

# RHEUMATIC HEART DISEASE CONTROL PROGRAMS

Quick Reference Guide for Health Organisations



*This quick reference guide is derived from 'National Heart Foundation of Australia (NHFA) and the Cardiac Society of Australia and New Zealand (CSANZ) Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia — an evidence-based review. 2006'.*

## What is rheumatic heart disease?

Rheumatic heart disease (RHD) is damage to the heart valves caused by acute rheumatic fever (ARF). ARF is an auto-immune response to bacterial infection with group A streptococcus (GAS). Recurrences of ARF may cause further valve damage, leading to steady worsening of RHD. Secondary prevention of ARF is therefore of great importance.

## Who gets rheumatic heart disease?

Although ARF is relatively rare in industrialised countries, it is a significant cause of disease among Aboriginal and Torres Strait Islander peoples. Incidence of RHD is also high among these populations, with significant rates of procedures and death among young adults.

## How can RHD be controlled?

Secondary prophylaxis of ARF with 4-weekly benzathine penicillin G (BPG) injections is the only RHD control strategy shown to be effective and cost-effective at both community and population levels.

The appropriate duration of secondary prophylaxis is determined by age, time since the last episode of ARF and potential harm from recurrent ARF, but is likely to be 10 years or more.

Effective RHD management involves regular clinical follow-up with specialist review and echocardiography.

## Problems with control of RHD

While strategies for controlling RHD are proven, simple, cheap and cost-effective, they are not adequately implemented in the populations at highest risk of the disease. Persistent high rates of recurrent ARF in high-risk populations highlight the continued failure of secondary prevention.

Organised approaches are needed to increase the effectiveness of secondary prevention of ARF and management of RHD. This should include strategies aimed at improving the delivery of secondary prophylaxis and patient care, the provision of education, coordinating available health services and advocacy for necessary and appropriate resources.

## ORGANISATIONAL APPROACHES TO RHD CONTROL

- A coordinated control program is the most effective approach to improving adherence to secondary prophylaxis of ARF and clinical follow-up of people with RHD.
- Central to coordinated control programs at the individual, community and national level are registers of people with RHD or a history of ARF. Register-based programs improve case detection, increase adherence to secondary prophylaxis, reduce recurrences of ARF and decrease hospitalisations from ARF/RHD.
- Registers also provide a mechanism for monitoring patient movements, orientating staff to ongoing care requirements, identifying individuals with poor adherence to long-term therapy, and monitoring the success of programs and changes in disease epidemiology.

### RHD control programs aim to:

- improve uptake of and adherence to secondary prophylaxis
- improve clinical care and follow-up
- identify and register new cases of ARF and RHD
- provide education and training for health care providers
- provide education and health promotion for individuals, families and the community
- promote primary prevention aimed at preventing initial episodes of ARF
- use data to monitor patient outcomes and improve program strategies.

## RECOMMENDED ELEMENTS OF RHEUMATIC HEART DISEASE CONTROL PROGRAMS

- A single centralised (preferably computerised) ARF/RHD register, established within existing health care networks, and linked to local registers in regions and individual communities. The register may be stand-alone, part of a more comprehensive chronic disease register, or be housed within clinical departments or public health units. Registers should:
  - maintain patient confidentiality
  - conform to privacy legislation
  - be established with the relevant institutional and/or individual approval
- Commitment from national, regional and local services, particularly to ensure long-term funding
- Activities guided by locally relevant, evidence-based guidelines
- A dedicated, centrally based coordinator for each control program
- A commitment to partnerships between clinicians and public health services to support the needs of people with ARF/RHD and the community
- An effective advisory committee that includes cardiologists, paediatricians, general practitioners, physicians, epidemiologists, nurses, public health practitioners, and relevant community representatives (eg Aboriginal and Torres Strait Islander Australians)
- Antibiotic prophylaxis prioritised and delivered within the framework of primary health care (see specific strategies below)
- A stable supply of benzathine penicillin ensured through planning and advocacy, and sustainable secondary prophylaxis planned for in the event of supply reductions
- The ability to find new cases of ARF and RHD, and to assess and monitor the burden of disease
- Education for health practitioners, the community, those with disease and their families
- Support for the provision of health education within the local community, community health services and for community health workers
- Legislation and/or regulations warranting the notification of ARF/RHD, supported by public health surveillance activities at the state or territory level
- A priority system that ensures services are delivered to those at highest risk
- A mechanism for monitoring delivery of secondary prophylaxis and ongoing care, program reporting and independent evaluation

## IMPROVING UPTAKE OF AND ADHERENCE TO SECONDARY PROPHYLAXIS IN PRIMARY CARE

- Employ recall and reminder systems (based on a local ARF/RHD register where established) to accommodate the high mobility of individuals and groups:
  - ensure that recall systems extend beyond community boundaries
  - establish networks for timely communication between health clinics
  - use a centralised coordinator and register to assist in monitoring movement
- Identify local, dedicated staff members responsible for delivery of secondary prevention and coordination of routine care
- Support and utilise the expertise, experience, community knowledge and language skills of Aboriginal health workers
- Minimise staff turnover in remote and rural primary health care centres and regional hospitals
- Improve staff awareness of diagnosis and management of ARF and RHD
- Improve quality and delivery of health education
- Focus on improving communication between health staff and patients/families
- Implement measures to reduce pain of injections (eg use 23-gauge needle, warm syringe to room temperature before using, deliver injection very slowly)

## SURVEILLANCE

- Passive surveillance of ARF usually depends on case identification from health care providers. Historically, this has under-estimated the burden of disease due to inaccuracies and incompleteness. In under-resourced settings, problems with passive surveillance are exacerbated by high turnover of staff and lack of awareness of ARF and RHD.
- Ideally, active surveillance should be used to augment passive surveillance. This entails establishing mechanisms to identify new cases of ARF and RHD, and to update information about existing cases. This could include mechanisms allowing access to hospital separation data; echocardiography reports; specialist review correspondence; primary health care clinic information; and notifiable diseases databases. Where possible, these processes should be automated (eg with regular downloads of information regarding patients admitted to hospital with a diagnosis of ARF or RHD).
- When active surveillance is established, an initial apparent increase in the prevalence of RHD is expected, primarily due to the detection and recording of existing cases, rather than the appearance of new cases. Similarly, improved access to specialist care may also result in greater rates of valvular surgery in the initial years after commencing a program.

## RHD REGISTERS

- Some programs have all the data suggested below entered into the centralised register. Others choose to have a subset of data (eg recording of individual doses for secondary prophylaxis) entered only into the local register.
- Where provision of secondary prophylaxis is not entered into a central register, local health staff should have clear guidelines about identifying and managing patients overdue for secondary prophylaxis, and when to notify the coordinator of these patients.
- It is suggested that coordinators be notified when patients are more than 2 months overdue for secondary prophylaxis, so that they and local health staff can institute strategies to improve adherence (eg developing individualised education strategies for patients, and/or tracking patients if they have moved).
- Communities should also provide data to the coordinator every 6 months on the number of BPG doses due to be delivered and the number of doses actually delivered for each patient in the community. If the community wishes, these data can be de-identified. They are important in detecting communities with low overall adherence levels, so that their approach to delivery of secondary prophylaxis can be reviewed if necessary.

DOMAIN	DATA ELEMENTS
Demographics	Name, date of birth, address/community, alternate address/community, parent/guardian, ethnicity
ARF diagnosis	Onset date of primary episode of ARF, place first diagnosis made, presence (and severity) of carditis, presence of chorea
RHD diagnosis	Onset date/date of diagnosis, documented history of ARF, valvular dysfunction and disease severity at time of diagnosis
ARF recurrences	Onset date, presence of carditis, other symptoms and signs at each recurrence
Secondary prophylaxis	Agent, dose and frequency, date commenced on prophylaxis, expected date of cessation, number of doses received over preceding 12 months
Surgical intervention	Date surgery recommended, date, site, procedure and outcome of surgery
Medications	Anticoagulant prescribed: type, dose, date commenced, frequency of monitoring, therapeutic target (international normalised ratio range) Type and dose of other cardiac medications
Follow-up/recall	Date and place of last review, and date and place of next scheduled review by each provider (cardiologist, paediatrician, physician, surgeon, local medical officer, echocardiographer)
Mortality	Date and cause of death according to agreed criteria (eg due to RHD, not due to RHD)

## SCREENING FOR RHD

- RHD control programs should also coordinate screening to detect previously undiagnosed RHD in high-risk populations, wherever possible.
- Although RHD prevalence is highest in adults, they are difficult to screen — screening of school-age children is recommended (eg cardiac auscultation at school entry, and at age 10 years).
- If time and other resources allow, consideration should be given to conducting more intensive screening programs in which children of all ages are reviewed, and attempts are also made to examine children who miss school-based screening.

## LEGISLATED NOTIFICATION OF ARF/RHD

- ARF is a notifiable condition in the Northern Territory and Queensland.
- RHD is not currently notifiable anywhere in Australia.

## INDICATORS FOR EVALUATING ARF/RHD CONTROL PROGRAMS

- Control programs for ARF/RHD should be evaluated against criteria for routine care and key epidemiological objectives (see below).
- Consideration should be given to assessing the delivery of specialist cardiology services; availability and accessibility of echocardiography; referral practices and structures; transportation for patients; and support and follow-up processes.

### Secondary prophylaxis

- The proportion of scheduled BPG injections delivered in the previous 12 months
- Individual, community and regional figures, expressed as:
  - median percentage of doses delivered
  - proportion of patients who receive 80% or less of scheduled doses
  - proportion of patients who receive 50% or less of scheduled doses

### Medical review

- Proportion of registered individuals who are more than 3 months overdue for specialist or other medical officer review, as defined by local guidelines
- Proportion of individuals who have echocardiography performed within 3 months of scheduled timing
- Median time elapsed between recommendation and performance of valvular surgery

### Epidemiology

- Yearly (or other appropriate time frame) age-specific incidence rates of ARF
- Proportion of ARF episodes in the register classified as recurrences
- Rates of ARF recurrence per 100 patient-years
- Number of deaths and age-standardised rates of mortality due to ARF/RHD in the previous 12 months (or other appropriate time frame)
- Yearly age-specific and overall point prevalence of RHD
- Proportion of ARF cases notified to and recorded by public health authorities (where appropriate) in the previous 12 months (or other appropriate time frame)
- Proportion of newly registered individuals with an initial diagnosis being established as RHD (rather than ARF)

## FURTHER INFORMATION

The full evidence-based review from which this quick reference guide is derived provides detailed information on the diagnosis and management of ARF, secondary prevention and RHD control programs, and diagnosis and management of RHD.

Other quick reference guides are:

- *Diagnosis of Acute Rheumatic Fever*
- *Management of Acute Rheumatic Fever*
- *Secondary Prevention of Acute Rheumatic Fever*
- *Management of Rheumatic Heart Disease.*



These publications are available from the National Heart Foundation of Australia through:

**Heartline** 1300 36 27 87 or  
[heartline@heartfoundation.com.au](mailto:heartline@heartfoundation.com.au)

**Heartsite** [www.heartfoundation.com.au](http://www.heartfoundation.com.au)