Rheumatic fever and rheumatic heart disease know no boundaries

Jennifer Cottrell¹, Marea Fittock², M Russell²

¹South Australian Rheumatic Heart Disease Control Program, Communicable Disease Control Branch, SA Department for Health and Ageing, ²Northern Territory Rheumatic Heart Disease Control Program, Centre for Disease Control, NT Department of Health

Background

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) occur at very high rates among Aboriginal and Torres Strait Islander people.¹ These diseases affect young people and are important causes of premature mortality, yet almost all cases of RHD and associated deaths are preventable. Central to reducing the burden of disease of RHD in Australia is the delivery of secondary prophylaxis to prevent recurrences of ARF.

ARF is an illness caused by an immunological reaction to infection with the bacterium Group A Streptococcus (GAS).¹ It causes an acute, generalised inflammatory response, and is an illness that affects only certain parts of the body, mainly the heart, joints, brain and skin. The damage to the heart may remain once the acute episode has resolved. This is known as RHD. Recurrences of ARF cause further cardiac valve damage. Hence, RHD steadily worsens in people who have multiple episodes of ARF. The most cost effective approach to controlling RHD is preventing ARF through regular injections with long acting penicillin, known as secondary prophylaxis.³

The incidence of ARF is highest in 5–14 year olds, ranging from 150 to 380 per 100,000.⁵ A study in 1990 found a point prevalence of RHD, among all age Aboriginal people in the Northern Territory (NT) of 11.8 per 1000.⁶ Prevalence rates of RHD since 2000 have steadily increased to almost 2% of the Aboriginal population in the NT and 3.2% of Aboriginal people aged 35–44 years. Studies in far North Queensland and the Kimberley region of Western Australia found slightly lower prevalences of 1.14% and 1%, respectively, but these are early data, and are comparable to the rates found in the Northern Territory in the late 1990s, when the control program was just beginning.⁷,⁸

A project was undertaken in 2011 to determine the prevalence of RHD in South Australia (SA).⁹ There were 193 definite cases of RHD identified. The estimated prevalence in the Aboriginal population was 6.3 per 1,000, compared to the non-Aboriginal prevalence of 0.01/1,000. While the rates in Aboriginal South Australians are lower than Aboriginal population rates in the north of Australia it is accepted that once a control program is established case detection will improve and rates will increase.

It is recommended that all regions of Australia that have high risk populations for ARF or RHD establish a coordinated control program.²

RHD control programs have been running in Northern Territory (NT), Queensland and Western Australia since 1997, 2006 and 2009 respectively. Following the introduction of a control program in Central Australia, 96% of all clinical ARF episodes were notified to the program (compared to 24% previously).³ In the first 2 years of the RHD control program in the Top End of the NT, there was a decline in the recurrence rate from 40% (of all ARF episodes) prior to commencement, to 28% in the first year, and 16% in the second year.⁷ Reduction of recurrence rates is an important indicator of program effectiveness. In Far North Queensland, the program focused on increasing awareness of ARF, particularly among medical practitioners. This resulted in fewer missed cases of ARF, increased notification of ARF and a significant decline in ARF recurrence.²

RHDAustralia was established in 2009 as the National Coordination Unit to support control of rheumatic heart disease in Australia. Funded under the Australian Department of Health and Ageing Rheumatic Fever Strategy, RHDAustralia is based at Menzies School of Health Research in Darwin. One of the key roles of RHDAustralia is to support control programs in the States and Territories by providing technical assistance and promoting best practice.
Registers of people with RHD or a history of ARF are a key element of control programs aiming to increase the delivery of secondary prophylaxis and reduce recurrences of ARF. In Australia, achieving good adherence to secondary prophylaxis in primary health care services is challenging due to an often highly mobile patient population, high staff turnover and limited staff awareness of ARF and RHD. 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.

The NT RHD Control Program and RHD Register have been running since 1997 and strong networks have been successfully built up across the Territory that facilitate implementation of their program. Seeding funding for the SA RHD Control Program and RHD Register began in 2010. Initial work included a scoping project for development of a register, establishment of an expert advisory group to provide guidance for the program and engagement with the relevant people and organisations in the health sector. Working in Aboriginal health requires cultivating trust and respect with both the community and health services to show that there is a genuine commitment to improving health outcomes and building these foundations takes time. SA RHD program activities, including the development of a register, commenced in 2012 and the Register was operational by September 2012.

The SA RHD Control Program decided to work closely with the NT from the outset due to a shared border where there are high numbers of Aboriginal patients living and to the highly mobile nature of the patients living in this cross border region. State and Territory borders do not exist for Aboriginal and Torres Strait Islander people; boundaries are drawn according to birthplace and the relationship to those places. Programs working in Aboriginal and Torres Strait Islander communities need to acknowledge this and accommodate accordingly.

There is significant movement across the SA/NT border every day and with the complicated and regular management plan required for ARF and RHD, this movement leads to a huge potential for loss of follow up for ARF/ RHD patients. While a substantial number of South Australians have been enrolled on the NT RHD Register for some time, due to limited resources these patients have not received the assistance with coordination of care associated with being on a register.

In developing the SA RHD Control Program it was imperative to acknowledge and recognise the experience within the NT RHD Control Program, both technical and clinical, as a result of 14 years of operation. This collaboration meant that existing infrastructure was incorporated and built upon and that reinvention of the wheel was avoided.

South Australia, with the assistance of the Northern Territory, set up the state-wide RHD Register for SA based on national data standards in 2012. This Register aims to improve RHD control through reducing recurrences of ARF in patients in SA and in the cross border region of SA and NT. This paper outlines the collaboration between South Australia and the Northern Territory to develop the SA RHD Register.

**Method**

The SA and NT Programs have worked closely and cooperatively throughout this process. In particular, the sharing of NT experience and information in the set up of the SA Program was invaluable and the allocation of time given by NT is acknowledged.

Following the decision to work closely with the NT, conversations were held regarding the options available. An important aim was to ensure that a seamless service was provided to both the health workforce and the large number of patients in Central Australia. As a result it was decided that SA and the NT would share the same electronic platform for the RHD Register. This enabled the recording, storing and use of data of SA patients with ARF or RHD (SA RHD Register data) by the SA RHD Control Program alongside of NT RHD Register data on the same electronic platform. Informed consent is obtained from the patient (or parent/guardian) prior to being included on the Register. This
consent gives permission for information to be collected, as well as for that information to be provided to registers in other States/Territories if the patient moves. This transfer of information across borders is crucial to ensure continuity of care.

A Memorandum of Agreement was signed by Communicable Disease Control of NT Health and Communicable Disease Control Branch of SA Health for a period of 24 months, outlining key responsibilities of each program. Data recorded on the SA RHD Register is reported separately to NT data and there is ongoing maintenance of the system with regard to integrity, confidentiality and availability.

Close coordination of education activities and alignment of key messages was also an important part of the collaboration. Regular meetings, teleconferences and emails ensured communication remained a priority during initial stages. Staff from the SA program undertook visits to both Central Australia and the Top End to foster relationships and learn about the NT RHD Register. South Australia was also invited to attend the steering committee meetings of the NT RHD Control Program. This enabled SA to gain a better understanding into the operational aspects of running a RHD control program and register.

The NT program ran a search for SA cases on the NT RHD Register to determine the extent of patients requiring follow up. Once found, the process of collecting consent for them to be on the SA RHD Register began. Communication occurred with local SA health services to establish these patients’ home community and local health care workers were then requested to seek consent from these patients. Almost 90 South Australian patients were found on the NT RHD Register, the majority of who were not being followed up with regard to secondary prophylaxis adherence and overdue appointments. Close communication between health services in Alice Springs, central Australia and the NT and SA RHD Registers about these patients was established to assist this process. In addition to the NT, RHDAustralia played a large role in providing support to SA through assistance with determining appropriate data elements to collect and the provision of patient, family and health professional resources.

Results

The ultimate aim of this collaboration is to improve the health outcomes of SA patients with ARF and RHD. Preliminary indicators are promising. Thirty-four SA patients are enrolled on the SA RHD Register as of March 2013, with numbers increasing each month. The value of this is the ability to assist in coordination of care of these patients to reduce recurrences of ARF and improve delivery of secondary prophylaxis.

The other benefits of working together have included the sharing of experiences and feedback for the NT on their register from a new perspective. This resulted in some minor amendments being made to improve the accuracy of data collected by the register.

Informing health professionals in the cross border region of SA and the NT about the collaboration has also had positive outcomes. A joint presentation was delivered by staff from the SA and NT Programs to nurses from central Australia in Alice Springs. The implementation of the SA RHD Register, complementary to the existing NT RHD Register was explained, as was the aim of improving health outcomes for patients in the cross border region. This presentation also provided the opportunity to reinforce the importance of preventing ARF recurrences and improving secondary prophylaxis adherence in patients in this area. Regular communication with nurses in this region is now occurring from both NT and SA.

Challenges of working across two jurisdictions have included negotiating the different practices and delivery of services within each jurisdiction. The patient information management systems used in local health services and tertiary hospitals in the NT and SA vary distinctly so that experiences from the NT have not been relevant for SA and in some cases existing register variables have needed to be tailored to
the SA context. The complexity of the SA landscape with different services using different systems was also given much consideration by SA to determine the most efficient and effective way to collect data for the register.

Another challenge has been consideration of confidentiality issues with two jurisdictions using the same electronic platform to store patient data. These issues are being managed through regular communication with information technology teams in SA and the NT to ensure that the data for each is stored separately. In both jurisdictions, laws that govern how information is used, collected and reported are being followed.

**Conclusion**

Collaboration between and commitment from organisations is fundamental for the improvement of the health and wellbeing of individuals and communities. It was recognised that SA needed to work with existing control programs to ensure program implementation was in line with national recommendations and to benefit from past experiences with regard to barriers and enablers for RHD control.

Rheumatic heart disease affects people regardless of where they live and services should reflect this, regardless of state/Territory borders. Despite some challenges, the benefits of SA and the NT working cooperatively to maintain a RHD register that is seen as one service are immeasurable. This collaboration will ensure that people identified with ARF and RHD in SA or the NT receive adequate follow-up to prevent or reduce cardiac disease.

With the support of the NT, the SA RHD Control Program is laying the foundation for improved health outcomes for RHD patients in SA, in particular in the cross border region of SA/NT.

**References**


2. RHDAustralia (ARF/RHD writing group), National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand. Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition). 2012


