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Evaluation of the Rheumatic Fever Strategy

Final report

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Acronyms

AIHW Australian Institute of Health and Welfare

ARF Acute rheumatic fever

BPG Benzathine penicillin G

DCS Data collection system

DoH Commonwealth Department of Health

GAS Group A streptococcus

NCU National Coordination Unit

nKPI National Key Performance Indicator

NSW New South Wales

NT Northern Territory

PoCT Point of care testing

Qld Queensland

RFS Rheumatic Fever Strategy

RHD Rheumatic heart disease

SA South Australia

WA Western Australia

WHO World Health Organization

Executive summary

The Commonwealth Department of Health (Commonwealth DoH) engaged Health Policy Analysis to undertake an evaluation of the Australian Government's Rheumatic Fever Strategy (RFS).

Background

Rheumatic Heart Disease (RHD) is a disease of poverty, entirely preventable, and almost exclusively found in Aboriginal and Torres Strait Islander communities in Australia.

RHD is characterised by damage to the valves of the heart, caused by repeated episodes of acute rheumatic fever (ARF). ARF is caused by an auto-immune reaction to an infection with the bacterium group A streptococcus (GAS) to the skin or throat. Certain living conditions contribute to GAS infections, making ARF more likely. Known risk factors include poverty, overcrowding and limited access to medical care for diagnosis and treatment.

Register-based control programs (focusing on secondary prevention) reduce recurrence of ARF, decrease hospitalisations, and help to avoid costly and life-threatening heart surgery for young Indigenous Australians. However, the disease can only be eradicated by addressing the underlying environmental risk factors and providing timely and effective health care to ensure that throat and skin infections do not progress to ARF.

Dramatic falls in the rates of ARF and RHD in developed countries have occurred over the last 50 to 150 years, restricting ARF to sporadic outbreaks and or disadvantaged communities. This history demonstrates ARF and RHD are entirely preventable.

The Rheumatic Fever Strategy

The RFS has focused on secondary prevention to address high rates of ARF and RHD, through:

- State-based register and control programs to improve detection, monitoring and management of ARF and RHD.
- National coordination to develop national education and training resources, support jurisdictions and establish a data collection system.

The RFS National Partnership Agreement commenced in 2009, with Northern Territory (NT), Queensland (Qld) and Western Australia (WA) participating. It was subsequently expanded to include South Australia (SA).

The key focus of the RFS has been to build the necessary infrastructure and capacity in each funded state and territory to facilitate a patient recall system that supports secondary prophylactic treatment of ARF. This aligns with indicated best practice identified in the Australian Guideline and the World Health Organization (WHO) technical report on rheumatic fever and RHD (WHO, 2001).

Each participating jurisdiction has established an ARF/RHD register and control program. The control programs are supported by a Commonwealth DoH-funded National Coordinating Unit (NCU), known as RHDAustralia, located within the Menzies School of Health Research.

An objective of the RFS was to establish a system for collection and provision of data for national monitoring and reporting of ARF and RHD, and measuring program effectiveness.

Data reporting to the NCU for national monitoring and reporting and epidemiological analysis has not been fully achieved. The several factors that have impeded reporting to the NCU are explored further in this report.

The current National Partnership Agreement expires in June 2017.

The evaluation

Seventy-two individuals from 35 organisations were consulted, including RHD Australia (the NCU), jurisdictional control program and registry staff, state and territory health department staff, clinicians, Aboriginal Health Workers, academics, and key stakeholders such as expert advisors and peak non-government organisations. The evaluation focussed on five questions:

1. Has the RFS been implemented as expected and what have been the enablers/barriers to implementation?
2. Have the expected outcomes of the RFS been achieved or are they likely to be achieved?
3. Are there other tools or methods of prevention, detection, monitoring or treatment that could be funded to improve diagnosis and treatment outcomes without significantly increasing the cost of the RFS?
4. What is the overall cost of implementing the RFS and to what extent does the Commonwealth's contribution represent value for money?
5. How sustainable are the RFS initiatives beyond the agreed funding period?

Key achievements

The evaluation team has identified the following key achievements of RFS:

- Improved monitoring and surveillance of ARF and RHD that was not possible prior to the RFS.
- Increased awareness in areas where ARF and RHD are prevalent.
- Increased number of people on the registers and receiving prophylactic injections.
- Improvements in adherence to secondary prophylaxis, with significant improvement in two jurisdictions, NT and SA.
- Agreement on a minimum data set for NCU reporting and key performance indicators.
- Establishment of a data collection system (DCS) for monitoring ARF and RHD and clinical benchmarking.
- Improved estimates of ARF and RHD incidence and prevalence and associated processes of clinical care.
- Revisions to the Australian Guideline for prevention, diagnosis and management to reflect new and emerging evidence.
- Establishment of registers in two participating jurisdictions, with support for improvement and expansion in the other two.
- Establishment of recall systems in two participating jurisdictions, with support for improvement and expansion in the other two.
- Development of training material for health workers and clinicians.
- Development of some educational resources for patients and communities.

Challenges

The evaluation noted that more work was needed to refine the state-based programs, to overcome challenges in areas such as staff retention, education and training, and in the collection, use and reporting of data on the registers.

Opportunities identified

Future opportunities could include:

- A strengthened role for primary care in the prevention, detection and management of ARF and RHD.
- Development of additional models of clinical education to complement existing web-based delivery, and redevelopment of existing modules to improve completion rates as the current modules are complex and not time efficient or tailored to the needs of different clinicians.
- Improved strategies, practices and educative materials to engage and educate patients, families/carers and communities to improve prevention, detection and adherence to secondary prophylaxis.
- Develop clinical processes/strategies to reduce the pain of benzathine penicillin G (BPG) injections.
- Improved web-based platform access (for those jurisdictions without) to registry data by clinicians across jurisdictions and increased automation of patient data capture and reporting to individual registries.
- Use registry data to support collaboration across agencies and programs, especially for primordial prevention.
- Streamlining data sharing by states and territories for national monitoring/reporting.
- The use of My Health Record could have significant benefit for patients that regularly travel across health services and state boundaries to improve real-time monitoring and access to clinical notes, as current access to some registers by clinicians is limited, and the target population is highly mobile.
- Introduce primordial and primary prevention strategies and processes to prevent new cases of ARF.

Key recommendations

1. Renew the RFS and National Partnership Agreements for a further four-year period to maintain and build on momentum and to assist in attracting and retaining staff.
2. Maintain the existing focus of the RFS on secondary prevention, but also consider broadening preventative efforts to include primordial (environmental prevention) and early intervention health care measures (primary prevention).
3. Streamline the provision of data from jurisdictions to the national data collection system (DCS) by considering alternative governance arrangements for the DCS that would overcome existing barriers and delays.
4. Participating jurisdictions to increase the automation of patient data capture and reporting, and seek to enable real-time access to clinicians and health services to registry data and patient records.
5. Improve education and training for health care providers, individuals, families and communities to raise awareness, and improve detection, prevention and management.

Other recommendations for consideration

- ❖ Investigate whether transferring the function of national data coordination from the NCU to another organisation would alleviate or exacerbate current delays.
- ❖ That BPG adherence (as measured by 'days at risk') be considered for inclusion as a National Key Performance Indicator (nKPI).
- ❖ Participating jurisdictions consider utilising My Health Record to facilitate better sharing of information on the registers and to facilitate improved adherence to secondary prophylaxis antibiotics.
- ❖ Develop additional mixed modes of clinical education to complement existing web-based delivery, and redevelop existing modules to improve completion rates as the current modules are complex and not time efficient.
- ❖ Improved strategies, practices and community-relatable educative materials to engage and educate patients, families/carers and communities to improve detection and adherence to secondary prophylaxis.
- ❖ Identify mechanisms and opportunities for the interdepartmental sharing of RFS data analyses to foster collaboration in addressing the primordial causes of acute rheumatic fever and associated diseases, including trachoma.
- ❖ Investigate strategies to strengthen the role of primary care in the management of ARF and RHD.

The Rheumatic Fever Strategy

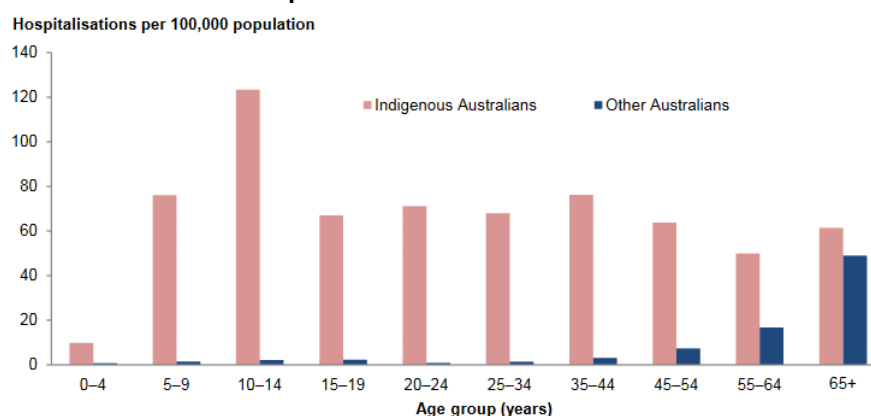


Acute rheumatic fever

Acute rheumatic fever (ARF) is caused by an autoimmune reaction to a group A streptococcal (GAS) infection in the throat (Guilherme et al., 2006; Remenyl et al., 2013). It has been suggested that GAS skin infections could also lead to ARF (Carapetis et al., 2016). ARF manifests as a general inflammation which affects the heart, joints, brain and skin. People suffering from ARF are generally in a great deal of pain, feel very unwell, and require hospitalisation. Although there is no lasting effect of ARF on the joints, brain or skin, there is often residual damage to the heart valves, particularly the mitral and aortic valves. This damage to the heart valves is known as rheumatic heart disease (RHD). It is estimated that 60% of people develop RHD after their first episode of ARF (Carapetis et al., 2005; Remenyl et al., 2013). Once a person has had an episode of ARF, they are more likely to have other episodes, and with each subsequent episode, there is the potential for a worsening of the damage to the heart valves.

ARF is a disease of poverty and mainly occurs in younger people from developing countries or low-resourced areas in wealthier countries. In Australia, ARF and RHD are far more likely to occur among Indigenous Australians. In 2013 an Australian Institute of Health and Welfare (AIHW) report demonstrated large inequalities in rates of ARF and RHD hospitalisations for Aboriginal and Torres Strait Islander people compared with other Australians (Figure 1) (AIHW, 2013).

Figure 1 - Hospitalisation rate for ARF and RHD by age group and Indigenous status in the period 2007-08 to 2009-10



Notes

1. Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.
2. Based on patients usually resident in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory; excludes private hospitals in the NT.
3. Other Australians include peoples whose Indigenous status was 'Not stated'.

Source: AIHW Hospital Morbidity Database.

Evidence base for the prevention and management of ARF and RHD

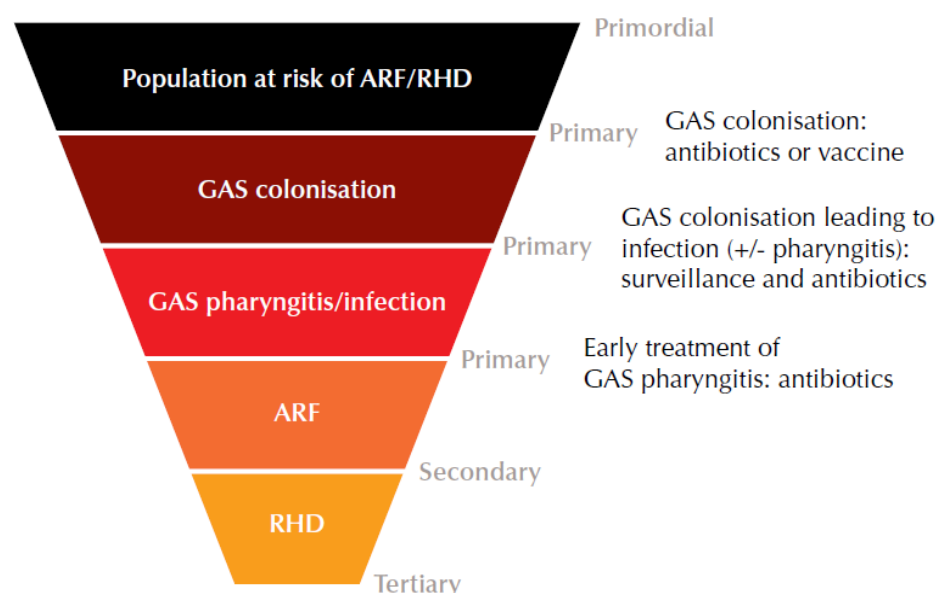
In 2006 the Heart Foundation and the Cardiac Society of Australia reviewed evidence relating to the prevention and treatment of ARF and RHD, and subsequently published the *Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease* (1st edition). The guidelines were updated and extended in 2012. They are available on the RHD Australia website (<http://www.rhdaustralia.org.au/ARF-rhd-guideline>). (A third revision of the guidelines is currently underway, led by RHD Australia.) The second edition of the guidelines cover:

- primary prevention of ARF;
- diagnosis of ARF;
- management of ARF;
- secondary prevention of ARF;
- management of RHD;
- RHD in pregnancy; and
- RHD control programs.

(RHD Australia et al., 2012).

The second edition of the guidelines includes the work of Remond (2014), which describes interventions to prevent ARF and RHD. Interventions are classified as primordial, primary, secondary and tertiary.

Figure 2 - Outline of structure for preventative strategies for GAS pharyngitis colonisation and pharyngitis



Source: The Australian Guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition)(RHD Australia et al., 2012)

Primordial interventions are targeted at removing the risk factors associated with the disease. For ARF and hence RHD, this involves intervening on the social, economic, environmental and cultural conditions that increase the risk of developing ARF, including reducing the risk of

exposure to GAS. The evidence relating to the risk factors for GAS comes from observational studies, which make it difficult to identify the specific factors that increase an individuals' risk, particularly given that the potential risk factors tend to cluster in low socio-economic groups. Two factors that are good candidates for intervention are overcrowded living conditions and poor education (particularly in relation to health awareness). These risk factors appear repeatedly in the literature and have real biological plausibility.

The guidelines outline locations in the biological pathway where a primary prevention strategy could reduce the incidence of ARF. These include preventing infection by GAS, preventing GAS colonisation, and providing early treatment for GAS (Figure 1). The guidelines suggest a vaccine to prevent infection would be the most sustainable primary prevention strategy and suggest that research in this area should be a priority. The WHO technical report on rheumatic fever and RHD states:

Although a cost-effective vaccine for group A streptococci would be the ideal solution, scientific problems have prevented the development of such a vaccine. (WHO, 2001)

In other settings alternative approaches to primary prevention are recommended, for example, the WHO technical report indicates the main approach to the primary prevention of ARF is to commence antibiotic therapy once a diagnosis of acute streptococcal pharyngitis has been made (WHO, 2001). The evidence for primary prevention is based on the meta-analysis conducted by Robertson et al., which pooled a series of studies conducted in the 1950s and early 1960s. Most of the trials were conducted in young adult males who had recently been recruited into the military, and only one study was conducted in children. A meta-analysis of all the data indicated there was a benefit of treatment with penicillin. In the study conducted in children, over 1,200 children with upper-respiratory-tract disease and laboratory-confirmed diagnosis of GAS were randomised to receive either 600,000 units of intramuscular penicillin or control (symptomatic treatment). Of the 605 children who did not receive penicillin, only two developed ARF compared to zero out of 608 in the penicillin group (Robertson et al., 2005). This was a non-statistically significant reduction in risk of suffering an ARF episode.

Based on the data from the Robertson et al. meta-analysis, the estimated number need to treat to prevent one case of ARF among those with a GAS infection is 302.5. Furthermore, only 20-40% of pharyngitis episodes are due to acute streptococcal infection. Therefore, this primary prevention strategy ideally requires a diagnosis of streptococcal pharyngitis to be made quickly so that the antibiotic therapy can be targeted to those who are at risk of ARF. Obtaining a laboratory-confirmed diagnosis of GAS promptly has been problematic in remote settings where most ARF cases occur in Australia. A recent study of a point-of-care molecular test for acute streptococcal infection reported 96% sensitivity and 94.6% specificity (Cohen et al., 2015). The current Australian guidelines state;

The validity and utility of clinical scoring systems, RADT and other rapid diagnostic techniques in facilitating the rapid detection and treatment of GAS pharyngitis in Aboriginal and Torres Strait Islanders as a mechanism for the primary prevention of ARF/RHD should be a priority for further study. (RHDAustralia et al., 2012, p.26)

Several studies have examined school or community-based approaches to swabbing children to determine if they have a GAS infection. As yet, there is no conclusive evidence of a benefit.

A more proactive approach recommended for very high-risk populations is to treat all children who present with a throat infection. The Australian guidelines state:

Overall, there is currently no convincing argument or consistent evidence to suggest that structured programs focusing on the early treatment of GAS pharyngitis are likely to be effective in the primary prevention of ARF in high-risk populations. Nonetheless, the lack of good evidence should not dissuade action in providing appropriate, accessible and high-quality early management of pharyngitis as part of comprehensive primary healthcare. (RHDAustralia et al., 2012, p.27)

The goal of secondary prevention is to prevent ARF recurrences and therefore prevent the progression of or to RHD. In their editorial in *Heart*, M. McDonald et al. (2005) argue that secondary prevention requires a diagnosis of ARF or RHD followed by long-term treatment with antibiotics. The authors suggest that a secondary prevention strategy must be implemented through a register-based program. Manyemba and Mayosi (2002) conducted a systemic review of the evidence for the use of penicillin for the secondary prevention of rheumatic fever. The review compared penicillin to placebo, and compared different penicillin formulations and regimens for preventing streptococcal infection and rheumatic fever recurrence. The authors concluded:

Intramuscular penicillin seemed to be more effective than oral penicillin in preventing rheumatic fever recurrence and streptococcal throat infections. Two-weekly or 3-weekly injections appeared to be more effective than 4-weekly injections. However, the evidence is based on poor quality of trials. (Manyemba & Mayosi, 2002, p.8)

The review was updated in June 2009, but no new studies were identified, and therefore the conclusions remained the same.

A potential limitation to the effectiveness of secondary prevention of ARF through using this approach is that it is challenging to achieve adherence to treatment over the long term. A recent review by Remond et al. (2016) examined evidence on methods for improving adherence to secondary prevention therapies. Although there was limited evidence available, the authors concluded,

The evidence ... suggests that register/recall systems, dedicated health teams for delivery of secondary antibiotic prophylaxis, education about ARF and RHD, linkages with the community (particularly between health services and schools), and strong staff-patient relationships may be important. (Remond et al., 2016)

Ralph et al. (2013) conducted a study in Indigenous communities in the NT to “increase understanding and improve the quality of RHD care through development and implementation of a continuous quality improvement (CQI) strategy.” Their study failed to improve the key indicator of ≥80% of scheduled patient benzathine penicillin G (BPG) doses, but improvements in some indicators were reported. A recent stepped-wedge cluster randomised trial conducted by Ralph et al. also failed to obtain a significant improvement in adherence rates but the qualitative data from the trial should provide insight into the causes of poor adherence (personal contact Anne Ralph & Jonathan Carapetis).

Tertiary interventions are interventions that are targeted at individuals with RHD to reduce symptoms, disability, and premature death. Cardiac valve surgery is the major tertiary intervention for RHD.

The Rheumatic Fever Strategy

The RFS is a National Partnership Agreement between the Australian Government and the governments of Queensland (Qld), Western Australia (WA), South Australia (SA) and the Northern Territory (NT) which aims to promote improved detection, monitoring and management of ARF and the resultant condition RHD. An initial allocation of \$11.2 million covering the period 2009 to June 2012, funded the establishment of and enhancement of RFS/RHD registers the NT, WA and Qld. The second Agreement between July 2012 and June 2016 involved a further allocation of \$15 million of Australian Government funding. The agreement was extended to include SA in 2013-14. The Partnership Agreement was extended a further 12 months to June 2017. The time frames for the various stages of the RFS are shown in Table 1.

The RFS aims to improve monitoring and management of ARF and RHD through:

- Expansion and/or maintenance of dedicated, state-wide patient registers and recall systems for ARF and RHD.
- Improved clinical care including improved delivery of and adherence to secondary prophylaxis antibiotics.
- Provision of education and training for health care providers, individuals, families, and communities.
- Collection and provision of data for national monitoring and reporting of ARF and RHD and measuring program effectiveness in the detection and management of the conditions.

Table 1 – RFS timeframes

Agreement	Year	RHDAustralia	Qld WA and NT	SA
National Partnership Agreement 2009-2012	2009-10	Funded	Funded	Not funded
	2010-11			
	2011-12			
National Partnership Agreement 2012-2016 NCU Agreement 2012-2015	2012-13	<ul style="list-style-type: none">- Education and training implementation plan- DCS implementation plan- Draft service level agreements- Signed Central Data Repository service level agreements- Jurisdictional performance framework (part 1)	<ul style="list-style-type: none">- Expansion/maintenance of dedicated statewide patient register and recall system- Improved clinical care including adherence to prophylaxis antibiotics- Provision of education and training to healthcare providers, patients and communities	<ul style="list-style-type: none">- Expansion/maintenance of dedicated statewide patient register and recall system- Improved clinical care including adherence to prophylaxis antibiotics- Provision of education and training to healthcare
	2013-14	<ul style="list-style-type: none">- Jurisdictional performance framework (part 2)	<ul style="list-style-type: none">- Collection and provision of data for national monitoring and reporting	
	2014-15	<ul style="list-style-type: none">- Deliver DCS- NCU performance management framework- Education and training implementation plan 2015-17		

Agreement	Year	RHDAustralia	Qld WA and NT	SA
		- Jurisdictional performance framework 2015-17		providers, patients and communities - Collection and provision of data for national monitoring and reporting
NCU extension funding, 2016	2015-16	- Jurisdictional data report from DCS		
National Partnership Agreement extension 2016-17 NCU extension funding, 2017	2016-17	- Jurisdictional data report from DCS	As above. Note: WA withholding data for 2014-15 until the new National Partnership Agreement is in place	As above

Roles

Commonwealth

As part of the RFS, the Commonwealth agreed to provide ongoing policy leadership and support to the National Coordinating Unit (NCU), including oversight and strategic advice to ensure that the NCU meets its objectives.

Under the Agreement the Commonwealth has also provided funding to each of the participating states and territories, to support the operation of the jurisdictional registers. In 2016-17 the NT, WA and Qld received an annual allocation of \$905,000 and SA received an allocation of \$395,000.

As part of meeting its role under the Partnership Agreement, the Commonwealth also provides funding to the NCU (RHDAustralia) based at the Menzies School of Health Research. The level of NCU funding for the latest year is around \$906,000. This funding supports a range of functions including education and training, national data collection and the development of a jurisdictional performance framework. RHDAustralia also supports various governance functions for the RFS through supporting the several cross-jurisdictional committees including the RHDAustralia Advisory Committee (formerly the Jurisdictional Reference Group).

States and territories

Under the National Partnership Agreement, the NT, WA, SA and Qld governments have agreed to work with the Commonwealth and other key stakeholders, including other state and territory governments and the NCU, to implement a strategy that was nationally consistent and collaborative. In doing so, they also agreed to:

- Use education, training and self-management resources developed by the NCU to support service delivery and data collection and reporting.
- Work with the NCU, to establish mechanisms and infrastructure, to enable nationally consistent data collection in a central data repository that aligns with ARF/RHD clinical dataset specifications and performance indicators.
- Provide all available and relevant ARF and RHD data as specified by the Commonwealth to the NCU and/or the Commonwealth (including the AIHW), noting

that the NCU will also provide the Commonwealth (including the AIHW) with data provided to it by the jurisdictions from time to time.

Shared roles and responsibilities

Under the National Partnership Agreement, the Commonwealth and participating states and territories have agreed to discuss and collaborate on the ongoing implementation, monitoring, and evaluation of the RFS, particularly through membership of the RHDAustralia Advisory Committee.

Governance of the RFS

Under the RFS, the Commonwealth has agreed to provide ongoing policy leadership. Other governance roles performed by the Commonwealth DoH include managing the funding arrangements with the NCU through its funding agreement, and monitoring progress of the RFS through what were six-monthly, but now annual, reports from each participating jurisdiction and the NCU.

RHDAustralia has established two governance committees, the RHDAustralia Advisory Committee and the Data Management Committee. The RHDAustralia Advisory Committee provides advice focusing on strategies and deliverables for the NCU including the ongoing review of aims and objectives of the NCU as well as advice on enhancing NCU-jurisdictional control program interactions. RHDAustralia Advisory Committee membership consists of Directors of RHDA, senior advisors from partner agencies including Baker IDI, South Australian Health and Medical Research Institute and TelethonKids, as well as expert advisors from individual jurisdictions. The Commonwealth DoH is not currently represented on this committee. The RHDAustralia Advisory Committee meets quarterly.

The Data Management Committee provides oversight of RHDAustralia Data Collection System activities including addressing issues of clinical interest and quality of care, advice on the collection and interpretation of data for use in programming and policy. Data Management Committee membership includes the deputy director of RHDAustralia, a representative of the RHDAustralia Advisory Committee, representatives from each control program funded under the RFS, National Aboriginal Community Controlled Health Organisation (NACHO), the Commonwealth DoH and RHDAustralia operational staff. The Data Management Committee meets quarterly.

Each participating state and territory government has established local governance committees and arrangements to oversee control program activities. WA and Qld have separated the governance between two advisory committees: one to monitor compliance with the National Partnership Agreement and another to advise on clinical aspects of control program activities. The NT and SA each use a single governance committee for both roles.

Evaluation methods and questions

Evaluation methods

The Commonwealth DoH commissioned Health Policy Analysis to undertake an evaluation of the RFS. The evaluation was conducted between October 2016 and December 2016 and involved:

- Analysis of various documents provided by the Commonwealth DoH, NCU, and the state/territory-based control programs, as well as additional documents provided during the stakeholder consultations.
- Review of the literature related to the prevention of ARF and RHD.
- Stakeholder consultations, including RHDAustralia (the NCU), jurisdictional control program and registry staff, state and territory health department staff, clinicians, Aboriginal Health Workers, academics, and other key stakeholders such as expert advisors and non-government organisations. In total 72 individuals from 35 different organisations were consulted.
- Analysis of summary data obtained from:
 - performance reports provided by jurisdictions to the Commonwealth DoH; and
 - data extracts from the NCU.

Evaluation questions

The following key evaluation questions were specified by the Commonwealth DoH:

1. Has the RFS been implemented as expected and what have been the enablers/barriers to implementation?
2. Have the expected outcomes of the RFS been achieved or are they likely to be achieved?
3. Are there other tools or methods of prevention, detection, monitoring or treatment that could be funded to improve diagnosis and treatment outcomes without significantly increasing the cost of the RFS?
4. What is the overall cost of implementing the RFS and to what extent does the Commonwealth's contribution represent value for money?
5. How sustainable are the RFS initiatives beyond the agreed funding period?

The next Chapter presents the findings, responding to each question in turn.

Evaluation findings and recommendations

Question 1: Has the RFS been implemented as expected and what have been the enablers/barriers to implementation?

This question has been addressed by considering, in turn, each of the primary objectives of the RFS:

- a. Implementation, expansion and/or maintenance of dedicated, state-wide patient registers and recall systems for ARF and RHD.
- b. Improved clinical care including improved delivery of and adherence to secondary prophylaxis antibiotics.
- c. Provision of education and training for health care providers, individuals, families, and communities.
- d. Collection and provision of data for national monitoring and reporting of ARF and RHD and measuring program effectiveness in the detection and management of the conditions.

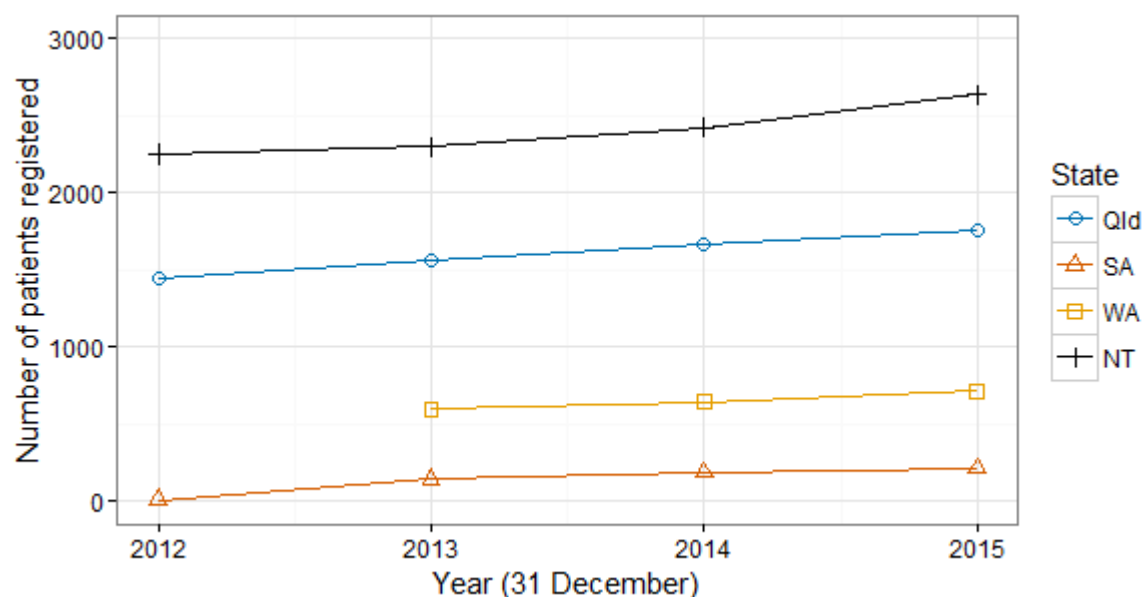
a. The implementation, expansion and/or maintenance of dedicated state-wide patient registers and recall systems for ARF and RHD

Dedicated, state-wide patient registers and recall processes for ARF and RHD are in operation in each of the four participating states and territories. There have been increases in the numbers of patients registered since 2012, increasing from 4,602 in December 2013 to 5,314 in December 2015. In 2015, the numbers of patients registered ranged from 214 in SA to 2,635 in the NT.

These registries are housed in stand-alone databases independent of each other, and independent of patient management systems within the states and territories. While there are some similarities between systems (i.e. WA and Qld systems share similarities, and the NT and SA systems share similarities), the registers are largely independent, with their associated processes and protocols developed within each state or territory. Their uniqueness of operation extends to how clinicians and health services interact with the register.

An outline of the functioning of the registers by state and territory is provided below.

Figure 3 – Number of patients registered on jurisdictional ARF/RHD registers



Source: jurisdictional six-monthly Performance Reports, Analysis by HPA

Northern Territory

Consultations were conducted with 15 individuals from four organisations, including the jurisdictional control program, the Northern Territory Centre for Disease Control, Primary and Tertiary Healthcare services. The evaluation team also analysed and reviewed the six-monthly progress reports prepared by the NT for the Commonwealth DoH.

The registry

An ARF register was established in the NT well before funding was available for one through the RFS. To guide implementation, expansion and maintenance of the register and control program activities, the NT has established the NT RHD steering committee to provide project governance. This steering committee meets quarterly and is made up of clinical representatives, representatives from the NT Department of Health, Primary Health Networks, Aboriginal Medical Services Alliance Northern Territory and RHD Australia. This group is charged with monitoring and evaluating control program progress as well as ensuring the control program activities link effectively with relevant national, regional or local initiatives.

The current iteration of the NT registry shares a common web-based platform with SA. While this platform is in place, the two registries have separate databases housing SA and NT data independently of each other. The platform is web accessible and allows any approved and registered clinician direct, real-time access to patient information housed in the registry. This information includes BPG administration and due dates, echocardiogram dates and reports, and a patient's projected prophylaxis cessation date.

Patient registration

ARF and RHD are notifiable diseases in the NT. Notification of diagnosis is typically carried out by the diagnosing clinician. This is done by completing the standard NT *Reporting of notifiable diseases* form and returning to the NT Department of Health Centre for Disease Control. The registry and the jurisdictional control program is located within the Centre for Disease Control. Recurring bouts of ARF are required to be reported as outlined above, but in practice, a phone call or email is sufficient for a recurrence to be recorded.

Data entry and recalls

Upon receiving a notification, control program staff attempt to confirm the diagnosis and populate all requisite fields within the registry. This is carried out through telephone calls, site visits, and emails to individual physicians or services. This process is also important in determining if the notification is a new diagnosis or a recurrence of ARF. This is an entirely manual process, where control program staff transcribe data into each requisite field. Data may also be directly entered into the registry by clinicians or designated staff at a primary health service. Patient recalls in the NT are primarily facilitated by individual primary healthcare providers. The NT registry provides monthly patient lists to services providing ARF and RHD services, where individual services providers cross check with their records, updating where appropriate. In some instances, this is done directly by services by logging into the registry, and in other cases, the list is faxed or emailed back to control program staff for manual data entry.

The NT control program is currently investigating ways in which data can be directly drawn from the disparate patient information systems and input into the registry automatically. As this work is unfunded, it is carried out on an ad-hoc basis and depends heavily on the workload of NT health staff outside of normal duties. The aim of this automation is to improve efficiency through reducing the manual data entry burden, as well as helping to reduce transcription errors by eliminating that need at various points.

Northern Territory-specific barriers and enablers

- Most reporting of the data to the registry remains by email and facsimile, with the responsibility of data entry falling on control program staff.
 - Clinicians and services have an option to enter data directly but are opting to fax or email the control program.
 - This means that patient information is manually transcribed from electronic patient systems, scanned, faxed or emailed to control program staff who manually enter it onto the registry. This process accounts for a significant proportion of control program resources, with the double handling creating increased opportunities for data errors to occur.
- NT Registry staff report 80% of the patients on the RFS/RHD register are also registered with *My eHealth Record (NT)*. (The *My eHealth Record (NT)* is an NT based shared electronic health record accessible by health care providers across the NT.) Registration for a *My eHealth Record (NT)* is strongly recommended to patients by control program staff upon registration. A proportion of this remaining 20% may be due to the fact that children and teenagers are over-represented in the incidence of ARF, and any infants born after a family has registered for a *My eHealth Record (NT)* require their own registration.
- It is difficult to track patients across state/territory boundaries. Although NT has an electronic health record - *My eHealth Record (NT)* - this is largely inaccessible by clinicians in other jurisdictions (although the NT Department of Health website indicates that clinicians in the Kimberly region in WA and clinicians in SA can access it).
- Being web based, the RFS/RHD registry has the capacity to be accessed interstate. Due to policies stemming from privacy legislation, registration and logins are required prior to access being granted to clinicians. An agreement between NT and SA Health

has enabled clinicians in either state to apply for and access the register of the other state.

South Australia

Consultations were conducted with 10 individuals from eight organisations, including the jurisdictional control program, the Communicable Disease Control South Australia, South Australian Health and Medical Research Institute, as well as primary and tertiary healthcare services. The evaluation team also analysed and reviewed the progress reports prepared by SA for the Commonwealth DoH. Annual reports published by the South Australian Rheumatic Heart Disease Control Program were also considered.

The registry

The SA registry has been in operation since 2012, established with the assistance and guidance of the NT control program. This close relationship resulted in an agreement between the NT Health Centre for Disease Control and the SA Communicable Disease Program, allowing SA to share a common web-based platform with the NT register. This means that as with clinicians in the NT, registered clinicians in SA can access the registry and patient data in real-time.

SA has established an RHD Program Advisory Group which provides strategic advice, guidance and support to the SA RHD Control Program operations, as well as playing a key role in assessing and evaluating program progress and outcomes. The group is comprised of key professionals and experts involved in the diagnosis and management of ARF/RHD in SA, including clinicians, SA Health departmental representatives (including Service Delivery Aboriginal Health branches), Local Health Networks, Aboriginal Health Councils in SA (including Nganampa), RHD Australia, Heart Foundation, and the Royal Flying Doctor Service.

Patient registration

In February 2016, both ARF and RHD were made notifiable diseases in SA. A notification is made to the Communicable Disease Control Branch via direct phone call or via the standard SA notifiable conditions reporting form. The Communicable Disease Control Branch database is separate from the SA Rheumatic Heart Disease register. Where the SA Rheumatic Heart Disease register requires patient consent prior to enrolment, the register maintained by the Communicable Disease Control Branch does not. While this has the potential to cause confusion, SA register staff noted it was extremely rare for patients to refuse consent to being placed on the control program register. Having two separate registers means a diagnosing clinician needs to make two separate notifications, the first to the Communicable Disease Control Branch, and the second to the SA Rheumatic Heart Disease register.

Data entry and recalls

Upon registration, SA registry staff attempt to access patient notes from primary and tertiary health organisations. In many instances, staff are required to file Freedom of Information requests to access this information. Following registration and population of the patient record, approved clinicians in SA can directly access patient information in the registry and enter and update information (i.e. as with the NT). As in the NT, there is little in the way of standardised protocols that prescribe this responsibility. It is left to policies and practices at each health care service (primary and/or tertiary) as to where the responsibility for updating the register falls.

The responsibility for patient recalls largely falls on the individual primary health services. The registry provides periodic patient lists to service providers to crosscheck, update and

reconcile with locally maintained records. These lists are provided via email and electronic spreadsheet, typically completed manually and returned to the registry via fax or email for entry. In some instances, local primary health service clinicians/staff will update the register through the web portal.

Cardiologists are becoming more aware of the register, and where patients have consented, they provide a copy of cardiology reports via fax or email to the SA register staff for manual upload. This process requires registry staff to manually extract pertinent data from these reports to update patient information (e.g. priority status) on the register.

Overall, SA control program staff believe the data in the registry to be of a good quality and is continuing to improve as awareness of ARF and RHD improves.

South Australian- specific barriers and enablers

- The five clinical and primary care service stakeholders stated that their ability to manage patients had improved as a result of the registry, primarily through real-time access to patient level data. This enabled them to make informed decisions on the care of those visiting from out of the area, and track the prophylaxis status of local patients who are away.
- While stakeholders agree improvements have been made in clinical knowledge over the funding period, stakeholders from each of the eight organisations and departments consulted suggested that this was from an extremely low baseline, and further improvements are not only possible but necessary.
- Lack of knowledge and awareness of ARF and RHD was identified as being greatest amongst clinicians based or trained in metropolitan areas. This included a lack of awareness in diagnostic criteria and/or treatment guidelines. (This is not a problem isolated to SA. Stakeholders across all jurisdictions expressed similar concerns. This was demonstrated most clearly in Qld, where control program staff had performed patient file audits in metropolitan Hospital and Health Services, identifying 600 previously unreported cases of ARF and RHD.)

Western Australia

Consultations included 11 individuals from six organisations, including the jurisdictional control program, the Communicable Disease Control Directorate, Kimberley Population Health Unit, as well as primary and tertiary healthcare services. The evaluation team also analysed and reviewed the progress reports prepared by WA for the Commonwealth DoH.

The registry

WA has separated its governance into two separate structures, one to ensure compliance with the National Partnership Agreement (Partnership Agreement Reference Group), and the other to advise and guide on Clinical activities (Clinical Advisory Group.)

Members of the WA Rheumatic Fever Strategy Partnership Agreement Reference Group are called on to identify system and service integration and improvement strategies, as well as designing and monitoring implementation. Meeting monthly, membership of this group includes WA Country Health Service (WACHS), WA Health Population Health, Kimberley Population Health, and the Chair of WA RHD Clinical Advisory Group.

The WA Rheumatic Heart Disease Clinical Advisory Group provides advice and guidance supporting clinical functions and interactions of the WA RHD Program. This group helps draft

WA action plans, monitoring their implementation by the WA control program and evaluating impact. Meeting quarterly, membership includes paediatric and adult cardiologists, primary health care providers, Aboriginal Health Council of Western Australia (AHCWA), Aboriginal Medical Services, ARF/RHD Experts, WA Communicable Diseases Control Directorate and WACHS.

WA utilises an SQL database to house the ARF and RHD registry, maintained behind the WA Health firewall. The location of the registry behind the WA Health firewall means direct access is limited to those with access to the WA Health shared systems, that is, those working within the WA public health sector. As a result, many primary care clinicians, for example, those working in Aboriginal Health Services, are unable to access the register directly. This impedes aspects of clinical management and results in a manual process of telephone calls and emails to assist primary care services in assessing treatment requirements.

This registry database was utilised as the basis for the Qld register.

Patient registration

ARF and RHD are notifiable diseases in WA. Unlike Qld (where the Communicable Diseases Branch maintain a cut-down, non-clinical register), the RFS registry serves as the sole collection point for WA. Upon diagnosis, clinicians are required to complete a *Notification of Acute Rheumatic Fever* form and return it to the Kimberley Population Health Unit (where the control program is located.) Once registry staff receive a notification, they manually search the patient information systems they have access to (in the public health sector) as well as contact the patient's primary health care provider to confirm the diagnosis and collect other relevant data.

Data entry and recalls

Data entry into the WA registry is predominantly a manual task, facilitated by email and/or fax. Registers generate written care plans and patient lists that are forwarded to the registered primary care providers. Primary health care providers administer care, update local patient management systems and/or registry lists appropriately. Lists are then faxed or emailed back to the control program for manual entry into the registry.

WA control program staff have worked closely with WA Health to develop a system to automate data extraction from *Cardiobase*, a cardiology patient information system used in WA Health. This system provides an automated extract of flagged relevant data contained within the system. While the extraction is somewhat automated, the entry into the registry is still a manual process.

Western Australian-specific barriers and enablers

- Currently, there is limited clinical access to the registry. Staff working within the WA public health system have access to the registry, but not primary care providers who are predominantly responsible for direct patient care. WA control program staff and clinicians estimate 80% of ARF and RHD patient care is performed in primary care.
- There is inconsistency between primary health care services in WA in the processes for generating patient recalls. Predominantly recalls are generated and followed up by the individual primary health services. However, some services rely on patient lists sent by the register to initiate a patient recall. These lists are sent out monthly, whereas prophylactic BPG should be repeated within 28 days, potentially contributing to an increased at risk period for patients.

- WA has made progress with Cardiobase cardiology patient management systems that can automatically extract data from patient records flagged with ARF or RHD for reporting to the registry.

Queensland

Consultations were conducted with 18 individuals from eight organisations, including the jurisdictional control program, the Communicable Diseases Branch Qld Health, Aboriginal and Torres Strait Islander Health Branch, the department of Tropical Health and Medicine at James Cook University, as well as primary and tertiary healthcare services. The evaluation team also analysed and reviewed the progress reports prepared by Qld for the Commonwealth DoH.

The registry

The Qld register has been in operation since 2009. The system implemented by the Department of Health Queensland (DoHQ) is based on the SQL database developed by WA. The Qld register is located behind the DoHQ firewall. Unlike WA, the Qld registry does not allow any direct access to clinicians; all information entered and extracted from the registry occurs through control program staff.

Qld control program has also established two separate governance groups to steer its activities, an Advisory Committee and a Clinical Advisory Group (CAG).

The Advisory Committee meets on a six-monthly basis and provides advice on policy development, program activity, and strategic planning in relation to the maintenance and growth of the register and control program. Membership includes representatives from DoHQ including Communicable Diseases and Aboriginal and Torres Strait Islander Health Branches, Tropical Public Health Services and the Rural and Remote Clinical Support Unit. Membership also includes representatives from Hospital and Health Services, Primary Health Networks, Indigenous Cardiac Outreach Services, RHD Australia, The Heart Foundation (Qld), The Royal Flying Doctor Service, and Queensland Aboriginal and Islander Health Council.

The CAG is a sub-group of the Advisory Committee and meets quarterly. CAG includes representatives with direct experience in the diagnosis, management and prevention of ARF/RHD. The group provide expert clinical guidance regarding current best practice and clinical policy, procedures, guidelines and protocols. Membership of the CAG includes Cardiologists/Medical Officers/clinicians from Hospital and Health Services across Qld as well as Aboriginal Medical Services and Cultural Advisors.

Patient registration

ARF is a notifiable disease in Qld. RHD is not. The Communicable Disease Branch of DoHQ maintains the Notifiable Conditions Register. This is the first place a diagnosis and recurrences of ARF are reported and recorded. After receiving a notification, the Communicable Disease Branch informs the Qld control program of this notification, where it is recorded in the control program's register. Control program staff then commence a manual search of public health patient information systems for patient data to populate the required register fields, as well as phone, fax, and email follow up with a patient's primary health care provider. As ARF is a notifiable disease in Qld, patient consent is not required, allowing these processes to take place as soon as a notification is made. In relation to RHD, control program staff require consent to register a patient. The absence of consent prevents reporting of information for a patient or generating recalls in the care of that patient.

Data entry and recalls

The Qld control program's system means all data contained in the registry is manually entered. Patient recalls across many primary health settings in Qld are activated by the patient lists sent by the control program monthly. These lists are sent by fax or email from the control program to up to 270 primary health care providers across Qld. These lists trigger the recall of a patient at the health service. Staff complete by hand, scan and fax or email the list back to the control program before the end of the month. The registry lists are closely scrutinised by the health service staff as they also serve as a means for notifying any newly registered or visiting patients. Where one is available, a chronic care nurse from the service completes the forms and updates local patient management systems where required. Additionally, health service staff will hand write at the bottom of the registry lists any newly diagnosed patients that have presented from out of the area for ARF treatment.

The recall process is repeated monthly for secondary prophylactic injections and quarterly for cardiology review.

Queensland-specific barriers and enablers

- The register is located behind the DoHQ firewall, preventing real-time access and clinical use.
- Systems in place require a large degree of double handling of data. Data is extracted from primary health care patient management systems, hand written, and provided to registry staff for manual entry into the registry.
- Patient recalls are driven by registry staff. While there are primary health services that generate their own BPG prophylaxis recalls, the primary health services visited relied heavily on the monthly patient lists distributed by the register to prompt this action. It was suggested by clinicians and control program staff that this was usual practice across primary health in relation to BPG injections as well as three monthly echocardiogram recalls across Qld.

Summary

Functioning registers and recall systems have been established in all funded states and territories. They do not have a common operating model. Control program staff in all jurisdictions perform a significant amount of manual data handling, sending, receiving and transcribing handwritten notes via fax and email to maintain registry records and associated functions. In developing the data specification for national reporting, the NCU and control program staff became aware of significant numbers of errors in data across all jurisdictional registers. The NCU and control program staff ascribe many data errors to manual entry, as many of these errors have been subsequently corrected after control program staff cross-referenced their records with health care providers. This checking and cleansing of the data was, and still is, a time-consuming process that requires control program staff contacting service providers individually to perform this record cross check. Cleansing and manual data entry represent a significant proportion of control program activity and resources.

There are technological solutions that can help reduce the number of times data are entered, transcribed and re-entered. This will require jurisdictions to investigate opportunities to automate system extracts, and/or system inputs. For example, templated patient information system extracts that allow direct upload into register database. At a minimum, control programs can stipulate that patient lists be provided to them in a prescribed format (Excel or CSV file). Additionally, many patient information systems have the ability for

functions to be built that will allow the required data to be extracted automatically in a prescribed format, with additional details added by the clinician reporting the relevant event. Minimising the need for manual transcription will improve data consistency and reduce errors. This will also reduce a significant burden on control program data staff, allowing them to focus on other tasks.

It should be a priority for all jurisdictions to collaborate and develop strategies and systems to improve the flow of information between jurisdictional registries and relevant health services. Improvements in this area are likely to flow onto the effectiveness of recall process, reduce manual data entry for registry and health service staff, improve the accuracy of registry data and the efficiency of registry operations. These initiatives could be led by the Commonwealth through specific inclusion in future iterations of the RFS.

Question 1. a. - Implementation and expansion/maintenance of a dedicated statewide patient register and recall systems for ARF and RHD

Key findings

- ARF/RHD registers established in all funded states and territories.
- Recall systems for secondary prophylaxis are in place in all funded states and territories.
- The mechanism by which recalls occur, differ in each jurisdiction.
- Registers in all funded states and territories rely heavily on fax/email notification and manual data entry. Particularly in WA and Qld where clinical access to the registry is limited or completely barred.
- Multiple patient management systems within each jurisdiction complicate reporting and data management processes at each registry.
- Arrangements for clinician access to the registers differ across jurisdictions.
- There are only limited arrangements for inter-jurisdictional access to the registers.

Recommendation

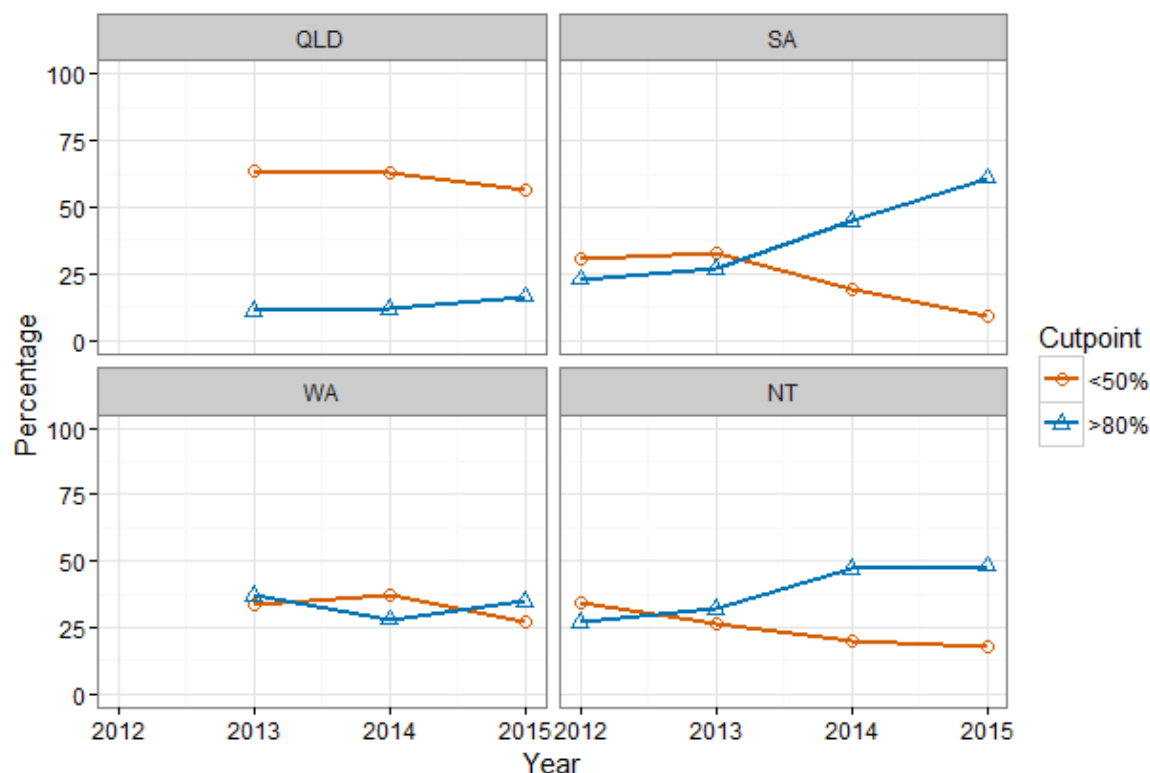
- ❖ Participating jurisdictions to increase the automation of patient data capture and reporting.

b. Improved clinical care including improved delivery of and adherence to secondary prophylaxis antibiotics

The World Health Organization (WHO) technical report on rheumatic fever and RHD strongly recommended secondary prophylaxis for addressing rheumatic fever across the globe (WHO, 2001). The report identified areas that governments or health organisations should address when establishing national ARF and RHD programs. These included health education activities, training health-care providers, and epidemiological surveillance. These recommendations were adopted when drafting the RFS.

Figure 4 shows the trends in patients receiving at least 80% of their scheduled BPG injections, by state and territory. The data show that from 2012 to 2015, adherence rates in both the NT and SA increased substantially. These increases were from very low bases. These trends were not replicated in WA or Qld. Adherence rates (patients receiving 80% or better of their scheduled doses) have remained static and relatively low in WA. There was a small increase in adherence in Qld, but rates remain very low.

Figure 4 - Percentage of patients on the register who are receiving $\leq 50\%$ of their scheduled doses of BPG and the percentage receiving $\geq 80\%$



Clinicians (cardiologists, GPs and health workers) in all jurisdictions reported an increased awareness of ARF and RHD amongst colleagues as a direct result of the RFS and individual control program activities. However, clinicians and control program staff identified clinician knowledge and access to patient information as enduring barriers to improving clinical care.

Clinical knowledge will be explored later in this document (see p. 25) when discussing education and training. Clinical access to patient information is impacted by the variety of patient information systems used across primary and secondary health care systems.

However, even when identical systems are used across different service delivery units, there is no guarantee that a clinician from one unit can access patient information in the others.

One function the registries perform is to help clinicians in delivering appropriate clinical care when patients move between geographic regions and different health systems. Direct access to this data also provide primary care clinicians and services with a means by which they can readily ascertain the status of their local patients, and as a back-up for clinical information recorded in local patient information systems. The lower levels of access by clinicians to registry data in WA and Qld compared with SA and NT is one factor that may account for the trends observed in Figure 4.

The NT benefits from a unique patient identifier that follows a patient anywhere in the NT health system. This significantly aids data sharing and linkage. In addition, the NT also maintains a shared eHealth record (now known as *My eHealth Record (NT)*), that is promoted to all patients on the registry. This allows a clinician in any part of the NT to log in and access patient information (broader than that contained in the registry) in real-time. The NT control program estimates 85% of patients on the registry have a *My eHealth Record (NT)* record. This has aided practitioner acceptance in the NT. There have been lower levels of participation in the national equivalent, *My Health Record* (Royle et al., 2013) although more recent developments, such as the introduction of opt-out arrangements are likely to impact on participation and use by clinicians.

Access to registries by clinician staff may be difficult in WA and Qld. Both jurisdictions support a greater number of Hospital and Health Services, where each has their own independent legal status, boards and structures, and in turn protocols to deal with data sharing. While difficult, it should not be impossible to allow real-time clinical access from anywhere in the state. For these states, creating the capacity for clinicians to access registry records could be a priority identified in the next stage of the RFS.

There are potential benefits from *My Health Record* for patients who travel regularly across health service and state/territory boundaries. These benefits will rely on the take-up by patients and clinicians to reach a threshold at which relevant clinicians can be confident that the information available through *My Health Record* is sufficiently current and accurate on which to base decisions. Steps towards this goal that could be identified as priorities in the next stage of the RFS include:

- Implementing protocols to encourage enrolment in *My Health Record* at the time a patient is diagnosed with ARF or RHD.
- Developing protocols and processes through which *My Health Record* can be regularly populated or updated with the latest data from the jurisdictional patient registers.
- Designing and evaluating the nature of reports loaded from registries into *My Health Record* so that these provide a succinct summary of each patient's current status in terms of prophylactic antibiotics and cardiology review.
- Encouraging primary care clinicians and specialist cardiologists caring for patients with ARF and RHD, to upload relevant information on events, specialist letters/assessments and diagnostic imaging reports.

In addition to clinical access to information and education, stakeholders with significant experience working clinically in remote communities (cardiologists, public health nurses and Aboriginal Health Workers), identified *continuity of care*, that is, the relationships built by clinicians with communities and patients, as vitally important for adherence to secondary prophylaxis. Clinicians in every jurisdiction offered anecdotes of individual nurses or health workers who maintained 100% adherence rates in specific communities over time, only to see these rates fall substantially when that nurse or health worker moved on.

While exploring strategies to improve continuity of care and retention rates of clinical staff, clinicians and control program staff in Qld nominated Aboriginal Health Workers as the most stable part of the health workforce in rural and remote communities. A limitation however, is that the scope of practice of Aboriginal Health Workers in Qld does not include the administration of BPG injections. In WA, where Aboriginal Health Worker scope of practice would allow BPG injection, clinicians, health service administrators and staff from Kimberly Population Health Unit and WA Country Health Service reported that retention of Aboriginal Health Workers was a challenge. A contributory factor to high turnover rates offered by stakeholders was that practices and services often failed to utilise Aboriginal Health Workers to the full extent of their scope of practice. WA Country Health Service and other stakeholders, including Aboriginal Community Controlled Health Services, are investigating strategies to improve workforce retention, including an Aboriginal Health Practitioner qualification that sets out a clearer scope of practice. The Aboriginal and Torres Strait Islander Health Practice Board of Australia are working, as a body within the Australian Health Practitioner Regulation Agency, towards nationally recognised scope of practice and regulatory guidelines for Aboriginal Health Workers and Aboriginal Health Practitioners. This work may help in some way with the issues highlighted above.

Finally, data are not available currently to allow analysis of other aspects of clinical care or longer-term outcomes. Improved data reporting to the NCU will enable analysis and reporting on other aspects of clinical care and long-term outcomes, for example, measures on ARF recurrences rates and patient RHD progression.

Question 1. b. - Improved clinical care

Key findings

- Clinicians in the four jurisdictions identified the increased general awareness of ARF and RHD by the clinical workforce is attributable to the RFS, and suggest that this has led to improved clinical care.
- Increases in adherence rates were observed between 2012 to 2015, in both the NT and SA. Increases were also observed in Qld, although overall adherence rates in that state remain very low. There is no clear evidence of an increase in adherence within WA.
- Stakeholders also identified barriers to improved clinical care, specifically that clinician access to registers is limited (WA) or not possible (Qld).
- Multiple patient management systems restrict real-time access to patient records.

- Real-time access to patient records is largely not possible when patients cross state boundaries.
- Clinical knowledge of ARF diagnosis and management is impacted by clinical workforce turnover in affected communities, contributing to gaps in clinical care.

Recommendations

- ❖ Participating jurisdictions to increase the automation of patient data capture and reporting, and seek to enable real-time access to clinicians and health services to registry data and patient records.
- ❖ Participating jurisdictions consider utilising My Health Record to facilitate better sharing of information on the registers and to facilitate improved adherence to

c. Provision of education and training for health care providers, individuals, families, and communities

The WHO technical report on rheumatic fever and the RFS identify the provision of quality training for health care providers and health education activities for patients, families and communities as vital in achieving primary and secondary prevention (WHO, 2001). The RFS

places the responsibility with the NCU to develop suitable education materials, making them available to support jurisdictions in educating health care providers and communities.

Health care providers

RHDAustralia provides several educational resources for clinicians including:

- on-line access to the *Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition)* (RHDAustralia et al., 2012);
- Guidelines and Diagnosis Calculator App (available for iPhone and Android devices), which includes key information from The Australian guideline; and
- A set of e-learning modules, together with a discussion forum.

The centrepiece of educational materials targeted at clinicians is the e-learning modules designed for clinicians and health workers, accessible via the RHDAustralia website. These modules provide a basic understanding of best-practice approaches to the prevention, diagnosis, and management of ARF and RHD. Five modules are available for health workers (each approximately 30 minutes in duration) and 15 modules for clinicians (each between 30-45 minutes in duration).

Clinicians in each jurisdiction (working independently of the control programs) reported that control program staff actively promote the education modules, the ARF/RHD Guidelines and the ARF/RHD Guidelines app, whenever on-site at individual health services. These modules have been accredited by the Australian College of Rural and Remote Medicine and endorsed by the Australian College of Nursing.

A review conducted for RHDAustralia by Argyle Research (Argyle Research, 2016) surveyed individuals who had undertaken the health worker modules, finding an improvement in self-rated knowledge of:

- basic understanding of ARF and RHD;
- diagnosing ARF;
- managing ARF; and
- managing RHD.

The review also reported that individuals who completed the modules tended to retain and apply the knowledge they gained in practice. Similar positive findings were reported about the modules for clinicians.

While not a key focus of this evaluation, our own reviewer, with approximately 20-years' experience delivering distance tertiary education, found the modules examined to be of high quality and easy to use. However, the labelling and organisation of the modules on the RHD Australia website could be confusing. The website layout makes it difficult to identify where a user is up to or which modules were appropriate to the user's qualification (medical, nursing or health workers). This was also voiced by clinicians interviewed with a working knowledge of the modules. Despite their quality and promotion, most clinicians indicated uptake and completion rates amongst colleagues remained low.

RHD Australia monitors the numbers of clinicians accessing and completing the modules, although there is no way of ascertaining how many clinicians are working in remote areas at any one time. For this reason, it is difficult to provide any further evidence or analysis on training uptake or to assess coverage.

Amongst the clinicians interviewed, the most commonly cited reason for not completing the modules was time. In WA and NT, Primary care clinicians and Health Workers working out of Aboriginal Community Controlled Health Organisations and ACCHO affiliated health services, suggested if time was offered to complete training during work hours it would boost completion rates. In WA, while time during work hours was not offered to complete the modules, one of the Aboriginal Community Controlled Health Services provided an in-house staff induction where ARF and RHD were a key focus. This provider had also worked closely with the WA control program to develop an ARF and RHD introduction module/video that is now hosted on the RHD Australia website. Additionally, clinicians in WA, NT and Qld suggested that entirely self-directed, online and didactic lectures do not suit preferred learning styles of some of the target audiences. Clinicians suggested other modes of education were required, for example, face-to-face training, interactive web-based lectures, and/or mixed mode online with face-to-face seminars.

RHD Australia staff are aware of the training uptake and completion issue. To address some of these concerns, RHD Australia, in partnership with local control programs, delivered two, two-day seminars; one in Alice Springs and one in Brisbane. The control program and RHD Australia report these sessions were well received. While clinicians were broadly supportive, several senior clinicians wanted to ensure clinicians and health workers in the remote communities are reached. To facilitate this, they proposed priority and travel subsidies be given to clinicians working remotely, something that RHD Australia and Qld control program report is currently happening.

Clinical awareness of RHD and ARF was an issue for every individual consulted who worked in an area related to patient care. Primarily, this issue was identified as one relating to gaps in the knowledge of primary health care clinicians trained in metropolitan centres. Clinicians trained in major metropolitan universities noted their own training failed to properly inform

them of ARF and RHD. Further investigation revealed that Charles Darwin University and James Cook Universities are amongst the only Australian universities that include ARF and RHD in their medical curriculums, and have done so only recently.

While inclusion of education about ARF and RHD in medical school curriculums is a step in the right direction, the transient nature of clinical health staff in these remote and rural communities, and the widespread use of locum and/or agency staff, make it extremely difficult to maintain high levels of clinical awareness of ARF and RHD. This presents significant barriers to appropriate diagnosis and administration of BPG as primary and secondary preventative treatments to patients. Individual states and territories could consider actions to help increase clinician knowledge; for example, including relevant content in induction training for all clinical staff working (or seeking work in) in rural and remote health settings. Additionally, there could also be opportunities for RHD Australia, and the Royal Australian College of General Practitioners in working together to help raise awareness within the broader primary care workforce.

The provision of clinical training and education is also a responsibility of control program staff in each jurisdiction. Progress reports from each jurisdiction identify the range of activities undertaken by control program staff.

As with any health-related area, there remains a continuing need for to maintain and fine-tune clinical education and training resources and mechanisms for the delivery of education and training. Specifically, these activities will include:

- Continual update of Australian Guideline.
- Incorporating changes in the Guideline into training materials.
- Redesigning aspects of the training and education modules to achieve better labelling and navigation for users, for example, providing clarity over modules that cover introductory or essential material, those relevant to health workers, clinicians, and those involve further in-depth education.
- Development and evaluation of alternative training/education delivery modalities that suit a broader range of learning styles. For example, mixed mode (online and face to face).
- Continual monitoring of primary care clinician awareness and use of the Australian ARF and RHD Guideline and others including the Central Australian Rural Practitioners Association Inc (CARPA) manual with respect to primary prevention related to GAS infections and secondary prophylaxis.

Education of individuals, families, and communities

Bringing a child to a clinic for a painful injection every four weeks, or having a sore throat medically assessed, is a major undertaking; one that relies on the combined knowledge of the individual, family/carers and clinician. Therefore, community education and clinical training need to complement each other. Patient and parents/carers need to be fully aware of the ongoing necessity and the importance of regular prophylactic BPG, as do clinicians. While patients and families were not directly consulted during this evaluation, every individual consulted working in patient care or related areas, identified patient and community education about ARF and RHD as a weak point of the current RFS.

There is currently limited community education material available through RHD Australia. The material available includes YouTube videos and links to resources produced by other organisations including the Heart Foundation in Australia and New Zealand. Recurring themes that emerged through consultation with all clinicians, health workers, and control program staff, suggested much of the material available is text heavy, culturally neutral, and inappropriate in many instances considering the health and general literacy levels of the target audiences. Those working in the communities, while appreciating the work done by RHD Australia in developing materials, believe that community education materials need to be developed in conjunction with the communities, that is, materials adapted to reflect the targeted community. For example, many of the materials developed by RHD Australia, depict red sandy landscapes alongside a red, orange and yellow colour palette, whereas artwork and colouring more appropriate in tropical areas of Qld are those depicting rainforests with blues and greens.

Individual control programs in SA and Qld have started to adapt the RHD Australia materials and messages, developing education materials that better reflect the patients and communities they are charged with. WA commenced this work, however, were later required to abandon it as funding and resources didn't allow them to proceed. This means patient and community education is largely limited to the education a patient receives on diagnosis. Understanding clinical training and community education complement each other in achieving secondary prophylactic goals, there remains a significant opportunity for the RFS to help realise improvements in care and incidence through well-designed, community and patient education health promotion strategies, to support the work being done clinically.

Several reviews and publications focusing on Indigenous health promotion (AIHW & AIFS, 2013) (NH&MRC, 1996; NSW Health, 2002) have identified the following areas, amongst others, as integral to promotion activities:

- Community consultation, identification of community health issues and developing messages that are relevant to the community;
- promotion initiatives need to be sensitive to, acknowledge, affirm and reflect the values of Aboriginal culture, within and between communities;
- effective Aboriginal health promotion practice means building the capacities of the community ensuring ongoing community involvement;
- Aboriginal health promotion acknowledges the holistic definition of health; and
- primary health care in Aboriginal communities incorporate Aboriginal health promotion.

A focus on improving patient outcomes by improving patient and community awareness will be a continuing requirement into the future. This requires a collaborative effort between RHD Australia, the control programs in each state and territory and health services. The principal role for RHD Australia should be to develop key messages for the relevant audience that are succinct and relevant for target audiences, and to facilitate collaboration between jurisdictions. Jurisdictional control programs and health services have important roles in collaborating with local communities to adapt national materials to be relevant and appropriate for these communities, as well as ensuring relevant programs are delivered in communities. For example, a specific community and clinical education initiative could be to challenge the normalisation of skin sores and sore throats as normal within Indigenous communities, urging parents and guardians to present children at clinics for treatment.

Collaboration is already occurring to some extent. Improved effort in this area across RFS-funded programs will help to minimise duplication and maximise efficiencies implementing these strategies. The role of the Commonwealth in this regard is to facilitate and foster these relationships through continual support and guidance of the National Partnership Agreements and the RFS.

Question 1. c. - Provision of education and training

Key findings

Health care providers

- The RFS has enabled the development of quality teaching materials for health workers and clinicians at a national level. The Australian Guideline and the associated app are important resources available for health care providers and those involved with control programs.
- Awareness of ARF/RHD amongst clinicians has increased over the period the RFS has been in place. Clinical stakeholders recognised the material provided by RHD Australia as well as education and awareness efforts of state and territory control program staff as important contributors. National organisation such as the Heart Foundation and Australian Medical Association have also played important roles in improving awareness of ARF/RHD within clinical communities.
- Clinical awareness of RHD Australia modules is high amongst experienced clinicians. However, uptake of the modules amongst clinicians and health workers more broadly is low.
- Some clinicians and health workers have suggested the modules are too long and that a different delivery mode would assist in their uptake.
- Transient workforces create challenges in maintaining high levels of clinical knowledge of ARF and RHD.

Individuals, families and communities

- The consumer/patient/community education material available needs to be fine-tuned to take account of potential audiences.
- Clinical training and community education need to complement each other to achieve further improvements in health and clinical care, including prevention activities and secondary prophylaxis.
- The community targeted material that is available needs to be community specific and culturally appropriate, for example incorporating:
 - community/area specific artwork; and
 - community co-developed resources.
- Health and general literacy of the target population need to be a paramount consideration in the developing/adapting education materials for local use.

Recommendations

- ❖ Develop additional mixed modes of clinical education to complement existing web-based delivery, and redevelop existing modules to improve completion rates as the current modules are complex and not time efficient.
- ❖ Improve education and training for health care providers, individuals, families and communities to raise awareness, and improve detection, prevention and management.

d. Collection and provision of data for national monitoring and reporting of ARF and RHD and measuring program effectiveness in the detection and management of ARF and RHD

The agreement between the Commonwealth DoH and RHD Australia requires RHD Australia to *“Establish and maintain a data collection system (DCS) and reporting system for measuring the progress and effectiveness of the register and control programs...”* RHD Australia is expected to work with the jurisdictions to facilitate data reporting.

The aim of the DCS is to support the participating jurisdiction to collect data and provide high-quality epidemiological reports to:

- improve monitoring of secondary prophylaxis;
- improve monitoring of other aspects of patient care;
- benchmark the work of the jurisdictions against their own performance in disease detection and management;
- allow comparisons of key performance indicators across jurisdictions; and
- allow comparisons with international best practice.

At the time of the establishment of the first RFS in 2008, it was decided to pursue a strategy of jurisdictional based ARF/RHD registers, rather than a single national register. The rationale for this approach has not been fully documented. Amongst other considerations, this arrangement takes advantage of the capacity jurisdictional based staff have in access to data from local systems (e.g. hospital and primary care information systems), and the role registers play in operational management in ensuring patients on the register receive prophylactic antibiotics.

During the first Partnership Agreement, Qld and WA pursued the establishment of registers. In this initial funded period NT sought to enhance an existing register, including the processes around it. The largely independent establishment of registers in WA, Qld and the NT has resulted in different underlying data structures and divergent operational definitions. The second National Partnership Agreement (and agreement between Commonwealth DoH and RHD Australia) included national data collation and reporting, facilitated by the establishment of the DCS to be built by the NCU. These agreements also provided for jurisdictional representation on a national governance committee via the Jurisdictional Reference Group. This group was charged with identifying the clinical data set specifications and performance indicators. This group was disbanded in 2015 (final meeting 10 March), with the Data Management Committee which jurisdictions are represented, charged with monitoring and reviewing the data collection arrangements.

The Jurisdictional Reference Group had agreed on a set of key performance indicators (Table 2) and a clinical dataset that aligns with the *Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition)*. With these data sets identified, the Data Management Committee provides comment and advice on modifications to the databases within each jurisdiction to produce appropriate data extracts. This committee also provides recommendations to address issues of clinical interest and quality of care arising from the analysis of registry data.

Table 2 – Key Performance Indicators (KPIs) for ARF/RHD (RHDAustralia, 2016)

Key Performance Indicators (KPIs) for ARF/RHD (RHDAustralia, 2016)	
1.1	ARF incidence by episode type
1.2	ARF recurrences
1.3	ARF and/or RHD deaths
1.4	RHD point prevalence
1.5	RHD incidence
2.1	Secondary prophylaxis (BPG by adherence category)
3.1	Priority levels of ARF/RHD cases by age group
3.2	Echocardiograms performed within designated timeframes for priority level 1 & 2
3.3	Waiting times of RHD cases accepted for cardiac surgery
3.4	Surgical procedures performed by type, age group
3.5	Deaths within 30 days and 1-year post-rheumatic cardiac surgery by age group

Concurrently, RHDAustralia progressed the development of an application (the DCS) through which extracts from state-based registers can be received and processed so it can be included in a clean national database. RHDAustralia experienced delays in developing the application, with it not fully operational in December 2015, some 15 months beyond the original due date of September 2014. The delays in the development and finalisation of the application were both necessitated change in software developers part way through the build, that also had an exacerbating effect on timelines. Initial software contractors, TelethonKids, performed jurisdictional and stakeholder consultation to develop an implementation plan for the DCS to support the build. At the completion of this work, and after marked delays, the contract with TelethonKids was discharged without delivery of the DCS, leading RHDAustralia to contract HealthConnex in July 2014 to complete the project. RHDAustralia took delivery of the DCS in December 2015.

RHDAustralia then commenced work on receiving 2013 data from SA, WA, and NT via the DCS. This process allowed the DCS, (and the NCU) to identify errors in the data supplied by jurisdictional control programs. The NCU then worked with the individual control programs through issues in respect to cleaning and validating the data. This data was then included in RHDAustralia's first national report to the Commonwealth in June 2016 (RHDAustralia, 2016). While this initial process of identifying issues, cleaning and resubmission took approximately five months to complete. All jurisdictional control programs reported the preparation of data for uploading to the DCS has been more labour intensive and time-consuming than initially anticipated. However, all valued the process in allowing jurisdictional staff to identify gaps or failings in their collections and processes.

Potentially adding to these challenges, staff filling data roles within several of the control programs do not have qualifications, or expertise in data analysis and management. This was evident in consulting directly with individuals filling these roles, as well as comments from health services liaising with control programs and data coordinators from the NCU.

The NCU and all control programs involved in this collection believe subsequent collections should be more streamlined.

Despite establishing a Data Management Committee and DCS, the major issue for the RFS and the NCU is the delay in the provision of data to the NCU from individual registries. The predominant issues manifest here as a result of delays in executing contractual arrangements. These include both National Program Agreements between WA and the Commonwealth, and service level agreements between Qld, WA and RHD Australia.

Service level agreements between RHD Australia and the participating jurisdictions are required to address relevant regulatory and ethical requirements related to data releases. Obtaining a service level agreement between Qld and the NCU has been drawn-out across the life of the RFS, and with WA limited to 2016-17.

In Qld, a significant contributor to the delay in executing a service level agreement have been their more rigorous and extensive regulatory requirements. Some of these requirements are due to the decentralised nature of the Qld health system, requiring cooperation and agreement across all 16 Qld Hospital and Health Services as separate legal entities, prior to execution. In addition, the transition to this decentralised model in 2013 was also named as a contributor to these delays. The final service level agreement was accepted and executed by the Director-General of the Qld Department of Health in December 2016, triggering the drafting of relevant regulations to allow data to be shared with the NCU, pending Ministerial approval. Throughout these processes, Qld control program staff have been engaged in work to ensure local registry data complies with the national data specifications and DCS formats. This means that as soon as ministerial approval of the relevant regulation has occurred, Qld control program can supply data immediately.

In WA, data for 2013 through to 2015 has been provided to the NCU, leaving 2016 and 2017 data still to be submitted. WA control program staff report that WA is in a position to supply this data to the NCU once the 2016-17 National Partnership Agreement has been executed with the Commonwealth, allowing for the service level agreement to be executed with RHD Australia. The evaluation team was informed by WA staff that as at April 2017, WA has not formally agreed to the extension as it is yet to progress through state based review processes. WA Control Program and Population Health staff indicated that once the National Partnership Agreement extension is executed there should not be an issue in finalising the service level agreement and the provision of data to the NCU.

Consultations with jurisdictional staff in WA and Qld revealed concerns over the governance arrangements for the RFS, which had impacted the governance of data related issues. The concerns were principally related to the disbanding of the jurisdictional Reference Group in 2015. The jurisdictional Reference Group had been established under The National Partnership Agreement 2012 and was identified as the mechanism by which the dataset specifications and performance indicators were to be agreed and the provision and use of the data to the NCU monitored.

Due to the lack of data from Qld and gaps for WA, as at April 2017, RHD Australia was preparing to provide the Commonwealth DoH with a final report with six years of data from NT and SA only. This report will not include data from Qld and WA. The absence of data from Qld and WA, has meant that only limited benchmarking and reporting back to individual control programs and/or service providers has been possible to facilitate jurisdictional performance monitoring and continuous quality improvement. This limited feedback has

frustrated clinicians, particularly in Qld. The lack of feedback was also raised in WA, but not NT or SA. Two clinicians from Qld and one from WA commented that feedback should be a responsibility of both state control programs and the NCU. Having worked in similar capacities in the NT, two of the three clinicians consulted in Qld indicated that they had received regular bulletins, updates and newsletters from the NT control program, and that these were valuable in their practice.

The delays in data reporting to and from the NCU is a significant issue for the RFS and its national coordination. Stakeholders have expressed the desire to have alternative arrangements for national data coordination to be canvassed to help improve national data reporting and coordination.

During the evaluation, stakeholders proposed several strategies to improve national data reporting. One of the major issues is whether the national data coordination functions should be re-located from RHD Australia to another organisation. This is discussed below. A second proposal was to tighten the performance requirements of the National Partnership Agreement by clearly linking progress payments to the supply of data to the NCU. However, the evaluation team was informed by the Commonwealth DoH that this is not feasible within the framework agreed for federal financial relations by Commonwealth, state and territory Treasurers.

A further proposal has been to consider making ARF and RHD nationally notifiable diseases. Stakeholders proposed the inclusion of ARF and/or RHD on the nationally notifiable diseases list for several potential flow-on effects: to expand the number of states in which these conditions are notifiable; improve the understanding of the epidemiology of these diseases; improve the profile of the conditions within clinical communities; and improve data collection on the disease nationally. A recommendation on including ARF/RHD on the national notifiable disease list is beyond the scope of this evaluation. Advice from the Commonwealth DoH is that neither ARF nor RHD sufficiently meet the criteria to be considered for listing as nationally notifiable diseases.

Location of national data coordination

RHD Australia (i.e. the Menzies School of Health Research) currently undertakes the national data coordination role. In considering the issue of delays in data provision, it is important to emphasise that the role of the national data coordination stated within the RFS includes both monitoring and reporting at the national level and the provision of clinically meaningful and regular benchmarking and data reports to the individual service providers who contribute to registry data.

To meet the second objective, the jurisdictionally agreed minimum dataset is extensive and includes items relevant to a range of clinical care processes. These data items extend beyond the items required to monitor incidence and prevalence of ARF and RHD. However, they are required to populate the key performance indicators developed jointly by RHD Australia and the participating jurisdictions. Data reporting and benchmarking involves feedback to clinicians and specific service units on their performance, therefore, the organisation providing the national data coordination role needs to implement a regular cycle of supply and reporting back (several times per year). It is also important that the organisation performing the national data coordination role has ready access to staff with good clinical knowledge of the data and the associated processes of care, as well as the capacity to access specialist clinical advice to address issues that will regularly arise in managing the data.

The evaluation team has also considered the issue of whether the failure to achieve national reporting has been impacted by the location of the NCU within the RHD Australia/Menzies School of Health Research. Our conclusions are as follows:

- Since 2012, there has been progress towards national reporting. The achievements are:
 - Reaching agreement on the minimum dataset for national reporting and the associated key performance indicators. This may appear to have been a slow process, but the rate of progress is not dissimilar to many national efforts to reach agreement on datasets involving the provision of data from several or all jurisdictions. As pointed out above, the minimum dataset that was agreed is designed to provide clinically meaningful performance indicators. This has meant the data included in the minimum dataset is more complex, and the process for agreeing on common definitions more challenging than many of the national minimum datasets.
 - The participating states and territories report they are willing, and have the ability, to supply their data in the prescribed format that complies with the minimum dataset.
 - RHD Australia has now implemented the computer application that can process, cleanse and load the data into the national data collection system.
 - Data from three of jurisdictions have been processed through the system, resulting in cleaning up of problematic data within the source registers.
 - RHD Australia has prepared the *First KPI Report 2013* based on data reported by NT, SA and WA (RHD Australia, 2016).
- The reasoning provided by states and territories for reporting delays suggest that the location of the NCU in a non-government research unit (part of Charles Darwin University) is only a minor impediment to the supply of data. The fact that the unit is located outside of government is principally an issue for Qld and WA, where the regulatory arrangements for release of health data are more stringent.
- At the finalisation of this report Qld was yet to provide any data to the NCU and 2015-17 data remained outstanding from WA. Despite this, both jurisdictions assert a commitment to resolving these issues.

A decision to change the current national reporting and associated functions should include consideration of how well the current arrangements are working, potential benefits of alternative approaches, and an assessment of the risks (of maintaining the current arrangements or changing to another organisation), and whether those risks can be managed.

The evaluation team's assessment is as follows:

- The remaining impediments to national reporting are contractual, specific to Qld and WA, and are likely to be resolved.
- There is a risk that changing from current NCU arrangements could lead to further delays in the establishment of the national data collection. Arrangements will need to

be negotiated with a new organisation. The new organisation will then need to develop expertise across the range of clinical aspects of the minimum dataset, implement a process for cleansing data, and implement systems for regularly reporting data back to participating registries and clinicians. Arrangements and approvals will also be required to allow the historical data held by RHD Australia to be transferred to the new organisation. The processes listed above will take time, and as national reports are already delayed, a change in organisation is likely to delay these reports further.

As a practical issue, a decision to move the data coordination role to another organisation will require the funding for this role to be disentangled from the roles played by RHD Australia in the coordination of the broader efforts under the RFS and development of education resources. RHD Australia currently supports the only fora through which participating states and territories come together with relevant clinical experts to address issues, including those related to data. Responsibility for support of the data committee will move with data coordination role, but other national coordination is required.

Clinicians were mainly concerned to ensure the process for clinical benchmarking reports commenced as soon as possible. Also, they advised that the organisation to assume the role of data collection and responsibility for clinical benchmarking requires expertise in ARF and RHD, and clinical input, to ensure clinically sound interpretation of data in the reports.

Criteria for selecting an organisation to provide the functions of an NCU could include:

- A governance structure that includes representation from key stakeholder groups involved with ARF/RHD service delivery, including clinicians.
- Capacity to manage the process for ongoing development and maintenance of data specification for national reporting and associated key performance indicators.
- Mechanisms to receive, cleanse and feedback issues to data suppliers to improve data quality.
- Capacity to generate benchmark reports for jurisdictions, clinical units, geographic units participating in the register, develop mechanisms to allow access to these reports.
- Capacity to generate national reports on incidence, prevalence and effectiveness of interventions.
- Access to staff with a clinical understanding of the data, data sources and potential clinical use of benchmark reports.
- Access to experts in epidemiology and biostatistics.

In summary, there are opportunities and risks associated with moving away from the current arrangements. The principal opportunities lie in potential to locate the function in an organisation which has strong credentials in managing health data collection processes. The principal risks lie in the potential for the transition process to lead to further delays in commencing national reporting and clinical benchmarking, disengagement of the relevant clinical community, and the possibility of increased costs for the Commonwealth DoH.

Question 1.d Collection and provision of data for national monitoring and reporting

Key findings

- A national DCS has been developed by the NCU to receive data from the jurisdictions.
- RHD Australia has established a robust governance structure for the DCU, and in August 2016, fed data on the key performance indicators back to three of the jurisdictions.
- WA is prepared to provide data to the DCS but is withholding its 2015 data until it signs an entirely new National Partnership Agreement with the Commonwealth.
- Drawn-out service level agreement negotiations have meant that Qld has failed to provide any data to the NCU.
- All jurisdictions report a willingness to supply data to the NCU, provided all contractual requirements are satisfied.
- ARF and RHD are more widespread than the funded states and territories.

Recommendation

- ❖ Investigate whether transferring the function of national data coordination from the NCU to another organisation would alleviate or exacerbate current delays.

Question 2: Have the expected outcomes of the RFS been achieved or are they likely to be achieved?

The RFS aims to improve monitoring and management of ARF and RHD. This suggests there are three principal outcomes of interest for the RFS:

- Improved detection of ARF/RHD;
- Improved monitoring of patients with ARF/RHD; and
- Improved clinical management of patients with ARF/RHD.

These can be considered intermediate outcomes which each, in turn, contribute to the longer-term outcomes which include reducing the incidence and recurrence of ARF, reducing the severity ARF when it occurs, and reducing the progression of patients who have been diagnosed with ARF to RHD.

Below, each outcome is considered in turn. The linkage between the activities funded under the RFS and these outcomes is laid out in a program logic

Detection

Table 3 – Program logic for the detection of ARF and RHD

Outputs			Outcomes – impact	
Activities	Products/services	Participation	Intermediate outcomes	Key outcomes
What is done?	What is the output?	Who is reached?	What are the intermediate results?	What are key results
<ul style="list-style-type: none"> • Develop and make available educational material for ARF/RHD • Develop and provide education and training material relevant for ARF/RHD • Develop and provide educational activities for ARF/RHD 	<ul style="list-style-type: none"> • Easily accessible educational material related to ARF/RHD • Culturally appropriate education, training, and quality improvement materials • Culturally appropriate materials /activities to raise the awareness of ARF/RHD 	<ul style="list-style-type: none"> • General population • Primary Health Care (PHC) providers • Other health care providers • Aboriginal Health Workers • Aboriginal & Torres Strait Islander communities 	<ul style="list-style-type: none"> • Increased use of educational material related to ARF/RHD • Increased use of education, training, and quality improvement materials among PHC workers and other health care staff • Increased awareness and knowledge of ARF/RHD in the communities 	<ul style="list-style-type: none"> • Increased detection and reporting of ARF/RHD • Reduced incidence & severity of ARF • Reduced recurrence of ARF

Secondary prevention strategies require the early detection of ARF and RHD so that effective management strategies can be put in place to prevent subsequent GAS infection, recurrence of ARF, and in turn further (or any) damage to the heart.

A study of Indigenous children aged between five and 15 years, conducted between 2008 and 2010 (concurrent with the first stage of the RFS), found that 53% of children screened and diagnosed with definite RHD were not known to the registries (Roberts et al., 2014). This demonstrates that, at least previously, a significant number of cases were going undetected.

The number of individuals on the registers is increasing across all jurisdictions (see Figure 3). It is impossible to definitively conclude what proportion of these are actual incident cases of ARF/RHD as opposed to identifying previously undetected cases; it is reasonable to conclude that detection has been significantly improved as a result of the efforts supported through the RFS. Jurisdictional control programs and related services have implemented a range of mechanisms to improve detection. Strategies have included auditing of medical records, and the inclusion of ARF and/or RHD as notifiable diseases, and improving awareness through education, training and day-to-day contact between control programs and health providers.

An example of medical records audits comes from the Midwest Population Health Unit in WA. The unit conducted an audit of hospital admission and discharge data for ARF and RHD in 2014, after similar audits in the Kimberley Region. Qld has also been auditing public patient files, searching discharge and emergency presentation coding reports to identify potential cases of ARF or RHD. As a result, an additional 354 patients had been identified by the end of 2015.

ARF is now a reportable disease in all the funded jurisdictions as well as in NSW. Making the disease reportable has improved awareness of these conditions amongst clinicians, contributed to increased identification and reporting, and provided additional data sources for registries to validate registry data.

Education and training of clinicians, individuals and the community are key activities that underpin increased detection and reporting of ARF/RHD. As canvassed in question 1b (improved clinical care, p. 22) and 1c (provision of education, p. 25), a number of barriers exist in reaching and maintaining a high level of clinical knowledge in target areas.

The RFS has directly influenced clinical knowledge and awareness around ARF and RHD, which have led to increased detection. The strategy of improving clinical knowledge/awareness through self-directed RHD Australia modules is challenging with a transient workforce as discovered in question 1c (p. 25). Furthermore, clinicians can only detect or diagnose the instances of disease that are presented to them. Therefore, community education to raise awareness of the symptoms and appropriate actions is required. All funded states and territories have the infrastructure in place to support reporting and identification of ARF. Further gains to be made in detection rates will require an increased focus on awareness building in communities and amongst clinicians.

Up until this point, a focus has been on clinical training to aid detection and management, but there is also need to educate the communities. There is scope for community education campaigns to cover primordial and secondary prevention issues, together with general awareness in the community of signs, symptoms and appropriate response (i.e. going to the health clinic) would help to improve detection. Unfortunately, patient and community

education activities appear to be relatively patchy across participating jurisdictions. Resource-limited control programs are not able to deliver education to all the communities that require it and need to collaborate with primary care and other health promotion/education staff. Examples of activities include: the WA control program in collaboration with most of its key stakeholders hosted a community screening of 'Take Heart,' a one-hour feature film that follows the true-life stories of young people living with RHD; SA has produced a calendar in conjunction with local communities, that doubles as an aid to help clinicians and health workers educate patients.

Question 2 – Detection

Key findings

- The number of people with ARF and/or RHD recorded on the register is increasing across all jurisdictions.
- Prevalence of ARF and RHD is higher than many clinicians first thought.
- ARF is a notifiable disease in all funded jurisdictions. RHD is a notifiable disease in WA and SA.
- While detection has improved, studies and case-finding initiatives by individual control programs suggest there are still many cases of ARF and RHD going undetected.

Monitoring

Table 4 – Program logic for the monitoring of ARF and RHD

Outputs			Outcomes – impact	
Activities	Products/services	Participation	Intermediate outcomes	Key outcomes
What is done?	What is the output?	Who is reached?	What are the intermediate results?	What are key results
<ul style="list-style-type: none"> • Establish and maintain an ARF/RHD register • Establish and maintain a system for recalling patients for their 4-weekly BPG injections • Establish and maintain a 'National' database of patients with a history of ARF/RHD and provide report on incidence, prevalence, and management of ARF/RHD 	<ul style="list-style-type: none"> • A data collection and reporting system • A governance structure and system for supporting the registers in their data collection and reporting system • A framework for using the data for reporting and benchmarking • Existence of strategies, in each state, to improve the monitoring and detection of ARF and RHD • Agreements between the NCU and the jurisdictions for the transfer of data • Protocol for the reporting of epidemiologic data against agreed benchmarks • Regular reports of up-to-date epidemiological data against agreed benchmarks 	<ul style="list-style-type: none"> • PHC providers • Other health care providers • Aboriginal Health Workers • Patients with ARF/RHD • jurisdictions • AIHW • Commonwealth DoH • Researchers 	<ul style="list-style-type: none"> • Accurate and complete information for all people on the register • Increased use of intramuscular BPG • Increased adherence to intramuscular BPG • Regular and timely publication of reports of epidemiological data on ARF and RHD at the level of the jurisdiction • Regular and timely publication of reports of epidemiological data on ARF and RHD at the national level 	<ul style="list-style-type: none"> • Reduced progression to RHD • Reduced recurrence of ARF

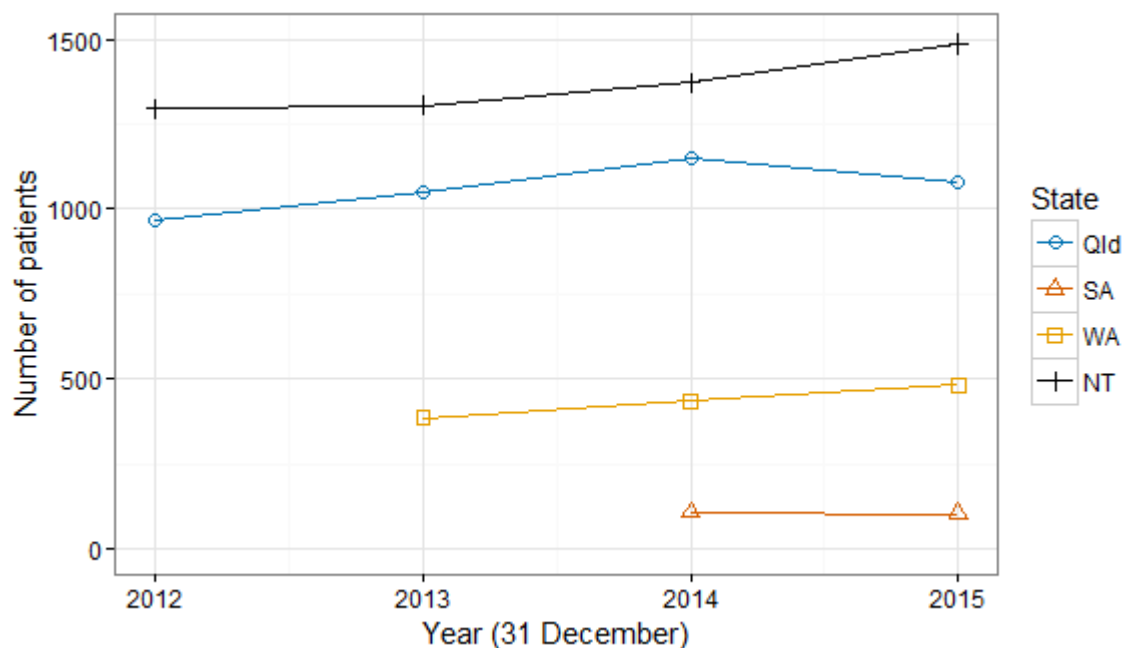
The establishment and maintenance of the registers and associated recall systems for four-weekly BPG injections, and the establishment and maintenance of a 'National' database, all feed into the monitoring of patients the recurrence of ARF and any progression of RHD (Table

4). Unfortunately, data is not available yet to determine to what extent the implementation of the RFS has impacted on the recurrence of ARF or progression of RHD. These issues were explored in depth in question 1d (p. 30).

While data reporting has been delayed in Qld and WA, those who have participated have improved the quality of the data in their registries due to the checks and analysis required prior to loading the data into the DCS. These checks and analysis are performed in two stages, firstly via the error checking routines built into the DCS itself, and secondly via the epidemiologist employed at the NCU examining the data.

Reporting data into the DCS has resulted in errors and inconsistencies being identified during the submission process, triggering investigation and rectification on the part of the control programs. This has had the effect of improving the quality of the data housed within each register.

Figure 5- Total number of patients on the register who are scheduled to receive intramuscular BPG in each jurisdiction



Where there have been issues in reporting to the NCU, control programs have been providing regular reports of aggregated epidemiological data to local governance and advisory committees, and the Commonwealth. Figure 3, which was discussed earlier in this report, shows there have been increases in the number of patients included on the registers. Figure 4 suggests there have been increases in the percentage of patients on the registers who are receiving greater than 50% of their scheduled doses of BPG. Figure 5 shows another aspect of this, that is, the absolute number of patients on the register who are scheduled to receive secondary prophylactic treatment (i.e. BPG). This is also increasing in most states, except Qld. (The reduction for Qld is most likely a result of improvement data quality and active case finding.) Together, these data indicate more patients are receiving relevant care in each of the participating states and territories.

Question 2 – Monitoring

Key findings

- Systems are in place to monitor patients with a history of ARF or RHD.
- Despite the improvement in the adherence to secondary prophylaxis, the administration of BPG remains suboptimal for many patients.

Clinical management

Table 5 – Program logic for the clinical management of ARF and RHD

Outputs			Outcomes – impact	
Activities	Products/Services	Participation	Intermediate outcomes	Key outcomes
What is done?	What is the output?	Who is reached?	What are the intermediate results?	What are key results
<ul style="list-style-type: none"> • Develop and provide training material to PHC providers and other health care staff regarding the management of patients with suspected Strep A infection, ARF, and RHD • Develop and provide educational material raising the awareness of the self-management of RHD 	<ul style="list-style-type: none"> • Easily accessible educational material related to the management of ARF/RHD • Culturally appropriate education, training and quality improvement materials for PHC providers and other health care staff • Culturally appropriate resources to support active self-management by patients 	<ul style="list-style-type: none"> • PHC provider and other health care staff • Patients with a history or ARF/RHD 	<ul style="list-style-type: none"> • Increased use of education, training, and quality improvement materials among PHC workers and other health care staff • Increased use of intramuscular BPG • Increased adherence to intramuscular BPG • Good access to and increased use of culturally appropriate resources to support active self-management by patients • Active promotion of self-management of ARF/RHD through engagement with communities 	<ul style="list-style-type: none"> • Reduced progression to RHD • Reduced recurrence of ARF

Table 5 presents a representation of the program logic associated with achieving improved clinical management of ARF/RHD. A fundamental objective of the RFS was to improve the level of secondary prophylaxis for patients requiring this treatment. Despite the enthusiasm generated by the control program and the efforts of the clinicians and health workers, adherence rates are still not optimal.

Amongst the KPIs developed for ARF/RHD is *KPI 2.1 Secondary prophylaxis (BPG by adherence category)*. For the 2013 year, the RHD Australia report indicates that only 28% of patients scheduled for BPG injections received greater than 80% of the required injections (RHD Australia, 2016). Data from the jurisdictions (Figure 4), suggests there have been improved in adherence rates, principally in the NT and SA.

Increasing the level above current rates will be challenging, but secondary prophylaxis with BPG has been shown to be the most cost-effective approach to prevent RHD (Carapetis et al., 2016). Therefore, there is a need to persevere with secondary prophylaxis as a prevention strategy and to find new approaches to improve adherence, some of which are canvassed below. More effective utilisation of the patient registers is key to further improvements.

The focus of the RFS to this point is to build infrastructure and clinical knowledge. It was clear from consultation that a working knowledge of ARF and RHD, prevention and management should not be assumed of any clinician or health worker. The Argyle Report into the education materials produced by RHD Australia suggested that individual control programs were not always promoting these materials (Argyle Research, 2016). However, this finding was not repeated in this evaluation.

ARF and RHD are rare in the general population and therefore receive little attention in university training. While each state and territory health authority and primary care service had various rules and induction processes, none mandated the RHD Australia clinical education modules even though all endorsed them as being extremely worthwhile. High turnover exacerbates the education gap, as it makes it difficult to gain traction, with education, training, and quality improvement initiatives, i.e. the knowledge you are attempting to build on is constantly lost when staff move on.

In addition to clinical knowledge, clinicians directly involved in administering BPG injections considered pain a real barrier to adherence. The problem is exacerbated when the patient, usually a child, had experienced a particularly painful injection at the hands of an inexperienced clinician. An example provided was of an inexperienced nurse who gave a child a BPG injection in the arm, resulting in significant pain and swelling which did not subside for days. Those trained appropriately know this injection should be administered in the gluteal muscle, a far larger muscle mass, where the pain and swelling are reduced and better tolerated by patients. Following this experience, it was understandably very difficult to get the child back. Because these injections are administered prophylactically, most people receiving them are not sick, nor do they perceive themselves as having a disease, and therefore do not realise the need or urgency for treatment. Again, staff turnover was consistently offered as a contributor as turnover of clinical staff disrupts the continuity of care and rapport built between the health care provider and the patient.

Consultations with senior clinicians and primary health service managers suggested adherence rates improved at the same time as the relationship or rapport built between clinicians and the communities they service. Therefore, investment in a stable clinical/health workforce, and or healthcare support workers, be it time and effort or otherwise, is a strategy worth exploring in future attempts to improve patient adherence rates to prophylaxis. Six primary health care organisations consulted through the evaluation reported that adherence rates benefited from case management. Case management is a collaborative process of planning, assessing and facilitating care coordination, for options and services to meet an individual's health needs. In the case of ARF and RHD, a health service manager or chronic disease manager takes on a caseload, planning and scheduling patient care plans, monitoring progress and following up on missed appointments.

We heard of several examples where high rates of adherence dropped dramatically when an enthusiastic health service manager left. Case management is not a role for control program staff to undertake. However, there would be a benefit in greater adoption of this approach amongst primary care services. As a first step, an 'annual cycle of care,' similar to that utilised in the care of patients with diabetes, could be developed from already existing ARF management plans. In some disease areas, practice incentive payments (PIP) are paid to clinics that reach a level of patient adherence to cycles of care or care plans. A similar system set up to incentivise patient adherence to ARF and/or RHD care plans may help fund and incentivise case management in primary care services.

Finally, the role Aboriginal Health Workers play is integral in reaching patients in the community. As canvassed in Q1b (p. 22), strengthening the role of Aboriginal Health Workers and standardising their scope of practice could help improve the continuity of care and reduce staff turnover.

With the infrastructure in place, the clinical aspect and the delivery of the injections is merely part of the overall picture. The fact that these injections are painful and inflicted on well and typically young individuals, means significant time and effort must be spent in educating these young people and their parents or carers about why the injections are necessary. While most young patients and their parents/carers do receive education on a one-to-one basis from control program nurses at their first episode, it is unclear how much contact or education they receive subsequently. As discussed above, it is not possible or appropriate for control program staff to perform continuous patient education or case management role, and these processes need to be driven from within primary care services.

As was the case in improving detection, an opportunity exists for a targeted awareness campaign to improve patient and community awareness of ARF/RHD, and the clinical management required.

Question 2 – Management clinical care

Key findings

Reduced progression to RHD:

- NCU analysis theoretically possible, but not performed or available yet.

Reduced recurrence of ARF:

- NCU analysis theoretically possible, but not performed or available yet.

Rates of secondary prophylaxis

- A lack of measurable targets in the current RFS makes it hard to assess success. It is unlikely a target of 50% of patients receiving 80% of prophylactic BPG injections would be considered successful. Only two states (NT and SA) have managed to reach this level.
- Continuity of care is an important issue that impacts on adherence to secondary prophylaxis (a relationship of trust is required between clinicians and patients):
 - Detection and clinical care suffer from poor clinical awareness.
 - ARF and RHD are not given much emphasis in the undergraduate programs of nurses and doctors.
 - It is difficult to maintain high levels of clinical knowledge of ARF and RHD with high levels of staff turnover.
- The skills and scope of practice of Aboriginal Health Workers are underutilised, fuelling turnover in some clinical environments.
- Currently, patient and community education is largely limited to those newly diagnosed.

Question 3: Are there other tools or methods of prevention, detection, monitoring or treatment that could be funded to improve diagnosis and treatment outcomes without significantly increasing the cost of the RFS?

Primordial prevention

Primordial prevention of ARF means preventing GAS infections through addressing social determinants of health. These include environmental, economic, social and behavioural conditions, known to increase the risk of infections. ARF and RHD are not the only diseases known to benefit from their improved social determinants. The incidence and/or existence of scabies, pyoderma and trachoma are all thought linked with the same social determinants of health as ARF (E. McDonald et al., 2008). Improvements in housing, education, employment, communications, transport and access to services in affected communities will help prevent or alleviate each of these conditions simultaneously.

In this area, the NT Department of Health is investigating a program in which new and or recurring cases of ARF are investigated in conjunction with the Environmental Health Branch of the Department, carrying out housing assessments and making recommendations. An acute event is required to trigger this investigation and is therefore technically secondary prevention. It is hypothesised that these actions will help target some of the primordial causal factors within the affected communities and environments.

Due to the RFS, registries are now accumulating data that can assist with prioritising interventions across government agencies. Considering ARF and RHD share close ties with scabies, pyoderma, and trachoma, ARF and RHD data accumulated by the registries should be considered alongside that available for these associated conditions to help create a richer picture of need and better target resources. There should be scope for collaboration and pooling of resources across departments, sectors, and associated groups in addressing each of these conditions simultaneously.

Question 3 – Primordial prevention

Key findings

- Registers are collecting data that has considerable value in addressing ARF and RHD, along with scabies, pyoderma, and trachoma. Addressing primordial risk factors will have an impact on all diseases simultaneously.
- Registries are now collecting data that could and should be used to highlight and prioritise target areas.
- NT is developing a pilot program where an environmental health assessment of a patient's home and community is triggered with a recurrence or new diagnosis of ARF.

Recommendation

- ❖ Identify mechanisms and opportunities for the interdepartmental sharing of RFS data analyses to foster collaboration in addressing the primordial causes of acute rheumatic fever and associated diseases, including trachoma.

Primary prevention

GAS has been shown to be associated with up to 37% of throat infections and 82% of skin infections in rural and remote indigenous communities (RHDAustralia et al., 2012). The aim of primary prevention is to identify GAS pharyngitis in those individuals most at risk of ARF (typically children aged 5–14 years), and eradicate the bacterium with antibiotic treatment before the immune response associated with ARF has been initiated (Carapetis et al., 2016). The Australian Guideline identifies two primary approaches to potentially pre-empt the GAS infection by prophylactic antibiotics and/or vaccination (RHDAustralia et al., 2012).

The Guidelines nominate vaccination against GAS as the ideal solution for the primary prevention of ARF/RHD. However, scientific and regulatory obstacles have prevented a GAS vaccine being readily available. Only one vaccine has entered a clinical trial stage over the past 30 years (RHDAustralia et al., 2012). Presently, the vaccine candidates in contemplation are only in pre-clinical trial preparation phases. This suggests the emphasis on primary

prevention should be placed on prophylactic treatment with antibiotics for the foreseeable future.

The *CARPA Standard Treatment Manual* (6th ed) (2014) indicates that sore throats and infected skin sores in remote and rural communities, as well as in urban Aboriginal Medical Services, are immediately treated with a single dose of BPG, as a means of preventing colonisation of GAS and the potential ARF immune response. These guidelines are relatively well known amongst the stable section of remote and rural clinical workforce, but the same could not be said for clinicians filling temporary roles. Clinicians consulted suggested this was a significant contributor, along with patient awareness, to missed opportunities in prophylactic treatment for primary prevention.

A more proactive and intensive primary prevention strategy has been suggested, where clinicians search communities for GAS infections rather than waiting for a patient to present. This proactive approach is the one adopted by the New Zealand Rheumatic Fever Prevention Programme. The interim evaluation of the New Zealand program suggests some benefit in this approach (Jack et al., 2015). However, the observations made in the New Zealand study are only preliminary, with a final evaluation yet to be completed. Studies in similar settings have failed to provide conclusive benefit in school or community-based throat swab approach to identifying GAS infection. The Australian Guideline concludes: "[T]here is currently no convincing argument or consistent evidence to suggest that structured programs focusing on the early treatment of GAS pharyngitis are likely to be effective in the primary prevention of ARF in high-risk populations" (RHDAustralia et al., 2012).

While support for the New Zealand approach was widespread amongst stakeholders, many noted that Australia is a far larger country than New Zealand. The geographical isolation of many of the Indigenous communities will make the implementation of a similar intensive primary prevention intervention far more challenging and costly than that in New Zealand.

The conclusion of the evaluation team is that implementing a national strategy such as New Zealand's across Australia would not be appropriate at this point in time. However, piloting the approach in a small number of communities is worth considering. We recommend that if a pilot is considered, it is conducted in such a way that it could be properly evaluated, providing valuable evidence as to its effectiveness in the Australian context. One way to achieve this would be to roll it out in a restricted number of communities using the approach of a stepped-wedge cluster randomised trial (Barker et al., 2016). The Menzies School of Health Research recently used this approach to trial a continuous quality improvement strategy to increase the adherence rate to secondary prophylaxis (Ralph et al., 2016).

Finally, a normalisation of skin sores (commonly called school sores) and sore throats has taken place, not only in communities but within clinical practice. Communities and clinicians need to be educated to know that unexplained sores and sore throats in this population require immediate treatment.

Question 3 - Primary prevention

Key findings

- CARPA Guidelines indicate immediate treatment with BPG antibiotics on suspicion of GAS sore throats and skin sores in remote and rural communities.
- Clinician and community knowledge is a limiting factor to this approach.
- The New Zealand sore throat management project screened school children for GAS as part of a primary prevention strategy. New Zealand investment totalled \$65 million over six years.
- Australia being geographically much larger means a school-based approach would prove more challenging and far costlier than the New Zealand experience.
- Several studies have failed to demonstrate a clear benefit to ARF rates through school or community-based GAS screening.
- The New Zealand study is still in progress; final results are yet to be realised.
- A normalisation of skin sores and sore throats has taken place in communities and clinical practice, leaving individuals untreated.

Recommendation

- ❖ Improved education and training for health care providers, individuals, families and communities to raise awareness, and improve detection, prevention and management.

Point-of-care testing

Obtaining a laboratory test to confirm a streptococcal infection is a more time-consuming undertaking in rural and remote communities. A reliable point-of-care test (PoCT) that provides conclusive results for GAS in five to 10 minutes (compared with two to three days for traditional laboratory testing) has long been desirable and thought to have significant potential to improve clinical decision-making and patient care.

Recent innovations in point of care testing have led to the development of a device that peer-review suggests has a high degree of sensitivity and specificity, and therefore accuracy in detecting GAS (Cohen et al., 2015). While this could signal a potential breakthrough, its effectiveness is yet to be evaluated under real world conditions (i.e. performance in remote communities, storage maintenance and calibration requirements, behaviour of enzymatic test cartridges in tropical climates). Lastly, the effectiveness of PoCT in general will only be as good as the clinical knowledge that underpins decisions to test patients. Current CARPA guidelines (see previous section p. 47) indicate that sore throats and infected skin sores in remote and rural communities, as well as urban Aboriginal Medical Services, should be immediately treated with a single dose of BPG (CARPA Standard Treatment Manual 6th edition). If treatment prompted on suspicion of GAS is the current standard, and evidence suggests that clinical knowledge of the CARPA guidelines is a limiting factor in immediate

treatment with BPG, similar issues are likely to be experienced when an additional step in PoCT testing on suspicion added into the clinical care process.

Suggestions have been made that PoCT may lead to a reduction in unnecessary painful treatment, as well as inappropriate or overuse of antibiotics. Experts consulted acknowledged that avoiding unnecessary pain, especially in young patients, is a worthwhile consideration but dismissed antimicrobial resistance through the over-prescription of antibiotics in these communities as a significant consideration. These experts, while supporting antimicrobial stewardship, highlighted that rates of antibiotic prescription is far lower in Indigenous Communities than it is in the general population.

PoCT still requires further investigation and evaluation before it is likely to be accepted by rural clinicians. That said the Commonwealth DoH and RHD Australia should continue to monitor developments in PoCT and its potential applications into the future.

Question 3 - Point of care testing

Key findings

- Laboratory testing for GAS can take days for results to return.
- CARPA guidelines indicate treating on suspicion of GAS to work around current limitations.
- Current PoCT devices can provide accurate results in five to 10 minutes.
- The maintenance, calibration and refrigeration requirements of new PoCT devices are largely unknown, and untested in real world situations.
- PoCT for GAS could:
 - reduce unnecessary and painful injections;
 - help reduce chances of antimicrobial resistance (BPG); and
 - benefit research and monitoring efforts.
- No evidence exists suggesting GAS is developing resistance to BPG.
- General antibiotic use is less common in Indigenous communities than in the general population.
- In view of CARPA guidelines, PoCT for GAS would currently provide limited utility in clinical settings.
- PoCT for GAS would have some research and monitoring utility.

Secondary prevention

The WHO technical report on ARF and RHD support secondary prophylaxis in preventing the progression from ARF to RHD and in preventing further consequences of RHD (WHO, 2001). In Australia, it appears clear the RFS has resulted in more people being administered BPG for secondary prophylaxis. However, as discussed in question 1b, *improved clinical care* (p. 22),

adherence to BPG among the population of patients recommended for secondary prophylaxis treatment is still too low to claim the RFS to date has been overly successful.

The Key Performance Indicator related to secondary prevention is *KPI 2.1 Secondary prophylaxis (BPG by adherence category)*. The current KPI is calculated as the number of injections a patient receives over the number of injections scheduled reported as a percentage (no. injections received /injections scheduled x 100). A value of 100% suggests the patient had complete antibiotic coverage for the period.

The Australian Guideline suggests secondary prophylactic BPG injections need to be administered on a 28-day cycle. That is, a single BPG injection will provide antibiotic protection against GAS infection for 28 days following that injection. If an injection is delayed, the patient is at risk of GAS infection, and in turn a recurrence of ARF, over those the intervening days. As the timing of injections is so important, several clinicians, researchers and other experts suggested that risk should be measured as 'days at risk'. This measure identifies the number of days within a 12-month window where a patient was not protected by a BPG injection. It would be calculated by counting the number of days between one injection and the next, less the 28 days protected period. Adopting a 'days at risk' measure could improve clarity and understanding of the effectiveness of secondary prophylaxis, and emphasise the importance of timely administration of injections.

It was pointed out by stakeholders that appointment schedules based on a strict 28-day cycle, created a rigidity that was likely to result patients being exposed to increased days at risk. That is, these arrangements left little room for flexibility meaning patient that missed or had to delay an appointment were immediately at risk. To combat this several health services had adopted a 21-day cycle to recall patients, subsequently minimising days at risk and improved adherence rates. An important role for RHD Australia is to ensure strategies designed to improve adherence to secondary prophylaxis are disseminated between control programs and health services.

Interviews with staff at the Menzies School of Medicine raised the concept of "secondary prophylaxis plus", that is, secondary prophylaxis plus an environmental assessment of the patient's home. The environmental assessment would assess the living conditions of the patient, their family, and community, and result in realistic recommendations on improvements that could reduce risks of re-infection. These improvements could include home maintenance (including flagging a priority with appropriate departments), changes to sleeping arrangements and hygiene education. The assessment/interventions provide an opportunity for family and community education on ARF which could also result in primordial and primary prevention. Along these lines, the NT Government is to conduct a pilot environmental assessment of patients' homes and communities with recommendations and patient education to supplement BPG prevention whenever a patient is newly diagnosed with ARF or suffers a recurrence.

Primary health care organisations, including Aboriginal health services, are central to improving adherence to secondary prophylaxis. As the Commonwealth DoH provides funding for many Aboriginal Health Services across Australia, it has a lever to prioritise identification, monitoring and management of ARF/RHD for these services. One vehicle through which this could occur is the reporting of National Key Performance Indicators (nKPIs) for Aboriginal and Torres Strait Islander primary health care providers. The nKPIs are a set of 24 performance indicators, developed under direction from the Council of Australian Governments (COAG).

The nKPIs are derived from extracted from local health care systems. Health services can calculate the indicators themselves or participate in a process through extracted data is submitted to a data warehouse (OCHREStreams), which is managed by a non-government organisation (Improvement Foundation) which is funded by the Commonwealth DoH. These data are then processed into a summarised format that does not contain data on individual clients and the resulting indicators submitted to the Commonwealth DoH.

The inclusion of an indicator related to ARF/RHD would signal that the Commonwealth DoH considers management of these conditions to be an important priority for health services. Ideally, such an indicator would relate to secondary prophylaxis, which is one of the areas in which primary health services have the central role.

Question 3 - Secondary prevention

Key findings

- More people being administered BPG for secondary prophylaxis as a result of the RFS.
- Adherence to secondary prophylaxis remains too low.
- Secondary prevention activity is currently limited to BPG injection and could be extended to include, as a matter of routine, an environmental assessment and intervention that occurs when each new case of ARF is identified.
- The current measure of patient adherence (percentage of patients receiving 80% of scheduled BPG injections) *could be supplemented* by an indicator of a patient's days at risk arising from non-compliance with the recommended schedule of injections.
- Patient recalls in some instances are generated monthly, where treatment with BPG is required every 28 days.

Recommendations

- ❖ Maintain the existing focus of the RFS on secondary prevention, but also consider broadening preventative efforts to include primordial (environmental prevention) and early intervention health care measures (primary prevention).
- ❖ That BPG adherence (as measured by 'days at risk') be considered for inclusion as a National Key Performance Indicator (nKPI).

Screening

Several studies have been conducted recently assessing the utility of echocardiography as a screening tool for RHD. The first of these is the gECHO study (getting Every Child's Heart Okay), a collaboration between the Menzies School of Health Research and Baker IDI in the NT, James Cook University (Qld), and the University of Western Australia (Roberts et al., 2014). The study performed 4,999 echocardiograms and observed:

- In 3,946 Indigenous children living in remotely across Northern Australia (high-risk communities):
 - 34 children (1 in every 120) had Definite RHD;
 - 66 children (1 in every 60) had Borderline RHD; and
 - over half of the cases of Definite RHD were previously undiagnosed.
- In 1,053 non-Indigenous children living in Darwin and Cairns (low-risk communities):
 - no children had definite RHD; and
 - five children (one in every 200) had borderline RHD.

The results of this initial study generated debate over whether an organised screening using echocardiography should be implemented in Australia. Authors of the study were among those consulted for this evaluation. They argued that before echo screening of this type can be recommended widely, a longitudinal follow-up of the borderline children is required to assess disease progression. This is because detection of some valvular dysfunction may not be indicative of RHD or current susceptibility to recurrent ARF. A longitudinal follow-up would answer questions related to the progression of the disease in these patients. The Rheumatic Fever Follow-Up Study (RhFFUS) is already underway with this objective. Results of the RhFFUS study are expected shortly.

The consultation identified several other issues associated with an echocardiography based screening program. The experience required to identify the specific nodules characteristic of RHD is currently limited to cardiologists. Accessing or screening all children is a significant undertaking considering the equipment required, distances and remoteness of the communities involved, and school attendance rates (the currently proposed 'capture' point).

Several clinicians and cardiologists believed echocardiography was a vital tool in treatment and assessment of RHD. However, echocardiography, as utilised in screening, represented a distraction from current efforts in reducing ARF and RHD. This was a consensus view shared by the Rheumatic Heart Disease Policy Roundtable convened by the Commonwealth DoH, held 1 November 2016.

It is the view of this evaluation that the Commonwealth DoH and RHD Australia will need to review the findings of the Rheumatic Fever Follow-Up Study (RhFFUS) and its implications for echocardiography based population-wide screening programs, prior to considering any future directions in this area.

Question 3 – Screening

Key findings

- Screening for RHD via echocardiography can identify cases previously undetected.
- Studies exploring echocardiography screening have identified several *borderline* cases with unclear implications and treatment options.
- A cardiologist is required to perform accurate screening for RHD via echocardiography.
- Screening has obvious benefits in identifying previously undiagnosed cases of RHD. There are currently several issues that need to be resolved before its full utility can be assessed.

Question 4: What is the overall cost of implementing the RFS and to what extent does the Commonwealth's contribution represent value for money?

Over the last three years, funding allocated to the RFS by the Commonwealth Government has approximately totalled \$4 million per year, which includes funding for the four jurisdictions as well as for the NCU. Other costs incurred by the Commonwealth DoH, which this review is not able to quantify are the costs incurred by staff employed by the Commonwealth DoH in Canberra to oversee the RFS. The Commonwealth DoH provides funding to Aboriginal health services, a proportion of which is used to support the role of these primary health services in the detection and clinical management of ARF/RHD. Patients with ARF/RHD also access a range of primary and secondary services which are supported through payments made under the Medical Benefits Scheme (MBS) and the Pharmaceutical Benefits Scheme (PBS).

Within jurisdictions, there has also been funding for additional staff to support the work of the control program. In WA, the Kimberley Aboriginal Medical Service (KAMS) funded a nursing position for two years (initially, the position was funded by the control program, but funding was subsequently withdrawn). Qld Health, through its Aboriginal and Torres Strait Islander Health Governance, Relationships, Improvement, and Priorities Branch funded four advanced Aboriginal Health Workers to assist with RFS implementation (Qld Progress Report 2015). The Centre for Disease Control in the NT funds the register coordinator position and a primary health care nurse position in Katherine (NT progress report 2015).

The AIHW estimated \$74 million was spent on ARF and RHD in 2008-2009 (AIHW, 2013). These estimates include primary and secondary health services and heart valve replacement surgery, but do not include additional costs accrued by the health system, such as patient travel, the social and economic burden on carers and family, and any costs relating to quality of life or life expectancy.

The RFS has achieved:

- increased the awareness in areas where ARF and RHD are prevalent;
- establishment of registers in participating jurisdictions;

- establishment of recall systems in all jurisdictions;
- some improvement in the adherence to secondary prophylaxis;
- development of training material for health workers and clinicians;
- development of educational resources for communities; and
- establishment of a DCS for monitoring ARF and RHD.

Objectives yet to be delivered:

- development of Self-management materials;
- data reporting from all funded jurisdictions;
- NCU national strategy epidemiological analysis; and
- jurisdictional and (service level) performance feedback reports.

However, in terms of an economic evaluation assessing value for health outcomes, this review is unable to comment on whether the Commonwealth's contribution represents value for money. This principal factor here is that it is not possible to determine whether there has been a reduction in the recurrence of ARF or whether there has been a reduction in the incidence of RHD over the period of the RFS. These are the real outcomes of interest. Our general conclusion is that the steps taken above are essential foundations for an effective Australian strategy to address ARF and RHD. However, these efforts need to persist for significant improvements in health outcomes to be realised.

Dramatic falls in the rates of ARF and RHD in developed countries have occurred over the last 50 -150 years, restricting ARF to sporadic outbreaks and or disadvantaged communities. This history suggests ARF and RHD are entirely preventable. ARF and RHD being chronic diseases means direct benefits or return on investment may take some time to realise.

The evaluation team has concluded that the potential gains in clinical outcomes and disease eradication that the RFS makes possible, exceed the cost of this program and with careful management, the costs to the health system as a result of ARF and RHD will fall into the future.

Question 4 – Value for money

Key findings

- The RFS objectives delivered:
 - increased the awareness in areas where ARF and RHD are prevalent;
 - establishment of registers in participating jurisdictions;
 - establishment of recall systems in all jurisdictions;
 - some improvement in the adherence to secondary prophylaxis;
 - development of training material for health workers and clinicians;
 - development of educational resources for communities; and
 - establishment of a DCS for monitoring ARF and RHD.
- Objectives yet to be delivered:
 - development of Self-management materials;
 - data reporting from all funded jurisdictions;
 - NCU national strategy epidemiological analysis; and

- jurisdictional and (service level) performance feedback reports.

The potential gains in clinical outcomes and disease eradication that RFS affords far outweigh the cost of administration.

Question 5: How sustainable are the RFS initiatives beyond the agreed funding period?

Sustainability can be assessed by the changes in existing structures that will support detection, monitoring, and management of ARF and RHD beyond the funding period.

Processes for registration and reporting are far more ingrained in clinical practice within NT and SA jurisdictions. Jurisdictional control programs in NT and SA are managed within units controlled centrally by their respective departments of health. This fact alone aids jurisdictional control program staff in reaching across service boundaries in accessing and verifying information.

The control program in WA is located within the Kimberly Population Health Unit, and in Qld the control program is located within Cairns and Hinterland Hospital and Health Service. Control program staff, in addition to the unit and department managers to which control program coordinators report, expressed difficulties in coordinating a state-wide program from within these services. These difficulties included employment award structures that required the payment of compensation, penalties and benefits to employees living and working in specific locations, communication and coordination between service areas and a lack of authority that stakeholders perceived comes operating outside of a central health department location. Additionally, a lack of automation in data collection meant the bulk of data acquisition and handling responsibilities for the entire state fell directly on control program staff in these jurisdictions.

The RFS has now made it possible to quantify the size of the problem and pinpoint priority areas. Withdrawing funding now would adversely impact on the detection, monitoring, and management of ARF and RHD. Prior to the RFS, non-government organisations such as the Heart Foundation supported the development of ARF and RHD treatment guidelines and clinician education. Following the establishment of the RFS, the Heart Foundation has maintained an active interest in the area and now plays a role in advocacy and awareness, developing education resources for general practices that operate outside the reach of control programs, and funding research projects investigating areas associated with ARF.

Changes that have occurred which will assist in making detection, monitoring and management of ARF and RHD patients sustainable include:

- ARF is notifiable in all funded jurisdictions;
- RHD is notifiable in two of the four funded jurisdictions and work is in progress to make it notifiable in all funded jurisdiction;
- the registers have been established;
- the minimum dataset has been established for jurisdictional reporting to the NCU;
- educational and teaching resources have been developed for health workers and clinicians;
- increased awareness among senior medical staff has resulted in their participation in steering and governance committees;

- various capacity building initiatives have been undertaken; and
- recall systems within the NT and SA are embedded within the patient information systems.

Changes that could occur to make detection, monitoring, and management of ARF and RHD patients sustainable include:

- greater integration of the RFS into the primary care setting; and
- increased automation of the data capture.

Strengthening the role of primary health care could improve sustainability, especially regarding secondary prophylaxis. The development of an ARF and RHD cycle of care, similar to those used in diabetes, could be considered for providing a framework for primary care in generating and maintaining patient care plans and generating recalls. This would create synergies with jurisdictional control programs, allowing control programs to focus on supporting and educating clinicians as opposed to case management, which is a more appropriate role for primary care.

As discussed previously, a potential lever for the Commonwealth DoH is to include a measure related to secondary prophylaxis for ARF within the nKPI for Aboriginal and Torres Strait Islander primary health care. Primary Health Networks could also be further engaged in relevant initiatives involving primary care. ARF/RHD will not be relevant considerations for many Primary Health Networks. However, for those that are responsible for communities where incidence and prevalence of ARF/RHD are highest, the inclusion of measures related to these conditions within the local performance indicator set would provide a means for engaging Primary Health Networks and utilising their expertise in addressing barriers to good primary care management of these conditions.

Question 5 - Sustainability

Key findings

- NT and SA are in the best position to maintain their registries in their current form if Commonwealth funding was to cease.
- The positioning of the control program in Qld and WA (within Cairns and Hinterland HHS and the Kimberly Population Health Unit) creates difficulties in statewide support for the RFS and control program activities.
- Advisory groups have been established in each funded state and territory, increasing interest and awareness of ARF/RHD, fostering local collaboration.
- Engagement with primary care is essential to continued improvement in ARF clinical care and management.

Recommendations

- ❖ Renew the RFS and National Partnership Agreements for a further four-year period to maintain and build on current momentum and to assist in attracting and retaining staff.
- ❖ Investigate strategies to strengthen the role of primary care in the management of ARF and RHD.

Conclusion

Key achievements of the RFS to date:

- Improved monitoring and surveillance of ARF and RHD that was not possible prior to the RFS.
- Increased awareness in areas where ARF and RHD are prevalent.
- Increased number of people on the registers and receiving prophylactic injections.
- Improvements in adherence to secondary prophylaxis, with significant improvement in two jurisdictions, NT and SA.
- Agreement on a minimum data set for NCU reporting and key performance indicators.
- Establishment of a data collection system (DCS) for monitoring ARF and RHD and clinical benchmarking.
- Improved estimates of ARF and RHD incidence and prevalence and associated processes of clinical care.
- Revisions to the Australian Guideline for prevention, diagnosis and management to reflect new and emerging evidence.
- Establishment of registers in two participating jurisdictions, with support for improvement and expansion in the other two.
- Establishment of recall systems in two participating jurisdictions, with support for improvement and expansion in the other two.
- Development of training material for health workers and clinicians.
- Development of some educational resources for patients and communities.

Achievements that support the RFS:

- ARF is a notifiable condition in the four participating jurisdictions. It is also notifiable in NSW.
- RHD is notifiable in two of the four funded jurisdictions and work is in progress to make it notifiable in the fourth funded jurisdiction. It is also notifiable in NSW.
- Senior medical staff are represented on steering and advisory committees in each of the funded jurisdiction.
- A number of capacity building initiatives have commenced in the funded jurisdictions. For example, environmental health assessment programs in the NT, an ARF occupational therapy and the paediatric outreach model of care, and novel approaches to reduce the pain associated with BPG antibiotic injections in Qld.
- The embedding of recall systems within the NT and SA patient administration systems in some services.

Issues/barriers that have affected RFS initiatives and/or greater realisation of patient outcomes:

- Clinician time pressures, a transient workforce and a single didactic delivery mode have affected clinical uptake of RHD Australia's ARF and RHD clinical modules, ultimately affecting overall levels of clinical knowledge of ARF and RHD.

- Register design and protocols in each jurisdictional control program require significant amounts of repeated manual data entry.
- Real-time clinical access to registry data is limited or barred in two jurisdictions (WA and Qld), limiting clinical decision making.
- Negotiation of service level agreements with WA and Qld has prevented data being shared with the NCU, preventing nationwide benchmark reporting as part of the jurisdictional Performance Monitoring Framework.
- Although now complete, NCU experienced delays with the development and build of the DCS, which would have delayed benchmarking reports if service level agreements had not.

Future opportunities for ARF and RHD in Australia broadly:

- A strengthened role for primary care in the prevention, detection and management of ARF and RHD.
- Development of additional modes clinical education to improve prevention, detection and patient management of ARF and RHD.
- Improved strategies, practices and educative materials to engage and educate patients, families/carers and communities to improve prevention, detection and adherence to secondary prophylaxis.
- Increased automation of patient data capture and reporting to individual registries.
- Improved clinical access to registry data across jurisdictions to aid real-time decision making.
- The use of My Health Record to benefit patients that regularly travel across health services and state boundaries to improve real-time monitoring and access to clinical records.
- Introduce primordial and primary prevention strategies and processes to prevent new cases of ARF.
- Use registry data to support collaboration across agencies and programs, especially for primordial prevention.
- Develop clinical processes/strategies to reduce the pain of BPG injections.
- Development of a vaccine for GAS.

Key recommendations for the RFS

1. Renew the RFS and National Partnership Agreements for a further four-year period to maintain and build on current momentum and to assist in attracting and retaining staff.
2. Maintain the existing focus of the RFS on secondary prevention, but also consider broadening preventative efforts to include primordial (environmental prevention) and early intervention health care measures (primary prevention).
3. Streamline the provision of data from jurisdictions to the national data collection system (DCS) by considering alternative governance arrangements for the DCS that would overcome existing barriers and delays.
4. Participating jurisdictions to increase the automation of patient data capture and reporting, and seek to enable real-time access to clinicians and health services to registry data and patient records.

5. Improved education and training for health care providers, individuals, families and communities to raise awareness, and improve detection, prevention and management.

Other recommendations for consideration

- ❖ Investigate whether transferring the function of national data coordination from the NCU to another organisation would alleviate or exacerbate current delays.
- ❖ That BPG adherence (as measured by 'days at risk') be considered for inclusion as a National Key Performance Indicator (nKPI).
- ❖ Participating jurisdictions consider utilising My Health Record to facilitate better sharing of information on the registers, to facilitate improved adherence to secondary prophylaxis antibiotics.
- ❖ Develop additional mixed modes of clinical education to complement existing web-based delivery, and redevelop existing modules to improve completion rates as the current modules are complex and not time efficient.
- ❖ Improved strategies, practices and community-relatable educative materials to engage and educate patients, families/carers and communities to improve detection and adherence to secondary prophylaxis.
- ❖ Identify mechanisms and opportunities for the interdepartmental sharing of RFS data analyses to foster collaboration in addressing the primordial causes of acute rheumatic fever and associated diseases, including trachoma.
- ❖ Investigate strategies to strengthen the role of primary care in the management of ARF and RHD.

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Appendix

Stakeholders consulted by jurisdiction

Jurisdiction /location	Interviewee	Position/organisation
Western Australia		
Broome	Janice Forrester	RFS Coordinator - Clinical Nurse Manager - RHD team Broome
Broome	Agi D'Amico	Senior Public Health Nurse - RHD team Broome
Broome	Sarah Macnee	Senior Public Health Nurse - RHD team Broome
Broome	Lynette Masuda	Administration Officer - RHD team Broome
Broome	Beth Fuller	Data Entry Officer - RHD team Broome
Broome	Dr Jaye Martin	Consultant Physician, General Medicine
Broome	Andrew Waters	Director of Kimberley Population Health Unit (KPHU)
Broome	Martin Cutter	Director of workforce development – Kimberley Aboriginal Medical Services Ltd
Perth	Dr Donna Mak	Public Health Physician Communicable Disease Control Directorate Health Department of Western Australia
Perth - teleconference	Dr Jeanette Ward	Consultant, Public Health Medicine, Kimberley Population Health Unit
Perth - teleconference	Kate Cross	Chair of the WA RFS Partnership Agreement Reference Group
South Australia		
Adelaide - teleconference	Jennifer Cottrell	RFS Coordinator- SA Health
Adelaide	Jane Raupach	Medical Consultant, Communicable Disease Control, SA Health
Adelaide - teleconference	Gavin Wheaton	Paediatric Cardiologist, Women's & Children's Hospital
Adelaide	Tanya McGregor	Acting Director, Aboriginal Health Branch, SA Health

Jurisdiction /location	Interviewee	Position/organisation
Adelaide	Penny Silwood	GP, Watto Purrunga (Aboriginal Primary Health Care)
Adelaide	Mark Shephard	Director Flinders University International Centre for Point-of-Care Testing
Adelaide	Wendy Keech	Researcher/Project Manager, SAHMRI
Coober Pedy - teleconference	Catherine Carroll	Rheumatic Heart Disease Project Officer, Aboriginal Health Council of South Australia
Alice Springs - teleconference	Stewart Roper	Project Officer Clinical and Population Health Nganampa Health Council
Alice Springs - teleconference	David Busuttil	Health Services Manager Nganampa Health Council
Northern Territory		
Alice Springs	Mark Russell	Remote Sexual Health Program Manager – Central Australia Sexual
Alice Springs	Melissa Van Leeuwen	Clinical Nurse Consultant (Public Health) Rheumatic Heart Disease - Alice Springs
Alice Springs	Dr Belinda Greenwood-Smith	Clinician Alice Springs – Centre for Disease Control NT Alice Springs
Darwin	Anna Ralph	Senior Clinical Research Fellow, Global and Tropical Health
Darwin	Bart Currie	Director RHDAustralia
Darwin	Claire Boardman	RHDAustralia
Darwin	Karen Dempsey	RHDAustralia
Darwin	Simon Burrell	RHDAustralia
Darwin	Catherine Halkon	RHDAustralia
Darwin	Marea Fittock	RFS Coordinator - NT
Darwin	Cath Millne	Data coordinator: Part time NT JCP and Part time RHDA NCU
Darwin	Christine Chamberlin	Public Health Nurse JCP
Darwin	Desley Williams	Public Health Nurse JCP
Darwin	Iyngaranathan Selvaratnam	Danila Dilba Health service Darwin
Darwin	Olga Havnen	Danila Dilba Health service Darwin
Darwin	Maida Stewart	Danila Dilba Health service Darwin
Darwin	James Doran	Danila Dilba Health service Darwin

Jurisdiction /location	Interviewee	Position/organisation
Darwin	Cynthia Brock	Danila Dilba Health service Darwin
Darwin	Karrina Demasi	Danila Dilba Health service Darwin
Queensland		
Brisbane	Greg Richards	Aboriginal and Torres Strait Islander Health Branch DoHQ
Brisbane	Daniel Williamson	Aboriginal and Torres Strait Islander Health Branch DoHQ
Brisbane	Stephen Lambert	Communicable and Infectious Diseases DoHQ
Cairns	Mellise Anderson	RFS Coordinator - Qld
Cairns	Robert Wilcox	Data Officer - RHD Control Program Qld
Cairns	Laurette Lubbers	Project Officer - RHD Control Program Qld
Cairns	Erin Howell	Clinical Nurse Consultant - RHD Control Program Qld
Cairns	Kylie McKenna	Clinical Nurse Consultant - RHD Control Program Qld
Cairns	Louise Axford-Haines	Clinical Nurse Consultant (based in Townsville) - RHD Control Program Qld
Cairns	Joanne Cranney	Clinical Nurse (based in Mount Isa) - RHD Control Program Qld
Cairns	Philly Nakata-Bradley	Senior Health Worker (Torres Cape Hospital and Health Service – southern sector) - RHD Control Program Qld
Cairns	Dr Richard Gair	Director Tropical Public Health Services (Cairns) - RHD Control Program Qld
Cairns	Dr Malcolm McDonald	Consultant Physician, Apunipima Cape York Health Council and Gurriny Yealamucka Health Service
Townsville	Professor Natkunam Ketheesan	Tropical Health and Medicine, James Cook University Townsville
Townsville	Dr Andrew White	Consultant Paediatric Staff Specialist, Townsville Hospital
Townsville	Dr Theunis Kotzee	Senior Medical Officer - Townsville Aboriginal & Islander Health Service
Townsville	Trish Hunt	Chronic Care Co-ordinator - Townsville Aboriginal & Islander Health Service
Cairns	Dr Benjamin Reeves	Paediatric Cardiologist
Experts		
Canberra	Prof Jonathan Carapetis	Director TelethonKids Institute
Teleconference	Rohan Greenland,	General Manager Advocacy, National Heart Foundation
Teleconference	Julie Anne Mitchell	Director of Cardiovascular Health Programs, Heart Foundation (NSW)

Jurisdiction /location	Interviewee	Position/organisation
Teleconference	Dr Sarah-Jane Kelley	Public Health Registrar, Heart Foundation (National)
Teleconference	Rachelle Foreman	Health Director, Heart Foundation (Qld)
Teleconference	Breanna Ellis	Health Director, Heart Foundation (NT)
Teleconference	Associate Professor Andrew Singer	Principal Medical Adviser - Health Services
Teleconference	Dr Bernie Towler	Principal Medical Adviser - Population Health & Sport Division
Teleconference	Ms Fadwa Al-Yaman	Australian Institute of Health and Welfare (AIHW)
Canberra - Preliminary findings briefing	Meredeth Taylor	Assistant Secretary, Programme, Services and Access support Branch, Indigenous Health Division
Teleconference	Brendan Gibson	Assistant Secretary, Department of the Prime Minister and Cabinet
Teleconference	Kate Brodie	Health Branch, Indigenous Affairs Group, Department of the Prime Minister and Cabinet
Teleconference	Dannielle Aeuckens	Health Branch, Indigenous Affairs Group, Department of the Prime Minister and Cabinet