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 (benzathine penicillin), 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 2017 include:

- 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 2017/18 financial year.
- A successful state-wide RHD workshop, supported by RHDAustralia, Heart Foundation SA, Country SA Primary Health Network and Aboriginal Health Council of SA, attended by over 80 health professionals from across the state.
- Ongoing strong support and commitment from key stakeholders, particularly in the promotion of the SA workshop and ongoing support for the Register in primary health care.
- Increased engagement with Country SA Primary Health Network and service providers Northern Health Network and Country and Outback Health.
- A continuing upward trend in the average adherence to secondary prophylaxis for patients on the Register.
- A half day planning session with members of the Program Advisory Group to inform future activity.
- An evaluation of the Program’s education calendar “Don’t miss out on the things you love” which revealed that the resource had high uptake in Aboriginal primary health care, was easy to use and resonated with the Aboriginal community.
- The development of an introduction to RHD video pairing a patient story with clinical information, with 1,230 views in the first six months.
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, Heart Foundation, RHD Australia, 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. In 2017, Country SA Primary Health Network was invited to become a member of the group.

Meetings of the Program Advisory Group were held in March and June of 2017. Minutes of these meetings are documented as per the Terms of Reference for the Group. Members also provided out of session advice when required.

In October 2017, a half day planning session was held to reflect on successes and challenges so far and to plan for the next four years of funding. Key discussions included the challenges of accessing information from hospital systems, increasing our activity in the primary and primordial prevention space, supporting patient systems within primary health care and involving patients in decisions around program direction. Areas for future activity included exploring options for the program to be alerted when someone on the register is admitted to hospital, ensuring dental review as part of the inpatient assessment for new RF diagnoses, collaborating with others working in the area of environmental health, particularly with the trachoma program, and to liaise with Aboriginal health workers and the community about an avenue to allow people living with RHD to contribute to the direction of the Program.

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.

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. Consent from the patient is required to enrol people on the Register, as this is a clinical management tool. Unless consent has already been obtained, all RF cases, all people under 50 years of age and all people identifying as Aboriginal and/or Torres Strait Islander or from an identified high risk group (Maori, Pacific
Islander, African, Asian or Middle Eastern) will be followed up to seek consent to be enrolled on the Register.

In 2017, 65 cases of RF and RHD were notified to the program (28 from active case finding through echocardiography departments or clinical pharmacy, 21 from medical professionals and 16 from primary health care), with 38 identified as meeting the criteria for inclusion on the Register.

Data not reported in graphs below, but captured on the Register, include eight valve surgeries performed in 2017 (six replacements; 2 repairs) and three deaths directly attributable to RHD. All surgeries and deaths occurred in people who identified as Aboriginal.

Register statistics

The number of patients on the Register continues to steadily increase, as seen in Figure 1, with 281 patients enrolled at December 31, 2017. There are currently 38 patients yet to provide consent to be on the RHD register. The opt-in consent process presents challenges when people have left hospital without consent or are seen at private GP practices. Increased efforts are being made with nursing staff to seek consent while people are in hospital.

Of these 281 patients:
- 66% are female;
- 59% are under 35 years of age;
- 52% are in remote SA*;
- 19% in regional SA*;
- 29% 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.

Figure 2. Diagnoses of newly enrolled Register patients, 2013 - 2017
There were 20 diagnoses of RHD enrolled on the Register in 2017:

- twelve people had existing RHD;
- eight were newly diagnosed with RHD, one at the time of their initial RF episode; and
- of those eight, seven had no previously known history of RF.

There were 18 diagnoses of RF in 2017, with five recurrences (Figure 3a). Four of these recurrences were in people who had stopped their benzathine penicillin, three in line with Australian guidelines and one ceased outside the guidelines. One recurrence occurred in a person who had been changed to the incorrect antibiotic. The age range of recurrences was 21-44 years. Most cases of RF were definite RF (Figure 3b) and were in 15-24 year olds (Figure 3c).

Figure 3a. RF Notifications to the Program

Figure 3b. RF Notifications to the Program, 2017, by RF status

Figure 3c. RF Notifications to the Program, 2017, by age at diagnosis
Figure 4. Register patients, by location, at December 31, 2017

Figure 5. Proportion of RF diagnoses, reported to the Program, by geographical location
Figure 4 shows the distribution of patients on the Register with large clusters in Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, Port Augusta and Adelaide. As with 2016, just over half of the new diagnoses of RF were in people from regional or urban South Australia (Figure 5). In all regions of SA the majority of patients are classified as having mild disease (Figure 6) with Urban SA having the highest proportion of patients classified as severe.

**Figure 6. Proportion of Register patients by region and severity of diagnosis, Dec 31, 2017**

![Proportion of Register patients by region and severity of diagnosis, Dec 31, 2017](image)

On average, SA patients received 86% of their scheduled doses of benzathine penicillin in 2017 (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 effective. However, the efforts of primary health care services must be recognised as having a crucial role in these improvements.

Figure 8 shows further improvements in adherence to secondary prophylaxis in 2017. However due to small numbers, any increases or decreases in adherence cannot be seen as significant. The proportion of patients on the Register who are receiving between 80% and 99%, and 100% of their required doses of benzathine penicillin continues to increase. The KPI is the number of people who receive over 80% of their injections, but this has been split to show the number of people receiving 100%. The proportion of patients who are receiving fewer than 50% of their required doses decreased slightly to 8%. Barriers to achieving good adherence to secondary prophylaxis include an often highly mobile patient population, the painful injection and high staff turnover.

**Figure 7. Average percentage adherence to secondary prophylaxis (Register patients), by year, 2012-2017**

![Average percentage adherence to secondary prophylaxis (Register patients), by year, 2012-2017](image)
Figure 8. Proportion of Register patients who received ≤50%, 50-79%, 80-99% and 100% of their scheduled secondary prophylaxis doses, by year

The Australian guideline for the prevention, diagnosis and management of rheumatic fever and rheumatic heart disease (2nd edition) recommends that Priority 1 (severe RHD) and Priority 2 (moderate RHD) 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, by year
Engagement with primary health care services

The Program provides support to individual health services through education and assistance with patient information management systems. In 2017, staff from the Program, or staff employed through the Program working for Nganampa Health Council or Aboriginal Health Council of SA, maintained close contact with all health services who have patients with RF and/or RHD on the Register, either through a site visit or phone contact where a visit was not possible.

Work undertaken 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 2017, engagement with private GP practices continued. There are now 16 private practices who are actively managing at least one person with RF or RHD. Work with these practices occurs primarily through practice nurses and the promotion of the Australian guidelines to support evidence based management.

Education and training

In addition to ongoing education with nursing, pharmacy and medical staff in hospitals, primary health care service staff and Certificate III and IV in Aboriginal and Torres Strait Islander Primary Health, there were two main focuses for education in 2017 – the SA RHD workshop and the development of an RHD orientation video.

More than 80 healthcare professionals attended the South
Australian RHD Education Workshop held 29 - 30 March 2017 at SAHMRI in Adelaide.

The workshop was developed with RHDAustralia, Heart Foundation SA, the Aboriginal Health Council of South Australia (AHCSA), SAHMRI and Country SA Primary Health Network (PHN), to provide an overview of RF and RHD and to educate participants on best-practice approaches to prevention, diagnosis and management. Content was provided through a combination of presentations by experts in the field and practical clinical sessions. The workshop concluded with patients and families living with RHD talking about their personal experiences. This was a powerful reminder of the importance of early diagnosis, best practice management and culturally appropriate care. Participants included nurses, midwives, Aboriginal Health Workers, doctors, Aboriginal liaison officers and allied health care professionals; participants came from Adelaide metro areas and regional and remote South Australia. Thanks to support from AHCSA, there was representation from each of the Aboriginal Community Controlled Health Services in South Australia.

In 2017 the Program developed a new RHD introduction video aimed at raising awareness amongst health care workers about the ongoing existence of RHD in SA by pairing a family story with a brief clinical summary of RHD. Viewers were also directed to further resources available, including the SA Program. The short compelling video can be accessed on You Tube via https://youtu.be/BrZLvBEHZjk.

The Program now routinely visits all new children diagnosed with RF, and their families, at the Women’s and Children’s Hospital to undertake comprehensive education, including the provision of resources and support material.

There has been ongoing education for Certificate III and Certificate IV in Aboriginal and Torres Strait Islander Primary Health Care students, primary health care staff, and nursing, dental and medical staff within SA hospitals.

The Program’s Education Calendar “Don’t miss out on the things you love”, launched in November 2015, was evaluated using a questionnaire that was emailed out to a sample of Aboriginal primary health care staff.

Response highlights are below:

- All respondents reported that the calendar was very easy to use. In particular staff reported that their patients liked the simple illustrations.
- Staff reported having the calendar on their desk was a good prompt to start a conversation with RHD patients.
- All respondents said that it increased their confidence in delivering education about the need for ongoing secondary prophylaxis. Staff liked that the information was on the back of the calendar and they didn’t have to remember off the top of their head.
- Staff found it beneficial in explaining the importance of having the injections on a regular basis and felt it motivated their patients to have their injections to some degree.
- Respondents stated that patients particularly enjoyed that images were of local people.
- Feedback resulted in the calendar being turned into a pocket-size notebook for convenience and wider dissemination.

Future directions

In 2018 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 improving patient outcomes and 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 through the Commonwealth Government’s Rheumatic Fever Strategy (RFS). At the time of this report, South Australia is awaiting the formal offer of the National Partnership Agreement for the RFS, for 2017 – 2021, from the Commonwealth.