SA Rheumatic Heart Disease Control Program

2022 Annual Report

Prepared for the RHD Program Advisory Group

May 2023

Government of South Australia

SA Health

SA RHD Control Program

Acute rheumatic fever (ARF) is an illness that may occur after a bacterial infection with group A Streptococcus (GAS) bacteria. This is often a sore throat, tonsillitis, or skin infection. Rheumatic heart disease (RHD) occurs as a complication of ARF. For more information see www.sahealth.sa.gov.au/youvegotwhat

The aim of the South Australian (SA) RHD Control Program (the Program) is to reduce morbidity and mortality associated with ARF and RHD through monitoring and improving delivery of secondary prophylaxis (benzathine benzylpenicillin), enhancing coordination of care, delivering educational activities and increasing ARF/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 ARF 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 primary prevention strategies.
- increase awareness of group A streptococcal infection and primordial prevention in the context of ARF and RHD among high-risk populations.

Program overview for 2022

Significant achievements include:

- Completion and dissemination of resources on group A streptococcal infections that were developed in consultation with the community, for the community.
- A suite of reports readily accessible for Program staff to use with primary health care, program monitoring and data provision to health professionals and stakeholders.
- An upgrade to the Register to allow data collection on disease severity rating as well as current priority classification, bringing it in line with recommendations in the Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (3rd edition).
- Creating an avenue for non-government organisations to have access to the Register.

The RHD Program within the Communicable Disease Control Branch of SA Health has found having an Aboriginal team member in our Program has been an extremely valuable addition, broadening our cultural understanding as a team as well as improving our engagement with clients and increasing stakeholder engagement with the Program.

Despite the challenges of COVID-19, the Program was able to maintain its strong relationships with key stakeholders and continue to have a strong presence in the Aboriginal primary health care sector, both Government and Aboriginal Community Controlled Health Services, with the provision of telephone support, assistance with audits, and staff training where possible.

The Register continues to grow with 527 confirmed cases of RHD and/or ARF enrolled on the Register at December 31, 2022, compared to 475 at the end of 2021. There were 27 diagnoses of ARF, 16 diagnoses of new RHD and 2 diagnoses of borderline RHD, in South Australians in 2022, as reported to the Register.

RHD Program Advisory Group

The Program Advisory Group is comprised of interested parties across SA including members from the Aboriginal Community Controlled Sector, Heart Foundation, RHDAustralia, 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 Program Advisory Group. The Program Advisory Group is an important source of advice and guidance on all policy, program, and service delivery matters. Additionally, the expertise on the Program Advisory Group means that the RHD

Program benefits from increased networks, enhanced dissemination of information and up to date and 'on the ground' health care and research knowledge and advice.

The Program Advisory Group met in May and November in 2022 and considered a range of issues and opportunities for the Program, such as development of the SA RHD Register, the impacts of COVID-19 on health services, implications of the new recommendations regarding borderline RHD and the revised case review group.

Members also provided out of session advice when required.

Register statistics as of 31st December 2022

Surveillance

The number of patients on the Register continues to increase with 527 patients registered as of 31 Dec 2022. Of these 527 patients:

- 65% are female.
- 59% are under 35 years of age.
- 40% reside in remote* SA, 15% reside in regional* SA, and 28% reside in urban* SA. The remainder are based outside SA but visit SA on occasion for health care.
- 88% identify as Aboriginal or Torres Strait Islanders.

Other ethnicities include migrants from countries such as Cambodia, Somalia, Iran, Burma, Afghanistan, Bhutan, Pakistan, Ethiopia, Kenya, Philippines, and Israel, as well as Caucasian Australians.

In 2022, 27 diagnoses of ARF and 18 new diagnoses of RHD (including two borderline diagnoses) were added to the Register for SA patients (Figure 1).

Of the 27 cases of ARF notified to the Program in 2022, the majority of these were in children aged 5 to 14 years (Figure 2) and from remote SA (Figure 3). Of these 27 cases, six were probable ARF and three were possible ARF. There were seven recurrences reported in 2022, most likely reflecting the low adherence figures.

There were three RHD deaths recorded on the Register, in SA patients, in 2022.

*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: ARF cases in persons who receive care in SA reported to the Register, by type, South Australia, 2018-2022

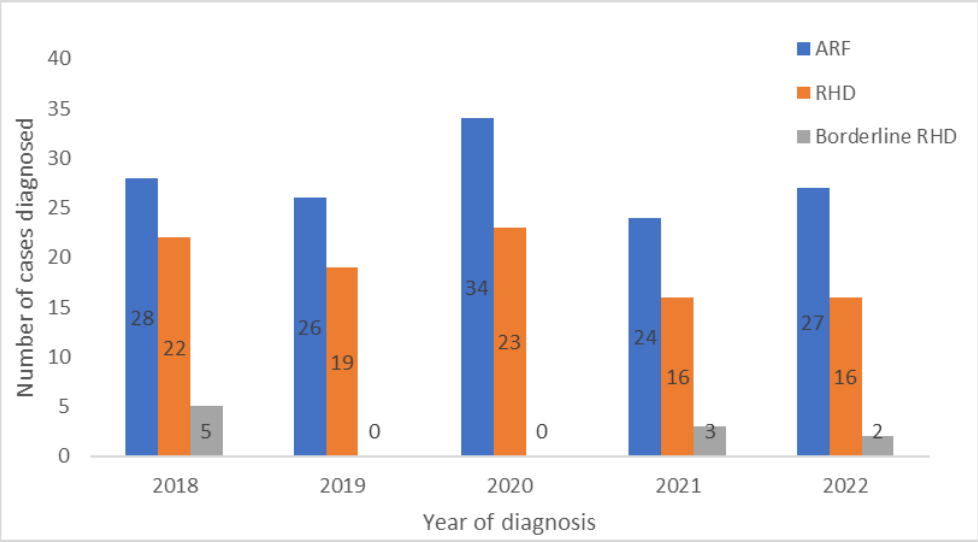


Figure 2: ARF cases in SA residents reported to the Register, by age at diagnosis and type, South Australia, 2022

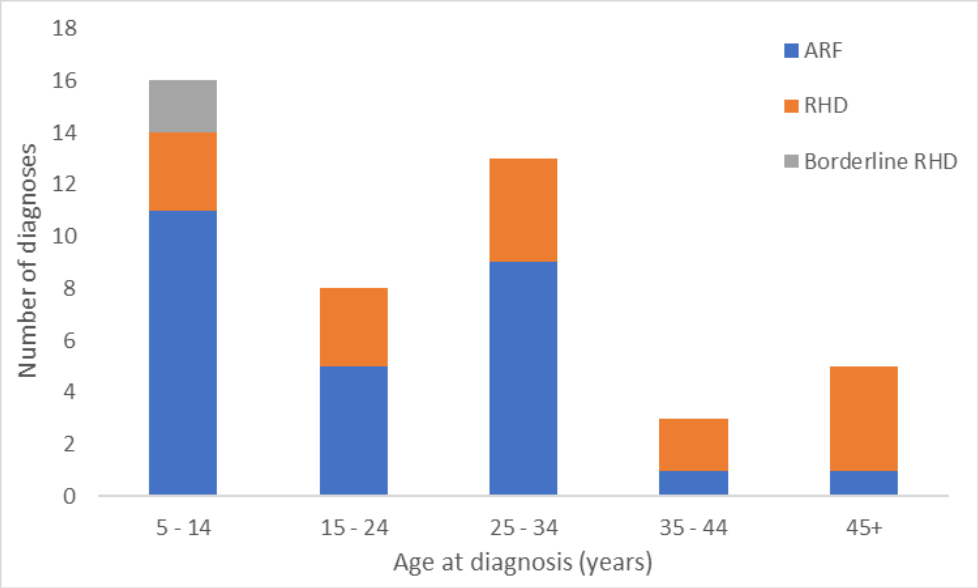
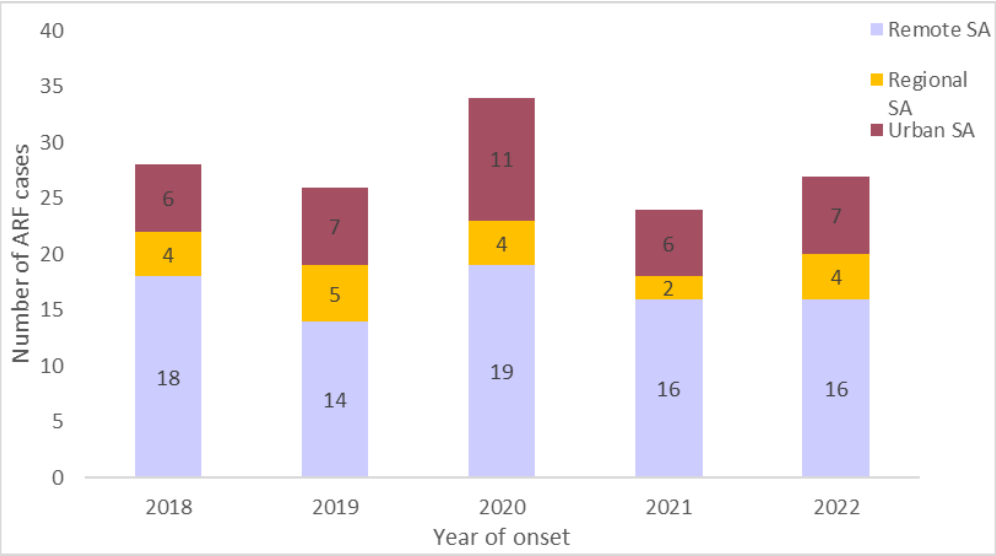


Figure 3: ARF cases in SA residents reported to the Register, by remoteness classification and year of onset, South Australia, 2018-2022



Adherence to prophylaxis

Many patients with ARF and RHD are recommended to receive regular antibiotics (usually penicillin) every 3-4 weeks to minimise the risk of further episodes of ARF and progression of RHD. This is called secondary prophylaxis. At the end of December 2022, there were 215 patients on the Register scheduled for secondary prophylaxis treatment with penicillin injections, and an additional 15 patients on oral penicillin.

In 2022, 41% of patients received at least 80% of recommended benzathine benzylpenicillin (BPG) doses, this is a decrease compared with 2021 when 48% of patients attained the same level of adherence. The proportion of people receiving 100% of BPG doses decreased from 28% in 2021 to 23% in 2022, while the proportion of people who received less than 50% of recommended doses increased from 25% to 32% (Figure 4).

When analysed by region, patients living in urban SA had the highest adherence percentage, and those living in remote SA had to lowest (Figure 5).

These changes must be interpreted with caution as the small number of patients scheduled to receive secondary prophylaxis in SA means that a small change in number of people receiving BPG has a large impact on percentage markers.

Figure 4: Delivery of secondary prophylaxis in SA residents reported to the Register, by adherence percentage, South Australia, 2017-2022

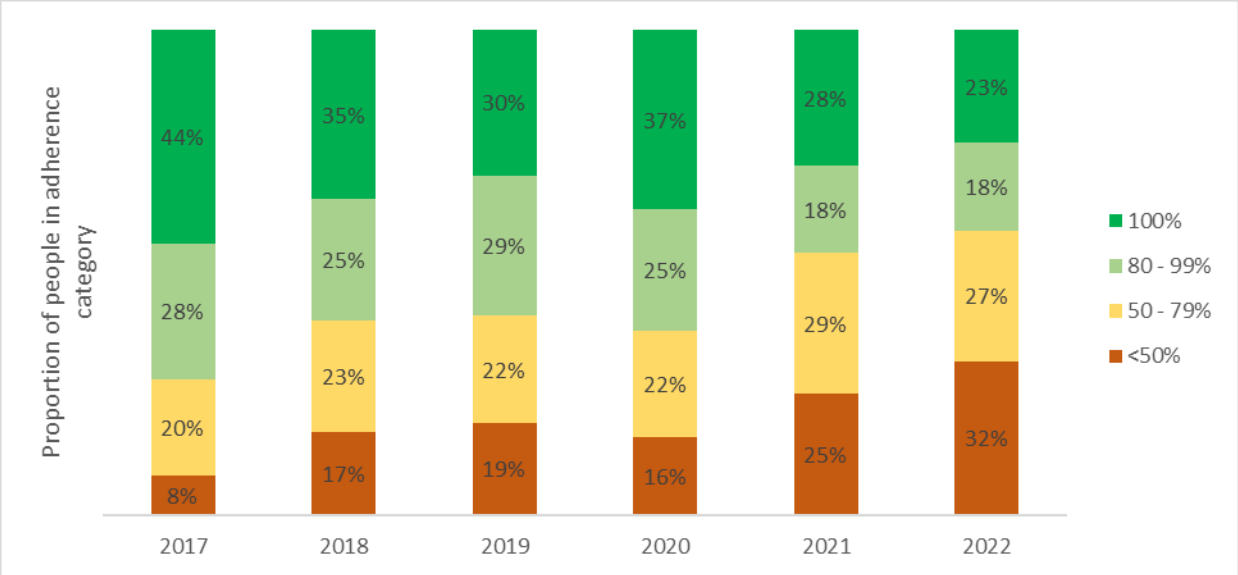
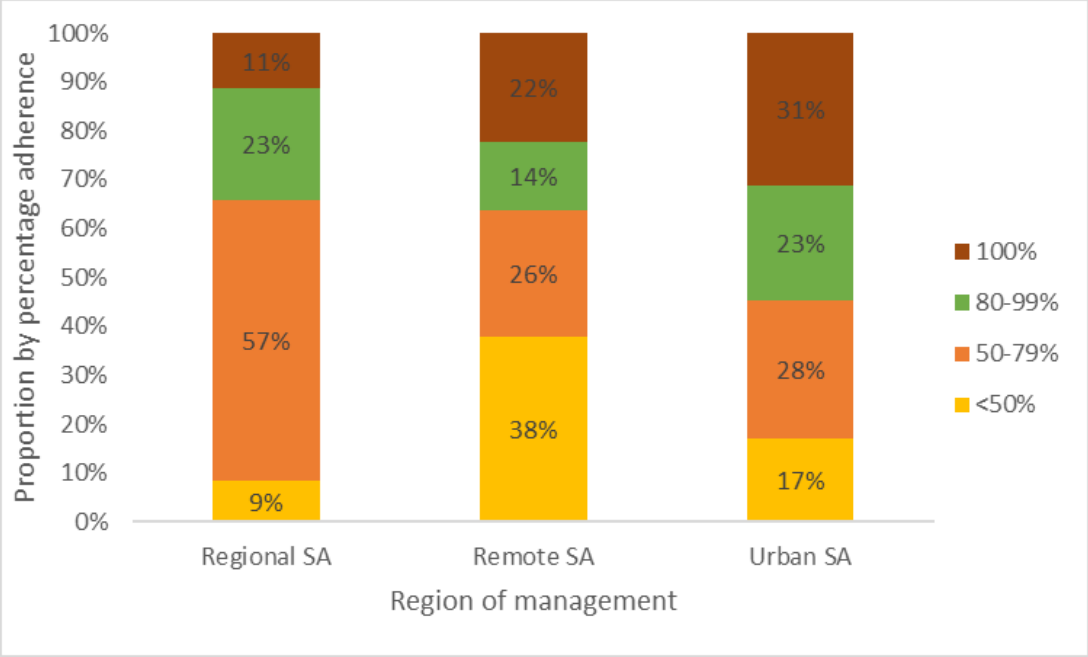


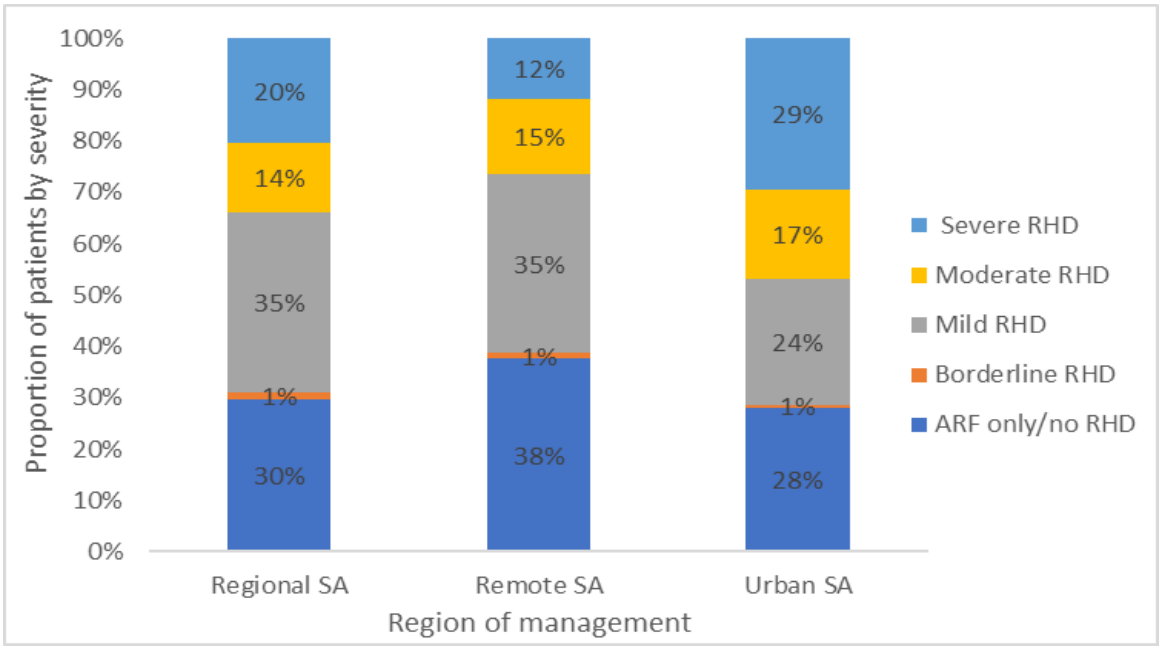
Figure 5: Delivery of secondary prophylaxis in SA residents reported to the Register, by adherence percentage and region, South Australia, 2022



Patient management

Register data in Figure 6 show that urban SA has the highest percentage of people living with severe RHD. This may be because some families choose to relocate to Adelaide due to the increased frequency of follow up when diagnosed with severe RHD (six monthly specialist reviews compared to three yearly for mild RHD).

Figure 6: RHD disease priority in SA residents reported to the Register, by region of management, South Australia, as at 31 December 2022



As per the Australian Guidelines, Patients with ARF and/or RHD require frequent echocardiography to monitor disease progression. Frequency depends on disease severity and whether that person is considered high risk for further episodes of ARF, and ranges from six monthly to three yearly. Accessing regular echocardiograms is often difficult in regional and remote areas of South Australia. This is reflected in the high proportion of regional patients being overdue for echocardiography (Figure 7). The exception is for patients living in the APY Lands, where there is a regular service provided and attendance is coordinated by local health staff. The high proportion of patients overdue for echocardiography in urban SA (Figure 7) may reflect access issues, transport issues or letters going to old addresses. Figure 8 shows that 71% of patients classified as Priority 1, and 56% of those classified as Priority 2 are overdue for echocardiography. Overdue status has been calculated as any patient more than three months overdue for echocardiography.

Figure 7: Echocardiography status in SA residents reported to the Register, by region of management, South Australia, as at 31 December 2022

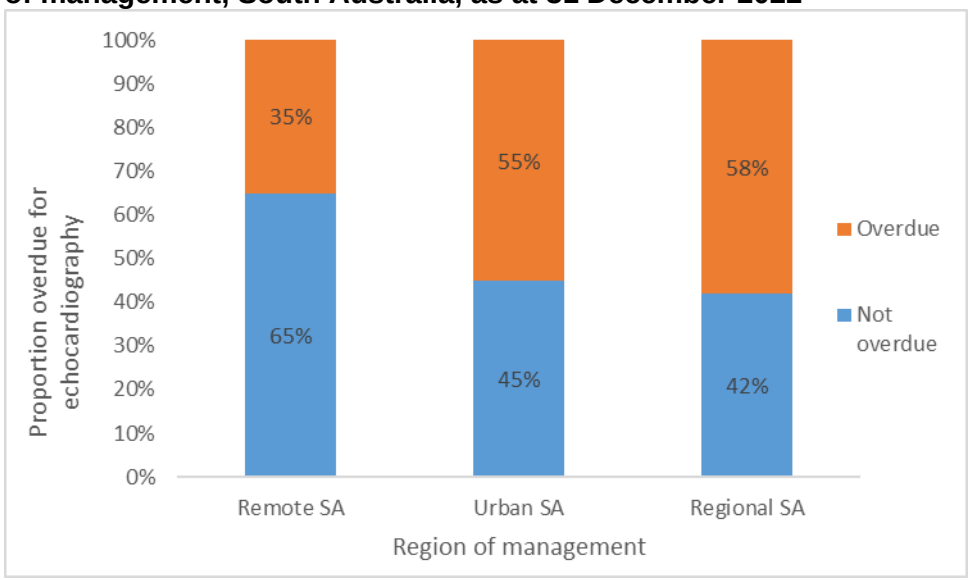
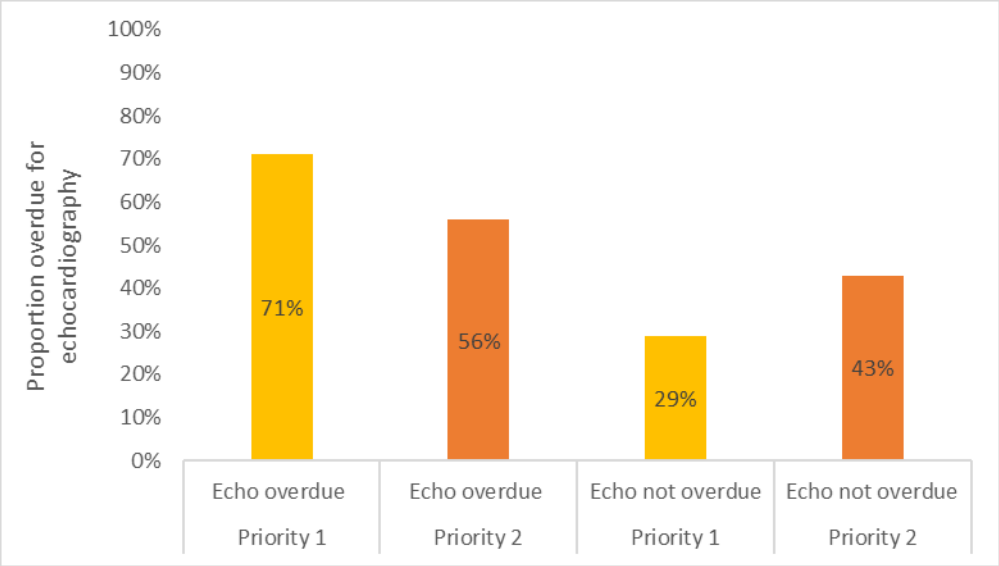
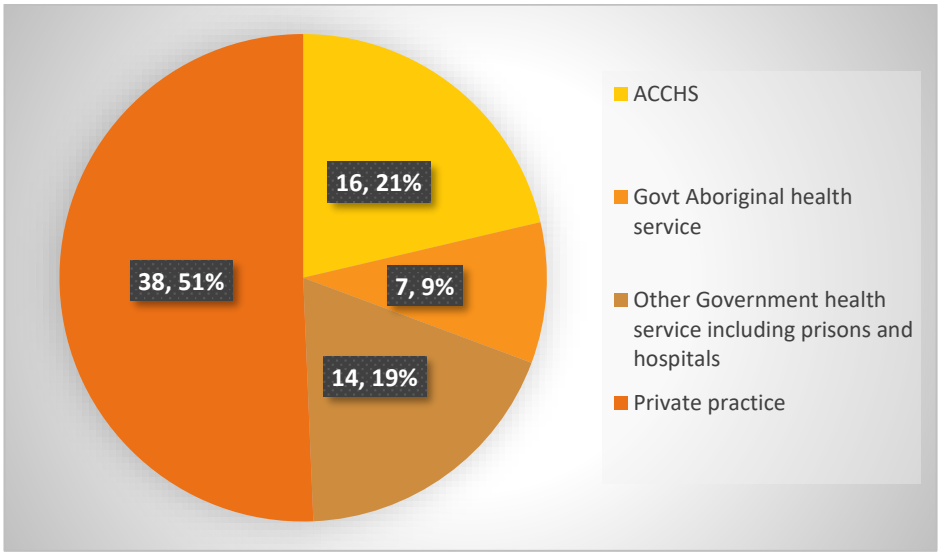


Figure 8: Echocardiography status in SA residents with RHD priority 1 or 2 reported to the Register, by priority, South Australia, as at 31 December 2022



The Program works with many private practices as part of providing support to primary health (Figure 9). Private general practitioners (GPs) and practice nurses are more likely to be in lower prevalence areas and may not have treated or managed an ARF/RHD patient previously. Given the lower ARF/RHD caseload, they often require more intense and ongoing education and support in the treatment and management of patients with ARF/RHD by RHD program staff. There were 31 patients on the Register listed as having an unknown health service in December 2022, down from 43 at the end of 2021. The Program has made a concerted effort to identify the whereabouts of all patients in the unknown category, through contact with previous health services, other jurisdictions and searching hospital records.

Figure 9: Total number of services with active Register patients, clinic type (count, percent), SA, December 2022.



Education

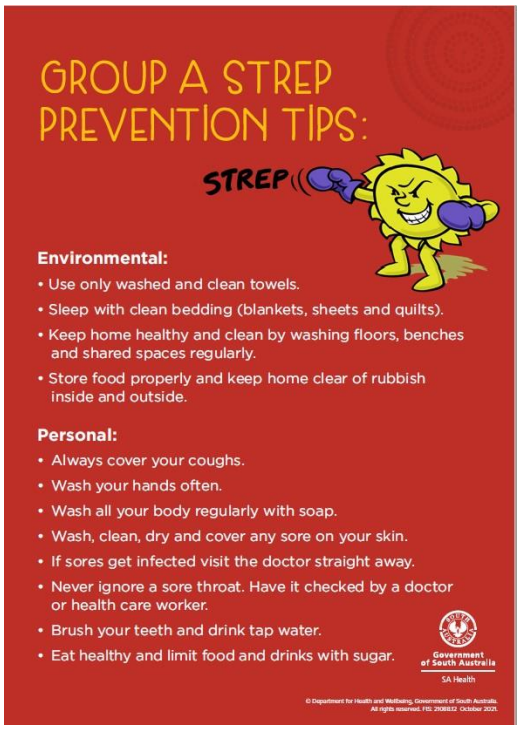
Patient and Community Education

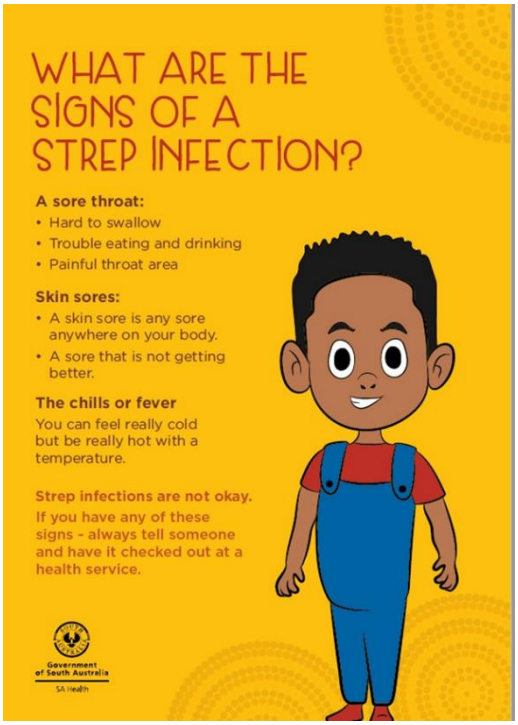
Initial education for patients and families continues to occur for all new ARF and RHD patients, and ongoing education is provided at outpatient clinics, primary health care services and during hospital admissions whenever possible. One challenge to providing timely education at diagnosis is that patients 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 primary healthcare provider and liaises with hospital staff to promote the role of the Program and offer education.

Resource development

Community consultation in the second half of 2021 identified that the Aboriginal community in in SA would benefit from targeted education to increase awareness of the importance of actively seeking treatment for sore throats and skin sores, and information about GAS. The Program worked with the community to develop the following resources, which were completed in 2022. These were provided to community groups, along with more detailed education, and are given out at education sessions and all community events attended by the Program.

Image 1. Resource cards promoting awareness of GAS





Health Care Providers

Education was less affected by the COVID-19 pandemic in 2022 than 2021, however in the latter half of the year due to staff resignation it was impacted by the Program not having a full complement of staff. A total of 64 sessions were delivered over the course of the year (Table 1).

Face to face delivery of training to the clinical workforce around ARF/RHD prevention, diagnosis and management was predominantly limited to urban settings although some regional centres were visited (Table 2). Education with staff in remote areas occurred over the phone or via video link.

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 2022, RHDA reported that 162 SA based health staff had accessed their online education modules, up from 81 in 2021. Students and Aboriginal health workers accounted for 60% of users.

There were a few medical practitioners who completed the Program in 2022 which may reflect increases in GP's workloads due to COVID-19 and reduced numbers of GP's state-wide.

The Program worked with RHDAustralia in the development of a poster encouraging health professionals to double swab for COVID and GAS in response to reports that patients with sore throats were being sent for COVID swabs only and not being assessed further, thus potentially missing an opportunity to prevent a potential ARF episode.

Image 2. Resource encouraging medical staff to swab for COVID and GAS

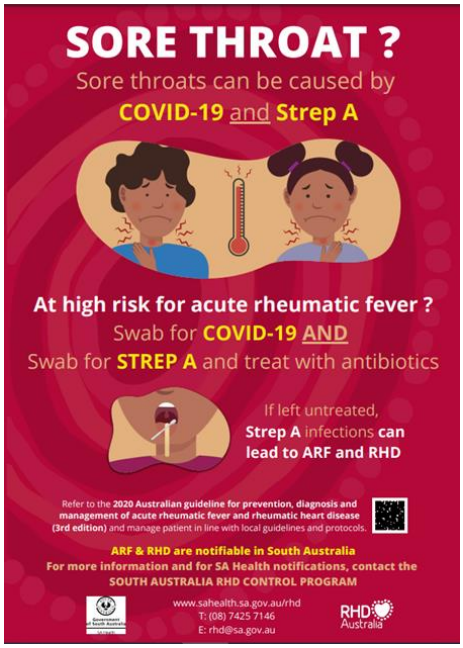


Table 1: Face to face education sessions provided by the Program, by audience, 2022

Provider type	Number of sessions
Nurses (registered and enrolled), midwives	11
New graduate nurses and midwives	8
Dentists, dental therapists	6
Aboriginal health workers / practitioners	4
Child protection, prison, residential care staff	4
Patients and family members	15
GP private practice	3
Pharmacists	2
Aboriginal education workers, teachers	6
Community	5
Total	**64**

Table 2: Face to face, or online education sessions provided by the Program, by region, 2022.

Region	Number of sessions
Urban	41
Regional	9
Remote	14
Total	**64**

Future directions for 2023

- Explore options for the development of a strategy for RHD in South Australia.
- Continue to work with hospitals to improve the flow of information with the Register.
- Increase engagement with the general practice workforce, including practice nurses and registrars.
- Host a state-wide workshop on ARF and RHD for health professionals in Adelaide.
- Host a workshop for non-health professionals in Adelaide to promote the importance of detecting and treating group A streptococcal infections early.
- Continue promotion and distribution of resources to increase awareness of GAS infections and treatments.
- Re-establish the presence of the Program in regional and remote SA following the absence due to COVID-19 through attendance at community events.
- Work together with the Aboriginal Community Controlled healthcare sector to develop ARF and RHD prevention strategies across the state, under the auspices of new governance of Rheumatic Fever Strategy co-design with National Aboriginal Community Controlled Health Organisation services.
- 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 promote new GAS resources.
- Work collaboratively with other organisations such as the Trachoma Program, HeartKids and the Heart Foundation to mutually value-add to patient outcomes.