

# Secondary prophylaxis delivery

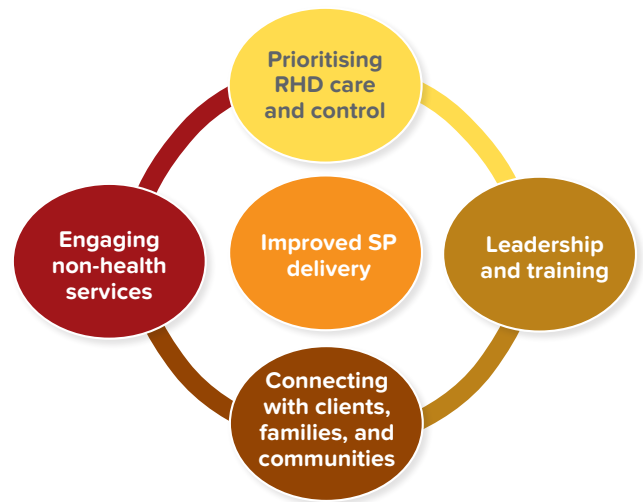
## Lessons learnt to date

**Secondary prophylaxis (SP)** is administration of regular antibiotics to young people with a history of acute rheumatic fever (ARF) or rheumatic heart disease (RHD). Timely delivery of benzathine penicillin G (Bicillin®, or BPG) injections prevents Strep A infections, which cause recurrences of ARF and accelerate heart valve damage of RHD. Most people need injections over a 10 year period, usually during childhood and adolescence.

The RHD Secondary Prophylaxis Trial (RHDSPT), conducted in the Northern Territory from 2013 – 2016, explored strategies to enhance delivery of BPG(1). This comprehensive study in 10 clinics provides the best available Australian data on supporting SP adherence (see separate summary of RHDSPT trial).

## Essential elements for improving RHD care and prevention

*The RHDSPT Trial, other research, and years of experience tell us that “silver bullet” solutions and solely health service-based solutions do not work. A comprehensive approach is needed that is focused at the level of communities but supported by programs and resources at jurisdictional and Commonwealth level, prioritises RHD care, allows health services to streamline care, and engages families as well as sectors outside of health. All four domains are critical. More specific guidance is provided below:*



### 1 Prioritising RHD care and control

<p><b>Operationalise this commitment through national and jurisdictional leadership which can be supported at clinic level</b></p>	<ul style="list-style-type: none"> <li>➤ Health clinic staff indicated that insufficient resources impeded their ability to provide optimal care for ARF/RHD patients. National and jurisdictional commitment to RHD control is critical, and may be supported with resource allocation to ARF/RHD prevention.</li> </ul>
<p><b>Monitor outcomes using national KPIs</b></p>	<ul style="list-style-type: none"> <li>➤ RHD Australia guidelines provide a set of agreed standards for RHD care delivery. Using these tools – alongside evolving metrics where needed – provides an opportunity for monitoring service delivery.</li> </ul>
<p><b>Support with optimised guidelines and improved metrics for measuring adherence</b></p>	<ul style="list-style-type: none"> <li>➤ The clinical spectrum of RHD severity can lead to confusion about the duration of SP and other follow-up. This should be clearly communicated through updated national guidelines. It may be necessary to prioritise SP delivery for particular groups. For example, young people are at greatest risk of ARF recurrence for the first 12 months after their last episode. In some settings, staff prioritise SP delivery to these people who are most likely to benefit from high quality SP delivery.</li> <li>➤ Establish appropriate metrics, using a variety of methodologies. For example, in addition to percentage adherence, “days at risk” may be appropriate to monitor effective SP delivery. “Days at risk” is an emerging concept to quantify population-level adherence to SP delivery; preliminary analysis of data from the NT indicates that reducing a person’s days at risk is associated with a reduced risk of having a recurrence of ARF, so monitoring days at risk on a regular basis could be beneficial. “Days at risk” may also be useful in communicating the risk of delayed injections to people living with RHD(2).</li> </ul>

## 2 Providing leadership, focus, and training for health staff

<p><b>Nominate an RHD Coordinator at clinic</b></p>	<ul style="list-style-type: none"> <li>➤ Recent experience in the NT confirms previous findings that clinics with a named RHD coordinator do better at delivering SP(3). This is likely to be a function of improved administrative efficiency, role familiarity, and fostering relationships with people living with ARF and RHD.</li> </ul>
<p><b>Regular staff training to mitigate high staff turnover</b></p>	<ul style="list-style-type: none"> <li>➤ ARF and RHD are rare diseases outside Indigenous health settings and staff may be unfamiliar with the importance of secondary prophylaxis. Dedicated training is needed to raise awareness and support quality of care delivery. High quality online training modules have been developed by RHD Australia(4) for this purpose and completion of these modules should be prioritised.</li> <li>■ People living with RHD indicated that high staff turnover impeded their relationship with the health services. High staff turnover is a well-known issue in such settings(5,6), and is understood to negatively affect quality of care whether for RHD or other conditions (7). Some strategies that have been proposed to reduce staff turnover include: appropriate funding/infrastructure of remote health services; providing realistic and competitive remuneration; improved management practices and systems; and providing social, family, and community support(8,9).</li> </ul>
<p><b>Enhance clinic systems to support SP delivery</b></p>	<ul style="list-style-type: none"> <li>➤ A suite of clinic-level activities can support engagement of people living with RHD. <i>These include:</i> <ul style="list-style-type: none"> <li>■ Changing injection recall from 28 days to 21 days to ensure late injections are minimised.</li> <li>■ Fast-tracking people living with RHD through waiting rooms to avoid unnecessary delay.</li> <li>■ Reminding people when injections are due by text message and reminders to health staff in patient information systems (recall notes).</li> <li>■ Individual care plans to support consistent care delivery even if staff turnover is high.</li> </ul> </li> </ul> <p>Clinics in the NT have found these strategies have improved the process of delivering care.</p>
<p><b>Foster culturally competent self-management support</b></p>	<ul style="list-style-type: none"> <li>➤ Self-management is an approach to chronic disease management that encourages people to make informed decisions about their care and behaviour, whilst understanding patients to be active participants in their own treatment(10). This approach requires culturally-appropriate adaptation to a “community group-based care” approach, suitable in the context of Aboriginal communities.</li> </ul>

## 3 Enhance connection of health service with clients, families and communities

<p><b>Community level engagement</b></p>	<ul style="list-style-type: none"> <li>➤ Ensure genuine community consultation in how to deliver RHD care and RHD literacy <i>such as:</i> <ul style="list-style-type: none"> <li>■ Using locally-tailored self-management support tools.</li> <li>■ Focusing on transition for young people to adult care.</li> <li>■ Ensuring that health education is provided in appropriate language and uses appropriate metaphors identified and supported by the community.</li> </ul> </li> </ul>
--	--

### 3 Enhance connection of health service with clients, families and communities (CONTINUED)

<b>Community level commitment</b>	<ul style="list-style-type: none"> <li>➤ Use culturally competent, consultative approaches.</li> <li>➤ Ensure that there is local prioritisation of RHD care and prevention. For example, a community may choose to identify as an END RHD Community.</li> <li>➤ Form a Community RHD Committee.</li> </ul>
<b>Peer support groups</b>	<ul style="list-style-type: none"> <li>➤ Peer support groups have been shown to help improve timely SP delivery in some settings. (11,12). The role of peer support remains open to exploration in the Aboriginal and Torres Strait Islander setting.</li> </ul>
<b>Community navigators /cultural brokers</b>	<ul style="list-style-type: none"> <li>➤ Employment of community members and Aboriginal Health Practitioners is critical for successful SP delivery. As well as ensuring culturally-appropriate delivery of services, this may provide greater continuity of care in the face of high non-local staff turnover. This may also incorporate expansion of community-based research projects which help clinics better identify local needs and respond to community concerns.</li> </ul>
<b>Cultural competency training</b>	<ul style="list-style-type: none"> <li>➤ One clinic in the RHDSP Trial with high adherence reported good engagement with community, including knowledge and understanding of Aboriginal culture. This reflects high quality evidence that cultural competency supports the delivery of effective primary care(13).</li> </ul>
<b>Provision of interpreters</b>	<ul style="list-style-type: none"> <li>➤ Australian health services operate largely in English, however, English is not a first language for many people living with ARF/RHD. People at risk of ARF, and living with RHD, report limited knowledge and understanding of ARF/RHD and the need for SP(14). In addition, people reported feeling powerless to ask questions about their condition/ treatment, due to language restrictions. People's understanding of health information is improved if the information is delivered in their own language(15).</li> </ul>

### 4 Engage non-health services (whole of government/whole of community approach)

Engagement outside the health sector acknowledges the wider view of health by many Aboriginal people. In one remote NT setting, community members nominated nutrition and teenage psychology as priorities for them towards improving SP(16), revealing a broader view of health than may be apparent to some practitioners.

<b>Education</b>	<ul style="list-style-type: none"> <li>➤ Equip school staff to assist in awareness raising and management of skin sores, sore throats, and symptoms of ARF, and to support children living with ARF/RHD; incorporate ARF/RHD and its causes, including social determinants, in school curriculum.</li> </ul>
<b>Housing</b>	<ul style="list-style-type: none"> <li>➤ Address functional high density living behaviours – including close sleeping for warmth, safety or security; improve environmental health.</li> </ul>
<b>Employment and training of community navigators</b>	<ul style="list-style-type: none"> <li>➤ Patients requested delivery of health-related information outside of the clinic setting, and communicated through means which draws on traditional knowledge and using appropriate culturally-relevant analogies.</li> </ul>

## REFERENCES

1. Ralph AP, Read C, Johnston V, de Dassel JL, Bycroft K, Mitchell A, et al. Improving delivery of secondary prophylaxis for rheumatic heart disease in remote Indigenous communities: study protocol for a stepped-wedge randomised trial. *Trials* [Internet]. 2016;17(1):51. Available from: <http://trialsjournal.biomedcentral.com/articles/10.1186/s13063-016-1166-y>
2. de Dassel JL, Fittock MT, Wilks SC, Poole JE, Carapetis JR, Ralph AP. Adherence to secondary prophylaxis for rheumatic heart disease is underestimated by register data. Bugiardini R, editor. *PLoS One* [Internet]. 2017 May 31 [cited 2017 Jun 1];12(5):e0178264. Available from: <http://dx.plos.org/10.1371/journal.pone.0178264>
3. Kennedy E, Vincente S La, Timeon P, Tiro T, Conway N, Nasi T, et al. Challenges Facing Sustainability and Integration of RHD Control and Prevention Programmes in Pacific Small Island Nations. *Glob Heart*. 2016;11(2S):2016.
4. RHD Australia. RHD Australia - E-Learning [Internet]. 2016 [cited 2018 Jan 31]. Available from: <https://www.rhdaustralia.org.au/e-learning-discussion-forum>
5. Wakerman J, Humphreys J, Bourke L, Dunbar T, Jones M, Carey TA, et al. Assessing the Impact and Cost of Short-Term Health Workforce in Remote Indigenous Communities in Australia : A Mixed Methods Study Protocol Corresponding Author : 2016;5.
6. Bailie J, Schierhout G, Laycock A, Kelaher M, Percival N, Donoghue LO, et al. Determinants of access to chronic illness care : a mixed-methods evaluation of a national multifaceted chronic disease package for Indigenous Australians. 2015;1–12.
7. Russell DJ, Zhao Y, Guthridge S, Ramjan M, Jones MP, Humphreys JS, et al. Patterns of resident health workforce turnover and retention in remote communities of the Northern Territory of Australia , 2013 – 2015. 2017;1–12.
8. Lenthall S, Wakerman J, Opie T, Dollard M, Dunn S, Knight S, et al. What stresses remote area nurses? Current knowledge and future action. *Aust J Rural Health* [Internet]. 2009 Aug 1 [cited 2017 Dec 20];17(4):208–13. Available from: <http://doi.wiley.com/10.1111/j.1440-1584.2009.01073.x>
9. Buykx P, Humphreys J, Wakerman J, Pashen D. Systematic review of effective retention incentives for health workers in rural and remote areas: Towards evidence-based policy. *Aust J Rural Health*. 2010;18(3):102–9.
10. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* [Internet]. 2002 Oct 1 [cited 2017 Dec 20];48(2):177–87. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12401421>
11. Sabate E. Adherence to long-term therapies: Evidence for action [Internet]. 2003 [cited 2017 Jun 2]. Available from: <http://apps.who.int/iris/bitstream/10665/42682/1/9241545992.pdf>
12. Kennedy E, Naiceru E, Ramaka A, Matatolu L, Silai M, Boladuadua S, et al. Innovations In Delivery Of Secondary Prophylaxis Treatment For People Living With RHD In Fiji Islands. In: 20th Lancefield International Symposium on Streptococci and Streptococcal Diseases. 2017. p. #224.
13. Freeman T, Edwards T, Baum F, Lawless A, Jolley G, Javanparast S, et al. Cultural respect strategies in Australian Aboriginal primary health care services: beyond education and training of practitioners. *Aust N Z J Public Health* [Internet]. 2014 Aug 1 [cited 2018 Jan 30];38(4):355–61. Available from: <http://doi.wiley.com/10.1111/1753-6405.12231>
14. Belton S, Kruske S, Jackson Pulver L, Sherwood J, Tune K, Carapetis J, et al. Rheumatic heart disease in pregnancy: How can health services adapt to the needs of Indigenous women? A qualitative study. *Aust New Zeal J Obstet Gynaecol* [Internet]. 2017 Nov 6 [cited 2018 Jan 30]; Available from: <http://doi.wiley.com/10.1111/ajo.12744>
15. Ralph AP, Lowell A, Murphy J, Dias T, Butler D, Spain B, et al. Low uptake of Aboriginal interpreters in healthcare: exploration of current use in Australia's Northern Territory. *BMC Health Serv Res* [Internet]. 2017 Nov 15 [cited 2018 Jan 30];17(1):733. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/29141623>
16. Menzies School of Health Research. Research - On Track Watch [Internet]. 2013 [cited 2018 Feb 1]. Available from: [https://www.menzies.edu.au/page/Research/Projects/Rheumatic\\_Heart\\_Disease/On\\_Track\\_Watch\\_OTW\\_“A\\_Grassroots\\_Rheumatic\\_Heart\\_Disease\\_Initiative\\_in\\_the\\_Northern\\_Territory”/](https://www.menzies.edu.au/page/Research/Projects/Rheumatic_Heart_Disease/On_Track_Watch_OTW_“A_Grassroots_Rheumatic_Heart_Disease_Initiative_in_the_Northern_Territory”/)

# The RHDSP Trial – evidence informing RHD care and prevention

<b>Study aim</b>	<ul style="list-style-type: none"> <li>To test whether a primary health care-based intervention could improve secondary prophylaxis delivery for ARF/RHD patients.</li> </ul>
<b>Methods</b>	<ul style="list-style-type: none"> <li>Stepped-wedge trial in 10 NT clinics, rolling out a multi-component intervention.</li> <li>Steps included baseline, intensive, and maintenance phases.</li> <li>Intervention aligned with Chronic Care Model (CCM), including continuous QI feedback.</li> <li>Comprised sets of "action plans" developed and implemented by health centres, including changes around clinical information systems; development of community linkages; decision support; health systems; delivery system design; self-management support.</li> <li>Primary outcome: proportion of people receiving <math>\geq 80\%</math> of scheduled penicillin injections, compared to baseline rate.</li> <li>Secondary outcomes: "days at risk" (i.e. number of days late for SP injections); ARF recurrence rates; and impact of intervention on other clinic activities.</li> </ul>
<b>Major findings</b>	<ul style="list-style-type: none"> <li>Overall, no significant increase in adherence comparing baseline to intensive phase.</li> <li>However significant improvement occurred from baseline to maintenance phase in patients receiving <math>\geq 90\%</math> of scheduled injections and non-significant improvement in those receiving <math>\geq 80\%</math>.</li> <li>Adherence was best among children, who have the highest risk of ARF recurrence.</li> </ul>

## Why did the study outcomes not match expectations? A combination of reasons:

### 1 Some signs of positive effect were identifiable:

- a Particularly in children and people with a good baseline level of adherence.

### 2 In retrospect, our study design didn't give the intervention the best chance of working:

- a Adherence at the start of the study (baseline) was higher than we expected:
  - This is good news, but we had less power than intended to show a difference.
- b The improvements during maintenance phase suggest that our 12-month intensive period may have been too short to detect a true effect given the complexity of the intervention.

### 3 There were barriers to implementing the intervention, the most important of which were:

- a Communities faced staff turnover of up to 8 RHD coordinators at one site in the 15 months of the trial.
- b Clinic-based system changes were most successfully implemented, whereas establishing effective community linkages and providing self-management support were least successfully implemented.
- c Success depends on addressing all areas of care, not just those based at the clinic.

