During the first systems assessment a
paediatric nurse stated, “The Paediatric department has specific care plans (for children with ARF and RHD), some care plans are done but ad hoc in other areas (referring to adults department).” Almost 49% of the clients audited at Site Three were children, yet two thirds of all clients with evidence of a care plan were children.

**Table 18. Systems assessment results for Site Three**

<table>
<thead>
<tr>
<th>Component</th>
<th>Item</th>
<th>Audit 1 Score (0-11)</th>
<th>Audit 2 Score (0-11)</th>
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<tbody>
<tr>
<td><strong>Delivery system design</strong></td>
<td></td>
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<tr>
<td>Team structure and function</td>
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<td>7</td>
<td>9</td>
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<tr>
<td>Clinical leadership</td>
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<tr>
<td>Appointments and scheduling</td>
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<tr>
<td>Care planning</td>
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<td>9</td>
<td>8</td>
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<tr>
<td>Systematic approach to follow up</td>
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<tr>
<td>Continuity of care</td>
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<td>4</td>
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<tr>
<td>Client access/ cultural competence</td>
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<td>Physical infrastructure, supplies and equipment</td>
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<td>11</td>
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<td><strong>7.4</strong></td>
<td><strong>9.5</strong></td>
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<td><strong>Information systems &amp; decision support</strong></td>
<td>Maintenance and use of electronic client list</td>
<td>0</td>
<td>0</td>
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<tr>
<td></td>
<td>Evidence based guidelines</td>
<td>2</td>
<td>5</td>
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<td></td>
<td>Specialist - generalist collaborations</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td><strong>Average score</strong></td>
<td></td>
<td><strong>2.7</strong></td>
<td><strong>4</strong></td>
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<tr>
<td><strong>Self-management support</strong></td>
<td>Assessment and documentation</td>
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<td></td>
<td>Self-management education and support, behaviour risk reduction and peer support</td>
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<td>10</td>
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<tr>
<td><strong>Average score</strong></td>
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<td><strong>6</strong></td>
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<tr>
<td><strong>Links with the community, other health services and other services and resources</strong></td>
<td>Communication and cooperation on governance and operation of health centre and other community based organisations and programs</td>
<td>0</td>
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<td></td>
<td>Linking health service clients to outside resources</td>
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<td>Working out in the community</td>
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<td>Communication and cooperation on regional health planning and development of health resources</td>
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<tr>
<td><strong>Average score</strong></td>
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<td><strong>0</strong></td>
<td><strong>1</strong></td>
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<td><strong>Organisational influence and integration</strong></td>
<td>Organisational commitment</td>
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<td>Quality improvement strategies</td>
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<td><strong>Average score</strong></td>
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<td><strong>7</strong></td>
<td><strong>8.7</strong></td>
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</table>
The score for self-management education and support improved (5, 10). While baseline data from client questionnaires were not available, all 21 clients who completed a questionnaire during the third audit reported receiving self-management support.

The systems assessment score for follow-up of clients who missed injections were reported to have improved, however follow-up of clients found during the audits remained low. Twenty-one clients who completed the client questionnaire, eight reported missing one or more BPG injections within the previous 12 months and none reported any follow-up by the health service. One nurse commented during the second systems assessment: “Follow-up (for missed injections) is undertaken in paediatrics and is starting in other areas (referring to adult services). Zone nurses don’t have reliable transport to follow up the patients.”

One goal set in the initial implementation plan by Site Three was to have access to the Australian disease management guidelines via computers in each department. The score for access to guidelines improved at the second systems assessment (2, 5) however it is not known how much of an influence access to the guidelines had in the overall management of clients in the clinical setting.

As with the other two sites, Site Three reported minimal links with community and external resources.

Discussion

Prior to the study all BPG injections were administered through the adult outpatient clinic. There was no dedicated staff member or designated clinic for injections, and clients often waited for long periods alongside clients waiting for other outpatient services. The aim of the paediatric injection clinic was to reduce the pressure on the adult clinic and to provide dedicated services to children and their families within the Paediatric environment.

The capacity of Site Three was based on a well-structured, multi-disciplinary team. Senior clinical staff had influence within the Ministry of Health to make changes to service delivery arrangements, and this was evident with the opening of a new paediatric clinic to improve
services for children with ARF and RHD. There were established pathways for client management, however there was room for improvement, as seen in the audit results. Senior staff were long-term incumbents who were familiar with their clients and actively supported the CQI study as a means to improving health outcomes. Site Three performed well, because senior staff were stable and participants engaged in the research process. A quality improvement process is employed when necessary to address adverse clinical incidents after they occur. The process was reactive following adverse events and there was no process for identifying potential incidents in advance.

3.8 **Summary of key findings**

1. The presence of stable senior clinical staff and a well-established multi-disciplinary approach were major contributing factors to positive outcomes of CQI.

2. The two hospital-based sites demonstrated improvements in providing clinical and investigational care for clients; this may have been related to the multi-disciplinary care available at this facilities. In contrast, the community health facility did not improve significantly in this area.

3. There was evidence of an impact on documentation of care, but not necessarily on delivery of services:
   1. Improvement in clinical documentation was demonstrated by all sites.
   2. Evidence of clinical management planning improved most significantly at the site where both inpatient and outpatient services for ARF and RHD were provided.
   3. Delivery of BPG injections increased slightly at one site, were maintained at high level at one site, and decreased at one site.

4. Support for clients who missed regular BPG injections remained low at all sites.

5. Improvements in service delivery reported during systems assessments – which were the opinions of staff - were not necessarily supported by the data found during the audits.
4. Reflections, Implications, Conclusion
4.1 **Reflections**

4.1.1 **Strengths of the study**

*The research model*

A number of participating senior clinicians reported that the study provided an opportunity for them to consider their ARF and RHD clients as a population, rather than as individuals with specific care needs. Participants were also interested to see the trends in clinical care provided to clients, particularly the proportion of BPG injection delivered at each audit.

Further, while individual clinicians were well-informed of and prepared for the needs of clients with ARF and RHD, the research findings exposed deficiencies in some aspects of health service delivery and provided insight for health staff into their capacity to change the way they deliver services. This was particularly evident in the establishment of a new paediatric injection at Site Three.

Not all of the data elements included on the adopted clinical audit tool were suitable for the Fiji context. Fortunately, the tool could be manipulated to accommodate relevant health data that were available in Fiji where they differed from data available in Australia (Table 13). Reports generated from the One21Seventy website database were designed around Australian data parameters but could be modified to adequately describe the research outcomes within the Fijian context.

4.1.2 **Limitations of the study**

There were a number of limitations that need to be considered when reflecting on the results and exploring the potential for future studies.

*Program capacity to support the research*

Providing support to study sites was difficult in the Fijian setting. The principal researcher was based in Australia, and local research staff were only available to support this study when there was reduced demand from other projects. The National RHD Project Officer resigned
during the second audit cycle, and this caused an interruption in a number of RHD-related projects in Fiji, including the CQI study. Diminished capacity of the national RHD program impacted on the auditing phases, with both timing and time available to support audits and systems assessments restricted. The audits were not evenly spaced, particularly at Sites Two and Three because travel by program staff to these sites needed to coincide with other activities at the sites. This resulted in visits occurring at a time that was not necessarily the most convenient for the study site.

Each study site incorporated goals into their implementation plan that relied on action from the RHD program, such as providing outpatient checklists and communicating regular client lists from the national RHD register. There was also diminished capacity of the national program to support some of the requests of study sites because members of the research team were not always in a position to respond. For example, Site Two staff requested support from the Fiji RHD program to undertake a group education session for clients and their families. The RHD program was unable to provide this support at the time due to restrictions with travel and changes in program staff.

Access to study sites and participants

A critical factor in site selection was accessibility for the research team. The chosen sites were located within range of ‘cities’ in each of the medical divisions and were deemed accessible in terms of reliability and frequency of air or road access. With the exception of Site One which was located within a 30 minute drive from the National RHD office in Suva, travel to study sites required either use of a Ministry of Health project fleet car or air travel, as well as hotel accommodation for the researchers.

Sites Two and Three were accessible but expensive. A single return trip from Suva to Site Two is approximately $500.00 FJD ($274.00 AUD) (Air Pacific website, December 2012 www.airpacific.com/). The local research team was able to travel to conduct essential audits with the funds that were available within the local program and with funds available through other programs including the Group A Streptococcal Research Project, of which one of the...
local researchers was an employee. Without the additional program funding support it would have been difficult for researchers to access the study sites.

Ongoing training in ARF and RHD, as well as constant orientation to the research process was required to engage participants at study sites. Also, and despite prior arrangements for system assessment and planning meetings, staff were frequently on leave, or off-site for other work-related business at the time of the meetings. For example, three staff members from an unrelated clinical area attended the second systems assessment at Site Two because some of the participating staff were attending another meeting. The second systems assessment at Site One was almost cancelled due to lack of attendance; however staff were released from duty later in the day to ‘attend’. Restrictions on the research team made it difficult to extend time at study sites for rescheduled meetings. These difficulties were unforeseen. Building CQI engagement around other activities may have had some impact on attendance; however health staff at participating sites reported being stretched between their clinical work, staff meetings and professional development commitments.

*Identifying eligible clients*

Despite the establishment and maintenance of a national RHD register since 2005, it was difficult to identify the eligible client population that could be audited at the study sites. Site-specific client lists generated from the national register did not accurately reflect the clients attending the sites, and there were no reliable client lists maintained locally. Eligible clients were found though a process of identification from BPG injection lists and from names presented by some of the local clinicians and nurses.

A relatively small number of charts were audited during the second audit at Site Three. Improved planning by the research team including pre-identification of clients and forward communication with the medical records department may have resulted in more medical records being available in the time allocated for the audit.
Distribution of client questionnaire

Results from the client questionnaire were intended to provide an understanding of care provided from the client perspective. This questionnaire was only used at Site Two during the first audit and Site Three during the third audit. The limited use of this tool was due to difficulties of the research team in disseminating and collecting the questionnaires. For the most part, client responses supported the audit data, however it was difficult to determine the value of this information given that questionnaires were not returned with each audit to see the impact on client responses over time, or how client responses compared with staff perceptions of practice. Nonetheless the responses did provide some broad insight into how clients perceive the care they received.

Interpreting medical documentation

The process of auditing client medical records was complex. Despite the availability of an audit protocol which assisted the research team to interpret medical entries, the records were sometimes difficult to read and interpret. Issues reported by the auditors included illegible writing, short or abbreviated entries, and dates often missing. Further, the acronyms ARF and RHD were sometimes used interchangeably, and this made interpretation of a specific diagnosis using the audit tool algorithm difficult.

4.1.3 Requirements for sustained improvement in health care

This was the first attempt to use a model of continuous quality improvement in Fiji’s primary health environment. The results did not represent the overall quality of care and health outcomes of clients with ARF and RHD, but they did provide some insight into the diversity of the level of RHD care provided to clients. The experience also identified some of the barriers to improving management of RHD.

For a fundamental and sustained improvement in the quality of health care there needs to be willing and active participation from a range of stakeholders. (87, 101) The health service needs to have a clear image of the improved system and a leadership hierarchy that is
committed to quality; visions of improved and more cost-effective service delivery need to be shared by clinical staff and administrators; measuring and monitoring of quality of service needs to occur regularly, and there needs to be an effective process change method that is achievable and suitable for the local environment. Finally, the health workforce needs to be able to interpret quality of care as well as providing care.

It is difficult to suggest a time frame in which this could be achieved. While some of the initial results in Fiji were encouraging, the Fiji CQI study only provided an introduction to the potential of CQI and the impact that it could have on health outcomes for the chronically ill.

4.2 Implications for policy and practice

The results of this study have a number of implications for policy and practice for the diagnosis and management of ARF and RHD in Fiji and beyond. Implications for the National Fiji RHD Program are presented as recommendations for improving current activities. Implications for the future of CQI-based interventions and research are presented as recommendations based on the Fiji experience.

4.2.1 Recommendations for the Fiji RHD Program

*Improve identification of client population*

It was difficult to determine the exact number of eligible clients at each site; partly because the national register data were not always accurate, and partly because staff at the study sites could not confirm which clients known to them were still attending the health service for primary care, even sporadically, and which clients might be receiving care through another facility.

At the time of the first audit there were 46 clients identified from the national RHD register to receive primary health care for ARF and/or RHD at Site One, 70 clients identified at Site Two and over 200 clients at Site Three. At all sites there were clients on these lists who were unknown to the local staff, and there were also clients who were attending the service and not known to the register. The national RHD register has the capacity to generate health service
site-specific lists for clients on the register; however this relies on the relevant primary care facility being accurately recorded for each client.

Exchange of client lists was not practiced routinely prior to the CQI study despite being a core requirement of the Fiji RHD Program. The RHD program has a responsibility to generate client lists from the register and forward to primary care facilities at regular intervals. Primary care staff can support the accuracy of the national register by reviewing their lists; updating existing client information, adding any clients who are not listed, and deleting clients who are not receiving treatment at the facility. Once amended lists are returned to the national register, client details can be updated. It would then be anticipated that the next client list is a more accurate representation of the client population attending each facility. Initially this process should be repeated every three to four months, and become less frequent when client populations are found to be stable.

*Improve support for benzathine penicillin G delivery*

Monitoring BPG injections delivered to clients is the responsibility of primary care staff. If clients who miss injections are followed-up quickly and provided with appropriate support, they will be better informed to make decisions as to whether to continue to receive injections on a regular basis. Primary care staff are also best placed to monitor injections delivered to their own client group to determine the impact of any local strategies that might be established to improve uptake of injections.

The Fiji RHD register has the capacity to report the proportion of clients who receive ≥80% of BPG injection each year. This is only possible where the number of injections required and the number received by individuals each year are recorded. Despite training of nurses at health centres across Fiji to report injection delivery data to the register, reporting is not done by the majority of health centres.

From a research perspective, the absence of injection data restricts comparison of sites where interventions are applied with non-intervention sites, and it is therefore not possible to
determine the level of impact of intervention on BPG delivery. The RHD program could also use injection data to inform health facilities about the ongoing risk of ARF for their clients, and offer additional support those facilities with less than adequate injection delivery to identify and reduce barriers and promote client self-management. Injection data would also enable the RHD program to determine the level of ongoing ARF risk for individual clients, and the overall success of the RHD control program at a national level. Further, comparing injection delivery with ARF recurrence data would help describe the impact of missed injections on disease progression.

The Fiji RHD program could increase injection data reporting by developing strategies to support primary care staff, including alerting staff when reporting is due, and providing client lists so that staff can record total injections delivered for each client on the list. Returned lists could be used by the RHD program to update the register.

Establishment of a Paediatric injection clinic at Site Three resulted, at least in the short-term, in greater improvements in injection delivery among children compared with adults. If the new clinic and the existing adult clinic are monitored over a longer period, the impact of this intervention – that is removing the demands of child services in the adult clinic and providing targeted services for children – will be clearer.

Follow up of clients who missed injections was low at all sites. Zone Nurses who provide outreach health services to the local community and rural areas are well placed to be engaged by clinic staff to conduct follow up. Primary care staff can identify at-risk clients who need additional support for injection delivery and pass this information to the Zone Nurses. Senior staff could further support this by using their influence within the Ministry of Health to ensure that Zone Nurses have reliable transport and resources to enable them to provide outreach support.
4.3 **Implications for future research in similar settings**

Use of the Australian CQI tool in Fiji provided some insights into the adaptability of the model and research process in a low income country. These insights may have value for other countries interested in implementing CQI to support existing RHD control, or countries interested in using the audit process to identifying the quality of primary care support for clients with ARF and RHD prior to establishing an RHD control program.

4.3.1 **Local capacity for research support**

The ability of the Fiji national RHD program to engage fully with the CQI study was problematic, and this resulted in gaps in support to study sites, particularly during the implementation phases. Given the length of time between audits, ongoing technical support is likely to be required by participating sites for many years. Dedicated personnel and resources will likely result in increased capacity to support sites during all phases of the CQI cycle (Figure 7).

If alternative strategies and resources are identified early, the supporting framework should experience only minimal impact in the event that suitable personnel are lost or there is a change in operational priorities.

In the event that resources to conduct ongoing CQI activity are limited, facilities that demonstrate a higher level of improvement during the pilot study and those that are more likely to benefit from CQI could be initially targeted. For example, a site that is struggling with some aspect of service delivery that also has authority for implementing system change is likely to see an impact from this study.

In a setting such as Fiji where the capacity of the nursing and medical workforce is stretched, conducting CQI was challenging also because this model of research requires a high level of activity by participants (94) who, in the clinical setting, also have responsibilities for providing direct services to clients. Consideration for the time and effort required by primary care staff to participate in CQI activities such as auditing, systems assessments and planning,
in addition to clinical work, is critical to determine the primary care system’s capacity to support the activity.

4.3.2 Selection of study sites

Selection of study sites in Fiji was based on the number of clients with ARF and RHD believed to be receiving regular care at a site and accessibility of the site for the research team. The three sites included in this study were accessible and had infrastructure to support researchers during site visits. The sites were believed to have the capacity to consider and implement change where it was in the interest of improving care delivery systems and client health outcomes. Yet there were still a number of challenges including the high human and financial costs related to travel.

Issues around access to study sites need to be carefully considered prior to establishing agreements with any health facilities; particularly if facilities are located in remote or difficult-to-reach locations. However, potential barriers and potential benefits of CQI should be balanced, particularly if sites or types of sites are overlooked by other quality improvement activities.

It is difficult to know how a long-term quality improvement activity will be conducted in a particular environment. If the majority of primary care facilities suitable for CQI selection are similar in function and capacity, such as found with the Australian ABCD study, it may be appropriate to pilot CQI in a number of facilities to determine how well the process is implemented. Results and comparisons between sites will provide an indication of how well a broader implementation of CQI is likely to be. If primary care facilities vary in size, structure and/or function, such as found with the Fiji study, it may be more appropriate to select sample sites to determine the capacity and impact of CQI within the different primary care models. Results can be used to tailor the process for different types of facility prior to expanding the activity.
4.3.3 Data collection and reporting (tools)

**Modified clinical audit tool**

The audit tool has been further modified based on the experience in Fiji (Appendix D). A corresponding audit protocol has also been developed (Appendix E). The modified audit tool is divided into five sections and the modifications to each section are discussed separately.

1. The first section *General Information* includes non-identifiable personal information about client and the name of the auditor. Placeholders have been included for Ethnicity (1.6) and District/Division (1.9). Options for these elements should be inserted to reflect local options, retaining the option *Not recorded* (‘9’) for ethnicity.

2. *Attendance at Health Service* includes date and reason for the client’s most recent attendance at the study site. There is also a question regarding the facility’s attempt to recall a client who is presumed to be receiving regular care at the site and who has not attended for more than 12 months. The recall question provides an indication of the health service’s approach to identifying clients who are potentially lost to follow-up.

3. The section *recording of key health information* focuses on documentation. Evidence of previous ARF and RHD diagnoses, as well as establishing risk classification and evidence of management planning and impending surgery are important indicators of clinical monitoring of clients with ARF and RHD. Modifications in this section include simplification of some of the wording. The restriction of impending heart valve surgery to high risk clients only has been removed because the Fiji experience with poor documentation of risk level reduced the opportunity to determine whether a client was on the waiting list regardless of the quality of documentation relating to diagnosis. This was particularly obvious at Site One where critical documentation tended to be held offsite. Due to this previous restriction it is anticipated that the number people on the surgery waiting list was under-reported in the Fiji study.
4. The audit of benzathine penicillin G injections includes a number of questions related to documented injection order, delivery of injections and follow-up following missed injections. The first question in the original document, “Is this patient receiving Benzathine penicillin injections?” was thought to be somewhat ambiguous since a number of people in Fiji were ordered injections but were not actually receiving them. This has been modified to “What is the current order for this person regarding secondary prevention of ARF?” with an exhaustive list of options for treatment options including No prophylaxis required (‘0’). The wording of options in questions related to documented BPG injection order has been changed (4.2 – 4.4). Aside from some word changes, no other significant modifications have been made to the questions regarding calculation of delivered injections or follow-up for missed injections.

5. The final section is an audit of ongoing care and self-management support. The option of Not available (‘9’) (during specified time period) has been included for echocardiography in questions 5.1 – 5.3 to support countries that rely on internally-sourced echocardiography services. Questions about alcohol and cigarette use and intervention have been collated into a single question each (5.7 and 5.8). An option for Not currently available (‘9’) was added to the questions related to influenza and pneumococcal vaccination because according to the World health Organisation summaries on vaccine coverage, these vaccines are currently only available in some Pacific Island countries. (102)

Evidence of primary care documentation on computer systems has been removed from the audit tool because the type of data required for the audit is not routinely or reliably available on computer in Pacific Island countries. These elements can be added if the relevant information is available in the future, and if evidence of accurate electronic documentation is considered to be an important element during future audits.
Modified Systems Assessment tool

The systems assessment tool facilitates an in-depth analysis of the health system structure and delivery of services for clients with ARF and RHD. The systems assessment used in the Australian and Fiji studies incorporate a wide range of system resources and deliverables beyond the critical requirements for RHD. Despite the length of time required to complete the systems assessment, modifications to the systems assessment tool are minimal; based predominantly around clarity of wording where it was found to be confusing (Appendix F), and omission of number of references to electronic information systems. Considerations have been provided at the end of each element to encourage participants to relate the component points specifically to clients with ARF and RHD where applicable. For example, 1.3 Appointments and Scheduling has a prompt for participants to “Consider whether individual clients are able to and encouraged to access the service for regular BPG injections at a pre-arranged time or during dedicated clinics.” The experience from Site One in the Fiji study was that dedicated clinics were available to clients with other conditions, (e.g. diabetes) and not clients with ARF and RHD. This prompt highlights consideration of current structure of care for clients with ARF and RHD regardless of whether appointments and scheduling exists for other conditions.

Data analysis and reporting system

Adoption of the proposed modified audit tool (Appendix D) together with any further modifications to the tool requires a compatible information system to support data analysis and reporting.

As mentioned previously, the One21Seventy website was used to support the Fiji study. (92) Following data entry, collation and analysis of data is done by the system when requested and a report is generated by the system. Text in the report can be modified by the user; however charts and graphs cannot be altered. These can be redone using Microsoft Excel (Redmond, Washington USA) chart functions.
Modification of the *One21Seventy* system by the user is not possible, therefore adjustments required during future RHD CQI activity using modified tools would be interpreted by the researchers following the standardised analysis. For example, options for ethnicity will vary between countries. Options could therefore be entered as *one*, *two*, and *three* … and the researchers develop a key to interpret local definitions for these options. The interpretation for Fiji, for example, would be *one*=Fijian; *two*=Indo-Fijian; *three*=other.

Currently, a complete record must be entered into the *One21Seventy* data system before it is saved. Researchers require continuous and reliable internet access so that part-records are not lost during data entry. This is likely to present problems in regions with unreliable or slow internet service.

Another option for data storage and reporting is development of a separate reporting system using readily available software that can be copied, modified and stored locally. This option negates the need for internet access and provides flexibility to accommodate local modifications to the audit tools.

The Microsoft Office Suite (Redmond, Washington, USA) is widely included as a standard computer package. The Microsoft Access database software can be structured with forms to mirror audit tools and underlying ‘queries’ to sort and analyse the data. A programmer could develop queries to answer key questions, and these should be set up as automated reporting functions. Importantly, modifications are easily possible after the system has been developed so that options unique to each country could be accommodated without compromising the underlying structure of reports. Another option is entry of data into a spread sheet system such as Microsoft Excel (Redmond, Washington, USA) which is also readily available.

These options might be suitable for countries interested in implementing part of the audit tool, and those with an interest tailoring analysis and reporting to answer specific questions that differ from the standard report produced by the *One21Seventy* system. Individuals with experience in this field need to be engaged to develop and support data systems for future
CQI research where required, including development of guidelines for use and training and support for researchers.

56. Robertson KA, Volmink JA, Mayosi BM. Antibiotics for the primary prevention of acute rheumatic fever: a meta-analysis. BMC Cardiovascular Disorders [Internet]. 2005; 5(1).


70. Fiji RHD Register. 2012.
96. ABCD. Work Practice Guidelines for Auditors and How to Generate a Random Sample. 2007.
**Appendix A – Acute rheumatic fever questionnaire**

**REPORTING CLINICIANS**
1. APSU Dr Code/Name: __________/________________________
2. Month/Year of Report: ______/_________
3. Date questionnaire completed: ___/___/_______

**PATIENT DETAILS**
4. First 2 letters of first name: ____  
5. First 2 letters of surname:____  
6. Date of Birth: ____/____/_______
7. Sex: ☐ M  ☐ F
8. Post code of family: __________
9. Child’s country of birth: ___________________________
10. Usual place of residence: ☐ Inner-city ☐ City Suburb ☐ Large town ☐ Small town/community ☐ Remote area
11. Child’s Ethnicity: ☐ ATSI ☐ Caucasian ☐ Asian ☐ Pacific Islander ☐ Middle Eastern ☐ African ☐ Other __________

*If this patient is primarily cared for by another physician who you believe will report the case, please complete the questionnaire details above this line and return to APSU. Please keep the patient’s name and other details in your records. If no other report is received for this child we will contact you for information requested in the remainder of the questionnaire.  The primary clinician caring for this child is:*

**Name:**
**Hospital:**

**Family details and relevant history**
12. Mother’s country of birth: _______________ ☐ DK
13. Father’s country of birth: _______________ ☐ DK
14. Number of other children in the family (siblings): ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ >5 ☐ DK
15. Number of siblings ever diagnosed with ARF: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ >5 ☐ DK
16. How many bedrooms are there in the child’s dwelling? ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ >4 ☐ DK
17. How many people usually sleep in the child’s dwelling? ☐ 1-4 ☐ 5-9 ☐ >9 ☐ DK
18. How many of these people are children aged <15yrs ☐ 1-4 ☐ 5-9 ☐ >9 ☐ DK
19. Does the child have a primary health provider? ☐ Yes ☐ No ☐ DK
*If yes: 19a. Who is the child’s usual primary health provider? ☐ GP ☐ Local hospital ☐ Aboriginal Health Worker ☐ Flying Doctor ☐ Other, specify:_________________

**Acute Rheumatic Fever (ARF) diagnosis**
20. Date of diagnosis for current ARF episode: ___/___/_______
21. Has this child been previously diagnosed with ARF? ☐ Yes ☐ No ☐ DK
*21a. Please provide months/years for previous diagnoses: __________/_________ ☐ DK

22. Please select all diagnostic criteria present in the current episode of ARF:
   **MAJOR criteria:** ☐ Carditis ☐ Polyarthritis ☐ Sydenham’s Chorea
   ☐ Erythema marginatum ☐ Subcutaneous nodules
   ☐ Polyarthritis (high risk groups) ☐ Aseptic mono-arthritis (high risk groups)
   **MINOR criteria:** ☐ Fever (highest temp________ °C) ☐ ESR ≥30mm/hr (highest ESR _______ mm/hr)
   ☐ Prolonged PR interval ☐ CRP ≥30mg/L (highest CRP _______ mg/L)
   ☐ Aseptic mono-arthritis (low risk groups) ☐ Polyarthritis (low risk groups)
23. If any of the arthritic features were present, which joints were involved? *(tick all that apply)*
   ☐ Wrist(s) ☐ Ankle(s) ☐ Knee(s) ☐ Elbow(s)
   ☐ Other joints. *(Please Specify): ___________________________________________________
24. Were any cardiac valve lesions present? ☐ Yes ☐ No ☐ DK  **If No, please go to question 27.**
*If yes: (tick all that apply)*
24a. ☐ Mitral valve regurgitation: Severity: ☐ None ☐ Mild ☐ Moderate ☐ Severe ☐ DK
24b. ☐ Mitral stenosis ☐ DK
24c. ☐ Aortic valve regurgitation: Severity: ☐ None ☐ Mild ☐ Moderate ☐ Severe ☐ DK
24d. ☐ Aortic stenosis ☐ DK
24e. ☐ Tricuspid valve lesion *(specify)_______________________________________________________ ☐ DK
24f. ☐ Pulmonary valve lesion *(specify)_____________________________________________________ ☐ DK
25. Evidence of valve lesions is based on ☐ Echocardiogram ☐ Clinical Assessment
*If echocardiogram, please de-identify and attach the echocardiogram report to this questionnaire if available.
26. Is the echocardiogram report attached? ☐ Yes ☐ No ☐ NA
27. Was there evidence of heart failure?  
☐ Yes  ☐ No  ☐ DK

28. Was there a sore throat (within 3 weeks of ARF symptoms)?  
☐ Yes  ☐ No  ☐ DK

If yes: 28a. Was medical attention sought for the sore throat?  
☐ Yes  ☐ No  ☐ DK

29. Was there evidence of skin sores (within 3 weeks of ARF symptoms)?  
☐ Yes  ☐ No  ☐ DK

30. Was there evidence of Group A streptococcal (GAS) infection?  
☐ Yes  ☐ No  ☐ DK

If yes, please provide the following details:
☐ Culture:  ☐ Yes  ☐ No  ☐ DK  If yes, identify site (throat, skin, other) ___________________________
☐ ASOT titre  Result ____________ Date ___/___/_______
☐ Anti DNase titre  Result ____________ Date ___/___/_______

31. Were antibiotics given within the 3 weeks prior to onset of ARF symptoms?  
☐ Yes  ☐ No  ☐ DK

If yes, 31a. Which antibiotic was used? ___________________________________________ ☐ DK

ARF management and outcome

32. Which treatments were given during the acute phase of this episode of ARF? (tick all that apply)
☐ No treatment given  ☐ Prednisolone  ☐ Carbamazepine
☐ Paracetamol  ☐ Frusemide  ☐ Valproic acid
☐ Aspirin  ☐ Digoxin  ☐ Penicillin
☐ Codeine  ☐ Other (specify): ___________________________________________________________

33. Was bed rest recommended?  
☐ Yes  ☐ No  ☐ DK

If Yes: 33a. How many days of bed rest did the child have? __________________

34. Was secondary prophylaxis initiated following this diagnosis?  
☐ Yes  ☐ No  ☐ DK

35. Which secondary prophylaxis regimen(s) was prescribed following this episode of ARF?
☐ Benzathine penicillin G (3-weekly)  ☐ Penicillin V 250mg (bd)
☐ Benzathine penicillin G (4-weekly)  ☐ Erythromycin 250mg (bd)  ☐ DK
☐ Benzathine penicillin G (every calendar month)

36. If this is an ARF recurrence, what do you believe is the primary cause?
☐ Secondary prophylaxis was not given, due to: ___________________________________________  ☐ DK
☐ Secondary prophylaxis given but failed, due to: ___________________________________________  ☐ DK
☐ Other reason (specify): _______________________________________________________________  ☐ DK

37. Was cardiac surgery recommended?  
☐ Yes  ☐ No  ☐ DK

If No or DK, go to question 38

If yes: 37a. If yes, has surgery been performed?  
☐ Yes  ☐ No  ☐ Awaiting surgery  ☐ DK

37b. If yes, describe procedure: _______________________________________________________

37c. Date of surgery: ___/___/_______  37d. Name of surgical unit/hospital: __________________

Barriers to diagnosis

38. Did you encounter any barriers to making the diagnosis of ARF for this episode in this child?  
☐ Yes  ☐ No  ☐ DK

If Yes, please answer 39 and 40. If No, Thank you, this is the end of the questionnaire

39. Delayed presentation to a health professional?  
☐ Yes  ☐ No  ☐ DK

If yes: 39a. Time between onset of symptoms and presentation to health professional _______ days.

39b. Describe reasons for delayed presentation: eg. (Lack of access to primary health services): __________________________________________________________

40. Delayed referral following initial presentation?  
☐ Yes  ☐ No  ☐ DK

If yes: 40a. Time from initial presentation _______ days or _______ weeks

40b. Describe reasons for delayed referral / other barriers to diagnosis? (eg. difficulty with ARF diagnosis – unclear presentation; lack of staff skills): __________________________________________________________
Appendix B – Sydenham’s chorea questionnaire

REPORTING CLINICIANS
1. APSU Dr Code/Name:    _____ /_______________ 2. Month/Year of Report: _____/_____
3. Date questionnaire completed: ____/____/_______

PATIENT DETAILS
4. First 2 letters of first name: ______  5. First 2 letters of surname:______ 6. Date of Birth: ____/____/_______

CLINICAL DETAILS
10. Date of onset of chorea symptoms: ____/____/_______
11. Duration of symptoms: _____ weeks  If ongoing: duration to date: _____ days, or _____ weeks, or _____ months
12. Severity of choreiform movements:
   □ Mild (e.g. not easily detected, not always present, don’t affect activities of daily living)
   □ Moderate (e.g. easily detected, present most of the time, affect activities of daily living such as eating, walking, writing, talking).
   □ Severe (gross movements, present all or most of the time, dramatically affecting activities of daily living)
13. Degree to which the following adversely affect the child and family: (0 = no affect … 5 = dramatic affect)

<table>
<thead>
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<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour disturbance</td>
<td></td>
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<tr>
<td>(school refusal, sleep</td>
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<tr>
<td>problems)</td>
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<tr>
<td>Obsessive compulsive</td>
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<tr>
<td>symptoms or signs</td>
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<tr>
<td>Emotional lability</td>
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</tbody>
</table>
14. Frequency of behaviour disturbance (school refusal, sleep problems)
   □ Not present
   □ Infrequent (< once/ week)
   □ Occasional (2-3 times/ week)
   □ Often (>3 times/ week)
15. Other features present at any time since onset of chorea symptoms (please tick as many as apply):
   □ Hypotonia
   □ Weakness
   □ Pendulous knee jerks
   □ Explosive or indistinct speech
   □ Milkmaid’s grip
   □ Darting tongue
   □ Pronator sign
   □ Facial grimaces
   □ Generalised restlessness
   □ Shrugging shoulders
   □ Dishing spoon hand
   □ Writhing
16. Treatments used to date, and impression of benefit:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Benefit</th>
<th>Features of illness that improved with treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(None, Mild, Moderate, Dramatic)</td>
<td>(e.g. movement disorder, behaviour etc)</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td></td>
<td></td>
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<tr>
<td>Sodium Valproate</td>
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<tr>
<td>Haloperidol</td>
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<tr>
<td>Other medication (specify)</td>
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<tr>
<td>Other (e.g. bed rest)</td>
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</tbody>
</table>
17. Comments: __________________________________________________________________________
Appendix C – Client questionnaire

INFORMATION ABOUT YOU

1.1 Today’s Date ..../…. /…..
1.2 Your DATE of Birth ..../…. /…..
1.3 Your age NOW: ……..
1.4 You are □ Fijian □ Indo-Fijian □ Other
1.5 You are □ Male □ Female
1.6 You have: □ Acute Rheumatic Fever (ARF) □ Rheumatic Heart Disease (RHD) □ Not sure
1.7 Have you ever had heart surgery for Rheumatic Heart Disease? □ Yes □ No

INFORMATION ABOUT MEDICATION

2.1 The year you first started treatment for ARF / RHD: ……..
2.2 Your age when you first started treatment: ……..
2.3 When you first started treatment, which treatment did the Doctor recommend? (Tick one)
   □ Injections Benzathine penicillin G □ Injections (not sure)
   □ Tablets Penicillin □ Tablets Erythromycin □ Tablets (not sure)
2.4 Has your doctor ever told you that you are allergic to Penicillin? □ Yes □ No
2.5 If yes, what happens to you when you take Penicillin? (Tick all that apply)
   □ Hives □ Dizziness or fainting □ Skin rash □ Feeling sick or vomiting
   □ Itchy skin □ “Shock” (red or pale skin, weak pulse, low blood pressure)
   □ Difficult breathing □ Stop breathing □ Swollen lips tongue or face □ Other …………………………………………..
2.6 Which treatment for ARF or RHD do you have NOW? (Tick one)
   □ Same treatment as first started □ Treatment for RF/RHD has changed to tablets
   □ Treatment for RF/RHD has stopped □ Treatment for RF/RHD has changed to injections
   □ Now on other medication only (e.g. Warfarin): ………………………………………………………………………..
2.7 If treatment for ARF/RHD has changed, it is because
   □ The doctor changed it or □ YOU asked for it to be changed
2.8 If YOU asked for treatment to be changed, please explain WHY you wanted it changed:
   …………………………………………………………………………………………………………………………………………………..
2.9 If treatment for ARF/RHD has stopped, it is because
   □ The Doctor stopped it or □ YOU stopped having the treatment
2.8 If YOU asked for treatment to stop, please explain WHY you wanted it stopped:
   …………………………………………………………………………………………………………………………………………………..
2.11 If you have injections NOW, have you ever missed any injections? □ Yes □ No
2.12 How many injections have you missed since this time last year (in the last 12 months)? (Tick one)
   □ 0 □ 1 or 2 □ More than 2 □ More than 5
2.14 If you take tablets NOW, do you ever miss any tablets? □ Yes □ No
2.15 For how many days did you miss in the last 4 weeks (the last month)? (Tick one)
   □ 0 days □ 1 or 2 days □ More than 2 days □ More than 1 week
2.16 If you missed injections or tablets, please explain WHY you missed them:
   …………………………………………………………………………………………………………………………………………………..
INFORMATION ABOUT HEALTH MANAGEMENT / SUPPORT

3.1 Why do you think you need to have regular treatment for Rheumatic Fever / Rheumatic Heart Disease?

3.2 Is there a special clinic time or day for people who need Benzathine penicillin injections?

☐ Yes ☐ No ☐ Not sure

3.3 Do staff from the health centre contact you if you are late for your Benzathine injection? (Tick one)

☐ Yes, contact me every time I am late for my injection ☐ No, do not contact me
☐ Yes, contact me sometimes, but not every time ☐ I do not have Benzathine penicillin injections

3.4 If yes, HOW do staff contact you? (tick all that apply)

☐ By telephone ☐ Visit to my school/ house/ work ☐ Other

3.5 Have you seen a specialist Doctor for ARF/RHD within the last 12 months? ☐ Yes ☐ No

3.6 If no, please explain WHY you have not seen a specialist Doctor within the last 12 months:

3.7 Have you ever had an echocardiogram (ultrasound) of your heart? ☐ Yes ☐ No

3.8 Have you received written information and education about ARF/RHD from a doctor or nurse?

☐ Yes, both education discussion and written information ☐ Yes, written information only
☐ Yes, education discussion only ☐ No information or education received

3.9 Health staff encourage you to manage the following for yourself (self-management): (tick all that apply)

☐ Regular Benzathine injections/tablets ☐ Smoking
☐ Regular follow-up by a Doctor ☐ Exercise, good food and nutrition
☐ Balancing health care with other priorities ☐ Good health after heart surgery
☐ Pregnancy and RHD ☐ No help with self-management

3.10 Do the doctors and nurses talk to you and/or your family when planning YOUR future health care? ☐ Yes ☐ No

Thank you for answering these questions.
Please talk to the nurse if you have any questions.
Appendix D – Modified clinic audit tool

SECTION ONE
General Information

1.1 Person ID

1.2 Health Number recorded
Yes 1
No 0

1.3 Date of Birth

1.4 Age at date of audit

1.5 Gender
Male 1
Female 2

1.6 Ethnicity:
One 1
Two 2
Three 3
Not recorded 9

1.7 Auditor’s initial & surname:

1.8 Audit Date:

1.9 Division/ District
One 1
Two 2
Three 3
Four 4

SECTION TWO
Attendance at Health Service (within the last 12 months)

2.1 Date last attended

2.2 Reason for last attendance:
Acute medical care 1
Benzathine penicillin injection 2
ARF/ RHD clinical review 3
Other reason 4
Did not attend within last 12 months 9

2.3 If not attended in last 12 months is there any record of follow-up attempt or effort to determine if relocated since last attendance?
Yes 1
No 0
Attended within last 12 months 9
SECTION THREE
Recording of key health information

3.1 Is there a record of the following diagnoses in the Medical Record?

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>In Medical Record</th>
<th>Date of diagnosis</th>
<th>No record</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definite acute rheumatic fever (first episode)</td>
<td>1</td>
<td>/ /</td>
<td>0</td>
</tr>
<tr>
<td>Suspected acute rheumatic fever (first episode)</td>
<td>1</td>
<td>/ /</td>
<td>0</td>
</tr>
<tr>
<td>Recurrent rheumatic fever</td>
<td>1</td>
<td>/ /</td>
<td>0</td>
</tr>
<tr>
<td>Suspected recurrent rheumatic fever</td>
<td>1</td>
<td>/ /</td>
<td>0</td>
</tr>
<tr>
<td>Rheumatic heart disease</td>
<td>1</td>
<td>/ /</td>
<td>0</td>
</tr>
</tbody>
</table>

3.2 Is the disease classification (ARF or mild, moderate or severe RHD) recorded in the Medical Record?

Yes 1
No 0

3.3 If not recorded, what is the RHD classification according to the Australian Priority Level Algorithm?

<table>
<thead>
<tr>
<th>Classification</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>High risk</td>
<td>1</td>
</tr>
<tr>
<td>Medium risk</td>
<td>2</td>
</tr>
<tr>
<td>Low risk</td>
<td>3</td>
</tr>
<tr>
<td>Unable to determine</td>
<td>4</td>
</tr>
<tr>
<td>Disease classification recorded</td>
<td>9</td>
</tr>
</tbody>
</table>

3.4 Is there a current ARF/RHD Management Plan documented anywhere in the Medical Record?

Yes 1
No 0

3.5 Is this person currently prescribed Warfarin?

Yes 1
No 0

3.6 If prescribed Warfarin, please record the two most recent INR results.

<table>
<thead>
<tr>
<th>INR Result</th>
<th>Date</th>
<th>Not prescribed warfarin</th>
</tr>
</thead>
<tbody>
<tr>
<td>/ /</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>/ /</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

3.7 Is this person waiting for heart valve surgery?

Yes 1
No 0
Unable to determine 9
SECTION FOUR
Audit of Benzathine penicillin G injections

4.1 What is the current order for this person regarding secondary prevention of ARF?
   Benzathine penicillin G (injections) 1
   Penicillin (oral) 2
   Erythromycin (oral) 3
   No prophylaxis required 0
   Unknown 9

Please answer the following questions if this person is prescribed benzathine penicillin G injections.

4.2 Where is the order for planned dose and frequency of injections recorded?
   Medical Record 1
   Benzathine injection book 2
   Medical Record AND Benzathine injection book 3
   Order not recorded 9

4.3 If recorded in both the Medical Record and the Benzathine injection book, are the two records the same?
   Yes 1
   No 0
   Not recorded in both 2
   Order not recorded 9

4.4 If not the same, which order is correct for age and weight?
   Medical record 1
   Benzathine injection book 2
   Neither is correct 0
   Not applicable 9

Please record the number of Benzathine penicillin G injections given over the last 12 months.

4.5 Number of injections planned in the last 12 months (12, 13 or 17) ______

4.6 Number of injections given over the last 12 months ______

4.7 If injections commenced within the last 12 months, record date of first injection ______

***If injections were commenced within the last 12 months refer to protocol for instructions on how to determine what percent of injections were received.

4.8 Calculate the percent of injections received over the last 12 months ______%

** See protocol for instructions on calculation of percent of injections received.

4.9 Has this person received at least 80% of planned injections in the last 12 months?
   Yes 1
   No 0
4.10 If less than 80% of planned Benzathine penicillin G injections were received, is there a record of:

<table>
<thead>
<tr>
<th>An attempt to recall the person back to the health centre for injection?</th>
<th>Yes</th>
<th>No</th>
<th>80% or more received</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Arrangements for injection to be given by outreach services or at another health facility where the person is attending?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Advice to the person about importance of receiving regular injections?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>A family meeting?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>An action plan made?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Other appropriate action?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

Details of other appropriate action:

4.11 Is there evidence of at least one definite recurrent rheumatic fever within the last 12 months?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

4.12 If there is evidence of at least one recurrent rheumatic fever and 80% or more of planned injections were received, is there a record of:

<table>
<thead>
<tr>
<th>Change to more frequent Benzathine penicillin injections if having injections?</th>
<th>Yes</th>
<th>No</th>
<th>No recurrent ARF</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Change to Benzathine penicillin injections if taking oral Penicillin?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Advice on role of throat and skin infections in leading to ARF?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Advice on the role of overcrowding increasing risk of ARF?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Action plan made?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Referral to support services (outreach health services, housing service, welfare)?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Other appropriate action?</td>
<td>1</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

Details of other appropriate action:
### SECTION FIVE

*Audit of ongoing care and self-management support*

#### Audit of scheduled services for HIGH RISK

5.1 Is there a **record of each of the following services** having been provided?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Date</th>
<th>No</th>
<th>Not available during last 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Medical Officer/Nurse Practitioner review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Cardiologist/ Physician/ Paediatrician review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Echocardiogram done</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

During the last **12 months**?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Date</th>
<th>No</th>
<th>Not available during last 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental Review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

#### Audit of scheduled services for MEDIUM RISK

5.2 Is there a **record of each of the following services** having been provided?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Date</th>
<th>No</th>
<th>Not available during last 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Medical Officer review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

During the last **12 months**?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Date</th>
<th>No</th>
<th>Not available during last 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiologist/physician/ paediatrician review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Echocardiogram done</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Dental review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

#### Audit of scheduled services for LOW RISK

5.3 Is there a **record of each of the following services** having been provided?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Date</th>
<th>No</th>
<th>Not available during specified period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor review</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

During the last **12 months**?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Date</th>
<th>No</th>
<th>Not available during specified period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children - during the last 2 years?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults – during the last 3 years?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Echocardiogram done</td>
<td>1</td>
<td>/</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

5.4 Is there a record of **influenza vaccination** within the previous 12 months?

- Yes 1
- No 0
- Not currently available 9

5.5 Is there a record of **pneumococcal vaccination** as per the current schedule?

- Yes 1
- No 0
- Not currently available 9
5.6 Is there a record that disease education and self-management support disease has been provided?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
</tbody>
</table>

5.7 If recorded in the Medical Record that this person is a cigarette smoker, is there also a record of intervention in the Medical Record?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Non smoker</td>
<td>2</td>
</tr>
<tr>
<td>Cigarette use not recorded</td>
<td>9</td>
</tr>
</tbody>
</table>

5.8 If recorded in the Medical Record that this person is a high risk alcohol user, is there also a record of intervention in the Medical Record?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Non-high-risk user</td>
<td>2</td>
</tr>
<tr>
<td>Alcohol use not recorded</td>
<td>9</td>
</tr>
</tbody>
</table>
**Appendix E – Modified audit protocol**

**CLINICAL AUDIT TOOL FOR RHEUMATIC FEVER / RHEUMATIC HEART DISEASE**

**About the Acute Rheumatic Fever and Rheumatic Heart Disease Clinical Audit**

Clinical audits can provide valuable information about the quality of care for people with acute rheumatic fever (ARF) and rheumatic heart disease (RHD). If audits are done repeatedly over time in a consistent way, they can show changes in the quality of care that may have occurred in association with developments at the health service. Clinical audits collect information that compares care delivered against specific criteria, usually in relation to best practice guidelines.

The ARF/RHD audit tool is based on best practice guidelines from the National Heart Foundation of Australia’s evidence-based review of diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia, June 2006. These guidelines were developed for Aboriginal Australians; however they are also relevant for Pacific Islander populations.

Audit results can be presented as performance measures. Providing feedback on these performance measures to participating health services can be useful in helping staff understand areas of strength and areas where they may need to focus more attention. Results can be useful in helping staff set specific goals for improvement in delivery of services. Interpretation of all of the information from the audits will need to be made in relation to availability and content of local guidelines, policies and protocols.

To fully understand how the health service is operating, the audit tool should be used together with a systems assessment tool. The system assessment tool focuses on health service systems to support best practice in rheumatic fever prevention. The systems assessment tool is designed to increase understanding of how service systems can improve best practice service delivery, and of how systems can be improved to encourage best practice. The systems assessment tool is therefore useful for developing strategies for improving practice.

This protocol explains how to select a sample of client’s health records for audit, and then explains how the audit form should be completed.

**Instructions to Complete the ARF/RHD Clinical Audit Form**

The auditor will need to be familiar with local guidelines, policies and protocols e.g. Benzathine penicillin dosing schedule, criteria for ARF diagnosis. These should be available to the audit team during the audits.

Wherever the term *medical record* is used in the audit form, the auditor will need to check:

- written notes in the client’s health record
- summary documents in the client’s health record, which may include:
  - Medical summary sheet
  - Adult/Child health check form
  - Benzathine penicillin needle chart
  - Hospital discharge summaries
  - Pathology result forms
  - Care plans
  - Specialist letters and referral letters

**Clinical Knowledge**

A level of clinical knowledge is required to complete some sections of the audit form. Auditors may need to consult with clinical colleagues to ensure that they have enough understanding of the clinical records to complete the audit correctly.

**Selecting a sample of people for the clinical audit**

To be included in the audit a client must:

- have a history of diagnosis with either ARF or RHD
- have been attending the health service for primary health care for at least 6 months of the last twelve months.
Sample Size

A sample of a total of 30 clients will be selected randomly at each participating health service.

If there are fewer than 30 ARF/RHD clients attending the health service all clients will be included.

If there are only slightly more than 30 ARF/RHD clients (e.g. 35 or 40 clients), all clients could be included to provide a complete picture of ARF/RHD management at the health service.

If there are many more than 30 clients (e.g. hundreds) a sample larger than 30 might be included.

The Sampling Procedure (using Microsoft Excel)

A new random sample of people will be selected for every audit. To select a random sample of 30 clients:

- Prepare an up-to-date list of all people with ARF and RHD attending the health service.
- Generate a random sample by using Microsoft Excel program (RAND function).

Step 1: Open Excel, in the first column A, enter the names of all clients attending the health service (one name per line). The second column B is the ‘random’ column.

Step 2: Type `=rand()` in the top box of column B and press ‘Enter’ in the keyboard. A number will appear.

Step 3: Click into this box and click onto the lower right corner. A solid cross + will appear.

Step 4: Left click on your mouse, hold down and drag down until you reach the bottom of the names. Now each person has a random number in column B.

Step 5: Select all the numbers in column B, right clicking on the mouse and select COPY.

Step 6: Right click again over selected column, then choose Paste Special. Click Ok.

Step 7: Select the first and second columns

Step 8: Go to main menu and click ‘data’, then select ‘sort’.

Step 9: Sort by Column B, then by Column A. Then click ‘ok’

The list of names has now been rearranged. Include the first 30 clients in the list in the current audit.
**SECTION ONE: GENERAL INFORMATION**

| 1.1 Person ID | A unique 5 digit identification number is given to each person included in the audit as follows:
|               | - The first 3 digits are the health service code assigned for the CQI project (e.g. 921);
|               | - The last 2 numbers will be a de-identified person number (e.g. 01).
|               | For each participating health service, the auditor will prepare a master list of people to be included in the audit that contains names, dates of birth, and allocated person numbers. This list will be marked ‘confidential’ and be stored securely and separately from the audit forms to prevent inappropriate identification of people’s records. |

| 1.2 Health Number recorded | Indicate whether the person’s health number recorded in his/her medical record. This may be a hospital number, clinic number or national health number. |

| 1.3 Date of birth | Record the person’s date of birth as stated in the medical record. Record as dd/mm/yyyy (e.g. 24/05/1987). |

| 1.4 Age at date of audit | Record the person’s age on the date of the audit. |

| 1.5 Gender | Record the person’s gender as stated in the medical record. |

| 1.6 Ethnicity | Record the person’s ethnicity as stated in the medical record. If there is no clear record of the ethnicity of the patient, circle Not recorded (9). |

| 1.7 Auditor’s initial and surname | The auditor completing the form writes his/her first name initial and full surname (e.g. J Smith). |

| 1.8 Audit date | The audit date is the date the current audit started at the health service. If the audit takes more than one day to complete, record the date audit started on all audit forms. Record as dd/mm/yyyy. (e.g. 05/12/2012). |

| 1.9 District/ Division | Record the Division or District in which the audit is being conducted. |

**SECTION TWO: ATTENDANCE AT HEALTH SERVICE**

| 2.1 Date last attended | Record the date the person last attended the health service. If the person left the facility without being seen by any health worker, record as ‘did not attend. If the person has not attended the health service during the previous 12 months they are still included in the audit. If the person has NOT attended within the last 12 months, record the date of last attendance (more than 12 months ago). |

| 2.2 Reason for last attendance | - Acute medical care – e.g. infections, trauma, asthma
|                               | - Benzathine Penicillin injections
|                               | - ARF/RHD clinical review – e.g. with Medical Officer, Medical Specialist, Cardiologist, echocardiogram
|                               | - Other reason – e.g. dental review, labour/delivery, surgery (including heart surgery)
|                               | If the person has NOT attended within the last 12 months, circle Did not attend within the last 12 months (9). |

| 2.3 If not attended in last 12 months is there any record of follow-up attempt or effort to determine if relocated since last attendance? | If the person has attended within the last 12 months circle Attended within last 12 months (9).
|                                                                            | If the person has NOT attended within the last 12 months, circle Yes (1) if there was an attempt to follow up during the last 12 months, or No (0) if there was no attempt to follow-up. |
### SECTION THREE: RECORDING OF KEY HEALTH INFORMATION

<table>
<thead>
<tr>
<th>3.1 Is there a record of the following diagnoses in the Medical Record?</th>
<th>The most recent diagnosis date for each diagnosis should be recorded on the audit form. Record as dd/mm/yyyy. (e.g. 24/05/1987)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definite acute rheumatic fever (first episode):</strong> this refers to a definite episode of acute rheumatic fever, usually diagnosed in hospital, or by an experienced medical practitioner.</td>
<td></td>
</tr>
<tr>
<td><strong>Suspected acute rheumatic fever (first episode):</strong> sometimes the diagnosis of rheumatic fever is uncertain, in which case the patient may have “suspected” or “possible” rheumatic fever recorded in their file.</td>
<td></td>
</tr>
<tr>
<td><strong>Recurrent rheumatic fever:</strong> recurrent rheumatic fever is rheumatic fever which occurs in a person who has had acute rheumatic fever in the past. This may have happened many times; Circle (1) if there is at least one episode of recurrent rheumatic fever recorded. Record most recent recurrent diagnosis date.</td>
<td></td>
</tr>
<tr>
<td><strong>Suspected recurrent rheumatic fever:</strong> this refers to a record of “suspected” or “possible” rheumatic fever recorded when rheumatic fever has been recorded previously. Record most recent suspected recurrent diagnosis date.</td>
<td></td>
</tr>
<tr>
<td><strong>Rheumatic heart disease:</strong> Rheumatic heart disease usually involves the heart valves and may be recorded as a specific heart valve problem, such as “mitral regurgitation”, “mitral incompetence” or “aortic regurgitation”. Diagnosis may be included on an echocardiogram report, or written in the Medical Record during clinical review or hospital admission.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.2 Is the disease classification (ARF only or mild, moderate or severe RHD) recorded in the Medical Record?</th>
<th>Circle Yes (1) if the disease classification is recorded anywhere in the Medical Record. Classification may be included on an echocardiogram report, or written in the Medical Record during clinical review or hospital admission.</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.3 If not recorded, what is the rheumatic heart disease classification according to the Australian Priority Level Algorithm?</td>
<td>This can be estimated from information written in the medical record or echocardiogram report/s. <strong>High risk:</strong> Rheumatic heart disease with severe valvular disease; or moderate to severe valvular lesions with symptoms of heart failure such as breathlessness, unable to lie flat in bed or swelling of their feet and ankles; or if they have tissue prosthetic valves and valve repairs. These people have the greatest risk of further damage to their valves and worsening of the heart function if they should have an attack of recurrent rheumatic fever. Circle High risk (1). <strong>Medium risk:</strong> Rheumatic heart disease with any moderate valve lesion in the absence of symptoms and with normal left ventricle function (This information will be contained in their echocardiogram reports, look for the phases ‘left ventricular function’ or ‘ejection fraction’. Check with senior clinical staff if uncertain.) People may also be classified as medium risk if they have had valve replacement surgery using a mechanical prosthetic valve. These people are at moderate risk from recurrent rheumatic fever. Circle Medium risk (2).</td>
</tr>
</tbody>
</table>
**Low risk:** A history of acute rheumatic fever with no evidence of rheumatic heart disease (i.e. no valve damage); or trivial to mild valvular disease. These people are at relatively low risk from recurrent attacks of rheumatic fever (but still require regular rheumatic fever prevention injections).

**Circle Low risk (3).**

3.4 Is there a current ARF/RHD Management Plan documented anywhere in the Medical Record?

A Management Plan includes any documented advice about future management, timing for next medical review, echocardiogram or cardiac surgery, or details about continuing or ceasing secondary prophylaxis.

3.5 Is this person currently prescribed Warfarin?

This may be recorded under a list of current medications or as part of a summary during clinical review.

3.6 If Warfarin is prescribed, please record the two most recent INRs including results and dates of these tests.

This may be recorded in the investigation or results section or as part of a summary during clinical review.

3.7 Is this person waiting for heart valve surgery?

This may be documented on a form or as part of a summary during clinical review.

### SECTION FOUR: AUDIT OF SCHEDULED BENZATHINE PENICILLIN INJECTIONS

4.1 What is the current order for this person regarding secondary prevention of ARF?

This information may be recorded in the medical record or in the Benzathine penicillin injection book.

4.2 Where is the order for planned dose and frequency of injections recorded?

This may be recorded in more than one place. If there is no Benzathine penicillin injection order in either the medical record or the Benzathine injection book, circle **Order not recorded (9)**

4.3 If recorded in both the Medical Record and the Benzathine injection book, are the two records the same?

Benzathine penicillin G injection orders may vary in dose and/or frequency of injections. If recorded in both and the same, circle **Yes (1)**, if not the same, circle **No (0)**. If the order is only recorded in one place, circle **Not recorded in both (3)**. If there is no Benzathine penicillin injection order in either the medical record or the Benzathine injection book, circle **Order not recorded (9)**

4.4 If not the same, which order is correct for age and weight?

If there is only one order or if there are two orders that are both correct, circle **Not Applicable (9)**.

4.5 Number of injections **planned** in the last 12 months. (12, 13 or 17)

Record the number of injections planned over the previous 12 months.
- **3-weekly** order requires 17 injections in 12 months
- **4-weekly** order requires 13 injections in 12 months
- ‘monthly’ order requires 12 injections in 12 months

4.6 Number of injections **given** in the last 12 months.

Count the number of injections recorded as given in the medical record or clinic Benzathine injection book over the previous 12 months. If Benzathine penicillin injections were started less than 12 months ago, record the number of injections given since started. If there is no record of any injections given in the last 12 months, record ‘0’

4.7 If injections started within the last 12 months, record date of first injection

Record as dd/mm/yyyy. (e.g. 24/05/1987)

4.8 Calculate the number of injections **received** within the last 12 months.

Calculate number given, divide by number planned, and multiply by 100. (e.g. if 13 were planned and only 7 were given, $7 \div 13 \times 100 = 54\%$)
If injections started within the last 12 months divide the number of injections given by the number of injections planned since the start date, and multiply by 100 (as above).

**4.9 Has this person received at least 80% of planned injections in last 12 months?**

Note: 80% of planned injections equals:

- 14 or more injections if planned *3-weekly*
- 11 or more injections if planned *4-weekly*
- 10 or more injections if planned *‘monthly’*

If less than 80% of injections were received within the last 12 months, circle **Yes (1)** or **No (0)** for each possible follow-up action.

If 80% or more of injections were received within the last 12 months, circle **80% or more received (9)** for each follow-up action.

**4.10 If less than 80% of planned Benzathine penicillin G injections were received, is there a record of:**

If less than 80% of injections were received within the last 12 months, circle **Yes (1)** or **No (0)** for each possible follow-up action.

If 80% or more of injections were received within the last 12 months, circle **80% or more received (9)** for each follow-up action.

This may be recorded as an outpatient assessment or a hospital admission.

**4.11 Is there evidence of at least one definite recurrent rheumatic fever within the last 12 months?**

If there is evidence of recurrent rheumatic fever within the last 12 months and 80% or more of injections were received, circle **Yes (1)** or **No (0)** for each possible follow-up action.

If there is no evidence of recurrent rheumatic fever within the last 12 months, circle **No recurrent RF (9)** for each follow-up action.

**SECTION FIVE: AUDIT OF ONGOING CARE AND SELF-MANAGEMENT SUPPORT**

See 3.3 for risk classifications

<table>
<thead>
<tr>
<th>5.1 Is there a record of each of the following services having been provided?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete this section if the person was identified as <strong>High Risk</strong></td>
</tr>
<tr>
<td>Some of these services should be provided more frequently for some people. Record the date of the most recent review/service. Record as dd/mm/yyyy. (e.g. 05/12/2012)</td>
</tr>
<tr>
<td>Circle <strong>Yes (1)</strong> or <strong>No (0)</strong> for evidence of each service within the specified time periods. If echocardiogram services were not available at the health service or at any other facility (by referral) within the last 6 months, circle <strong>Not available during last 6 months (9)</strong>.</td>
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</table>

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<thead>
<tr>
<th>5.2 Is there a record of each of the following services having been provided?</th>
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<tbody>
<tr>
<td>Complete this section if the person was identified as <strong>Medium Risk</strong></td>
</tr>
<tr>
<td>Some of these services should be provided more frequently for some people. Record the date of the most recent review/service. Record as dd/mm/yyyy. (e.g. 05/12/2012)</td>
</tr>
<tr>
<td>Circle <strong>Yes (1)</strong> or <strong>No (0)</strong> for evidence of each service within the specified time periods. If echocardiogram services were not available at the health service or at any other facility (by referral) within the last 12 months, circle <strong>Not available during last 12 months (9)</strong>.</td>
</tr>
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<thead>
<tr>
<th>5.3 Is there a record of each of the following services having been provided?</th>
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<tbody>
<tr>
<td>Complete this section if the person was identified as <strong>Low Risk</strong></td>
</tr>
<tr>
<td>Some of these services should be provided more frequently for some people. Record the date of the most recent review/service. Record as dd/mm/yyyy. (e.g. 05/12/2012)</td>
</tr>
<tr>
<td>Circle <strong>Yes (1)</strong> or <strong>No (0)</strong> for evidence of each service within the specified time periods. If echocardiogram services were not available at</td>
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<td>Question</td>
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<tr>
<td>5.4 Is there a record of influenza vaccination within the previous 12 months?</td>
</tr>
<tr>
<td>5.5 Is there a record of pneumococcal vaccination as per the current schedule?</td>
</tr>
<tr>
<td>5.6 Is there a record that disease education and self-management support has been provided?</td>
</tr>
<tr>
<td>5.7 If recorded in the Medical Record that this person is a cigarette smoker, is there also a record of intervention in the Medical Record?</td>
</tr>
<tr>
<td>5.8 If recorded in the Medical Record that this person is a high risk alcohol user, is there also a record of intervention in the Medical Record?</td>
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TOOL COMPONENTS

The model used for describing primary health care service systems has five components, and each component is made up of a number of items. The five components of the model are:

1. **Delivery system design** - refers to the extent to which the design of the health centre’s infrastructure, staffing and care processes maximise the potential effectiveness of the centre.
   a. Team structure and function
   b. Clinical leadership
   c. Care planning
   d. Systematic approach to follow-up
   e. Continuity of care
   f. Client access / cultural competence
   g. Physical infrastructure, supplies and equipment

2. **Information systems and decision support** - refers to structures and processes to support the planning and delivery of care, including clinical decision support.
   a. Maintenance and use of electronic client list
   b. Evidence based guidelines
   c. Specialist – generalist collaborations

3. **Self-management support** - refers to structures and processes that support clients and families to play a major role in maintaining their health, managing their health problems, and achieving safe and healthy living environments.
   a. Assessment and documentation
   b. Self-management education and support, behavioural risk reduction and peer support

4. **Links with the community, other health services and other services and resources** - refers to the extent to which the health centre: uses external linkages to inform service planning, links clients to outside resources, works out in the community, and contributes to regional planning and resource development. It is primarily through this component of the tool that the quality of population programs and activities is assessed.
   a. Communication and cooperation on governance and operation of the health centre and other community based organisations and programs
   b. Linking health centre clients to outside resources
   c. Working out in the community
   d. Communication and cooperation on regional health planning and development of health resources

5. **Organisational influence and integration** - refers to the use of organisational influence to create a culture and support organisational structures and processes that promote safe, high quality care; and how well all the system components are integrated across the centre.
   a. Organisational commitment
   b. Quality improvement strategies
   c. Integration of health system components

1. **DELIVERY SYSTEM DESIGN**
Effective delivery of primary health care requires that service delivery infrastructure, staffing and care processes are designed to meet the specific needs of different client groups and their families. This involves more than simply adding additional interventions or programs to an existing system focused on acute care. It often necessitates significant changes to the organisation of care.

1.1 Team structure and function

Fully developed support:

1. There is a fully established **team approach** in this area, with secure and ongoing availability of all the clinical personnel required.
2. Team leadership is clearly defined and recognised, and the leader has an **appropriate level of formal authority** within the practice team.
3. There is **very good definition of team members’ roles and responsibilities** and lines of reporting, and these are integrated into delivery system design.
4. There is **good communication and cohesion** within the team; the team meets regularly and has established processes for **effective decision making**.
5. There is an **on-going strategic approach to developing team members’ skills and roles**, including in use of information systems, decision support, self-management support, and links with the community.

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<th>Limited or no support</th>
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<td>3 4 5</td>
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<tr>
<td>1 No team approach; clinical staff needed for team approach not available</td>
<td>Some efforts to establish a team approach; clinical staff needed for team approach sometimes available, but not secure or ongoing</td>
<td>Team approach becoming well established; clinical staff needed for team approach usually available, becoming more secure and ongoing</td>
<td>Fully established team approach; secure, ongoing availability of clinical staff needed for team approach</td>
</tr>
<tr>
<td>2 Team leadership not clearly defined</td>
<td>Team leadership becoming defined and recognised, leader acquiring formal authority</td>
<td>Team leadership clearly defined and recognised, leader has formal authority</td>
<td></td>
</tr>
<tr>
<td>3 Definition of team roles, lines of reporting and integration in system design are fair</td>
<td>Definition of team roles, lines of reporting and integration in system design are good</td>
<td>Definition of team roles, lines of reporting and integration in system design are very good</td>
<td></td>
</tr>
<tr>
<td>4 Fair communication and cohesion within the team; team meets irregularly; decision-making is fair</td>
<td>Good communication and cohesion within the team; team meetings becoming regular; decision-making is good</td>
<td>Very good communication and cohesion within the team; team meetings regular; decision-making is very good</td>
<td></td>
</tr>
<tr>
<td>5 Development of team members’ skills and roles is fair</td>
<td>Development of team members’ skills and roles is good</td>
<td>Development of team members’ skills and roles is very good</td>
<td></td>
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</tbody>
</table>
1.2  Clinical leadership

Fully developed support:
1. Clinical leadership in this area is fully established and recognised.
2. Clinical leadership contributes to the centre’s vision for high quality care for the client group.
3. Clinical leadership helps to ensure that the centre remains knowledgeable about research evidence and that the evidence is interpreted and appropriately applied to the centre’s clinical services and population programs.

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</table>

- No or minimal clinical leadership
- Clinical leadership emerging
- Clinical leadership becoming established and recognised
- Clinical leadership fully established and recognised

- Contribution of clinical leadership to centre’s vision for high quality care is fair
- Contribution of clinical leadership to centre’s vision for high quality care is good
- Contribution of clinical leadership to centre’s vision for high quality care is very good

- Contribution of clinical leadership to knowledge and application is fair
- Contribution of clinical leadership to knowledge and application is good
- Contribution of clinical leadership to knowledge and application is very good
1.3 Appointments and scheduling
Fully developed support:
1. There is a fully established appointment system for this area that has the flexibility to systematically accommodate the needs of the client group including a) drop-ins; b) long or family consultations; and c) clients seeing multiple providers in a single visit as required.
2. Specific clinics and/or sessions (with specialist support available as appropriate) are part of routine practice for this area.
3. Planning and scheduling the service’s community based activities and programs in this area ahead of time is routine practice.

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<tbody>
<tr>
<td>0</td>
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<td>3</td>
</tr>
<tr>
<td>1 No appointment system</td>
<td>Some appointments made; flexibility is ad hoc</td>
<td>Appointment system becoming established; flexibility becoming systematic</td>
<td>Appointment system fully established; flexibility is systematic</td>
</tr>
<tr>
<td>2 Specific clinics and/or sessions not used</td>
<td>Specific clinics and/or sessions used in ad hoc way</td>
<td>Specific clinics and/or sessions becoming part of routine practice</td>
<td>Specific clinics and/or sessions part of routine practice</td>
</tr>
<tr>
<td>3 No or few community based activities</td>
<td>Scheduling of activities/programs is ad hoc</td>
<td>Planning/scheduling of activities/programs becoming routine practice</td>
<td>Planning/scheduling of activities/programs is routine practice</td>
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</tbody>
</table>

Acute rheumatic fever and rheumatic heart disease
Consider whether individual clients are able to and encouraged to access the service for regular benzathine penicillin g injections at a pre-arranged time or during dedicated clinics.
1.4 Care planning

Fully developed support:
1. Care planning for clients in this area is part of routine practice.
2. Care planning includes the following elements:
   - consistent with best practice guidelines;
   - done jointly by providers and clients/families;
   - includes goal setting;
   - incorporates self-management goals and strategies.

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<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10 11</td>
<td>No or minimal care planning</td>
<td>Care planning is ad hoc</td>
<td>Care planning becoming part of routine practice</td>
</tr>
<tr>
<td>1</td>
<td>Some elements included</td>
<td>Most elements included</td>
<td>All elements included</td>
</tr>
</tbody>
</table>

Acute rheumatic fever and rheumatic heart disease
Consider care planning in terms of immediate, short-term and long-term needs of the client, including plans for ongoing secondary prevention treatment and clinical and investigational follow-up requirements.
1.5  **Systematic approach to follow-up**

**Fully developed support:**

1. Alerts and reminders are consistently used to support client care in this area.
2. Follow-up of clients in this area for regular services and reviews in accordance with best practice is part of routine practice.
3. Follow-up of abnormal pathology and other test results is a systematic part of routine practice in this area.
4. Health centre staff and community knowledge and resources are used to enhance follow-up in this area in a way that balances duty of care with client self-management.

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<tr>
<td>9</td>
<td>10</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>1 No alerts/reminders</td>
<td>Alerts/reminders sometimes used to support client care</td>
<td>Alerts/reminders usually used to support client care</td>
<td>Alerts/reminders consistently used to support client care</td>
</tr>
<tr>
<td>2 No or minimal follow-up of clients</td>
<td>Follow-up of clients for regular reviews is ad hoc</td>
<td>Follow-up of clients for regular reviews is becoming part of routine practice</td>
<td>Follow-up of clients for regular reviews is routine practice</td>
</tr>
<tr>
<td>3 No or minimal processes for follow-up abnormal results</td>
<td>Follow-up of abnormal test results is ad hoc</td>
<td>Follow-up of abnormal test results is becoming part of routine practice</td>
<td>Follow-up of abnormal test results is routine practice</td>
</tr>
<tr>
<td>4 No or minimal use of available resources to enhance follow-up</td>
<td>Use of available resources to enhance follow-up is fair</td>
<td>Use of available resources to enhance follow-up is good</td>
<td>Use of available resources to enhance follow-up is very good</td>
</tr>
</tbody>
</table>

**Acute rheumatic fever and rheumatic heart disease services**

Consider whether the current alerts and reminder systems are accessed in a way to identify clients who are due for ARF/RHD services and provide reminders to service providers at the time of encounter for delivery of specific services, consistent with best practice guidelines.
1.6  **Continuity of care**

**Fully established support:**
1. The delivery system is designed to enhance continuity of care in this area by having the following elements:
   - well organised and clear documentation;
   - scheduled follow-up visits;
   - continuity of provider(s);
   - team approach to care;
   - individual client case management;
   - orientation of health centre staff to processes to enhance continuity of care.

2. An effective system for communication between hospital(s) and the health centre following discharge of clients in this area is fully established.

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<tr>
<th></th>
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<th>Basic support</th>
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<th>Fully developed support</th>
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</thead>
<tbody>
<tr>
<td><strong>1</strong> Delivery system is not designed to enhance continuity of care</td>
<td>Delivery system beginning to be designed to enhance continuity of care (some elements in place)</td>
<td>Delivery system quite well designed to enhance continuity of care (most elements in place)</td>
<td>Delivery system very well designed to enhance continuity of care (all or almost all elements in place)</td>
<td></td>
</tr>
<tr>
<td><strong>2</strong> No or minimal communication between hospital and the health centre post-discharge</td>
<td>Post-discharge communication between hospital and the health centre is on an ad hoc basis only</td>
<td>System for routine post-discharge communication between hospital and the health centre becoming established</td>
<td>System for routine post-discharge communication hospital and the health centre fully established</td>
<td></td>
</tr>
</tbody>
</table>
1.7 Client access / cultural competence

Fully developed support:

1. Health centre design and processes address physical, communication and transport barriers to access to clients in this area, including client privacy and confidentiality, the use of translators (as required) and transport support for referrals.

2. There is a systematic approach to ensuring that all health centre staff providing care in this area are culturally competent, including through staff orientation and training.

3. There are processes in place to ensure respect for gender-related issues in this area, including appropriate staffing.

4. All members of staff are respected and inform clinical practice and community based activities in this area.

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<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3 4 5</td>
</tr>
<tr>
<td>1 No or minimal attention given to barriers</td>
<td>Barriers beginning to be addressed but many remain</td>
<td>Barriers addressed quite well but some remain</td>
<td>Barriers addressed very well and few or none remain</td>
</tr>
<tr>
<td>2 No or minimal attention given to cultural competence; not included in orientation and training</td>
<td>Level of attention to cultural competence is fair; sometimes included in orientation and training</td>
<td>Level of attention to cultural competence is good; usually included in orientation and training</td>
<td>Level of attention to cultural competence is very good; always included in orientation and training</td>
</tr>
<tr>
<td>3 No or minimal respect for gender-related issues</td>
<td>Respect for gender-related issues is fair</td>
<td>Respect for gender-related issues is good</td>
<td>Respect for gender-related issues is very good</td>
</tr>
<tr>
<td>4 No or minimal respect for certain members of staff</td>
<td>Respect for all members of staff is fair</td>
<td>Respect for all members of staff is good</td>
<td>Respect for all members of staff is very good</td>
</tr>
</tbody>
</table>
1.8 Physical infrastructure, supplies and equipment

Fully developed support:

1. **Physical infrastructure** for provision of care in this area is highly suitable.
2. **Supplies of consumables** for this area are appropriate and always available.
3. All the appropriate **equipment** for this area is available and is of very good quality and very well maintained (e.g. does not need to be shared between or borrowed from other consulting areas due to limited availability or poor maintenance).

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<tr>
<td>Physical infrastructure unsuitable</td>
<td>Physical infrastructure somewhat suitable</td>
<td>Physical infrastructure quite suitable</td>
<td>Physical infrastructure highly suitable</td>
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<tr>
<td>2</td>
<td>Appropriate and availability of consumables is poor</td>
<td>Appropriate and availability of consumables are fair</td>
<td>Appropriate and availability of consumables are good</td>
</tr>
<tr>
<td>3</td>
<td>Equipment appropriateness, quality and maintenance is poor</td>
<td>Equipment appropriateness, quality and maintenance are fair</td>
<td>Equipment appropriateness, quality and maintenance are good</td>
</tr>
</tbody>
</table>

**Acute rheumatic fever and rheumatic heart disease**
Consider reliable supply of consumables including intramuscular benzathine penicillin g medication, injection equipment and emergency care medication (e.g. Adrenaline for anaphylaxis).
2. INFORMATION SYSTEMS AND CLINICAL DECISION SUPPORT
Effective health centres ensure that information systems contain up-to-date client information that is used to support the planning and delivery of care, including decision support. Evidence based guidelines and other resources should be available through the systems in formats that are appropriate and accessible for all members of the health team. In addition, advice may be available through specialist collaborations and other mechanisms.

2.1 Maintenance and use of a client list
Fully developed support:

1. There is a list of clients that is regularly reviewed according to an established protocol and is up to date, including record of place of residence and Health/Hospital number.
2. The list is routinely used to identify regular clients in this area to support service planning and delivery – e.g. for identifying clients for preventive and early detection services according to demographic and risk characteristics.
3. The list is routinely used to identify regular clients in this area with specific conditions to support service planning and delivery – e.g. to generate lists of clients for follow-up or regularly scheduled services.
4. Strategies to reach client groups in this area are implemented as part of routine practice.

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**Acute rheumatic fever and rheumatic heart disease services**
In addition to the above, consider whether current client lists have the capacity to prioritise clients according to risk of disease progression, and whether the current system supports other functions relevant to ARF/RHD care such as regular specialist review and regular echocardiography.
2.2 **Evidence based guidelines**

**Fully developed support:**

1. Evidence-based guidelines, protocols and other resources for this area suitable to the service setting are available and accessible.
2. Evidence-based guidelines, protocols and other resources for this area are used as part of routine practice.
3. Training in and/or orientation to the use of these resources is well integrated into in-service training.

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<th>Limited or no support</th>
<th>Basic support</th>
<th>Good support</th>
<th>Fully developed support</th>
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<td>0 1 2</td>
<td>3 4 5</td>
<td>6 7 8</td>
<td>9 10 11</td>
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</tr>
<tr>
<td>1 No or minimal availability or accessibility of evidence-based resources</td>
<td>Availability and accessibility of evidence-based resources is fair</td>
<td>Availability and accessibility of evidence-based resources is good</td>
<td>Availability and accessibility of evidence-based resources is very good</td>
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<tr>
<td>2 No or minimal use of evidence-based resources</td>
<td>Use of evidence-based resources is ad hoc</td>
<td>Use of evidence-based resources becoming part of routine practice</td>
<td>Use of evidence-based resources part of routine practice</td>
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</tr>
<tr>
<td>3 No or minimal staff training in use of evidence-based resources</td>
<td>Staff training in use of evidence-based resources is fair</td>
<td>Staff training in use of evidence-based resources is good</td>
<td>Staff training in use of evidence-based resources is very good</td>
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</table>
2.3 **Specialist – generalist collaborations**

Fully developed support:

1. There is a strategic approach to specialist – generalist collaboration in this area that results in:
   - enhanced decision support for clinical care;
   - effective generalist-specialist communication about client needs and care;
   - culturally appropriate care across the spectrum of generalist-specialist care; and
   - specialist engagement in the development of community-based programs that promote healthy social and physical environments.

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<td>0 1 2</td>
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<td>6 7 8</td>
<td>9 10 11</td>
</tr>
<tr>
<td>1 No or minimal specialist-generalist collaboration – i.e. traditional referral only</td>
<td>Specialist-generalist collaboration is fair</td>
<td>Specialist-generalist collaboration is good</td>
<td>Specialist-generalist collaboration is very good</td>
</tr>
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</table>

**Acute Rheumatic Fever and Rheumatic Heart Disease**

Consider resources provided by the international community in this area including visiting or offshore cardiology and surgery services where applicable.
3. **SELF-MANAGEMENT SUPPORT**

Self-management support refers to health centre structures and processes that support clients and their families to play a major role in maintaining their health, managing their health problems, and achieving safe and healthy environments. Effective self-management support strategies include assessing and documenting self-management needs and activities, providing education and support and behaviour change interventions and promoting peer support. Involving clients’ families in these activities is important. Health centres can organise internal and community resources to maximise potential for community members to contribute to the creation and maintenance of their own health and to healthy social and physical environments.

3.1 **Assessment and documentation**

Fully developed support:

1. Self-management for clients in this area is supported as a central, strategic part of health care.
2. Self-management needs for clients in this area are routinely assessed and documented in a standardised way.
3. Clients/families in this area are routinely engaged in the assessment and documentation processes.
4. Use of client held records to promote self-management is part of routine practice in this area - i.e. tools that are designed to assist clients to adhere to self-management programs and to set goals, track their progress and understand the reasons for health visits.

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<tr>
<td>1 No or minimal support for self-management</td>
<td>Fair support for self-management</td>
<td>Good support for self-management</td>
<td>Very good support for self-management</td>
</tr>
<tr>
<td>2 Self-management needs are rarely assessed</td>
<td>Self-management needs sometimes assessed and documented but on an ad hoc basis only</td>
<td>Assessment and documentation of self-management needs becoming routine practice</td>
<td>Assessment and documentation of self-management needs is routine practice</td>
</tr>
<tr>
<td>3 No or minimal engagement of clients/families in assessment processes</td>
<td>Clients/families engagement in assessment and documentation is ad hoc</td>
<td>Clients/families engagement in assessment and documentation becoming routine practice</td>
<td>Clients/families engagement in assessment and documentation is routine practice</td>
</tr>
<tr>
<td>4 No or minimal use of client held records</td>
<td>Use of client held records is ad hoc</td>
<td>Use of client held records becoming part of routine practice</td>
<td>Use of client held records is part of routine practice</td>
</tr>
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**Acute Rheumatic Fever and Rheumatic Heart Disease**

Effective self-management support strategies include assessment, goal-setting, action planning, problem solving and follow-up.
### 3.2 Self-management education and support, behavioural risk reduction and peer support

**Fully developed support:**

1. **Self-management education and support** in this area are routinely provided by staff with recognised training and skills in self-management support.
2. Involvement of families in self-management education and support activities in this area is part of routine practice.
3. There is a systematic approach to **behavioural risk reduction** in this area. Behaviour change interventions – e.g. brief intervention for alcohol and tobacco risk reduction – are routinely provided by staff with recognised training and skills in behavioural intervention.
4. Use of **good quality educational resources** for clients and families to support behavioural risk reduction self-management is part of routine practice in this area.
5. Promotion and support for community peer support programs and activities is a central, strategic part of health care in this area.

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<td>3</td>
</tr>
<tr>
<td>1 No or minimal self-management education or support</td>
<td>Some self-management education and support by staff with limited training and skills</td>
<td>Good self-management education and support by staff with relevant training and skills</td>
<td>Very good self-management education and support by staff with relevant training and skills</td>
</tr>
<tr>
<td>2 No or minimal engagement of families in education/support activities</td>
<td>Engagement of families in education/support activities but on an ad hoc basis only</td>
<td>Engagement of families in education/support activities becoming routine practice</td>
<td>Engagement of families in education/support activities is routine practice</td>
</tr>
<tr>
<td>3 No or minimal use of resources to support self-management</td>
<td>Some use of resources to support self-management</td>
<td>Use of resources to support self-management becoming routine practice</td>
<td>Use of resources to support self-management is routine practice</td>
</tr>
<tr>
<td>4 No or minimal provision of behaviour change interventions</td>
<td>Some behavioural interventions provided but by staff with limited relevant training and skills</td>
<td>Behavioural interventions by staff with relevant training and skills becoming part of routine practice</td>
<td>Behavioural interventions by staff with relevant training and skills part of routine practice</td>
</tr>
<tr>
<td>5 No or minimal promotion or support for peer support</td>
<td>Promotion and support for peer support ad hoc</td>
<td>Promotion and support for peer support is becoming central, strategic part of care</td>
<td>Promotion and support for peer support is a central, strategic part of care</td>
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**Acute rheumatic fever and rheumatic heart disease services**

Consider interventions related to uptake of benzathine penicillin injections, regular follow-up, smoking, other medications, physical activity, food and nutrition; and the emotional, social, economic and environmental factors that may have important influences on these behaviours.
4. LINKS WITH THE COMMUNITY, OTHER HEALTH SERVICES, AND OTHER SERVICES AND RESOURCES

Good links and partnerships between the health centre and the community, and other community based organisations and programs are important in primary health care. They allow the centre to have effective community input to planning, to link its clients to outside resources, to work with population groups out in the community and to contribute to regional activities such as service planning and the development of resources.
### Communication and cooperation on governance and operation of the health centre and other community based organisations and programs

#### Fully developed support:

1. There are well-functioning arrangements for **community input to health centre governance**.
2. There is a systematic approach to involving the service population in this area in service planning and feedback, that includes input through an annual general meeting or reference groups/committees and formal mechanisms for dissemination of health service performance information.
3. **Client satisfaction** with the health centre’s services in this area is systematically and routinely assessed.
4. There are **formal agreements** between the health centre and mainstream primary care services and other health and community services relevant to this area that involve good communication and ongoing, strategic activities.
5. There are well-functioning arrangements for the health centre to work in **partnership with relevant community groups** in this area – e.g. municipal councils, schools, women’s centres, resource centres, art centres, child care centres, sport and recreation groups, cultural programs - to help ensure community programs have a positive health impact.
6. Community social, education and other programs and organisations relevant to this area have a strong **health orientation**.

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<td>0</td>
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<tr>
<td>1 No community input to governance</td>
<td>Community input to governance is fair</td>
<td>Community input to governance is good</td>
<td>Community input to governance is very good</td>
</tr>
<tr>
<td>2 No service population involvement in planning and feedback</td>
<td>Service population involvement in planning and feedback is ad hoc</td>
<td>Service population involvement in planning and feedback is becoming systematic</td>
<td>Service population involvement in planning and feedback is systematic</td>
</tr>
<tr>
<td>3 Client satisfaction never or rarely assessed</td>
<td>Assessment of client satisfaction is ad hoc</td>
<td>Assessment of client satisfaction becoming systematic and routine</td>
<td>Assessment of client satisfaction is systematic and routine</td>
</tr>
<tr>
<td>4 No formal agreements with other services</td>
<td>Formal agreements with other services with fair communication and levels of activity</td>
<td>Formal agreements with other services with good communication and levels of activity</td>
<td>Formal agreements with other services with very good communication and levels of activity</td>
</tr>
<tr>
<td>5 No or poor partnerships with community groups</td>
<td>Partnerships with community groups are fair</td>
<td>Partnerships with community groups are good</td>
<td>Partnerships with community groups are very good</td>
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<tr>
<td>6 Health orientation of community programs is weak</td>
<td>Health orientation of community programs is fair</td>
<td>Health orientation of community programs is good</td>
<td>Health orientation of community programs is very good</td>
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### 4.2 Linking health centre clients to outside resources

**Fully developed support:**

1. There are systematic arrangements in place to link individual clients in this area to outside health and health-related resources.
2. The resource directory that supports these arrangements are comprehensive, regularly updated, is easily accessible and widely used by staff.
3. Linkage arrangements relating to these resources are well integrated into staff orientation and in-service training programs.

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<tr>
<td>No or minimal arrangements for linking clients to outside resources</td>
<td>Arrangements for linking clients to outside resources ad hoc</td>
<td>Arrangements for linking clients to outside resources becoming systematic</td>
<td>Arrangements for linking clients to outside resources are systematic</td>
</tr>
<tr>
<td>2</td>
<td>No resource directory</td>
<td>Resource directory – comprehensiveness, updating accessibility and use are fair</td>
<td>Resource directory – comprehensiveness, updating accessibility and use are good</td>
</tr>
<tr>
<td>3</td>
<td>No or minimal integration of linkage arrangements in staff orientation or training</td>
<td>Integration of linkage arrangements in staff orientation or training is fair</td>
<td>Integration of linkage arrangements in staff orientation or training is good</td>
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</table>
### 4.3 Working out in the community

Fully developed support:

1. Staff engage in community health promotion/development activities (e.g. in pre-schools and schools; men’s, women’s and youth groups; community centres; community stores) relevant to this area.
2. Community activities in this area are well-designed to meet identified needs of different groups.
3. Community activities in this area are fully integrated into the centre’s programs.

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</tr>
<tr>
<td>1 No or minimal staff engagement in community health promotion/development</td>
<td>Level of staff engagement in community health promotion/development is fair</td>
<td>Level of staff engagement in community health promotion/development is good</td>
<td>Level of staff engagement in community health promotion/development is very good</td>
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<tr>
<td>2</td>
<td>Design of community activities is fair</td>
<td>Design of community activities is good</td>
<td>Design of community activities is very good</td>
</tr>
<tr>
<td>3</td>
<td>Integration of community activities into centre’s programs is fair</td>
<td>Integration of community activities into centre’s programs is good</td>
<td>Integration of community activities into centre’s programs is very good</td>
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</table>
### 4.4 Communication and cooperation on regional health planning and development of health resources

**Fully developed support:**
1. Health centre staff actively engage in and promote regional planning in this area.
2. Health centre staff actively contribute to the development and promotion of standard resources for health services that have region-wide relevance in this area.
3. Local community plans relevant to this area are systematically used to inform regional planning processes and allocation of resources.

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</tr>
<tr>
<td><strong>1 No or minimal engagement in regional planning</strong></td>
<td>Level of engagement in regional planning is fair</td>
<td>Level of engagement in regional planning is good</td>
<td>Level of engagement in regional planning is very good</td>
</tr>
<tr>
<td><strong>2 No or minimal contribution to the development of resources</strong></td>
<td>Contribution to the development of resources is fair</td>
<td>Contribution to the development of resources is good</td>
<td>Contribution to the development of resources is very good</td>
</tr>
<tr>
<td><strong>3 No or minimal use of community plans</strong></td>
<td>Use of community plans is ad hoc</td>
<td>Use of community plans is becoming systematic</td>
<td>Use of community plans is systematic</td>
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</table>
Primary health care will be more effective if there is an organisational culture that is committed to addressing the needs of specific client groups; promotes good relationships and communication; and safe, high-quality care and quality improvement. In addition, effective primary health care requires the integration of the health centre’s system components.

### 5.1 Organisational commitment

#### Full developed support

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<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1 No plans; little or no interest in a plan</td>
<td>Plans in place; level of commitment is good</td>
<td>Plans in place; level of commitment is very good</td>
</tr>
<tr>
<td>2 No specific funding</td>
<td>Specific funding; level is good and/or medium term</td>
<td>Specific funding; level is very good and/or long term</td>
</tr>
<tr>
<td>3 Minimal staffing; no specific roles defined</td>
<td>Level of staffing is good; most roles defined and reflected in job descriptions</td>
<td>Level of staffing is very good; all roles defined and reflected in job descriptions</td>
</tr>
<tr>
<td>4 Poor relationships and little or no communication</td>
<td>Relationships and communication are fair</td>
<td>Relationships and communication are very good</td>
</tr>
<tr>
<td>5 Range of training and in-service opportunities is poor</td>
<td>Range of training and in-service opportunities is good</td>
<td>Range of training and in-service opportunities is very good</td>
</tr>
<tr>
<td>6 Range of service delivery strategies is poor</td>
<td>Range of service delivery strategies is good</td>
<td>Range of service delivery strategies is very good</td>
</tr>
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</table>

1. The strategic and business plans reflect commitment to this client group – i.e. vision statement, policies, financing, staffing, strategies.
2. There is specific funding for this area that is at an adequate level and long-term.
3. Staffing for this area is at levels that meet the established need; all the relevant roles are defined and these are reflected in job descriptions.
4. There are very good relationships and regular, clear communication among staff in this area; staff morale is high and there is a feeling among line staff that senior staff understand their work and needs.
5. There is a very good range of training and in-service opportunities for staff working in this area.
6. There is a range of service delivery strategies in this area across individual clinical, group and population based activities (as appropriate).
5.2 **Quality improvement strategies**

Fully developed support:

1. Senior staff fully and consistently **support for quality improvement** in this area – i.e. it is resourced, staff training is provided, participation is encouraged, staff have authority to make improvements, and effectiveness is evaluated.

2. There are systematic **quality improvement processes** in this area that are used consistently – i.e. cyclical processes of evidence-based assessment of health centre performance using good quality data, review and planning involving the whole team, and service improvement.

3. The electronic client information system is routinely used to **report on health centre performance** in this area including profiles and needs of client groups, care delivery and client outcomes.

4. There are systematic **processes for dealing with errors and problems** with care delivery in this area that include routine identification, examination of root causes and follow through (appropriate action and regular review).

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<tr>
<td>0</td>
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<td>3 4 5</td>
</tr>
<tr>
<td>1 No or minimal senior staff support for quality improvement</td>
<td>Limited senior staff support for quality improvement</td>
<td>Senior staff support quality improvement but not fully or consistently</td>
<td>Quality improvement fully and consistently supported by senior staff</td>
</tr>
<tr>
<td>2 No or minimal quality improvement processes</td>
<td>Ad hoc quality improvement processes</td>
<td>Systematic quality improvement processes but not used consistently</td>
<td>Systematic quality improvement processes used consistently</td>
</tr>
<tr>
<td>3 No electronic client information system</td>
<td>Use of the system for reporting on centre performance is ad hoc</td>
<td>Use of the system for reporting on centre performance becoming routine</td>
<td>Use of the system for reporting on centre performance is routine</td>
</tr>
<tr>
<td>4 No or minimal processes for dealing with errors or problems</td>
<td>Processes for dealing with errors or problems are ad hoc</td>
<td>Processes for dealing with errors becoming systematic</td>
<td>Processes for dealing with errors systematic</td>
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</table>
5.3 **Integration of health system components**

Fully developed support:
There is clear recognition of the need for and importance of integration across the health centre in this area - for example, how well the information system supports clinical decision making (by making guidelines accessible) or self-management (by allowing recording of client goals); how well the funding and human resources arrangements support team care; how well work within and outside the health centre complement each other; and how well staff training supports continuity of care. This is reflected in all documents/processes/activities including:

- business plan
- policy statements
- financing arrangements
- information system
- regulation/legislation
- deployment of human resources
- leadership and advocacy roles
- care processes
- education and in-service programs
- work outside the health centre
- partnership arrangements

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<td>1</td>
<td>No or minimal integration</td>
<td>Fair level of integration</td>
<td>Good level of integration</td>
<td>Very good level of integration</td>
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</table>
Key resources used in the development of this Systems Assessment Tool

Preventive Services and Chronic Disease

- Assessment of Chronic Illness Care (ACIC) scale. Bonomi et al., 2002
- National guide to a preventive health assessment in Aboriginal and Torres Strait Islander peoples. Prepared by the National Aboriginal Community Controlled Health Organisation for the Royal Australian College of General Practitioners. August 2004.

Maternal and Child Health

- Maternal and Child Health Care Services: Actions in the Primary Health Care Setting to improve the Health of Aboriginal and Torres Strait Islander Women of Childbearing Age, Infants and Young Children. Sandra Eades, Menzies School of Health Research. In the Aboriginal and Torres Strait Islander Primary Health Care Review: Consultation Report Number 6 2004.
- Review of current interventions and identification of best practice currently used by community based Aboriginal and Torres Strait Islander health service providers in promoting and supporting breastfeeding and appropriate infant nutrition. Office for Aboriginal and Torres Strait Islander Health Services, Commonwealth Department of Health and Family Services. November 1997.
- Improving Health in Aboriginal and Torres Strait Islander mothers, babies and young children: a literature review. Dr Ana Herceg. Office of Aboriginal and Torres Strait Islander Health, Australian Government Department of Health and Ageing. 2005
- National Aboriginal and Torres Strait Islander Child and Maternal Health Exemplar Site Initiative: Site Reports 2005. Compiled by Office of Aboriginal and Torres Strait Islander Health (OATSIH). 2005
- Maternal and Child Health Service Delivery Scoping Reports.
  - Analysis of Maternal and Child Health Services in Selected Aboriginal Community Controlled Health Services in Queensland, Cindy Shannon and Kate Panaretto, 2005
  - Early Childhood in Alice Springs Reports on the Child and Maternal Health Mapping Project, Central Australian Aboriginal Congress, 2004
  - Koorie Maternal and Child Services Victoria, Karen Adams, 2005