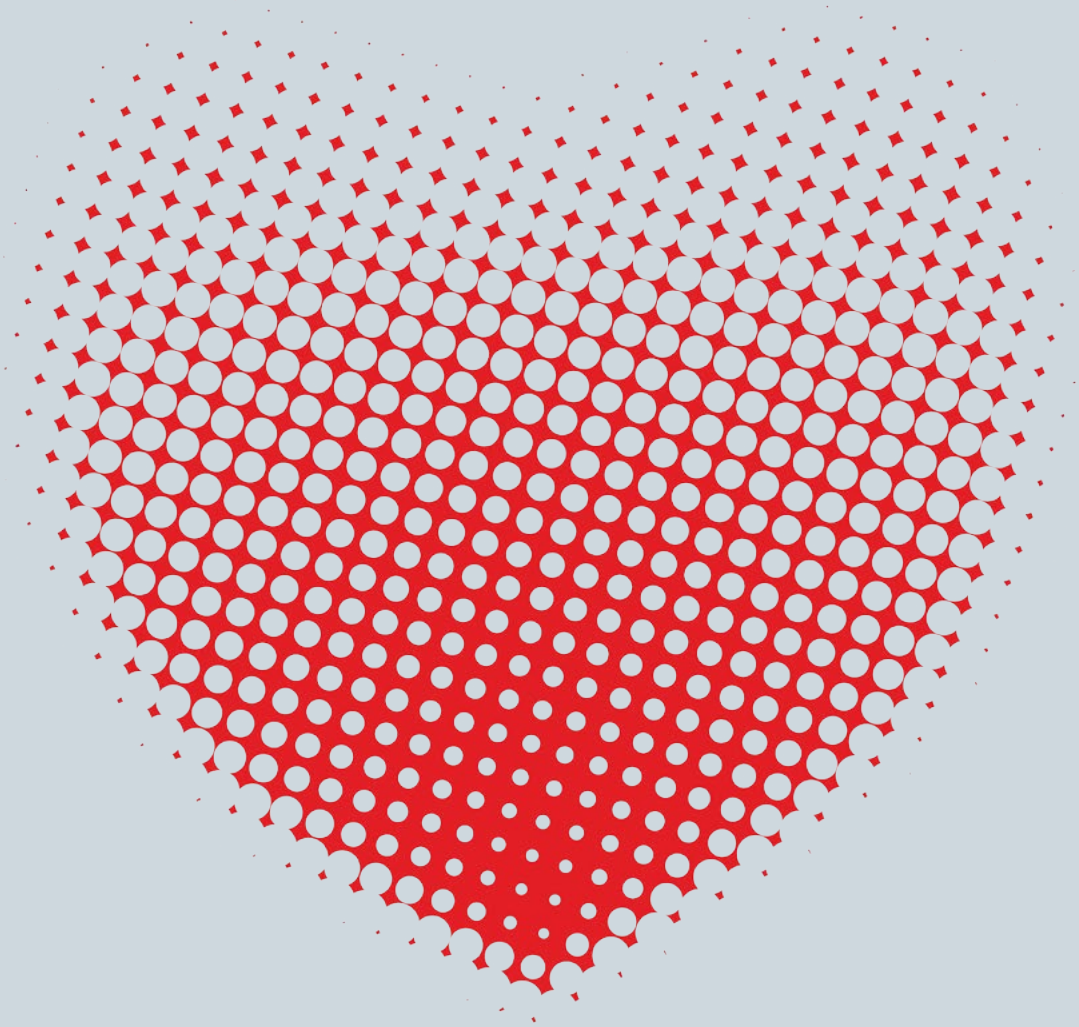
ACI NSW Agency for Clinical Innovation

FRAMEWORK

Acute Rheumatic Fever and Rheumatic Heart Disease in NSW

Chronic Care for Aboriginal People



Collaboration. Innovation. Better Healthcare.

The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this through:

- *service redesign and evaluation* – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services
- *specialist advice on healthcare innovation* – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment
- *initiatives including Guidelines and Models of Care* – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system
- *implementation support* – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW
- *knowledge sharing* – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement
- *continuous capability building* – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A key priority for the ACI is identifying unwarranted variation in clinical practice. ACI teams work in partnership with healthcare providers to develop mechanisms aimed at reducing unwarranted variation and improving clinical practice and patient care.

www.aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building
67 Albert Avenue
Chatswood NSW 2067

PO Box 699 Chatswood NSW 2057
T +61 2 9464 4666 | F +61 2 9464 4728
E aci-info@health.nsw.gov.au | www.aci.health.nsw.gov.au

SHPN (ACI) 150063, ISBN 978-1-76000-138-4.

Produced by: Chronic Care for Aboriginal People

Further copies of this publication can be obtained from
the Agency for Clinical Innovation website at *www.aci.health.nsw.gov.au*

Version: V1.7

Trim: ACI/D17/517

Date Amended: June 2017

Acknowledgments

This document is based on guidance from RHDAustralia and was developed in collaboration with the NSW Ministry of Health, Health Protection NSW and Cox Inall Ridgeway. Acknowledgments also go to a wide group of stakeholders including local health districts, the Aboriginal Health & Medical Research Council, Aboriginal community controlled health services, the Heart Foundation and primary health networks.

The artwork is called 'Baalee'. It is inspired by the original artwork of Aboriginal artist Tanya Taylor and designed by the National Aboriginal Design Agency. This artwork symbolises the Centre for Aboriginal Health working in partnership with Aboriginal people to support wholistic health and wellbeing and its role in the health system to build culturally safe and responsive health services.

Contents

Overview

Acute rheumatic fever (ARF) is an illness that can occur after a throat or skin infection with group A streptococcus (GAS). Episodes of ARF can cause permanent damage to heart valves, known as rheumatic heart disease (RHD). People who have had an episode of ARF need long-term treatment to prevent repeat episodes, which may cause further damage to the heart.

Acute rheumatic fever and rheumatic heart disease are not common in NSW, but are important health conditions because they cause serious illness, impact mainly children and young adults, disproportionately affect Aboriginal and Torres Strait Islander people, Maori and Pacific Islander people and migrant communities, and because they are preventable diseases.

This framework provides a guide to help health services develop local approaches to address ARF and RHD. Figure 1 summarises the framework's main elements.

Principles

This framework is underpinned by the following principles.

- **Holistic and patient-centred care**

Acute rheumatic fever and rheumatic heart disease influence, and are influenced by, a range of social, cultural, environmental and health factors. It is necessary to consider these factors, and the needs and values of patients and their families, to ensure actions to address ARF and RHD are responsive and appropriate.

- **Collaborative local partnerships**

Responding to ARF and RHD requires strong relationships between individuals, families and communities, and the different parts of the health system. Health services likely to be involved in caring for people with ARF and RHD include local health district hospitals, public health units, Aboriginal community controlled health services, general practices and other primary care services.

- **Empowering patients, families and communities**

There is considerable strength, experience and positive health action among individuals, families and communities. Empowering patients, families and communities to build on these strengths will contribute to more appropriate and successful ARF and RHD action.

1. **Reduce risk of group A streptococcal infection: Primordial prevention**
2. **Improve the management of sore throats and skin infections: Primary prevention**
3. **Improve diagnosis, notification and enrolment on the New South Wales RHD Register**
4. **Improve secondary prevention of ARF and RHD**
5. **Improve long-term care and access to specialist services: Tertiary prevention**
6. **Strengthen workforce training and education**
7. **Raise community awareness of ARF and RHD**

Figure 1. Framework to address ARF and RHD in NSW

What are ARF and RHD?

Acute rheumatic fever is an illness caused by a reaction to a bacterial throat or skin infection with group A streptococcus. Specific parts of the body affected include the heart, joints, brain and skin. Permanent damage to heart valves can result and this is known as rheumatic heart disease. Recurrent episodes of ARF may cause further heart valve damage, leading to steadily worsening RHD. Preventing recurrent episodes of ARF is therefore very important.

Who is affected by ARF and RHD?

Acute rheumatic fever and rheumatic heart disease have largely been eliminated in industrialised countries. However, in Australia ARF and RHD continue to affect specific high-risk groups, including Aboriginal and Torres Strait Islander people, Maori and Pacific Islander people, and people from countries where ARF is more common.

Acute rheumatic fever primarily affects children between the ages of 5 and 14 years. New South Wales hospital records indicate that approximately 24 people are newly diagnosed with ARF in the state each year. However, this may be an underestimate of the actual number affected.[1]

How are ARF and RHD diagnosed and treated?

Currently, there is no single laboratory test to diagnose ARF. Diagnoses are based on careful assessment by a clinician, supported by diagnostic criteria. Rheumatic heart disease is diagnosed by an ultrasound of the heart (echocardiogram). The treatment of ARF and RHD focuses on managing a patient's symptoms and preventing worsening of the disease.

How are ARF and RHD prevented?

Acute rheumatic fever and rheumatic heart disease can be prevented by improving environmental conditions known to increase the risk of GAS infection, treating GAS infections early, and supporting people with ARF to prevent further episodes. Preventive treatment for those diagnosed with ARF involves antibiotic (benzathine penicillin G) injections every 21-28 days. This treatment is recommended for a minimum of 10 years following the last episode of ARF.

Regular contact with healthcare providers, including cardiac services, during the recommended follow-up period is important to monitor heart health and minimise risk factors for other acute and chronic diseases.

Acute rheumatic fever in people of any age, and rheumatic heart disease in people under 35 years, became notifiable conditions in NSW in October 2015. New South Wales has introduced a register to support people with ARF and RHD, so they can obtain regular antibiotic injections and follow-up at appropriate times.

[1] Unpublished analysis of NSW Admitted Patient Data. Health Protection NSW, 2014

Section 1

Reduce risk of group A streptococcal infection: Primordial prevention

Preventing GAS infections, which can lead to ARF, is an important part of addressing ARF and RHD in NSW. Group A streptococcal infections can be prevented by improving environmental conditions known to increase the risk of infection, such as poverty, crowding and inadequate living conditions. This is known as primordial prevention.

Primordial prevention initiatives should be informed by, and carried out through, collaborative partnerships with high-risk communities and their local leaders.

LOCAL ACTIONS

- Collaborate with local communities, community organisations and leaders to deliver locally and culturally-appropriate initiatives that aim to address environmental risk factors for ARF and RHD.
- Engage with public health units around local programs, such as Housing for Health, that aim to improve environmental living conditions together with Aboriginal communities.
- Deliver initiatives to improve hygiene in high-risk populations. Examples include school or community-based educational programs about hand washing, such as the Mister Germ Hygiene and Nutrition Program delivered through public health units.

Section 2

Improve the management of sore throats and skin infections: Primary prevention

Timely and appropriate treatment of sore throats in high-risk populations can reduce the risk of ARF. This is known as primary prevention.

It is important to educate high-risk populations and healthcare workers about the management of sore throats.

In communities with RHD, episodes of ARF may also be triggered by skin infections with group A streptococcus. In this setting, prompt treatment and control of skin infections is an important part of preventing RHD.

LOCAL ACTIONS

- Raise awareness among high-risk populations about the importance of seeking medical attention for sore throats and skin infections.
- Promote understanding among local clinicians about the importance of following the NSW Health guideline GL2014_21, Infants and children: Acute management of sore throat and the NSW Health Impetigo fact sheet.
- Ensure health services are culturally safe and acceptable to high-risk populations, and address any financial or other barriers to accessing medical attention.

Section 3

Improve diagnosis, notification and enrolment on the register

In October 2015, NSW Health added ARF in people of any age, and RHD in people aged less than 35 years, to the NSW notifiable diseases list. NSW Health has also established a voluntary register for people diagnosed with ARF and RHD. This register aims to support patients, their families and their healthcare providers to manage the long-term preventive treatment and clinical reviews required to prevent further ARF episodes and cardiac complications.

The notification process for ARF and RHD cases is the main mechanism to identify people eligible for inclusion on the NSW RHD Register. The patient or their guardian must provide consent before they are added to the register.

Each local health district has an RHD coordinator to help identify people with ARF and RHD, enrol them on the register, and support their ongoing management. More information and fact sheets about the register are available on the NSW Health website.

LOCAL ACTIONS

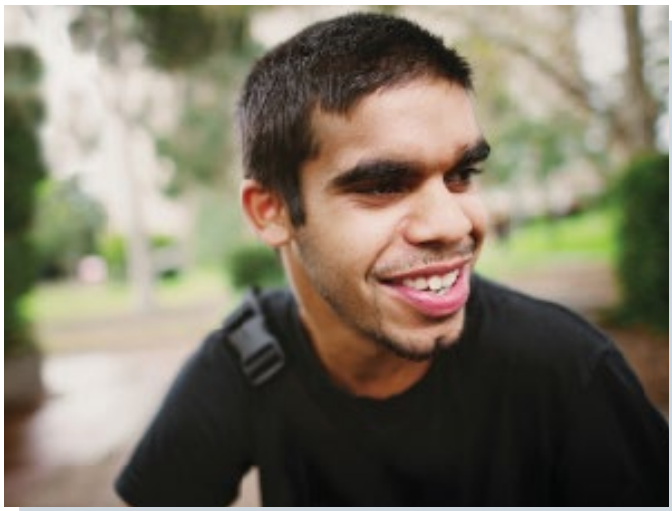
- Support clinicians to participate in relevant training to increase their knowledge and understanding of ARF and RHD.
- Support clinicians to access tools to support RHD diagnosis, such as the RHDAustralia smartphone application.
- Ensure clear and simple systems are in place for clinicians to notify the local public health unit of all suspected cases of ARF and RHD. Contact Details for Public Health Units
- Promote collaborative partnerships between health providers and the local RHD coordinator to ensure newly-diagnosed patients are linked to appropriate services.
- Identify staff to provide care for patients with ARF and RHD, and support the process of consent for the register.

Section 4

Improve secondary prevention of ARF and RHD

Preventing recurrent episodes of ARF is important, to avoid further heart damage leading to worsening RHD.

Injections of the antibiotic benzathine penicillin G every 21-28 days are recommended for people with ARF or RHD. This regimen should continue for a minimum of 10 years following the last episode of ARF, and may be required for longer. This is known as secondary prevention. For success, it is critical to develop flexible, patient-centred approaches and sustainable models to support the patient and coordinate their care.



LOCAL ACTIONS

- Ensure health services focus on building strong and positive relationships with ARF and RHD patients and their families, and provide adequate education and support for patients to lead their own care.
- Ensure culturally-appropriate educational resources are available to patients, such as material from RHDAustralia, and the NSW Health video Rayboy. Watch Rayboy on the RHD/ARF Health Professionals webpage.
- Identify staff able to take on a care-coordination role.
- Draw on the experience, community knowledge and language skills of Aboriginal health workers or other community health workers to support the long-term care of patients.
- Assist services to work collaboratively with the local RHD coordinator and statewide RHD program.
- Support services to engage effectively with the range of health providers who may be involved in the patient's care. This includes services in other locations, to ensure continuity of care if the patient travels or relocates to another area.
- Promote holistic patient care that addresses risk factors for other acute or chronic diseases. Where possible ARF and RHD activities should be integrated with existing primary healthcare programs and activities.
- Strengthen health education for patients, families and communities, including peer support programs, to enable people with ARF and RHD to learn from and support one another.

Section 5

Improve long-term care and access to specialist services: Tertiary prevention

When caring for patients with RHD, the long-term management goals are to prevent ARF episodes, minimise disability resulting from RHD, and prevent premature death. This is known as tertiary prevention. In addition to long-term benzathine penicillin G injections and access to primary care services, best-practice care for people with ARF and RHD requires access to a range of other health services, such as oral health, maternal health and cardiology.

LOCAL ACTIONS

- Ensure access to a specialist physician, paediatrician and cardiologist (preferably the same specialist), for regular follow-up visits.
- Support access to echocardiography.
- Ensure adequate monitoring of anticoagulation therapy in patients with atrial fibrillation or mechanical prosthetic valves.
- Ensure access to cardiothoracic and interventional cardiology services.
- Support access to oral health services.
- Support fertility discussions with women who have RHD, ensuring pregnancy is carefully planned together with specialist cardiology services and obstetric services through tiered maternity networks.
- Ensure pregnant women with RHD access specialist obstetric care through tiered maternity networks.
- Ensure financial and transport barriers to the access of ARF and RHD care are addressed.

Section 6

Strengthen workforce education and training

Acute rheumatic fever and rheumatic heart disease are not common in NSW, and many health professionals have little or no experience diagnosing and managing these conditions. It is therefore essential to educate and train health professionals, particularly those who work with high-risk populations, to ensure they identify and treat people with ARF and RHD.

RHDAustralia has developed a free online clinical education package for a range of health professionals. The material covered ranges from an introduction to ARF and RHD, through to tertiary management of RHD. The modules are available on the RHDAustralia website:

- health worker modules
- clinician modules.

All modules are endorsed by the Australian College of Nursing and accredited by the Australian College of Rural and Remote Medicine. The modules attract continuous professional development or continuous medical education points.

LOCAL ACTIONS

- Help relevant staff access existing tools and resources to support diagnosis and management of ARF and RHD.
- Ensure relevant staff understand the process for notifying cases and enrolling patients on the NSW register.
- Liaise with local Primary Health Networks to promote awareness of ARF and RHD, and use of RHDAustralia guidelines.
- Ensure clinicians have opportunities to learn from people with ARF and RHD about their health needs and experiences, and apply that knowledge to improve the care they deliver.

Section 7

Raise community awareness of ARF and RHD

Aboriginal and Torres Strait Islander peoples, Maori, Pacific Islander people and other migrant communities living in NSW have existing strength, knowledge and experience in responding to health issues. However, health literacy regarding ARF and RHD is low across the population, including high-risk communities. In particular, awareness could be improved among high-risk communities about when to seek medical attention for children with sore throats, and among people with ARF and RHD about the importance of regular engagement with health services.

LOCAL ACTIONS

- Work with high-risk communities, their organisations and leaders to deliver locally and culturally appropriate awareness-raising activities.
- Promote RHDAustralia community and family resources.
- Use local events as opportunities to raise awareness about ARF and RHD.
- Encourage opportunistic education by staff in health settings.

FOR ALL ARF/RHD RESOURCES, PLEASE GO TO THE NSW HEALTH WEBPAGE

www.health.nsw.gov.au/Infectious/rheumatic