Priority 4 – Strengthen the prevention, diagnosis and treatment of rheumatic heart disease (RHD)

What is the challenge?
Acute rheumatic fever (ARF) is an easily treated illness caused by the body’s inflammatory response to infection with streptococcal bacteria. RHD is a long-term condition caused by permanent damage to one or more of the heart valves following ARF. This can lead to heart failure and sometimes the need for cardiac surgery to repair or replace the heart valves.

Because RHD is a complication of ARF, the best way of preventing RHD is to prevent episodes of ARF. People who have had ARF need regular penicillin injections to prevent recurrences and consequent heart complications. People with RHD require regular check-ups, tests and medications.

The Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease was updated in 2012 and has been widely endorsed by key organisations in Australia. Central to these guidelines is the need to establish coordinated control programs, which include registries to enable active follow-up and recall of patients for secondary prevention and further management, and to improve epidemiological surveillance.

ARF and RHD are highly preventable conditions, yet ARF incidence and RHD prevalence in remote Aboriginal and Torres Strait Islander communities of northern and central Australia remain some of the highest in the world.

As these conditions were practically eradicated in Australia, except in Aboriginal and Torres Strait Islander communities, many health professionals lack the experience in diagnosing and managing ARF and RHD. In addition, diagnosis is a challenge because clinical manifestations can be atypical and Aboriginal and Torres Strait Islander peoples often delay presentation to health services. Control of the disease is also impeded because patients don’t adhere to the recommended treatment.

A nationally coordinated program is the most effective approach to controlling RHD in regions where the disease is common, yet progress to establish a national program in Australia is slow. Data limitations prevent comparisons among states and territories resulting in unreliable disease incidence and prevalence data, which impedes the accurate assessment of disease burden.
Key facts

- Almost all cases of ARF in the Northern Territory between 2005 and 2010 were for Aboriginal and Torres Strait Islander peoples (98%) and 58% of cases were among 5–14 year olds.¹
- The prevalence of ARF among Aboriginal and Torres Strait Islander peoples was 75 times the rate of non-Indigenous people, while RHD was 26 times higher.¹
- One in five (20%) Aboriginal and Torres Strait Islander peoples with heart failure aged 20–54 years had a history of RHD, significantly higher than non-Indigenous people (14%).
- The death rate from RHD among Aboriginal and Torres Strait Islander peoples was five times higher than non-Indigenous people between 2004 and 2007.¹

What needs to happen?

Establish a national RHD control program with a single register covering all Australian jurisdictions.

Significant improvements in controlling this very preventable condition can be achieved by ensuring persons with suspected ARF or RHD receive guideline-based prevention, diagnosis and treatment.

To strengthen the prevention, diagnosis and treatment of RHD, a structured and adequately funded control program that covers all Australian states and territories must be promptly established. A national control program would improve adherence to treatment, clinical follow-up of patients and overall coordination of care across the continuum. The program needs to include a single national register to ensure accurate epidemiological surveillance and active monitoring of patients with ARF and RHD and should be underpinned by a national strategy covering all jurisdictions.

Maintain and strengthen state-based RHD control programs and registers.

The state and territory RHD control programs and registers identify individuals who require high-level acute care and those who need long-term treatment. They enable active follow-up and recall of patients for secondary prevention and further management, and as such play a crucial role in epidemiological surveillance. The Commonwealth Government should continue to fund the four state and territory RHD control programs, through Rheumatic Heart Disease Australia, to allow expansion of state- and territory-based registers and control programs, and development of national education and training resources.

Improve health professional capability and capacity to diagnose and manage acute rheumatic fever and rheumatic heart disease according to current clinical practice guidelines.

To strengthen the control of RHD, education strategies to improve health professional capability and capacity to diagnose and manage ARF and RHD in line with the current guidelines must be implemented. There should be a particular focus on providing an echocardiogram as early as possible.

Under the National Rheumatic Fever strategy, the National Coordinating Unit has developed clinical resources for use by health professionals to assist in the accurate and timely diagnosis of ARF and RHD. The use of these resources and guidelines should be promoted to all health professionals, particularly those who work in high-risk or endemic communities.
Improve patient, family and community awareness of the importance of adhering to treatment and ongoing management of ARF and RHD.

Secondary prevention of RHD is proven to work and is cost effective at the community and population level. It includes the administration of regular prophylactic antibiotics to those who have had an episode of ARF to prevent the development of RHD, or to those who have established RHD to prevent the progression of disease. However, poor adherence to treatment regimens remains a major challenge in Aboriginal and Torres Strait Islander communities; less than 50% of patients receive their benchmark of 80% of scheduled antibiotic treatment.

We could achieve improved adherence to medical and surgical treatments and ongoing follow-up if we provided culturally appropriate health education that promotes the importance of secondary prophylaxis in preventing recurrent ARF and the development or worsening of RHD.

What will this achieve?

- Reduction in the annual incidence and proportion of all ARF episodes among Aboriginal and Torres Strait Islander peoples.
- Increased adherence by patients to treatment and ongoing management through improved health literacy.

References