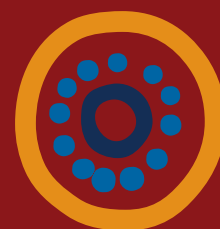


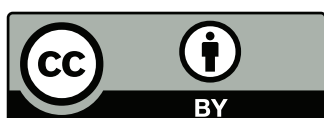
Queensland Aboriginal and Torres Strait Islander

# Rheumatic Heart Disease Action Plan 2018 – 2021



## Queensland Aboriginal And Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021

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### For more information contact:

Aboriginal and Torres Strait Islander Health Branch,  
Department of Health, GPO Box 48, Brisbane QLD 4001,  
phone 07 3708 5557 or email  
[ATSIHB\\_Corro@health.qld.gov.au](mailto:ATSIHB_Corro@health.qld.gov.au).

An electronic version of this document is available at  
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# Abbreviations

<b>AHPRA</b>	Australian Health Practitioner Regulation Agency	<b>JCU</b>	James Cook University
<b>AICCHOs</b>	Aboriginal and Islander Community Controlled Health Organisations	<b>NPA</b>	National Partnership Agreement
<b>AMAQ</b>	Australian Medical Association Queensland	<b>NWHHS</b>	North West Hospital and Health Service
<b>ARF</b>	Acute Rheumatic Fever	<b>NT</b>	Northern Territory
<b>A&amp;TSIHB</b>	Aboriginal and Torres Strait Islander Health Branch	<b>PaRROT</b>	Pathways to Rural and Remote Orientation and Training
<b>CDB</b>	Communicable Diseases Branch	<b>PHN</b>	Primary Health Network
<b>CE</b>	Chief Executives	<b>PHU</b>	Public Health Unit
<b>CED</b>	Clinical Excellence Division	<b>QAIHC</b>	Queensland Aboriginal and Islander Health Council
<b>CHHHS</b>	Cairns and Hinterland Hospital and Health Service	<b>QLD</b>	Queensland
<b>CMOHRB</b>	Chief Medical Officer and Healthcare Regulation Branch	<b>RFS</b>	Rheumatic Fever Strategy
<b>DoE</b>	Department of Education	<b>RHD</b>	Rheumatic Heart Disease
<b>GAS</b>	Group A streptococcus bacterial infection	<b>RRCSU</b>	Rural and Remote Clinical Support Unit
<b>HHS</b>	Hospital and Health Service	<b>SCCN</b>	Statewide Cardiac Clinical Network
<b>HPB</b>	Health Protection Branch	<b>T&amp;CHHS</b>	Torres and Cape Hospital and Health Service
<b>ICOP</b>	Indigenous Cardiac Outreach Program	<b>THHS</b>	Townsville Hospital and Health Service
		<b>WQPHN</b>	Western Queensland Primary Health Network

# Foreword

## Minister for Health and Minister for Ambulance Services

The *Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018–2021* sets priorities and actions that Queensland Health and its partners will take to lessen the impact of both acute rheumatic fever (ARF) and rheumatic heart disease (RHD) on Aboriginal and Torres Strait Islander people in Queensland.

Despite recent gains made in reducing the fatal burden of cardiovascular disease for Aboriginal and Torres Strait Islander people, it still remains a leading contributor to the overall burden of disease. The ongoing prevalence of ARF and RHD identifies there is still significant work to do in this area.

While this Action Plan addresses actions to improve clinical-based care for ARF and RHD it also strengthens Queensland's response in areas such as environmental health, preventative health and primary health care. As such this Action Plan has been developed in partnership with Hospital and Health Services, primary health care providers, including the Aboriginal and Torres Strait Islander Community

Controlled Health Sector, Heart Foundation (Qld), Primary Health Networks and the Commonwealth Department of Health.

I am pleased to present this Action Plan as part of the reforms under *My health, Queensland's future: Advancing health 2026* and the *Making Tracks Implementation Plan 2018–2021*.



**Hon Steven Miles MP**  
**Minister for Health and Minister for Ambulance Services**

# Introduction

**“While acute rheumatic fever has become a rare curiosity in Australia’s non-Indigenous population, its incidence in Indigenous Australians living in remote areas remains among the highest reported in the world. It is unlikely that such a stark contrast between two populations living within the same national borders exists for any other disease or on any other continent.”<sup>1</sup>**

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) illustrate the ongoing health gap between Aboriginal and Torres Strait Islander Queenslanders and non-Indigenous Queenslanders. They personify Indigenous disadvantage and the legacy of colonisation and dispossession of the last two centuries.

ARF and RHD are diseases of social injustice with the disease burden borne almost exclusively by the disadvantaged. Aboriginal and Torres Strait Islander people are significantly over-represented for people with these diseases, and this reflects that more work is required to address the broader socio-economic and health disadvantages.

While the incidence and prevalence of both ARF and RHD remain unacceptably high in Aboriginal and Torres Strait Islander Queenslanders and the challenges are many, there is much that can be done. On the pathway to eliminating ARF

and RHD, it is critically important to ensure that people with, or at risk of, these diseases receive optimal treatment and management, preventive care, information to support them and their carers, and co-ordination of care.

This Action Plan seeks to build on the collective will and commitment of the entire health system to improve the response which will be a significant step forward in reducing the number of people with ARF and RHD.

It is acknowledged that ARF and RHD also disproportionately affect the Māori, Pacific Islander and refugee populations of Queensland. While this Action Plan is directed towards Aboriginal and Torres Strait Islander people and the care they receive, it is anticipated that implementation of relevant elements of this Action Plan will have a positive effect on all people impacted by ARF and RHD.

# Patrick Wasiu's story

**Patrick's story of Acute Rheumatic Fever and Rheumatic Heart Disease is one of strength and resilience, highlighting the need to raise awareness, to protect future generations from needlessly following the same path.**

Born in Cairns, Patrick is a Torres Strait Islander who grew up in Bamaga in the Northern Peninsula Area of mainland Australia. This is one of the most remote locations in Queensland. With a population of around 2000, they are the original descendants of Saibai Island which is closer to Papua New Guinea than mainland Australia. Growing up the important things in life were family and culture. Swimming in the local creek and living with his large extended family was "all the norm" for Patrick's early years. This was the community lifestyle in the Islands.

Like most people in Australia, Patrick and his family knew little about Acute Rheumatic Fever and Rheumatic Heart Disease. It was not something that you heard about or talked about. Common illnesses such as a sore throat and skin sores were seen to be a part of growing up and not a cause of too much concern. Like most families, you just went to the doctor to get patched up and then got on with life. Patrick and his family did not know these were signs of Acute Rheumatic Fever.

At a young age, when Patrick and his family moved to Bamaga, that's when he first heard the words "Acute Rheumatic Fever" and "Rheumatic Heart Disease". The term "holes in your heart" was a more often term used to describe it. Patrick and his family knew little of these conditions or how serious they could be, and there were very few resources available to help them to learn more.

Growing up Patrick developed Acute Rheumatic Fever and got really sick. Patrick remembers his mum "wrapping him in cotton wool" and not letting him join in sporting activities, school trips and social events because of his health and he was seen as different and a sick kid, leading to constant bullying and name calling as he was growing up. This was a particularly challenging time for Patrick who, as the eldest of his siblings, had additional responsibilities in his family.

Growing up, Patrick needed to take antibiotics every day to stop his heart from being permanently damaged. He thought hospitals

"I now know that if a child or adolescent shows signs of school sores, sore throat, fever or aching joints take them to the local health clinic to be checked for Acute Rheumatic Fever. ...Every child, family, teacher, health worker, and health professional needs to know this message".



were places of death, where people go to die, so being told he had to fly to the hospital in Cairns for treatment had him wondering “am I going to live?” But it wasn’t only the thought of going to hospital, Cairns is approximately 1,000 kilometres away from Patrick’s home. The prospect of spending a long time away from his dad and siblings was hard. Although Patrick’s mum was able to travel with him, and the hospital staff were very friendly, it was a very tough time for him and his family to be so far apart.

In Grade 7, doctors told Patrick that his Acute Rheumatic Fever had caused Rheumatic Heart Disease – he now had permanent damage to his heart. As a young man he now had to live with this for the rest of his life.

Management of Rheumatic Heart Disease is through regular antibiotic injections. Extremely painful and needing to be administered every 28 days, it is a very difficult task for any adult let alone a young person only just reaching their teens. Patrick will never forget the injections, and the trauma of one experience that saw him admitted to the Intensive Care Unit, stays with him today.


At the age of 20, Patrick received the news from doctors that the Rheumatic Heart Disease had worsened, and his heart valves were now severely damaged. His cardiologist told him that he needed to have open heart surgery, or he might not live to the age of 23. As frightening and daunting as this was, Patrick knew it was best for him.

Undergoing surgery in Townsville, Patrick recalls that his positive emotional frame of



“Although it is hard, if you have RHD it is critical you take warfarin daily and penicillin antibiotic injections every 28 days.”

mind helped him through the surgery and the extensive recovery phase. From the hundreds of health professionals Patrick has seen in his life, he recalls the special bond he formed with his cardiologist while in hospital. Being far from home, alone and recovering from major surgery, this was one of the key things that kept him positive.



**“When dealing with Indigenous patients, you must remember you are not only dealing with their physical health but also their spiritual, mental and emotional health.”**

.....

**“A positive emotional frame of mind and never giving up helped me through my surgery and recovery phase.”**

Now in his 30s, Patrick’s journey with Rheumatic Heart Disease continues. It has been far from easy, and he has spent many months in hospital over the years, including two long stays in the Intensive Care Unit. But Patrick takes strength and inspiration from his mum, aunties, uncles and cousins he grew up with and his grandparents memories and their motto of “never give up”.

Now, more than 15 years since his open heart surgery, Patrick takes medication regularly including warfarin and penicillin so that his heart remains stable.

As an Indigenous Health Worker in the Cape, Patrick spends much of his time spreading the word about the lifestyle risks for Acute Rheumatic Fever and Rheumatic Heart Disease. As a role model in his community he helps

other families with children who have Acute Rheumatic Fever and Rheumatic Heart Disease to understand what it means, and to know they are not alone.

Patrick is passionate about raising awareness about Acute Rheumatic Fever and Rheumatic Heart Disease. He believes that early education for families so they can pick up the early signs of Acute Rheumatic Fever are the key and had they been available when he was growing up, his life might be quite different.

Patrick’s story is one of inspiration and resilience. He is now able to enjoy his favourite pastime of fishing. He is also very passionate about being healthy and looking after yourself. He enjoys playing different sports and still does his traditional Torres Strait Island dancing which keeps him fit.

# Rationale

**Despite ongoing efforts, the incidence and prevalence of ARF and RHD in Queensland remain high. This Action Plan will complement the national Rheumatic Fever Strategy and will incorporate primordial, primary, secondary and tertiary prevention strategies to assist in reducing the rate of Aboriginal and Torres Strait Islander Queenslanders with ARF and RHD.**

The Action Plan looks to strengthen the connections between the different parts of the health system, increase awareness of best practice care and share information to support better coordinated care for the patient. In addition, the Action Plan will work to address group A streptococcus (GAS) bacterial infections and subsequent ARF to reduce the number of patients burdened by these conditions. The Rheumatic Heart Disease (RHD) Register will also be enhanced to assist health services so that more patients receive appropriate care, including their required Bicillin injections.

## Consultation to inform this Action Plan

To develop a comprehensive and inclusive approach to ARF and RHD in Queensland, extensive consultation was undertaken. This included four Steering Committee Meetings and direct consultation with other key stakeholders.

Organisations and key people consulted include:

- Hospital and Health Service (HHS) clinical and executive staff, including staff from cardiology, environmental health, nursing and Aboriginal and Torres Strait Islander health disciplines

- the Department of Health's Communicable Diseases Branch, Health Protection Branch, Clinical Excellence Division, Statewide Cardiac Clinical Network and eHealth Queensland
- the Aboriginal and Torres Strait Islander Community Controlled Health Sector, including the Queensland Aboriginal and Islander Health Council (QAIHC) and individual Aboriginal and Islander Community Controlled Health Organisations (AICCHOs)
- Queensland's seven Primary Health Networks
- Commonwealth Department of Health
- the Australian Medical Association Queensland (AMAQ)
- the Heart Foundation (Queensland)
- the Department of Education
- relevant academic and clinical experts in the fields of Aboriginal and Torres Strait Islander health, ARF and RHD.

Feedback was provided by a broad range of interested parties and Queensland Health is appreciative of their ideas, contributions and support provided in the submissions received.

# Our shared priorities

**Five priority areas** were identified to address ARF and RHD among Aboriginal and Torres Strait Islander Queenslanders:



## **Promote, prevent, empower**

Ensure patients have the information they need and enable them to make the best decisions on their health.



## **Improve the patient experience**

Provide patients with a comfortable clinical experience, coordinated streamlined service delivery and positive engagement with health care providers.



## **Strengthen the approach**

Work cohesively to establish new relationships and partnerships with health service providers, and build on existing ones.



## **Foster clinical knowledge**

Enable health professionals to appropriately prevent, diagnose and manage ARF and RHD.



## **Enhance the Queensland RHD Register and Control Program**

Enable the Register to fully meet the needs of patients, other stakeholders and the requirements of the RFS and this Action Plan.

## Implementation of the Action Plan

**The priority areas will be addressed by implementing specific actions. These actions are listed for ease of reference, on the following pages.**

Each action has an associated description, proposed time frame for completion and the group(s) responsible for the implementation of the action. Under each action, the group(s) listed in bold text have primary responsibility for ensuring the action is undertaken.

## Governance

**The implementation of this Action Plan will be oversighted by a Rheumatic Heart Disease Action Plan Governance Committee.**

The Governance Committee will be jointly chaired by the Director of Cardiology and the Director of Public Health from the Cairns and Hinterland HHS. Secretariat support will be provided to assist in the oversight of the Action Plan and Governance Committee.

# Background

## ARF and RHD: what are they and how are they treated?

### Acute rheumatic fever (ARF)

ARF is an autoimmune response to a group A streptococcus (GAS) bacterial infection. GAS can be spread from person to person by large respiratory droplets, for example via sneezing, or direct contact with people infected by the bacteria. People who live in poor quality housing or overcrowded environments are at higher risk of GAS infections. Infections with GAS can lead to symptoms of sore throats (pharyngitis) and skin infections (impetigo). If left untreated or inadequately treated, GAS infections can progress to ARF.<sup>1,2</sup>

ARF can lead to symptoms such as fever, joint pain and rashes as well as affecting the heart, joints, brain and skin. The damage to the heart can be long lasting.<sup>3</sup> The age group at greatest risk for ARF is children aged 5–19.

The diagnosis of ARF can be complex with symptoms of ARF non-specific to the infection. Diagnosis of ARF is based on an assessment of symptoms combined with the individual's clinical history rather than a diagnostic test. Due to the clinical intricacies of diagnosis, misdiagnosis can and does occur.

As an autoimmune disease ARF is not spread from person to person but it is possible for patients with ARF to have repeated episodes leading to increased risk of progression to RHD. The incidence rate of recurrent ARF is greatest in the first year after the first episode of ARF (3.72 per 100 person-years, compared to 1.31 per 100 person-years at 5–10 years since diagnosis).<sup>4</sup>

### Rheumatic heart disease (RHD)

RHD occurs when untreated, recurrent episodes of ARF cause a valvular inflammatory response predominantly damaging the mitral and aortic valves of the heart.<sup>5</sup> This condition is diagnosed using echocardiography, which is also used for the ongoing monitoring of disease progression and valvular damage. A recent Northern Territory (NT) study of patients on the NT Register identified the cumulative incidence of progression to RHD after the first episode of ARF is 27.1% at 1 year, 44.0% at 5 years, and 51.9% at 10 years.<sup>4</sup>

Complications of RHD include atrial fibrillation, stroke and heart failure. Those burdened with RHD often require surgery and have a lower life expectancy.<sup>6,7</sup>

Pregnant women with RHD are at risk of further complications as the increase of blood volume during pregnancy can worsen the effects of pre-existing valvular disease.

In Queensland, ARF and RHD are key contributors to poor cardiovascular health in Aboriginal and Torres Strait Islander children and young adults. The drivers for onset of ARF and RHD are principally poor social determinants which differs from ischaemic heart disease which is principally linked to lifestyle choices.

## ARF and RHD treatment

With appropriate support and monitoring, ARF and RHD are manageable diseases. Historically there have been multiple challenges of access, transition between services, and long-term commitment, which have led to poor compliance with treatment and patients being lost to the system.

To prevent recurrent episodes of ARF, patients with ARF and RHD require frequent prophylactic treatment with penicillin antibiotics, for at least ten years.

Benzathine penicillin G (Bicillin) is the medication most commonly used and is given as an intramuscular injection at least every four weeks administered in the buttocks or thighs. These injections cause discomfort and can be extremely painful and distressing, particularly for children. Due to the extent of the treatment required, Bicillin uptake is low.

In addition to this prophylactic treatment, patients require regular echocardiography monitoring and specialist (cardiologist) review to detect or monitor the progression of RHD.

When RHD causes significant damage to the heart, heart failure may develop requiring complex heart failure therapy. In some instances surgical interventions are required. These include valvular repair or valvular replacement

by open-heart surgery. These surgeries can only be offered in major tertiary health centres often away from family and community.<sup>3</sup>

Surgery does not signify the end of the disease process. Following surgery, patients will require ongoing cardiology review and maintenance of Bicillin injections and in many cases daily anticoagulant therapy, which involves regular blood tests and monitoring.

### The importance of Bicillin, in the ongoing management of ARF and RHD

Studies have shown that regular penicillin is beneficial in the prevention of recurrent ARF, and that intramuscular injections with Bicillin are superior to oral penicillin in the reduction of recurrent ARF and RHD including the reduction of mortality.<sup>3</sup>



## Acute Rheumatic Fever and Rheumatic Heart Disease in Queensland

ARF is a notifiable disease in Queensland as per the *Public Health Act* (2005) and the *Public Health Regulation* (2005). It is also notifiable in the Northern Territory, Western Australia, South Australia and New South Wales. ARF is a notifiable condition on clinical diagnosis.<sup>8,9</sup> All cases of ARF must be notified to the local Public Health Unit (PHU) by the diagnosing clinician.

Unlike most other notifiable conditions, such as measles and whooping cough, ARF is not

diagnosed or notified through pathology testing. Therefore the notification of the condition relies purely on the clinician and their capacity to diagnose ARF. Due to the complexities of diagnosis, misdiagnosis can occur and as a result clinicians sometimes do not make the appropriate notification to their PHU, and more importantly, do then not develop an appropriate ongoing care strategy for their patient.

RHD is a notifiable condition in Western Australia and South Australia, and in New South Wales for people under 35 years of age. At the time of writing, RHD is not a notifiable condition in Queensland, however there is work underway to assess the need and benefit of including RHD as a notifiable condition here.

### Queensland ARF and RHD Snapshot

Source: Queensland RHD Register and Control Program as at 1 July 2017

The median age of onset for ARF is **12 years** for both Indigenous and non-Indigenous Queenslanders (RHD Register Data).

Between 1999 and 30 June 2017, there were **1,151 notifications** of ARF in Queensland of which **1,018 (88%)** were for Aboriginal and Torres Strait Islander Queenslanders.

There are **1,055 Aboriginal and Torres Strait Islander Queenslanders with RHD** currently listed on the Queensland RHD Register. The rates of RHD across the state are depicted in **Table 1**.



**Table 1: Rates of Aboriginal and Torres Strait Islander patients on the Queensland RHD Register with RHD, by Hospital and Health Service**

**Rates per 100,000 Aboriginal and Torres Strait Islander population**

Cairns and Hinterland	892
Central Queensland	159
Central West	375
Darling Downs	245
Gold Coast	21
Mackay	65
Metro North	43
Metro South	66
North West	1,996
South West	111
Sunshine Coast	12
Torres and Cape	2,028
Townsville	672
West Moreton	52
Wide Bay	42
Queensland	507

(As at 1 July, 2017. Source: Queensland RHD Register and Control Program. Rates calculated using the 2015 estimated residential population, Australian Institute of Health and Welfare)

As the data in Table 1 demonstrates, the current known burden of ARF and RHD is principally within North, Far North and North West Queensland and therefore these regions should remain a priority for efforts to address ARF and RHD.

It is important to note that in looking at other locations in Queensland, recent clinical audits indicate that clients outside the northern areas of the State are less likely to be linked to the RHD Register, and subsequently are underrepresented in this snapshot. It is important to build awareness of ARF and RHD and appropriate client care, including linking to the RHD Register, across all parts of the State to understand the full statewide picture and ensure that all patients are supported to receive the best care.

## Rheumatic Fever Strategy

In 2009, the Australian Government developed the Rheumatic Fever Strategy (RFS). This is a National Partnership Agreement (NPA) between the Australian Government and the governments of Queensland, Western Australia, Northern Territory, and later, South Australia. The aim of the RFS is to improve detection, monitoring and management of ARF and RHD.<sup>10</sup>

In its 2017–18 budget, the Australian Government announced the continuation and expansion of the NPA.<sup>11</sup> The expansion will include additional funding for focused prevention activities in high-risk communities.<sup>11</sup>

## Queensland RHD Register and Control Program

**The Queensland RHD Register and Control Program (RHD Register) is an initiative funded predominantly by the Commonwealth Government, under the RFS, and supplemented by Queensland Health. The RHD Register is hosted by the Cairns and Hinterland Hospital and Health Service (CHHHS).**

**The RHD Register aims to improve detection, monitoring and management of ARF and RHD including in Aboriginal and Torres Strait Islander communities. The key roles of the RHD Register are:**

implementation and maintenance of a dedicated statewide patient register and recall system for ARF and RHD

improvement of clinical care including improved delivery of and adherence to secondary antibiotic prophylaxis

provision of education and training for health care providers, individuals, families and communities

collection and provision of data for national monitoring and reporting and measuring program effectiveness in the detection and management of ARF and RHD.



**The RHD Register is a statewide service. Activities undertaken by the RHD Register include:**

statewide monitoring of the presence and system management of ARF and RHD

providing education for health staff

providing advice and support to clients and family members in conjunction with local health service staff

providing advice on treatment requirements for patients

developing educational and promotional materials and resources

building capacity in local communities and health service facilities.

The RHD Register is not directly responsible for the provision of client care, but supports local health services, primary and acute, in the translation of best practice and guideline-based care.

The RHD Register stores ARF notification data and, with patient consent, also records the details of patients with RHD, and the progress of the patient's medical management. This information is used to support patient recall. The success of this relies to a significant extent on local clinicians providing accurate and up to date information on their patients to the RHD Register.

The RHD Register is also responsible for monitoring the incidences of ARF and RHD in Queensland, and reporting on Queensland's health system performance in the management of clients.

# 1

## Promote, prevent, empower

ARF and RHD awareness among patients, families and communities is key in the early intervention and diagnosis of these conditions. This knowledge will lead to activities and behaviours that can help prevent ARF and RHD.

**The following actions will better equip Aboriginal and Torres Strait Islander Queenslanders to approach their health and wellbeing.**

### Our focus

Empower patients and communities to lead healthy lives.

Increase community awareness of ARF and RHD by providing the community with resources, including educational resources.

Prevent new cases of ARF through primordial prevention strategies, including addressing the environmental health risk factors that contribute to ARF and RHD.

### Current actions

These actions will remain in place and will be strengthened over the duration of the Action Plan.

Collaborate with communities to identify if current educational resources can be improved by translating into local Indigenous languages.

**AICCHOs**, RHD Register

Provide culturally appropriate educational material on sore throats, skin sores and ARF through a variety of media platforms.

**RHD Register**, HHS PHUs, Heart Foundation (Qld), RHD Australia

Continue the 'Reward and Recognition' strategy for patients with 100% uptake of their Bicillin injections.

**RHD Register**

## Targeted actions

<p>Undertake additional school and family based education in areas of high risk, in partnership with the Department of Education (DoE).</p> <p><b>RHD Register</b>, Health Workers, DoE</p>	<p>This action will educate students and their teachers on sore throats and skin infections, how they may lead to ARF and RHD and the importance of going to the clinic when unwell.</p>	<p>Duration of the plan</p>
<p>Develop and distribute patient stories on living with ARF and RHD.</p> <p><b>Heart Foundation (Qld)</b>, A&amp;TSIHB, RHD Register</p>	<p>Providing success stories of Aboriginal and Torres Strait Islander patients who are undergoing, or have completed, treatment can demonstrate that a positive outcome is possible for patients.</p>	<p>June 2019</p>
<p>Develop an Aboriginal and Torres Strait Islander Environmental Health Plan.</p> <p><b>HPB</b>, A&amp;TSIHB</p>	<p>The Environmental Health Plan will outline how the Department of Health can support healthy living environments.</p>	<p>July 2018</p>
<p>Establish a clinical referral system so that patients are referred to local environmental health services and/or staff.</p> <p><b>HPB</b>, HHSs, RHD Register</p>	<p>This action will work to minimise the risk of spread and reinfection of GAS within a patient's home.</p>	<p>December 2019</p>
<p>Work with social housing providers to identify home environment risk factors that contribute to cases of ARF and RHD.</p> <p><b>HPB</b>, Environmental Health Workers, A&amp;TSIHB</p>	<p>This will build an understanding of the impact of the home environment on health outcomes.</p>	<p>Duration of the plan</p>

## 2

# Improve the patient experience

Patients and their carers should have positive experiences during their visits to health care facilities. Given the long-term nature of ARF and RHD management, it is particularly important that health services are culturally appropriate, accessible and efficient for Aboriginal and Torres Strait Islander patients. **These actions are about better linking the patient journey within and between various parts of the health system.**

This focus area will be in line with the *Specialist Outpatient Strategy: Improving the patient journey by 2020*, which aims to improve the patient's whole journey from general practitioner referral to outpatient procedure and any required intervention.

## Our focus

Ensure patients have a positive experience and are treated with cultural respect during their visit to their health care provider.

Enhance the health care workforce.

Focus on the needs of patients in rural and remote areas, given the high burden of disease.

## Current actions

These actions will remain in place and will be strengthened over the duration of the Action Plan.

Improve training for staff who manage patients, including providing Bicillin injections, to be able to do so in a safe, culturally appropriate manner, minimising discomfort to the patient.

**RHD Register, RHD Australia**

Primary health care services to provide home-based Bicillin injections where appropriate.

**Primary health care service providers**

Amend legislation to enable Aboriginal and Torres Strait Islander Health Practitioners, registered as such under AHPRA, to administer relevant medications as per the *Health (Drugs and Poisons) Regulation 1996*.

**Workforce Strategy Branch, CMOHRB**

Work with HHSs to increase the number of Aboriginal and Torres Strait Islander Health Practitioners (registered as such under AHPRA) to be employed within Queensland Health.

**Workforce Strategy Branch**

Ensure cardiac outreach services, including echocardiography, have a focus on supporting clients with ARF and/or RHD when providing services to rural and remote areas.

**CHHS – Cardiology, SCCN, ICOP, RHD Register**

Increase the use and reach of Telehealth specialist services in rural and remote locations.

**CHHS – Cardiology, SCCN**

## Targeted actions

<p>Use data to inform the resources required to undertake primary prevention activities in high-risk communities as per the Rheumatic Fever Strategy.</p> <p><b>A&amp;TSIHB, RHD Register</b>, Commonwealth Department of Health, QAIHC</p>	<p>Undertake ARF and RHD data analysis to identify communities at high-risk of these conditions. This will inform where prevention activities are best placed to occur.</p>	<p>December 2018</p>
<p>Provide support and an expert level of healthcare co-ordination to patients with ARF and RHD in high-risk areas.</p> <p><b>CHHS – Cardiology, THHS-Cardiology, SCCN</b></p>	<p>New Nurse Navigator positions will facilitate effective patient-centred care by enhancing systems integration, reducing fragmentation and barriers and establishing a personalised care pathway. These positions will be established in selected tertiary hospitals.</p>	<p>Duration of the plan</p>
<p>Develop and implement an ARF/RHD Discharge Plan document for hospitalised patients that can be used in public hospitals statewide.</p> <p><b>CHHS – Cardiology, SCCN</b></p>	<p>The ARF/RHD Discharge Plan will provide information for the patient on ARF and RHD and outline the dates for next Bicillin, echocardiography and specialist outpatient appointments.</p>	<p>December 2018</p>
<p>Develop and implement statewide service directory pathways.</p> <p><b>CED, RHD Register, RHDAustralia, SCCN, HealthPathways</b></p>	<p>Engage HealthPathways to ensure GPs are aware of appropriate specialists and referral pathways.</p>	<p>December 2019</p>



<p>Facilitate patients to have shared cardiology care during the transition from paediatric to adult medicine.</p> <p><b>CHHHS – Cardiology, SCCN</b></p>	<p>Patients will be offered shared cardiology care for one year to reduce the number of patients lost to follow up.</p>	<p>Ongoing activity</p>
<p>Ensure that any echocardiograph indicative of RHD is reviewed by a cardiologist.</p> <p><b>CHHHS – Cardiology, SCCN, RHD Register</b></p>	<p>Develop a pathway to ensure that possible cases of RHD (identified through echocardiograph) are reviewed by a cardiologist. This will allow prompt diagnosis of RHD.</p>	<p>December 2018</p>
<p>Improve the interoperability between the Queensland Cardiac Outcomes Registry (QCOR) and the RHD Register to support improved reporting via QCOR on ARF/RHD patient outcomes.</p> <p><b>RHD Register, CHHHS – Cardiology, SCCN,</b></p>	<p>This action will support improved reporting via QCOR on ARF/RHD patient outcomes.</p>	<p>December 2018</p>

# 3

## Strengthen the approach

Addressing ARF and RHD in Aboriginal and Torres Strait Islander Queenslanders requires a coordinated multijurisdictional approach.

**It is important to build these linkages across the health system to strengthen a whole of system response and better support integrated patient care.**

### Our focus

**Build on existing relationships between key partners and relevant stakeholders. This specifically includes improving engagement between the Commonwealth and Queensland Departments of Health, the RHD Register, HHSs, AICCHOs, primary health care providers, Primary Health Networks (PHNs), community-based organisations, community leaders, community members and patients.**

**HHSs to develop a localised strategic response to target ARF and RHD in their areas.**

## Targeted actions

<p>Develop regional service plans to support actions to prevent, treat and manage ARF and RHD among Aboriginal and Torres Strait Islander people within HHS areas.</p> <p><b>HHS CEs, QAIHC, AICCHOs, PHNs, Community Health Services</b></p>	<p>To enable implementation of this Action Plan, each HHS will be required to develop a regional service plan in partnership with other health services.</p>	<p>NWHHS, T&amp;CHHS, CHHHS, THHS January 2019; Other HHSs July 2020</p>
<p>Support AICCHOs in high risk areas to deliver guideline-based management of clients with ARF and RHD and to ensure strong linkages with health services and the RHD Register.</p> <p><b>QAIHC</b></p>	<p>This action, coordinated by QAIHC, will improve linkages between the RHD Register and AICCHOs to support improved patient care in line with guidelines.<sup>3</sup></p>	<p>Duration of the plan</p>
<p>The Queensland Aboriginal and Torres Strait Islander Health Partnership to include implementation of the Action Plan as a standing agenda item for meetings.</p> <p><b>QAIHC, Queensland Health, Commonwealth Department of Health</b></p>	<p>This will enable learnings to be shared across the health system and for key partners to work cooperatively to address system barriers.</p>	<p>Duration of the plan</p>
<p>Assess the option of including RHD in the list of notifiable conditions under the <i>Public Health Regulation 2005</i>.</p> <p><b>CDB</b></p>	<p>Making RHD a notifiable condition in Queensland would improve reporting of the disease, potentially leading to increased patient engagement and better health outcomes.</p>	<p>July 2018</p>
<p>Establish a Governance Committee to review, monitor and drive the implementation of this Action Plan</p> <p><b>CHHHS - Cardiology and Public Health Units</b></p>	<p>The Governance Committee will be jointly chaired by a nominated Cardiologist and a nominated Public Health Physician. A secretariat will be established to assist with the administrative requirements of the Governance Committee.</p>	<p>Duration of the plan</p>

# 4

## Foster clinical knowledge

ARF and RHD have complicated disease processes that can be difficult for patients, caregivers and clinicians to understand. By ensuring health professionals have the best possible understanding of ARF and RHD we can **maximise prevention, diagnosis and treatment for Aboriginal and Torres Strait Islander patients** across all parts of Queensland.

### Our focus

Ensure clinicians are aware of ARF and RHD prevention, treatment and management requirements as per current clinical guidelines (the *Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease*, the *Primary Clinical Care Manual*, and the *Chronic Conditions Manual*).

Maintain relevant clinical guidelines to ensure patients are receiving evidence-based management.

Ensure clinicians recognise that women who are pregnant are at high risk of complications should they have ARF and/or RHD.

Reduce the progression of ARF through investigation and appropriate treatment of sore throats and skin sores in high-risk patients.

### Current actions

These actions will remain in place and will be strengthened over the duration of the Action Plan.

Ensure ARF and RHD data is readily accessible through Queensland Health notifiable conditions reports and/or the annual Closing the Gap report.

**A&TSIHB, CDB, RHD Register**

Routinely provide education to clinicians who work in key entry points to the hospital and other acute care services including emergency, obstetrics and gynaecology and outpatient departments as well as community health services.

**RHD Register, HHS Directors of Medical Education**

Conduct hospital-based Grand Rounds presentations to secondary and tertiary hospitals.

**RHD Register, SCCN**

Conduct routine primary healthcare provider education in line with national guidelines.

**PHNs, RHD Register, SCCN**

Provide education workshops for Aboriginal and Torres Strait Islander health workers on the management of ARF and RHD.

**RHD Register**

Engage with Queensland universities and specialist medical colleges annually to review the curriculum and education material presented to medical students on ARF and RHD and Aboriginal and Torres Strait Islander health.

**RHDAustralia, RHD Register**

Conduct biennial reviews of the Primary Clinical Care Manual and the Chronic Conditions Manual to ensure that they align with national guidelines.

**RRCSU**

## Targeted actions

Make training resources available prior to rural and remote secondments through the Pathways to Rural and Remote Orientation and Training (PaRROT).

**RRCSU**

Training clinicians prior to secondment will arm them with the knowledge required to address ARF and RHD. PaRROT will link in with RHDAustralia resources to enable this action.

December 2018

Ensure appropriate clinical policies and procedures are in place for:

- management of ARF and RHD during pregnancy
- presentation of ARF and RHD in Emergency Departments.

**Hospital and Health Services**

This will ensure appropriate clinical direction is available for HHS staff to support appropriate provision of care in line with national guidelines.

December 2018



# Enhance the Queensland RHD Register and Control Program

The key priorities of the RHD Register are to improve the detection, monitoring and management of ARF and RHD in Aboriginal and Torres Strait Islander people and other high-risk population groups. In addition, the RHD Register manages the data collection and surveillance system for patients with ARF and RHD.

**Having an efficient, well-resourced RHD Register will support Queensland in delivering an enhanced statewide framework to address ARF and RHD.**

## Our focus

**Augment the governance and functional capacities of the RHD Register to ensure the requirements set out in this Action Plan and the Rheumatic Fever Strategy are met.**

**Further improve the existing ARF and RHD data collection and surveillance system to drive continuous improvement in patient care, coordination, research, policy and practice.**

**Ensure treating clinicians have access to patient history and management information.**

**Improve the capacity of the RHD Register to ensure that data collection and surveillance is accurate and up to date.**

## Current actions

These actions will remain in place and will be strengthened over the duration of the Action Plan.

Provide education to clinicians and PHUs on the mechanisms and requirements of making a notification of ARF under the *Public Health Act (2005)*.

**CDB, RHD Register, PHUs**

## Targeted Actions

<p>Enable the RHD Register by incorporating a Public Health Physician role into the program.</p> <p><b>CHHS, A&amp;TSIHB, CDB</b></p>	<p>This clinical leadership position will enable the RHD Register to meet the objectives set by this Action Plan and the RFS.</p>	<p>December 2018</p>
<p>Enhance data management capabilities of the RHD Register by incorporating a Data Manager role into the program.</p> <p><b>RHD Register, A&amp;TSIHB, CDB</b></p>	<p>This position will enable the RHD Register to maintain and improve the data surveillance system to ensure that accurate and timely data is available.</p>	<p>September 2018</p>
<p>Increase the interoperability of the RHD Register to enable sharing of client information between health systems and services.</p> <p><b>RHD Register, eHealth</b></p>	<p>Allowing treating clinicians to directly review patient information, including where possible non-Queensland Health clinicians, will assist patients to receive the treatment they require. In addition, this will facilitate the streamlining of reporting on client management to the RHD Register.</p>	<p>June 2021</p>



# Monitoring and Evaluation

The Aboriginal and Torres Strait Islander Health Branch will support reporting against the implementation of this Action Plan each year through the inclusion of an update as part of its annual published *Closing the Gap* report.

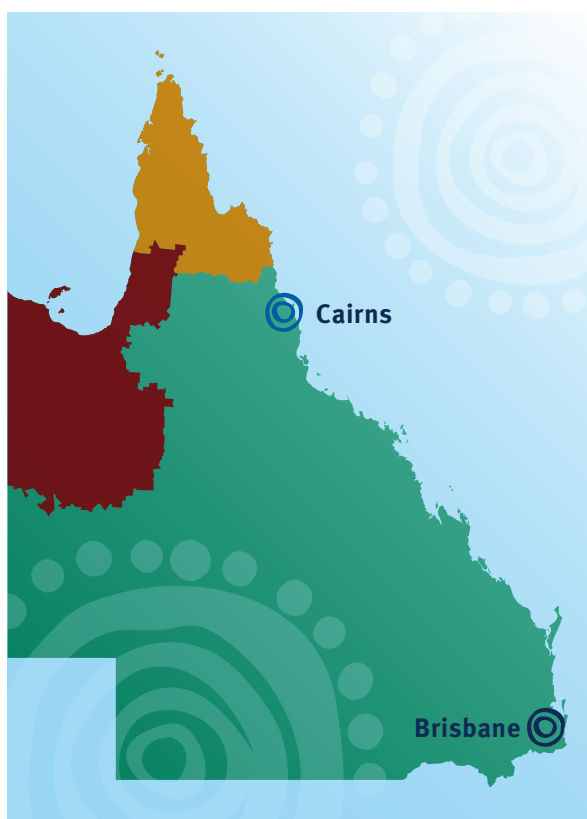
This update will include a summary of progress against each of the actions as well as monitoring against the key system performance indicators. The review and assessment of additional performance indicators will be undertaken by the Governance Committee.

Measure	Frequency
Number of patients with 100% compliance over 12 months	Annual
Number of ARF notifications (confirmed, probable and possible)	
Number of new RHD cases	
Percentage uptake of Bicillin injections	
Number of patients overdue for echocardiogram	
Number of clients on waitlist for echocardiogram	
Number of Aboriginal and Torres Strait Islander Health Practitioners employed within Queensland Health	

Indicators for success
<p><b>Increase compliance with ARF and RHD management</b></p> <p>Increase the proportion of clients compliant with Bicillin</p> <p>Increase the proportion of clients with on time echocardiograms</p>
<p><b>Progressively reduce the incidence of ARF and RHD</b></p> <p>Reduce the incidence of ARF</p> <p>Reduce the rate of clients progressing to moderate or severe RHD, including both children and adults</p>
<p><b>Improve the notification of ARF and RHD</b></p> <p>As measured by the number of missed cases of ARF or RHD reported through enhanced surveillance</p>



# Current initiatives



## ● North West Queensland

The North West Hospital and Health Service (NWHHS), together with James Cook University (JCU) and the Western Queensland PHN (WQPHN), are developing evidence based approaches to support clinical guidelines for general practices. The aim is to improve the sensitivity and assessment of ARF and RHD risk factors in presenting patients.

## ● North West Queensland

The NWHHS is delivering a Healthy Skin Indigenous Infection, Prevention and Control Program. The purpose of this project is to deliver an outpatient community care program to improve the early detection, prevention and treatment of pathogens causing skin infections to reduce the current mortality and morbidity rates of Aboriginal and Torres Strait Islander people associated with skin related infections.

## ◎ Brisbane

Metro South HHS is implementing a RHD Prevention and Control Program. This program will include a clinical care coordination role that is working with the Brisbane South PHN, general practitioners and local communities.

## ◎ Cairns

The RHD Register and Control Program is developing a Health Worker training module on ARF and RHD diagnosis, management and prevention. This module will be implemented for Aboriginal and Torres Strait Islander Health Workers across Queensland.

## ● Torres and Cape

The Torres and Cape HHS has successfully developed a clinical procedure to provide guidance in administering Entonox® (pre-mixed nitrous oxide) for a short duration to reduce procedural pain and anxiety reduction during the administration of Benzathine Penicillin (Bicillin) where use of other pain relief and stress reduction techniques has failed.

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