Summary

Rheumatic heart disease (RHD) results from one or more episodes of rheumatic fever (RF). RF is an illness caused by a reaction to a bacterial infection with group A Streptococcus (GAS). RHD can be prevented through regular long term antibiotic prophylaxis (3-4 weekly injections of benzathine penicillin for a minimum of ten years) for those who with a previous history of RF or RHD (secondary prophylaxis). Aboriginal and Torres Strait Islander populations have some of the highest rates of diagnosed RF and RHD in the world.

The aim of the South Australian (SA) RHD Control Program (‘the Program’) is to reduce morbidity and mortality associated with RHD through monitoring and improving delivery of secondary prophylaxis, enhancing coordination of care, delivering educational activities and increasing RF/RHD case detection and surveillance activities. Specific objectives are to:

- maintain the state-wide RHD Register (the Register),
- support local health services to manage patients with RF and RHD through local registers and recall systems that share data with the Register,
- facilitate education and training of the clinical workforce in case recognition and clinical follow-up and,
- increase awareness of RF and RHD among high risk populations.

Guidance is provided by the RHD Program Advisory Group, comprised of key stakeholders from across the state. This group provides advice and support to the Program to achieve its aims and objectives, as well as in relation to operational issues.

Highlights for the Program in 2016 include:

- Participation in national advocacy activities leading to funding agreement for the 2016/17 financial year.
- Funding agreements with Nganampa Health Council and Aboriginal Health Council of SA for positions within their organisations to undertake RHD control activities extended for the 2016/17 financial year.
- RF and RHD were declared notifiable conditions in South Australia (SA) under the South Australian Public Health Act 2011.
- Ongoing strong support and commitment from key stakeholders, in particular around advocacy for future funding.
- A continuing upward trend in the average adherence to secondary prophylaxis for patients on the Register.
- A presentation was given at the Cardiac Society of Australia and New Zealand (CSANZ) Annual Scientific Meeting 2016 titled: Still think of rheumatic fever in urban and regional South Australia.
RHD Program Advisory Group

The RHD Program Advisory Group is comprised of interested parties across SA including members from the Aboriginal Community Controlled Sector, Cardiology Clinical Network, National Heart Foundation (SA Division), RHDAustralia, South Australian Health and Medical Research Institute (SAHMRI), Royal Flying Doctor Service, Country Health SA, Central and Northern Local Health Network, Women’s and Children’s Local Health Network and South Australian Department for Health and Ageing.

Meetings of the Program Advisory Group were held in April, July and October of 2016 with good attendance. Minutes of these meetings are documented as per the Terms of Reference for the Group. Members also provided out of session advice when required.

SA RHD Register

The purpose of the Register is to collect, analyse, and report on patient data and to implement strategies to assist with the management of patients with RF and/or RHD. The Register includes patients with new, recurrent or probable episodes of RF, and/or definite or borderline RHD, based on the case definition in the Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd ed). The Register collects information based on national standards and written consent is required before patient data can be recorded.

A Memorandum of Agreement between the Northern Territory Health Centre for Disease Control and the SA Health Communicable Disease Control Branch is in place for the Register to use the platform of the Northern Territory (NT) web based RHD Register.

Register statistics

The number of patients on the Register continues to steadily increase, as seen in Figure 1, with 246 patients enrolled at December 31, 2016.

Of these 246 patients:

- 66% are female;
- 69% are under 35 years of age;
- 55% are in remote SA*;
- 18% in regional SA*;
- 27% urban SA*;
- 92% identify as Aboriginal, the remaining 8% identify as migrants from countries where there is a high prevalence of RHD (Somalia, Iran, Burma, Afghanistan, Bhutan) or are Caucasian Australians.

*The Australian Institute of Health and Welfare (AIHW) remoteness classifications have been used, but are collapsed to three regions (urban, regional and remote) for reporting purposes to prevent identification of individual health services.
There were 11 new diagnoses of RHD notified to the Program in 2016:

- One was diagnosed with RHD at the time of their RF episode.
- Six people had no known history of RF.
- Three students were identified RHD through the school screening project.
- One had had moved to Australia from overseas with established RHD but no recorded medical history of RF.

Eleven cases of borderline RHD were notified to the RHD Program as part of the school screening project; so far seven of these have given consent to be on the SA Register.

There were 14 diagnoses of initial RF in 2016, including one probable case. The one episode of recurrent RF was in someone who had ceased secondary prophylaxis two years earlier, as per Australian guidelines. There were also two RF diagnoses that were ultimately excluded, as they were post-streptococcal arthritis. These cases are not included the data presented in Figure 2.

Just over half of the RF diagnoses notified to the Program in 2016 were in patients from urban or regional South Australia.

**Figure 3. Proportion of RF diagnoses, reported to the Program, by geographical location**
The majority of cases of RF were in children aged 5-14 years (Figure 4a); there was one probable RF (Figure 4b) and almost equal numbers of male and female cases (Figure 4c).

Figure 4a. RF Notifications to the Program, 2016, by age at diagnosis

Figure 4b. RF Notifications to the Program, 2016, by RF status

Figure 4c. RF Notifications to the Program, 2016, by sex
Just under half of the patients on the Register are from the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, with other large clusters in Adelaide and Port Augusta (Figure 5). In all regions of SA the majority of patients are classified as having mild disease (Figure 6).

**Figure 5. Register patients, by location, at December 31, 2016**

**Figure 6. Proportion of Register patients by region and severity of diagnosis, Dec 31, 2016**
RHD registers assist with monitoring patient movements, identifying individuals with poor adherence to secondary prophylaxis and providing education for patients and health professionals.

On average, SA patients received 84% of their scheduled doses of benzathine penicillin in 2016 (Figure 7). Average adherence percentage has increased each year since the commencement of the Register, suggesting that the state-wide monitoring and support for primary health care undertaken by the Register is contributing to improved adherence.

Figure 8 further demonstrates the significant improvement in adherence to secondary prophylaxis. The proportion of patients on the Register who are receiving 80% or more of their required doses of penicillin continued to increase, reaching 67% in 2016. The proportion of patients who are receiving fewer than 50% of their required doses of penicillin remained stable at 9%. When examined further, it was seen that many of these patients are the same as 2015. Barriers to achieving good adherence to secondary prophylaxis include an often highly mobile patient population, the painful penicillin injection and high staff turnover. The efforts of primary health care staff to achieve these improvements given these challenges must be acknowledged.

**Figure 7. Average percentage adherence to secondary prophylaxis (Register patients), by year, 2012-2016**

![Figure 7](image_url)

**Figure 8. Proportion of Register patients who received ≤50%, 50-79% and ≥80% of their scheduled secondary prophylaxis doses, by year.**

![Figure 8](image_url)
The Australian guideline for the prevention, diagnosis and management of rheumatic fever and rheumatic heart disease (2nd edition) recommends that Priority 1 and Priority 2 patients receive an echocardiogram every six months and every year respectively. Figure 9 shows a slight improvement in the proportion of Priority 1 and Priority 2 patients receiving timely echocardiography in line with these recommendations.

Figure 9. Proportion of Priority 1 (severe RHD) and Priority 2 (moderate RHD) patients on the Register who received serial echocardiography within the last year, per recommendations in the Australian guideline (2nd edition).

Register

Reports on secondary prophylaxis adherence, overdue status for specialist appointments and patient demographics are generated from the Register on a regular basis. These reports:

- provide information to each health service to track their progress with managing RF/RHD patients locally;
- provide specialists with accurate information on their patient adherence to prophylaxis; and
- allow for planning, allocation of resources, and provision of support by the RHD Program.

The Register works collaboratively with local systems in numerous health services to facilitate the sharing of data to improve secondary prophylaxis management. The Register also provides an ongoing role in coordination of care of patients who are moving between health services or moving between SA, NT and Western Australia.

On 18 February 2016, the South Australian Public Health (Notifiable and Controlled Notifiable Conditions) Regulations 2012 under section 63 of the South Australian Public Health Act 2011 were varied to make RF and RHD notifiable conditions. The primary purpose of this is to improve the health of the community through appropriate public health action and to mitigate the burden of RHD in SA through the Register. Additionally, South Australian data, combined with data from other Australian jurisdictions, will be used to monitor trends, and plan and implement appropriate public health responses. Consent from the patient will still be required to enrol people on the Register, as this is a clinical management tool.

The challenge to achieve engagement with the Register and delivery of secondary prophylaxis in the hospital setting remains. The relationship with clinical pharmacy professionals in Adelaide metropolitan and some regional hospitals continues to be productive, with the Program increasingly finding out about cases through calls and emails from pharmacists. In late 2016, permission was gained for an ‘RHD Register’ alert to be included in the Oacis Clinical Care Suite used across SA hospitals. This alert has been added for all patients on the Register. It flags that the patient has a...
history of RF/RHD and may be on 4 weekly penicillin and advises the health professional to contact the Register.

In 2016, SA Health sent clean, robust data from 2013 and 2014 from the Register to the National Data Collection System (DCS). The DCS is a central national repository for the collection and reporting of RF and RHD data against a recommended clinical data set and key performance indicators.

The Register was also involved in two state-wide projects with SAHMRI. The Program has provided support to an RHD screening study of school aged Aboriginal children, through follow up of cases found during this screening who consented to be on the Register. The Program also provided advice and data (with appropriate approvals) to the State of Aboriginal Heart Health Project to assist in building a case for improved cardiac care for Aboriginal people in SA.

A presentation using SA RHD Register data (unidentified) was given at the CSANZ Annual Scientific Meeting 2016 titled Still think of rheumatic fever in urban and regional South Australia. It highlighted that RF still occurs in temperate urban and regional areas, and recommended that clinicians working in these areas of SA remain alert for cases and that support and resources must be provided in these areas.

Engagement with primary health care services

The Program undertakes regular visits to individual health services to provide education and support for patient management. In 2016, staff from the Program, or staff employed through the Program working for Nganampa Health Council or Aboriginal Health Council of SA, visited all health services with Register patients who have RF and/or RHD.

The support of the RFDS to allow staff from the Program to join the RFDS on trips to Oodnadatta and Yalata in 2016 must be acknowledged. These are towns the Program had not been able to access previously so these visits were very worthwhile.

Work undertaken during these visits included:

- refreshing staff knowledge in the use of the Register and information available on the SA Health RHD webpage (www.sahealth.sa.gov.au/rhd);
- auditing patient lists, including identifying patients who require consent to be on the Register; and
- reviewing electronic patient management systems to ensure recalls are being recorded correctly and are up to date.

In 2016, there was also improved engagement with private GP practices around patient management according to the Australian guidelines. There are now 15 people on the Register who are being actively managed by a GP working in a private practice.

Education and training

Delivery and coordination of training to the clinical workforce around RF/RHD diagnosis, management and prevention has occurred in a variety of settings including conferences, state-wide workshops and staff meetings.

The training video Diagnosis and management of rheumatic fever and rheumatic heart disease in the hospital setting has been completed. This video is designed for use within the hospital setting and enables a facilitator with limited knowledge of RF and RHD to conduct an education session for
nurses. The video promotes general awareness of RF and RHD, and the important role nurses can play in diagnosis and management of these conditions in the hospital setting.

There has been ongoing education for primary health care staff, nursing, dental and medical staff within SA hospitals. Education highlights for 2016 include:

- An evening session for GPs working in Port Pirie, run collaboratively with the Country SA Primary Health Network.
- Education sessions to all cardiology departments in SA metropolitan public hospitals about the Register and RF/RHD now being notifiable conditions.
- A presentation to Royal Australian College of Physicians trainees about the Australian guideline for diagnosing RF and the Register.

RF and RHD continued as an education topic in the Certificate III and Certificate IV in Aboriginal and Torres Strait Islander Primary Health Care run through Aboriginal Health Council of SA. This provides the opportunity to educate Aboriginal Health Workers who are starting in their careers about the importance of these diseases and why their role is so crucial in patient management. The RHDAustralia online education modules are now embedded into the assessments for the Certificate IV qualifications.

To complement the RHD educational calendar that was developed last year for education with people who have been diagnosed with RF and/or RHD and their families, additional resources have been developed for the wider community. These additional resources use the same imagery as the calendar but have a call to action around early detection of GAS infection and early diagnosis of RF. The resources aim to increase awareness among all Aboriginal people of the symptoms of RF, and the GAS bacterial infection that causes RF. They include magnets, water bottles and T-shirts, and the message encourages them to go to the clinic for treatment if they are experiencing symptoms.

Future directions

A national advocacy event was held in Brisbane in March 2016, including a breakfast with the Hon. Ken Wyatt AM, MP. The SA Program staff attended this event and actively participated in activities to support the need for future funding for RHD control in Australia.

In 2017 the Program will continue to work with and support existing health care services to ensure that people with RF/RHD are managed according to best practice, thus leading to significant health savings from prevention of hospitalisations and cardiac surgery, with a particular focus on:

- Managing and maintaining the Register including collaboration with primary health and cardiology to ensure accurate data, monitoring of secondary prophylaxis adherence and regular reporting and evaluation;
- Strengthening the capacity of local health services to manage their patients with RF and RHD through regular telephone support and visits where required;
- Training and up-skilling of the clinical workforce in case recognition and clinical follow-up and management; and
- Undertaking active and passive surveillance to find new cases of RF and RHD.

The Program is currently funded until June 2017 by the Commonwealth Government’s Rheumatic Fever Strategy. At the time of this report, there was no decision regarding future Commonwealth funding.