



South Australian Rheumatic Heart Disease Control Program

Annual Report 2020

Prepared for the SA RHD Program
Advisory Group



Government
of South Australia

SA Health

Summary

Rheumatic heart disease (RHD) results from one or more episodes of acute rheumatic fever (ARF). ARF 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 five years) for those who with a previous history of ARF or RHD (known as secondary prophylaxis). Aboriginal and Torres Strait Islander populations have some of the highest rates of diagnosed ARF 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 ARF/RHD case detection and surveillance activities. Guidance is provided by the RHD Program Advisory Group, comprised of key stakeholders from across the state. Specific objectives are to:

- maintain the state-wide RHD Register (the Register)
- support local health services to manage patients with ARF/RHD through local registers and recall systems that share data with the Register
- facilitate education of the clinical workforce in case recognition and clinical follow-up in line with Australia guidelines <https://www.rhdaustralia.org.au/arf-rhd-guideline>
- increase awareness of ARF and RHD among high risk populations

Significant achievements in 2020 include:

- Dissemination of the 2020 Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (3rd edition) (the Guideline)
- Separation of the Register from the Northern Territory
- Stronger relationships with SA Dental Service
- Improved exchange of information with SA public hospitals
- A full day workshop on the delivery of benzathine benzylpenicillin(BPG) injections, based on the recommendations in the Guideline
- Participation on the Aboriginal Environmental Health Framework Committee
- Recruitment of a new position within the Program for clinic engagement and support
- Engaging the services of a woman living with RHD to support training and education of health professionals

Challenges for the Program in 2020 included:

- Ensuring meaningful engagement with an increasing number of clinics, as numbers on the Register increase. The total number of clinics on the Register with at least one patient is 66, with an additional six clinics in contact with the Program regarding patients who attended their service for part of the year.
- A continued increase in the number of people on the Register using private General Practice (GP). In 2020 the number of private GPs with at least one patient rose by 13 to a total of 36. Private GPs often require more intense and ongoing education and support, as they may not have treated or managed an ARF/RHD patient previously.
- The high number of patients who regularly move between jurisdictions creates time-critical follow up work to seek and exchange current treatment and social information that may influence patient care.
- Seeking out opportunities for patient, family and community engagement to increase awareness and understanding of ARF and RHD. Empowering individuals and communities in how to reduce transmission of Group A *Streptococcus* (GAS) and when to seek appropriate treatment for skin sores and sore throats is crucial, yet it is often difficult to reach these audiences.
- Receiving accurate and timely information on when someone on the Register has an echocardiogram, specialist review or hospital admission.

Strategies to address challenges and maximise outcomes:

- ✓ Continued development of partnerships with key stakeholders who are experts in health coordination, patient recall systems, clinician education, health service capacity building and cultural safety.
- ✓ Work collaboratively with other organisations such as the Trachoma Program, Deadly Kids and the Heart Foundation to mutually value-add to patient outcomes.
- ✓ Maintain the excellent relationships with other jurisdictional RHD programs for ease of communication and information exchange.
- ✓ Negotiate access to hospital systems such as Sunrise, to increase identification of cases at diagnosis/admission and access to echocardiography.
- ✓ Increase engagement with the GP workforce, including practice nurses.

RHD Program Advisory Group

The RHD Program Advisory Group (PAG) is comprised of interested parties across SA including members from the Aboriginal Community Controlled Sector, Heart Foundation, RHD Australia, South Australian Health and Medical Research Institute (SAHMRI), Royal Flying Doctor Service and Local Health Networks. There has been an increase in the representation of Aboriginal and Torres Strait Islander persons on the SA RHD PAG, which now has five people who identify as Aboriginal on the group, out of a total of 20 people.

PAG meetings were held in April and November of 2020 and minutes were documented as per the Terms of Reference. Members also provided out of session advice when required.

The PAG is an important source of advice and guidance for the Program on policy and service delivery matters. The Program benefits from the expertise of members through networking, dissemination of information and current health care and research knowledge.

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 ARF/RHD. The Register includes patients with new, recurrent, probable or possible episodes of ARF, and/or definite or borderline RHD, based on the case definition in the Australian guidelines. The Register collects information based on national standards and provides data annually to the Australian Institute of Health and Welfare (AIHW) for national monitoring and reporting of ARF and RHD. 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 ARF/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 Program.

The Register provides an ongoing role in coordination of care of patients who are moving between clinics or moving between SA, Northern Territory and Western Australia. The Program promotes the Register to all health professionals and encourages use of the Register to improve data accuracy.

A big focus of 2020 was the development of the SA RHD Register following separation from the Northern Territory (NT) Register platform. Since 2012, the SA Program has been recording data relating to SA patients with ARF and RHD on the NT electronic platform, known as the NT RHD Register, under a Memorandum of Agreement between the two health departments. The NT received legal advice in November 2019 that the storage of SA patient information on their

Register is in breach of the Information Act 2002 (NT). A memo from the Chief Executive, NT Health, was sent to the Chief Executive, SA Health advising that SA data must be removed from the NT RHD Register.

A significant amount of work was undertaken to find, develop and implement a suitable solution for SA. Following advice from information technology experts and public health specialists, it was decided that SA Register data will be stored on the SA Health server using a copy of the NT database application fields, to be known as the SA RHD Register.

The SA Register officially split from the NT on 10 December 2020. All communication and resources about the register were updated accordingly. Register governance has remained unchanged. Work is underway to develop reports to allow Program functions to continue.

The SA Program works closely with the NT to manage the flow of patient information for people who travel frequently across the border, to ensure that a complete and accurate record of SA patient data is available to health care workers treating these people.

Work continues to improve the flow of information from hospitals to the SA Register. Further to earlier gains that were made through the availability of information of ARF/RHD admissions via ICD code reports, and access to inpatient echocardiography systems at all public hospitals, the Program has developed a strong relationship with the Aboriginal heart and lung nurse at a major public hospital in Adelaide. This relationship has enabled wider system changes such as the inclusion of a tick box on the echocardiogram referral form advising notification to the Register if the patient has a known or suspected history of RHD (see Image 1), and work towards the inclusion of RHD as a precaution on the hospital's patient management system.

Image 1. Screen shot of the CALHN echocardiogram referral form

The screenshot shows a web-based form for an echocardiogram referral. It includes the following fields:

- Requested Time Frame: [Dropdown menu]
- Scheduling Instructions: [Text input field]
- Clinical Urgency Inpatient: [Dropdown menu, value: Inpatient < 24hrs]
- Clinical Urgency Outpatient: [Dropdown menu]
- Common Indication: [Dropdown menu, value: Ischaemic Heart Disease / Myoca]
- Other Details: [Text input field]
- Agitated Saline: [Dropdown menu]
- Contrast Required: [Dropdown menu]
- Specify: [Text input field]
- Suspected/Known Rheumatic Heart Disease: [Dropdown menu, value: NO]
- if YES, please contact the Rheumatic Heart Disease Progr: [Checkbox]

Register Statistics

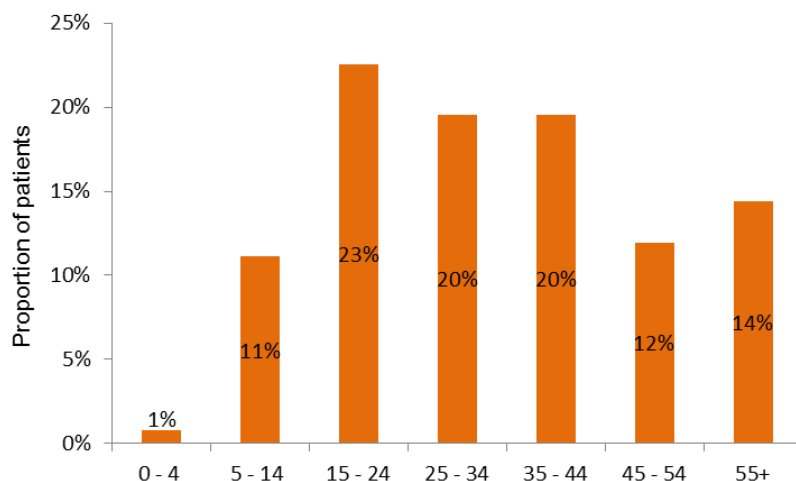
The number of patients on the Register continues to increase with 369 patients registered at the end of 2020. Of these 369 patients:

- 66% are female
- 57% are under 35 years of age
- 52% are located in remote SA, 18% in regional SA, and 30% in urban SA*
- 89% identify as Aboriginal or Torres Strait Islander Australians.

Other ethnicities include migrants from countries such as Somalia, Iran, Burma, Afghanistan, Bhutan, Pakistan, Ethiopia, Kenya and Israel, as well as 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 1. Age breakdown of Register patients, 31 Dec 2020



In 2020, 31 diagnoses of ARF and 18 diagnoses of RHD added to the Register (Figure 2). This is a very large increase in the number of ARF reported to the Program and the Program is exploring possible reasons for this increase. Of the 18 cases of RHD:

- five cases were diagnosed at the time of their first known episode of ARF, age range 5 – 25 years
- thirteen cases were new diagnoses without a known history of ARF, age range 8 – 72 years
- two cases were classified as borderline RHD, aged 8 and 11 years
- all but one identified as Aboriginal

There were 31 cases of ARF notified to the Program in 2019, with the majority of these in children aged 5 – 14 years (Figure 3) and from remote SA (Figure 4). There were six recurrences, all in people currently prescribed secondary prophylaxis. The 31 cases reported to the Register this year included nine probable cases of ARF and five possible cases of ARF. An increase was seen in the number of ARF cases in people residing in urban Adelaide and this has been raised with public health doctors in SA Health and the Aboriginal Health Council of SA as something to be noted. Education continues to ensure staff are aware that cases are occurring in urban areas.

There were four deaths recorded in Register patients in 2020, one attributable to RHD, aged 35. All four deaths occurred in people who were Aboriginal, with an age range of 35 - 82 years.

Figure 2. Diagnoses of newly enrolled Register patients, South Australia, 2016 - 2020

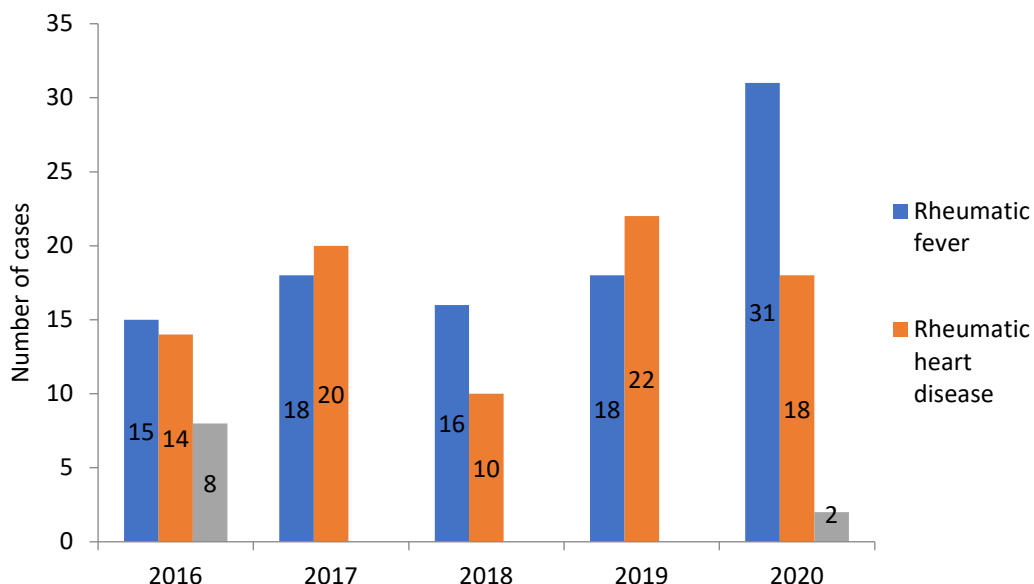


Figure 3. Cases of ARF and RHD added to the Register, by age group and type, South Australia, 2020

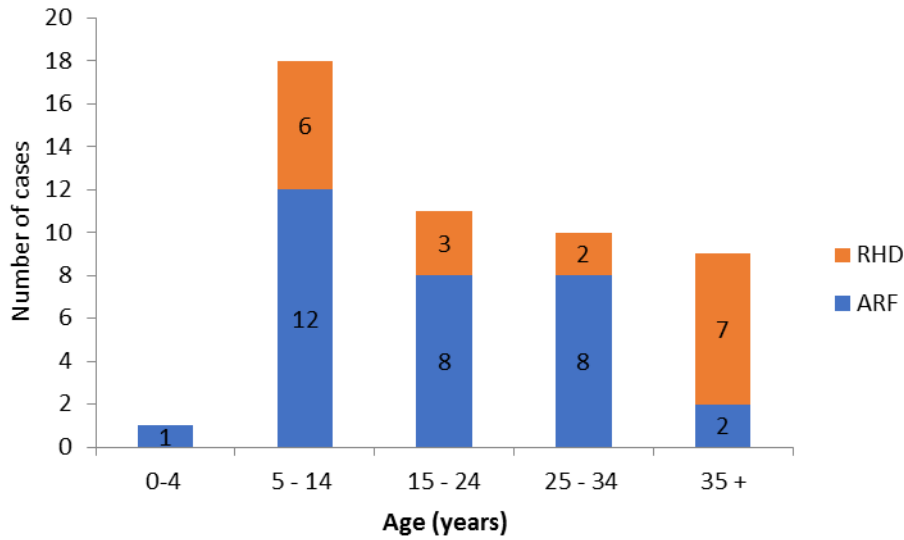


Figure 4. ARF Notifications to the Program, South Australia, 2020, by geographical location

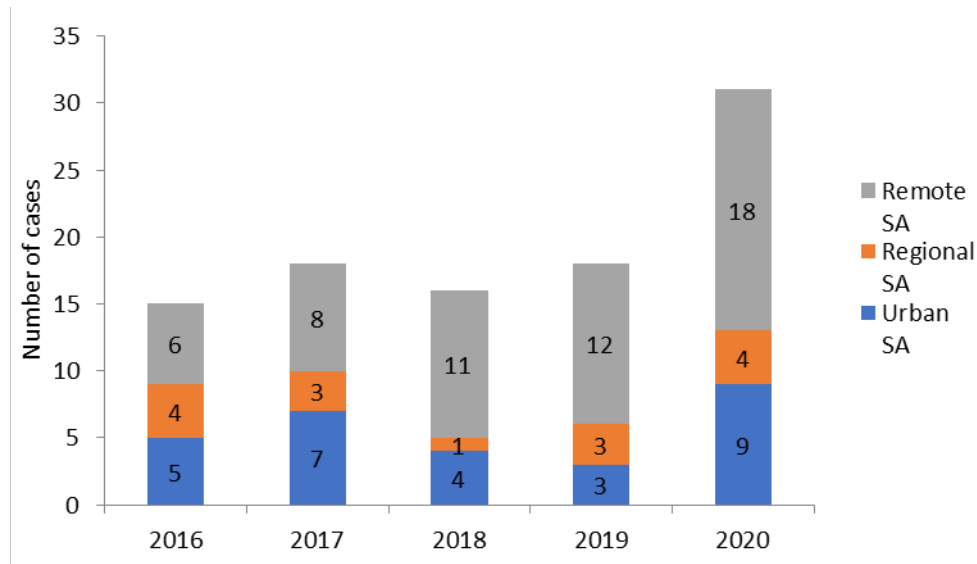


Figure 5. ARF Notifications to the Program, South Australia, 2020, by type

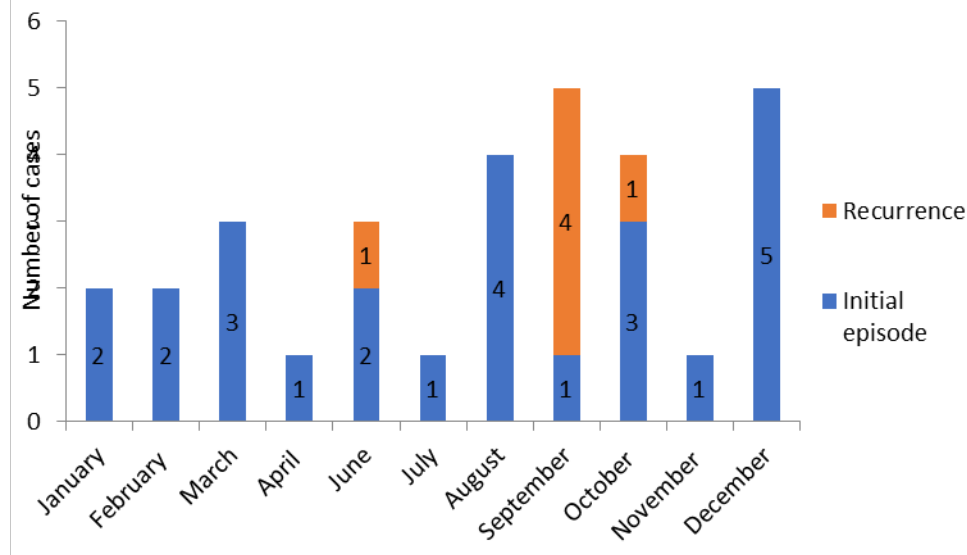
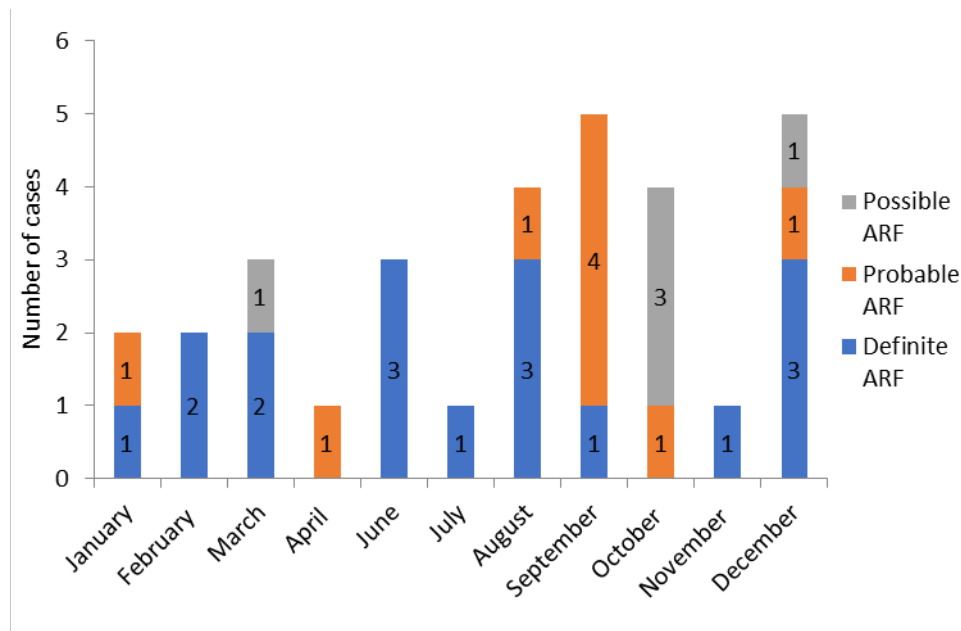
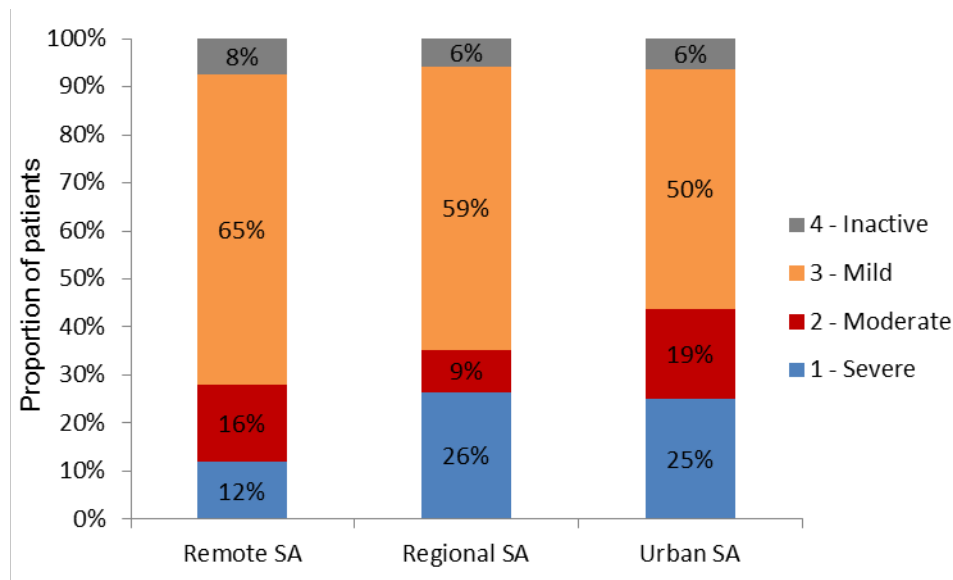


Figure 6. ARF Notifications to the Program, South Australia, 2020, by ARF status



In all regions of SA the majority of patients are classified as having mild disease (Figure 7), with remote SA having the least proportion of patients classified as severe. This may be reflective of the decision made by many families to move to Adelaide to be closer to specialists and tertiary hospitals.

Figure 7. Proportion of Register patients by region and severity of diagnosis, Dec 31, 2020



At the end of December 2020, there were 179 patients on the SA Register scheduled for secondary prophylaxis treatment with penicillin injections (46% of all patients on the Register), with nine of these patients on oral penicillin.

On average, SA patients received 78% of their scheduled doses of BPG in 2020 (Figure 8). Mean adherence has remained stable, however small increases or decreases in adherence must be interpreted with caution owing to the small overall patient numbers.

Given there were many people out of community and unable to get home for a significant part of the year, the Program worked closely with the camps set up to host people away from community to ensure that patients received the required injections.

There has been a slight increase in the number of people receiving 100% and a slight decrease in the number of people receiving under 50% of scheduled doses (Figure 9). Barriers to achieving

optimal adherence include:

- an often highly mobile and vulnerable patient population
- the pain associated with the injection
- high staff turnover in the Aboriginal PHC sector, which can impact on building long-term relationships with patients
- a low awareness of ARF/RHD, particularly in clinicians who have not worked in Aboriginal health previously.

Figure 8. Average percentage adherence to secondary prophylaxis for Register patients, by year, South Australia, 2016-2020

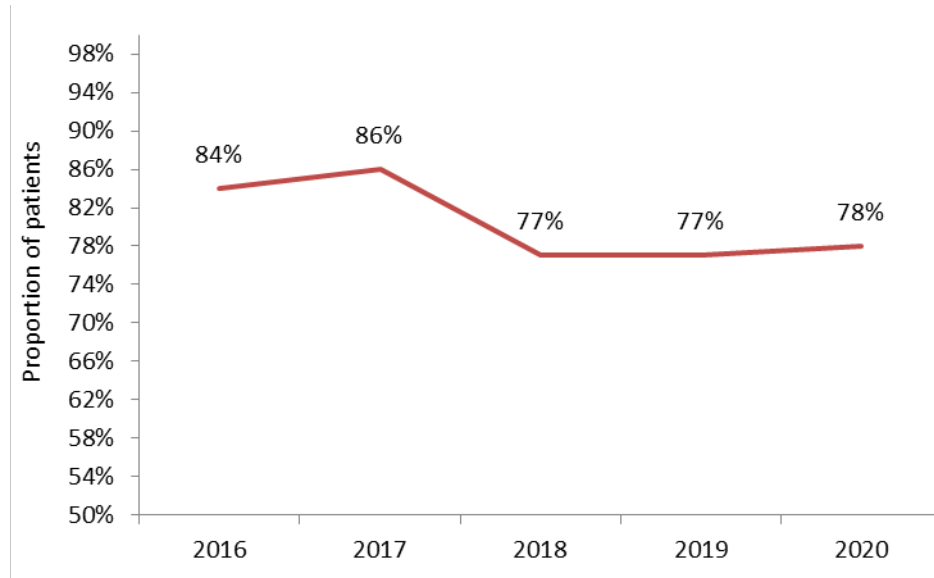


Figure 9. Proportion of Register patients who received ≤50%, 50-79%, 80-99% and 100% of their scheduled secondary prophylaxis doses, by year, South Australia, 2016-2020

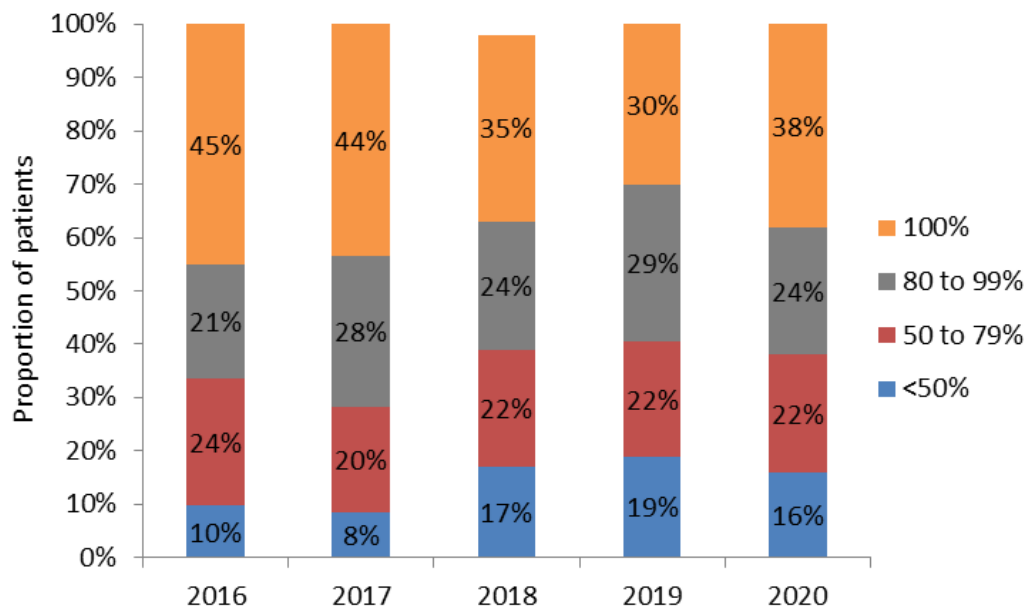
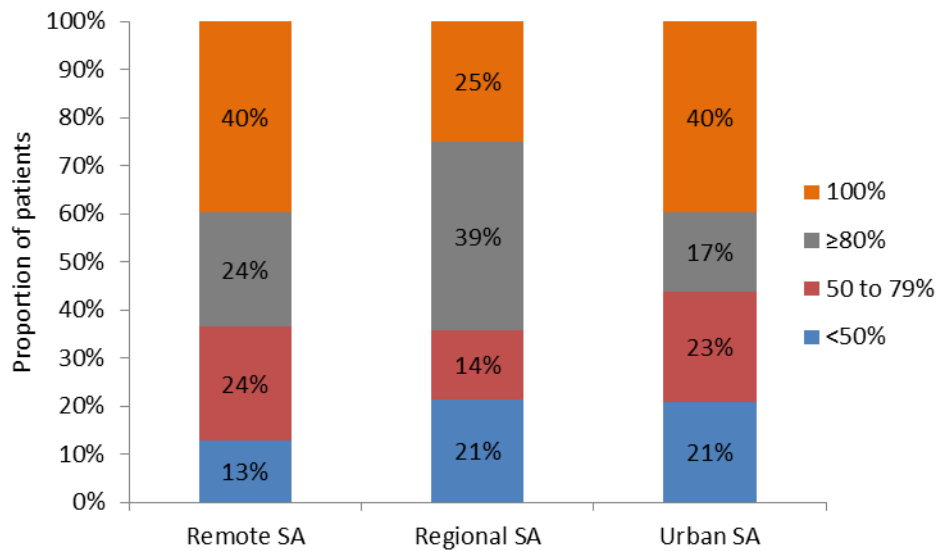


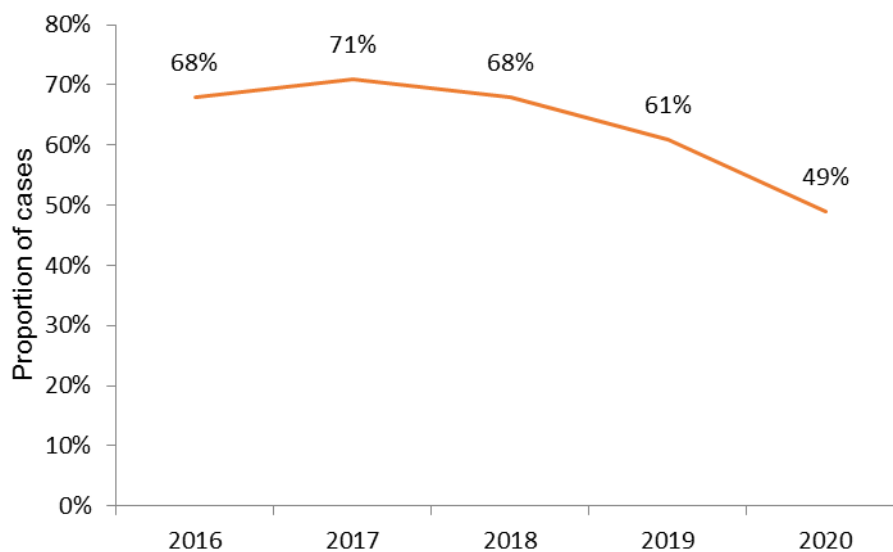
Figure 10. Proportion of Register patients who received ≤50%, 50-79%, 80-99% and 100% of their scheduled secondary prophylaxis doses, 2020, by region



The Australian guideline recommends that echocardiogram and cardiology review occur for Priority 1 (severe RHD) and Priority 2 (moderate RHD) patients every six months and every year respectively.

Data on the Register shows a downward trend in the proportion of Register patients receiving an echocardiogram in line with recommendations as above (Figure 11). It must be noted that these data reflect only what has been reported to the Register, however this is concerning. There are many challenges to patients receiving timely echocardiography including distance, lack of coordinated care, extended family responsibilities, poor understanding of the importance of echocardiography and lack of culturally safe health services. In 2020, many of the outreach clinics in regional and remote SA were cancelled or postponed due to COVID which may in part explain the large decrease in the proportion of patients receiving timely echo.

Figure 11. Proportion of Priority 1 and Priority 2 patients on the Register who received serial echocardiography within the six months, by year, South Australia, 2016-2020



Engagement with Primary Health Care Services

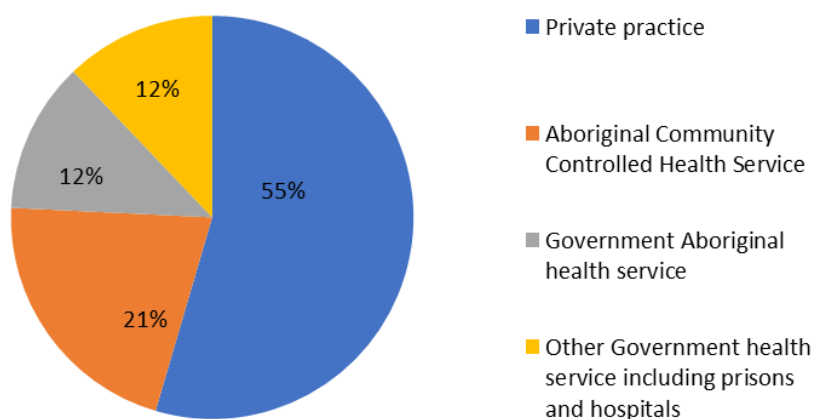
The Program provides support to individual health services through education and assistance with patient information management systems. Support visits focus on ensuring RHD management plans are in place and use of the Register. Outcomes are greatly assisted by the expertise and coordination activities provided by RHD projects at Nganampa Health Council (NHC) and Aboriginal Health Council of SA, funded through the Program.

Access to communities was restricted and health services were focused on their processes for managing COVID-19. In 2020, the majority of this support occurred over the phone as the usual process of reviewing patient files in each clinic could not be undertaken. However the staff at the PHC services were receptive to our calls and appreciated the efforts made to assist them with their patient lists.

The Program also supported RHD Australia in the dissemination of the Guideline, which was released in February 2020. There are some significant changes to recommendations around duration of secondary prophylaxis and priority classifications and routine follow up so it was crucial for the Program to liaise with PHC services about these changes. Any substantial changes to patient care were always following specialist review.

Across 2020 the number of people on the Register who accessed private GPs for their PHC increased by 13 to a total of 36, comprising 55% of all health services on the Register (Figure 6). Private GPs and practice nurses are more likely to be located in lower prevalence areas and may not have treated or managed an ARF/RHD patient previously. They often require more intense and ongoing education and support in the treatment and management of patients with ARF/RHD. Eleven percent of patients on the Register are listed as having an unknown health service, slightly down from 2019. The Program continues to attempt to identify the whereabouts of all patients in the unknown category, through contact with previous health services and other jurisdictions.

Figure 12: Total SA clinics with active patients – clinic type by percentage.



Education and training

Initial education for patients and families continues to occur for all new ARF and RHD patients, and ongoing education is provided at outpatient clinics, primary health care services and during hospital admissions whenever possible. One challenge to providing timely education at diagnosis is that patients may be discharged prior to the Program being notified of their diagnosis and hospitalisation. When this occurs, the Program follows up the family through their GP or PHC provider, and liaises with hospital staff to promote the role of the Program and offer education.

Due to COVID-19 the Program did not undertake any education at community events in 2020.

All education was significantly affected by the COVID-19 pandemic with only 25 sessions held for

the year (Figure 16). Access to communities was restricted and health services were focused on their processes for managing COVID-19.

Face to face delivery of training to the clinical workforce around ARF/RHD prevention, diagnosis and management was limited to urban settings only. Education with staff in regional and remote areas occurred over the phone or via video link.

In response to changes in the Guideline and requests from health professionals, the Program held a full day workshop on the delivery of BPG in September 2020. This workshop provided information on the different injection sites for administering BPG as well as strategies that may minimise pain of the injection. Information was also provided about diagnosis and management of RHD as per the Guidelines. Feedback from the day was very positive and many nurses report now using a different injection site and pain management strategies in their practice as a result of the workshop. Another workshop was planned for November but this was cancelled due to a state-wide COVID lockdown and was rescheduled for 2021.

Image 2. September 2020 workshop on delivery of benzathine benzylpenicillin (BPG)



The RHDAustralia (RHDA) e-learning education modules, the Guideline and the diagnosis phone app are promoted by the Program during all training sessions. By the end of 2020, RHDA reported that 236 SA based health staff had accessed their online education modules, up from 185 in 2019. Given the competing priorities of COVID in 2020, this was a satisfying result.

Figure 13: Face to face education sessions provided by the Program, by type, 2020

Provider type	Number of sessions
Nurses - Registered, Enrolled, Midwives	11
Aboriginal Health Workers / Practitioners	5
Child Protection, Prison, Residential Care staff	3
Patients and family members	2
GP Private Practice	1
Public Health Registrars	1
Pharmacists	1
Aboriginal Education Workers, Teachers	1
Total	25

Future directions

The Program will continue to maintain the Register and strengthen the capacity of primary health care services to ensure that people with ARF/RHD are managed in line with best practice. In 2021 a focus will be on the following areas:

- Continue to work with hospitals to improve the flow of information with the Register.
- Development of a community resource to increase awareness around the importance of getting GAS infections treated.
- Work with new stakeholders including Housing SA, non-government organisations such as Anglicare and Uniting Care Wesley, Department of Child Protection and community groups to deliver messaging around prevention of ARF, in particular treating GAS and managing household crowding and home hygiene.
- Continue to hold workshops on the delivery of BPG injections.
- Deliver GP education including a Royal Australian College of General Practitioners accredited education event in Port Augusta, and an online education workshop together with Heart Foundation and RHD Australia.
- Re-establish the presence of the RHD Program in regional and remote SA following the absence due to COVID-19 through attendance at community events and working with the community to develop a new resource.