



SA Rheumatic Heart Disease Control Program

Annual Report 2015

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 rheumatic fever (RF). RF is an illness caused by a reaction to a bacterial infection with group A streptococcus. 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. Aboriginal and Torres Strait Islander populations have one 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 (an injection with preventive antibiotics: 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,
- support local health services to manage patients with RF and RHD through local registers and recall systems that share data with the state-wide 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.

The highlight for the Program in 2015 was the completion and launch of the SA RHD educational calendar. This calendar was developed in conjunction with the Aboriginal community and staff working in Aboriginal primary health care, in both metropolitan and rural SA, and has been very well received.

In 2015 the Program continued to have a strong presence in the Aboriginal primary health care sector with the provision of support, assistance with audits, and staff training. This is reflected in ongoing improvements in adherence to secondary prophylaxis. Relationships with clinical pharmacy staff in public hospitals were strengthened in 2015, resulting in increased opportunistic delivery of secondary prophylaxis in hospitals.

Funding agreements with Nganampa Health Council and Aboriginal Health Council of SA for positions within their organisations to undertake RHD control activities were extended for another year. The Program currently has one full-time position and three part-time positions for RHD activity across the State, sitting within Nganampa Health Council, Aboriginal Health Council of SA and SA Health.

The SA RHD Register ('Register') continued to grow steadily in 2015 with 208 patients enrolled on the Register at December 31, 2015. There was a decline in the number of diagnoses of RF in 2015 compared with 2014 and an increase in the number of diagnoses of RHD with no known history of RF. Encouragingly, average adherence to secondary prophylaxis for SA patients continued to show an upward trend from previous years, now sitting at 80%, compared to 58% when the Program began in 2012.

Strong support and commitment from key stakeholders in 2015 has been fundamental to the success of the Program and 2016 will see a focus on maintaining these relationships.

RHD Program Advisory Group

The RHD Program Advisory Group is comprised of interested parties across South Australia (SA) including members from the Aboriginal Community Controlled Sector, Cardiology Clinical Network, National Heart Foundation (SA Division), RHD Australia, South Australian Health and Medical Research Institute (SAHMRI), 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.

Three meetings of the Program Advisory Group were held in March, June and October of 2015 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 implement strategies to assist with the management of patients with ARF and/or RHD. Recruitment is of patients with new, recurrent or probable episodes of ARF, and/or definite or borderline RHD, based on the case definition according to 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 NT Health Centre for Disease Control and the SA Health Communicable Disease Control Branch is in place for the SA RHD Register to use the platform of the Northern Territory web based RHD Register.

Register statistics

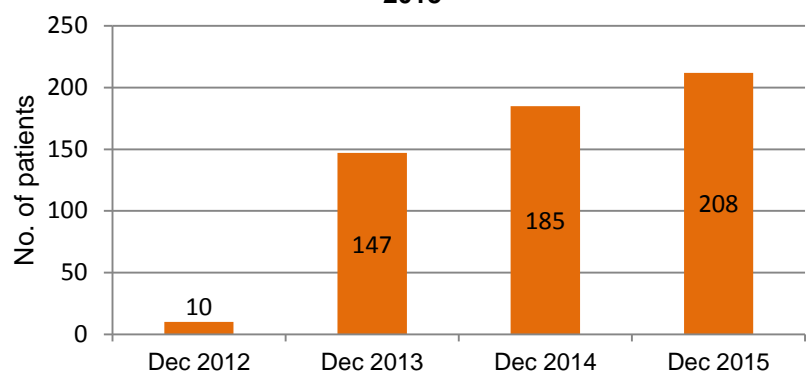
The number of patients on the Register continues to steadily increase, as seen in Figure 1, with 208 patients enrolled at December 31, 2015.

Of these 208 patients:

- 67% are female;
- 69% are under 35 years of age;
- 58% are in remote SA*,
- 16% in regional SA*
- 26% urban SA*;
- 94% identify as Aboriginal,

the remaining 6% identify as migrants from countries where there is a high prevalence of RHD (Somalia, Iran, Burma, Afghanistan, Bhutan) or are Caucasian Australians.

Figure 1. No. of patients on the Register 2012 - 2015



*The Australian Institute of Health and Welfare (AIHW) remoteness classifications have been used, but are collapsed to three region (urban, regional and remote) for reporting purposes to prevent identification of individual health services.

Figure 2. New diagnoses in SA (reported to the Register) from 2013, 2014 and 2015

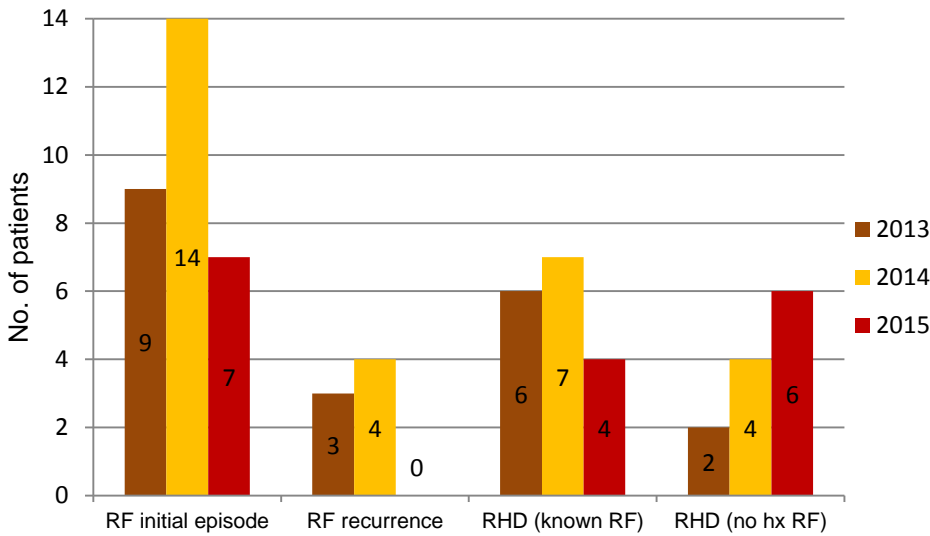


Figure 2 shows a notable decrease in diagnoses of initial episode of RF to the Register from 2014 to 2015. Reasons for this decrease have not been investigated, and these small numbers must be interpreted with caution. There were no episodes of recurrent RF in SA in 2015.

Reports continue to be received of people diagnosed with new RHD and no previous recorded history of RF. The median age of the six reported cases in 2015 was 22.5 years, with four of these presenting with moderate or severe RHD. There are two possible reasons for the increases in first presentations of RHD with no known history of RF. The first is that there continues to be missed episodes of RF that progress outside the awareness of the health system, representing a missed opportunity to intervene. The second is an increasing awareness of the disease among health professionals, with a resulting increase in diagnoses. Both reasons emphasise the need for ongoing education around awareness of the symptoms of RF among the community, and case identification among clinicians.

The majority (65% (11/17)) of all cases notified to the Register were in patients from remote South Australia; however the new cases in urban and regional SA highlight the importance of increasing awareness among all clinicians, not only clinicians in remote SA.

All cases of RF notified to the Register were definite cases. The majority of these were children aged 5-14 years (Figure 3a) and there were equal numbers of male and female cases (Figure 3b).

Figure 3a. RF Notifications to the Register, 2015, by age at diagnosis

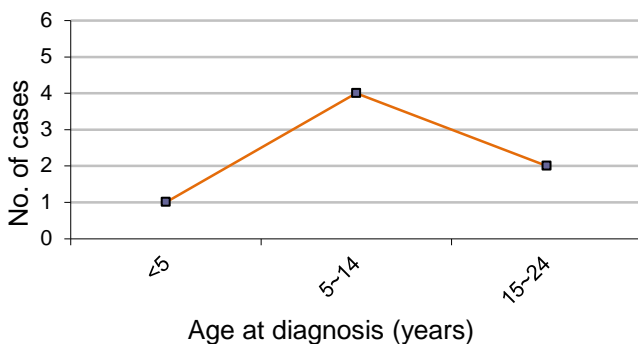


Figure 3b. RF Notifications to the Register, 2015, by sex

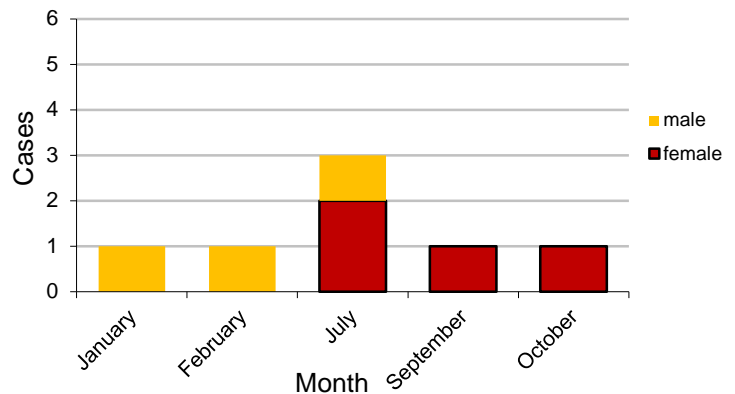


Figure 4. Register patients, by location, at December 31, 2015

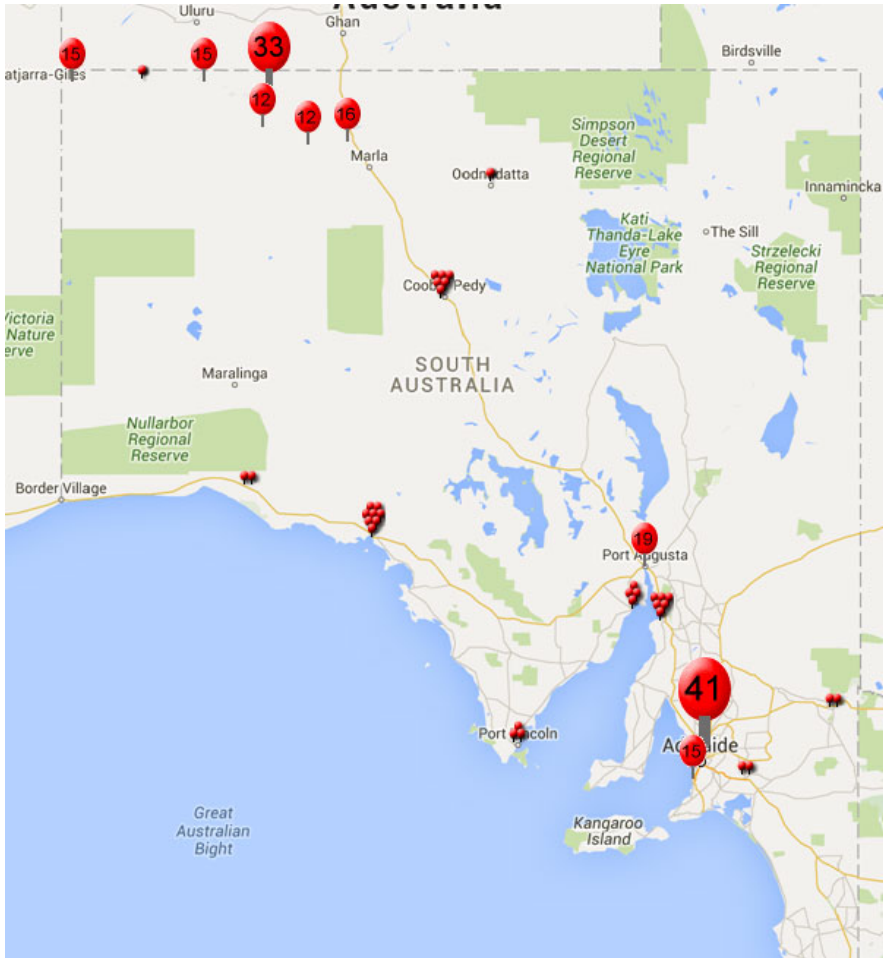
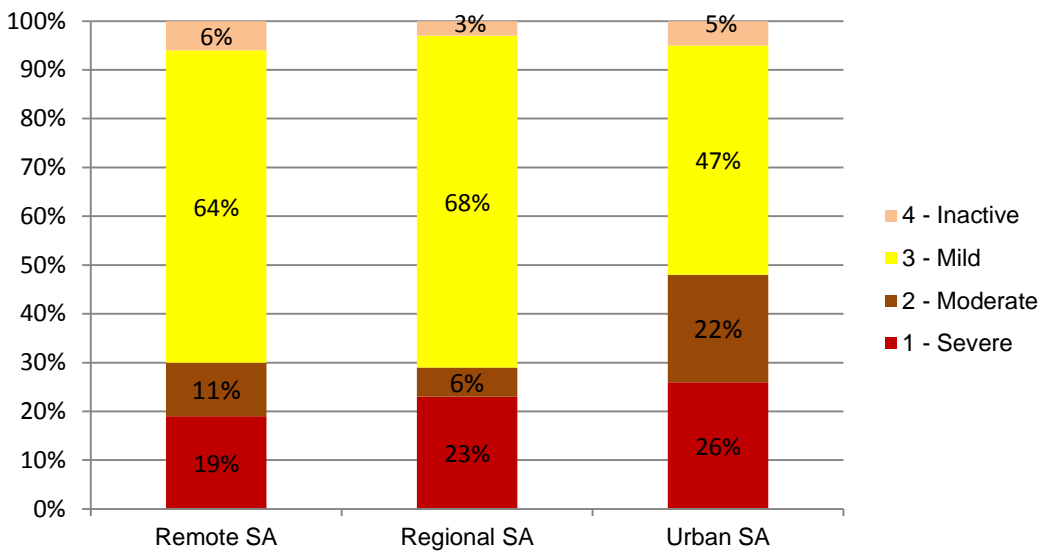
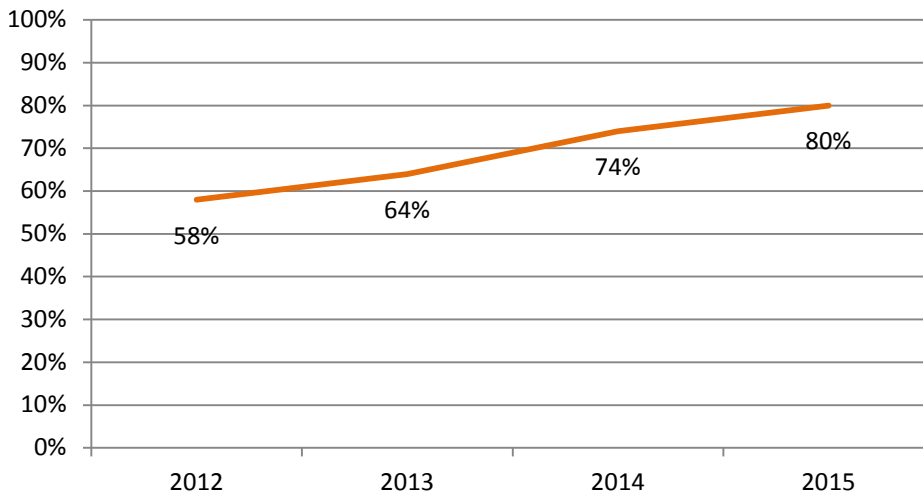


Figure 5. Proportion of Register patients by region and severity of diagnosis, Dec 31, 2015



Fifty percent of the patients on the Register are from the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, with other large clusters in Adelaide and Port Augusta (Figure 4). In all regions of SA the majority of patients are classified as having mild disease (Figure 5).

Figure 6. Average percentage adherence to secondary prophylaxis by register patients, by year, 2012-2015



RHD registers assist with monitoring patient movements, identifying individuals with poor adherence to secondary prophylaxis and providing education and training for patients, health professionals and health services.

On average, SA patients received 80% of their scheduled doses of benzathine penicillin in 2015 (Figure 6). Average percentage adherence 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 7. Proportion of Register patients who received $\leq 50\%$, 50-79% and $\geq 80\%$ of their scheduled secondary prophylaxis doses, by year.

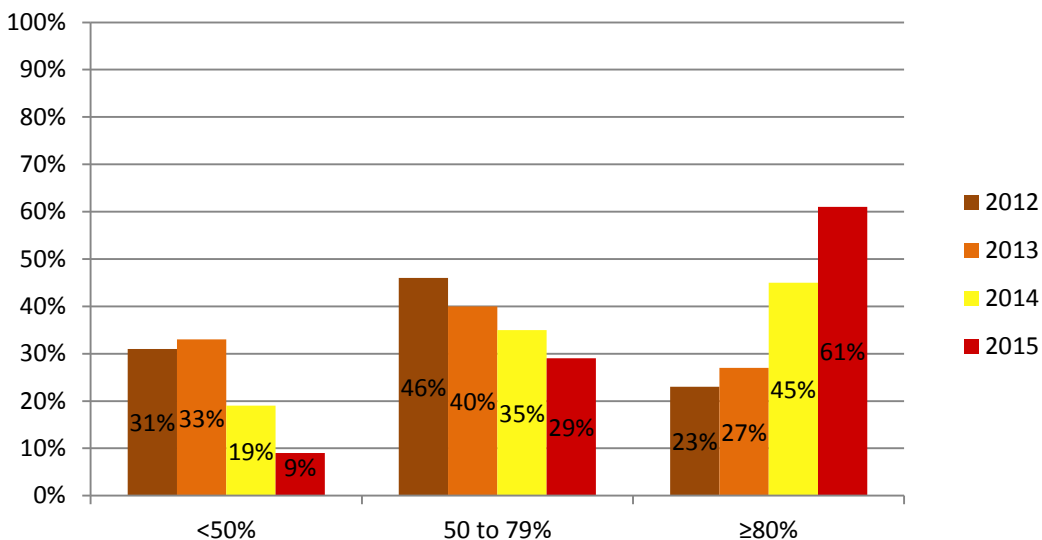
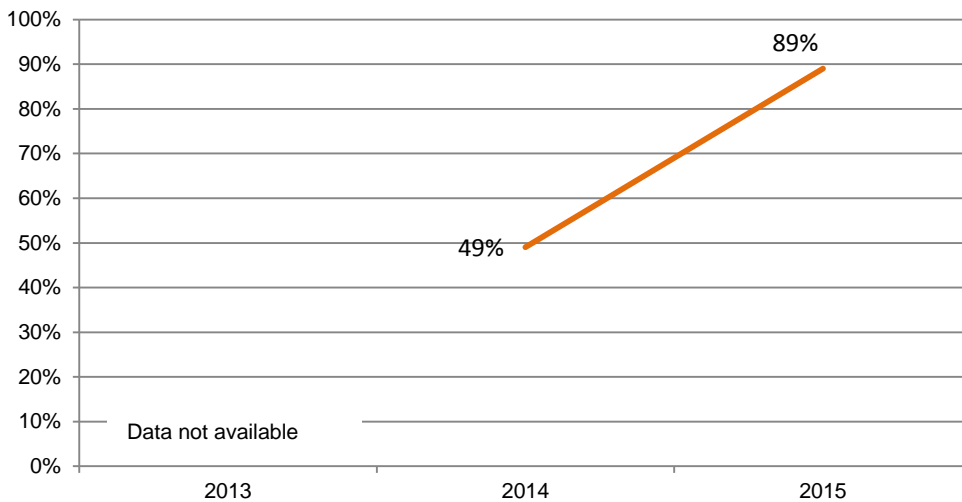


Figure 7 further demonstrates the significant improvement in adherence to secondary prophylaxis. The proportion of patients on the Register who are receiving over or equal to 80% of their required doses of penicillin increased from 45% in 2014 to 61% in 2015, and the proportion of patients who are receiving less than 50% of their required doses of penicillin decreased from 19% to 9% in this same period.

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 8. 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).



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 8 shows an improvement in the proportion of Priority 1 and Priority 2 patients receiving timely echocardiography in line with these recommendations.

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 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 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 South Australia, Northern Territory and Western Australia.

It has been challenging to achieve engagement with the Register and delivery of secondary prophylaxis in the hospital setting. In 2015 a decision to provide education for clinical pharmacists has been rewarded with a notable increase in engagement between the Register and tertiary hospitals. In the four month period following these sessions, there were seven calls from individual pharmacists requesting information from the Register, compared to two in the four months preceding. Of these seven calls, four resulted in RHD patients receiving a timely dose of penicillin during their admission.

In 2015, SA Health committed to sending clean, robust data from the Register to the National Data Collection System (DCS). The DCS is a central national repository for the collection and reporting of rheumatic fever (RF) and rheumatic heart disease (RHD) data against a recommended clinical data set and key performance indicators.

The Register is also involved in two state-wide projects with SAHMRI. The Program has provided support to an RHD screening study of school aged Aboriginal children, and will be notified for follow up of any cases found during this screening. The Program is also providing 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.

Engagement with primary health care services

The Program undertakes regular visits to individual health services to provide education and support for patient management. In 2015, Staff from the Program or staff employed through the Program working for Nganampa Health Council or Aboriginal Health Council of SA visited almost all health services with patients who have RF and/or RHD. Telephone support was provided to the more remote government health services where visits were not possible.

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.



Support visit to Ceduna Koonibba Aboriginal Health Service.



Showcasing resources available through RHD Australia and SA Health to staff at Umoona Tjutagku Health Service.

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 South Australian Program's achievements and progress were also highlighted in a presentation at a national rheumatic heart disease workshop held in Sydney in May 2015.

In addition to ongoing education for nursing and dental staff, medical professionals were a focus in 2015 and this focus will continue in 2016. Sessions this year included:

- An evening session for GPs working in Port Augusta, run collaboratively with the Country SA Primary Health Network. This was well attended with 13 GPs among the 27 participants. Evaluation was very positive indicating that all learning objectives were met and all participants found the information relevant to their work.
- Education sessions about the Register to General Practice registrars and all public hospital

obstetric departments.

- A presentation at the Cardiac Society of Australian and New Zealand South Australian Trainee Educational Meeting.

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.

For the first time since the commencement of the Program, education was also provided to Aboriginal Environmental Health Officers working across SA. The links between environmental health, in particular housing, and rheumatic fever are well established and this education focused on role of environmental health in reducing the risk factors associated with RF. Collaboration with environmental health will continue in 2016 to highlight the importance of addressing key environmental risk factors.



Training Cert IV Aboriginal Primary Health Care students

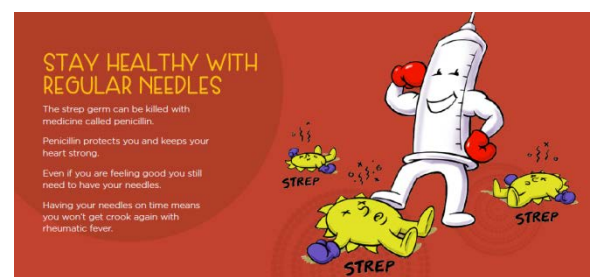
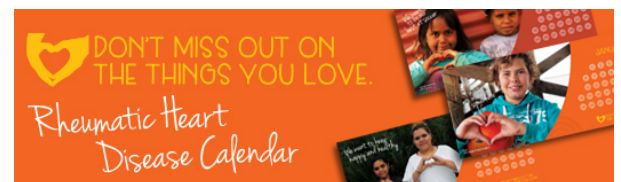
Following comprehensive consultation with the Aboriginal community and staff working in Aboriginal primary health care in both metropolitan and rural SA, the RHD calendar was completed in 2015. This calendar is an educational resource for health professionals and is given to people who are living with RF and/or RHD and their families. The resource has been positively received by both health staff and community, reflecting a thorough and effective consultation process.

The theme of the calendar is “Don’t miss out on the things you love”. The calendar contains photos of people from across South Australia talking about why they look after their hearts and what they don’t want to miss out on in life as well as important information about RF, RHD, and secondary prophylaxis. The calendar will be evaluated in 2016.

The launch of the calendar was held in November at Nunkuwarrin Yunti in Adelaide with excellent representation from primary health, key stakeholders, and most importantly by people living with RF and RHD and their families. The Honourable Katrine Hilyard opened the launch.



At the launch of the RHD Calendar with the stars of the calendar and their families.



Example page from the RHD calendar.

Future directions

In 2016 the Program will continue to work with and support existing health care services to ensure that people with ARF/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 SA RHD Register including collaboration with primary health and cardiology to ensure accurate data, monitoring of secondary prophylaxis adherence and regular reporting and evaluation;
- Supporting the RHD staff within Nganampa Health Council and Aboriginal Health Council of SA to undertake RHD control activities within their respective health services;
- Strengthening the capacity of local health services to manage their patients with ARF 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 ARF and RHD.

The SA RHD Control Program is currently funded until June 2016 by the Commonwealth Government's Rheumatic Fever Strategy and acknowledges their support. At the time of this report, there was no decision regarding future Commonwealth funding.