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## Ending rheumatic heart disease in Australia

The evidence for a new approach



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# Ending rheumatic heart disease in Australia: the evidence for a new approach



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Cover image: © Hayley Goddard, Telethon Kids Institute. Tenaya, diagnosed with RHD aged just seven, looks down at the scar caused by surgery to repair her heart valves.

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# Ending rheumatic heart disease in Australia: the evidence for a new approach

Rosemary Wyber<sup>1,2</sup> , Katharine Noonan<sup>2</sup>, Catherine Halkon<sup>2</sup>, Stephanie Enkel<sup>2</sup>, Jeffrey Cannon<sup>2</sup> , Emma Haynes<sup>3</sup>, Alice G Mitchell<sup>4</sup>, Dawn C Bessarab<sup>3</sup>, Judith M Katzenellenbogen<sup>2,3</sup>, Daniela Bond-Smith<sup>3</sup>, Rebecca Seth<sup>2,3</sup>, Heather D'Antoine<sup>4</sup>, Anna P Ralph<sup>4</sup> , Asha C Bowen<sup>2,5</sup> , Alex Brown<sup>6,7</sup>, Jonathan R Carapetis<sup>2,5</sup>, on behalf of the END RHD CRE Investigators Collaborators

## Summary

- *The RHD Endgame Strategy: the blueprint to eliminate rheumatic heart disease in Australia by 2031* (the Endgame Strategy) is the blueprint to eliminate rheumatic heart disease (RHD) in Australia by 2031. Aboriginal and Torres Strait Islander people live with one of the highest per capita burdens of RHD in the world.
- The Endgame Strategy synthesises information compiled across the 5-year lifespan of the End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE). Data and results from priority research projects across several disciplines of research complemented literature reviews, systematic reviews and narrative reviews. Further, the experiences of those working in acute rheumatic fever (ARF) and RHD control and those living with RHD to provide the technical evidence for eliminating RHD in Australia were included.
- The lived experience of RHD is a critical factor in health outcomes. All future strategies to address ARF and RHD must prioritise Aboriginal and Torres Strait Islander people's knowledge, perspectives and experiences and develop co-designed approaches to RHD elimination. The environmental, economic, social and political context of RHD in Australia is inexorably linked to ending the disease.
- Statistical modelling undertaken in 2019 looked at the economic and health impacts of implementing an indicative strategy to eliminate RHD by 2031. Beginning in 2019, the strategy would include: reducing household crowding, improving hygiene infrastructure, strengthening primary health care and improving secondary prophylaxis. It was estimated that the strategy would prevent 663 deaths and save the health care system \$188 million.
- The Endgame Strategy provides the evidence for a new approach to RHD elimination. It proposes an implementation framework of five priority action areas. These focus on strategies to prevent new cases of ARF and RHD early in the causal pathway from *Streptococcus pyogenes* exposure to ARF, and strategies that address the critical systems and structural changes needed to support a comprehensive RHD elimination strategy.

## Acknowledgements:

- Children, families and communities living with RHD — We thank the Aboriginal and Torres Strait Islander people for sharing their stories in the Endgame Strategy, and acknowledge that the research and data in this publication reflect the experiences of Aboriginal and Torres Strait Islander people and communities affected by the ongoing trauma of ARF and RHD.
- END RHD Review Working Group — We thank the following members of the END RHD Alliance, who formed an expert working group to review content of the Endgame Strategy for feasibility and acceptability, including review from a cultural perspective: Kate Armstrong, Lorraine Anderson, Karrina DeMasi, John Havnen, Imran Mansoor, A Merritt, Elizabeth Moore, Vicki Wade and Angela Young.
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## Chapter 1

# Introduction to RHD, the END RHD CRE and a national commitment to end RHD by 2031

Rosemary Wyber, Katharine Noonan, Catherine Halkon, Stephanie Enkel, Heather D'Antoine, Alex Brown, Jonathan Carapetis

Australia has committed to end rheumatic heart disease (RHD).<sup>1</sup> Achieving this goal by 2031 will prevent 8667 Aboriginal and Torres Strait Islander people from being diagnosed with acute rheumatic fever (ARF) or RHD, and avoid 663 deaths.<sup>2</sup> Critically, it will mean that action on the direct biological causes of RHD and on the indirect causes of its inequitable distribution have been successful. The only path to elimination of RHD is a comprehensive approach, stewarded by Aboriginal and Torres Strait Islander people, addressing the indirect causes of disease and supported by the best available scientific evidence. In this supplement, we provide a synthesis of technical evidence for eliminating RHD in Australia and highlight the environmental, economic, social and political contexts which are inexorably linked to ending the disease.

Over 6000 people currently live with the effects of ARF or RHD in Australia.<sup>3</sup> Between 2015 and 2017, 89% of new diagnoses of ARF occurred among Aboriginal and Torres Strait Islander people and 79% were in people younger than 25 years.<sup>4</sup> This disproportionate burden of disease means that RHD is the greatest cause of disparity in cardiovascular health between Aboriginal and Torres Strait Islander and non-Indigenous people in Australia.<sup>5</sup>

The direct cause of RHD is an abnormal immune reaction to *Streptococcus pyogenes* (Strep A) infection of the throat or skin.<sup>6</sup> Strep A is a human-only bacterial pathogen which causes: superficial infections (of the skin and throat); invasive infections (of soft tissue and bone), including sepsis; and post-infectious sequelae, including ARF and acute post-streptococcal glomerulonephritis. A small proportion of susceptible young people have an abnormal immune response to Strep A infection, manifesting some weeks later as ARF. ARF can cause sore joints, rashes, abnormal movements, fever and heart inflammation. Most of these symptoms resolve over a few weeks, but heart damage often remains. A severe episode of ARF, or multiple recurrent episodes, can lead to permanent damage to the heart valves, known as RHD. Over time, the heart valve damage leads to heart failure,

and increases the risk of stroke, arrhythmia, endocarditis and complications during pregnancy.

The inequitable burden of ARF and RHD on Aboriginal and Torres Strait Islander people stems from the syndemic association between direct biological causes and indirect causes: the political, colonial, economic, racial, social and environmental contexts in which Aboriginal and Torres Strait Islander people live.<sup>7-9</sup>

The End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE) received funding from the National Health and Medical Research Council in 2014 to develop an “endgame” for RHD in Australia. In the resulting publication — *The RHD Endgame Strategy: the blueprint to eliminate rheumatic heart disease in Australia by 2031* (the Endgame Strategy) — we outlined a comprehensive list of potential strategies for reducing the incidence of RHD, evaluated them according to an evidence framework, and synthesised considerations for communities and decision makers.<sup>10</sup> The focus is on preventing new cases of ARF and RHD, so the Endgame Strategy is weighted towards approaches which act early in the causal pathway from Strep A exposure to ARF. Priority has also been given to implementable actions, focusing on what can be done now, with existing knowledge, to end RHD. This supplement is based on the Endgame Strategy, which included references identified in literature reviews conducted until November 2019.<sup>10</sup> A small number of additional references, published up until 1 July 2020, are included in this supplement.

RHD elimination will not be achieved by synthesising the best available evidence alone. Technical content will only be meaningful if it can be used by Aboriginal and Torres Strait Islander people as they lead a new approach to comprehensive disease control. END RHD is a collaboration of Aboriginal and Torres Strait Islander peak bodies, professional groups and research organisations working together to ensure that no child dies from RHD.<sup>11</sup> The advocacy of END RHD and its partners, to ensure that evidence-based strategies are funded and implemented, will be a critical determinant of the success of the mission to eliminate RHD.

## Chapter 2

# Overview of the epidemiology of Strep A infections, ARF and RHD in Australia: a contemporary snapshot from the ERASE project

Judith M Katzenellenbogen, Rebecca Seth, Daniela Bond-Smith, Rosemary Wyber, Katharine Noonan, Catherine Halkon

**S***treptococcus pyogenes* (Strep A) causes superficial infections of the throat (pharyngitis) and skin (impetigo/pyoderma). Strep A throat infections, and likely skin infections, are precursors to acute rheumatic fever (ARF) and subsequent rheumatic heart disease (RHD).

Pharyngitis accounts for about 3% of presentations to urban general practitioners in Australia.<sup>12,13</sup> Most sore throats are caused by viral respiratory infections but Strep A can be isolated in up to 20% of symptomatic children and about 10% of asymptomatic children.<sup>14–16</sup> There are few data about pharyngitis presentations in remote Aboriginal and Torres Strait Islander communities.<sup>17</sup>

Skin infections are one of the most common reasons for Aboriginal and Torres Strait Islander children presenting to clinics for primary care. In a retrospective review of clinic presentations of children younger than 5 years in the Western Desert region of Western Australia, conducted between 2007 and 2012, skin conditions accounted for the largest proportion of presentations (16%).<sup>18</sup> Almost three-quarters of children (72%) presented at least once with skin infections during the study period.<sup>18</sup> Aboriginal children in remote communities generally have their first skin infection by 7 months of age.<sup>19</sup> Almost all skin sores among Aboriginal and Torres Strait Islander people in Australia are caused by Strep A.<sup>20</sup> Simultaneous infection with another bacterium (*Staphylococcus aureus*) is common, but *S. aureus* does not generally cause the primary infection.<sup>21</sup> The risk of Strep A skin infection is increased by co-infection with the *Sarcoptes scabiei* (scabies) mite, causing intense itching and damage to the skin.<sup>22–24</sup> The association between skin sores and ARF is outlined in Box 1.

### Burden of ARF

Data on ARF and RHD in this chapter have been primarily sourced from the NHMRC-funded End RHD in Australia: Study of Epidemiology (ERASE) project<sup>29</sup> (Box 2).

Between 2015 and 2017 in the Australian jurisdictions recording ARF and RHD rates (New South Wales, Northern Territory, Queensland, South Australia and WA), there were an average of 476 diagnoses of ARF each year. This represents an age-standardised rate of 4.9 diagnoses per 100 000 population over the period.<sup>4</sup> Of the people diagnosed, 89% were Aboriginal and/or Torres Strait Islander people.<sup>4</sup> The overall rate of ARF diagnosis in Aboriginal and Torres Strait Islander people was 72 diagnoses per 100 000 population, making them 123 times more likely to be diagnosed with ARF than non-Indigenous people of the same age.<sup>4</sup> Children aged 5–14 years were the most commonly affected by ARF, with Aboriginal and Torres Strait Islander children in this age group accounting for more than a third of diagnoses overall (Box 3).<sup>32</sup>

### 1 Association between skin sores and acute rheumatic fever (ARF)

- Very high rates of *Streptococcus pyogenes* (Strep A) skin sores in some Aboriginal and Torres Strait Islander communities raise questions about whether these infections contribute to ARF incidence. This was investigated through a prospective surveillance study of 1172 people in 49 households across three remote Aboriginal and Torres Strait Islander communities, conducted from 2003 to 2005. No symptomatic episodes of sore throat were reported and there was a low point prevalence of asymptomatic Strep A pharyngeal carriage (3.7%).<sup>25</sup> However, 37% of children had at least one skin infection during the study period and Strep A was isolated from wound swabs in 93% of infections. There was a very high incidence of ARF, with seven people diagnosed during the study period (equivalent to 350 per 100 000 population per year).<sup>25</sup> This suggests a potential aetiological role for Strep A skin infection in ARF.
- This hypothesis is further supported by the observation that Strep A strains generally associated with skin infection predominate in remote settings with a high burden of ARF.<sup>26</sup> The distribution of Strep A pharyngitis and ARF in New Zealand also suggests a causal contribution from skin sores, as does a case report of ARF following pyoderma from New Zealand.<sup>27,28</sup>
- To our knowledge, there are no data exploring whether antibiotic treatment of skin infections can prevent subsequent ARF. However, data on prevention of ARF following Strep A throat infections do exist. For the purposes of our strategy for eliminating rheumatic heart disease, we assumed that antibiotic treatment of skin sores provides equivalent primary prevention protection against ARF as does antibiotic treatment of pharyngitis.<sup>10</sup>

### 2 The End RHD in Australia: Study of Epidemiology (ERASE) project

- The ERASE project has compiled a comprehensive database of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) cases in Australia as a basis for improved monitoring and to assess prevention and treatment strategies.<sup>29</sup>
- The ERASE project uses linked administrative data (including information from ARF and RHD registers), hospital data, death records, and various other sources from 2001 to mid-2017 to characterise the population living with a history of ARF/RHD, and estimate the burden of and outcomes from ARF and RHD.<sup>4,29</sup>
- Data are available for the five Australian jurisdictions where the disease burden is the highest and where ARF/RHD registers have been established: New South Wales, Northern Territory, Queensland, South Australia and Western Australia. Together, these jurisdictions are home to 86% of Australia's Aboriginal and Torres Strait Islander population (at 30 June 2016).<sup>29,30</sup>
- The ERASE project is an ongoing research initiative and technical changes in case definitions are associated with small changes in absolute numbers across several publications, including recently refined estimates published in September 2020.<sup>4,29,31</sup>

Females are more likely to be diagnosed with ARF than males, representing 55.3% of all episodes between 2015 and 2017.<sup>4</sup> Females are most likely to be diagnosed with ARF during reproductive years (15–34 years, 63% of all episodes).

**3 Annual incidence counts (average over 3 years) and rates per 100 000 population of all ARF episodes and first-ever ARF episodes, by age and Indigenous status, 2015–2017\***

	All ARF episodes			First-ever ARF episodes		
	Indigenous	Non-Indigenous	Total	Indigenous	Non-Indigenous	Total
<b>Counts</b>						
0–4 years	13	< 5	15	12	< 5	14
5–14 years	217	23	240	171	20	191
15–24 years	104	15	119	66	12	78
25–34 years	62	8	70	32	7	40
35–44 years	26	6	32	14	5	19
All age groups (0–44 years)	422	54	476	296	46	342
<b>Rates</b>						
0–4 years	15.7	0.2	1.3	14.5	0.2	1.2
5–14 years	136.2	1.1	11.2	107.4	1.0	8.9
15–24 years	75.8	0.7	5.3	48.5	0.6	3.5
25–34 years	61.3	0.3	2.8	32.5	0.3	1.6
35–44 years	33.8	0.3	1.4	18.4	0.2	0.9
Crude rate, 0–44 years	75.7	0.5	4.6	53.2	0.5	3.3
ASR, 0–44 years	71.9	0.6	4.9	49.3	0.5	3.6
ASRR	123.3	–	–	98.0	–	–

\*Values presented are generated from 2015–2017 data for New South Wales, Northern Territory, Queensland and South Australia, and mid-2014 to mid-2017 data for Western Australia, and are adapted from Katzenellenbogen et al.<sup>4</sup> ARF = acute rheumatic fever. ASR = age-standardised rate (world standard population). ASRR = age-standardised rate ratio.

Geographically, the highest age-standardised rates of ARF are seen in the NT, with 413 diagnoses of ARF per 100 000 population over the period.<sup>4</sup> This accounts for more than half (58%) of all ARF episodes in the five jurisdictions studied. Overall, there is a clear pattern of markedly higher ARF rates in northern Australia (Box 4).

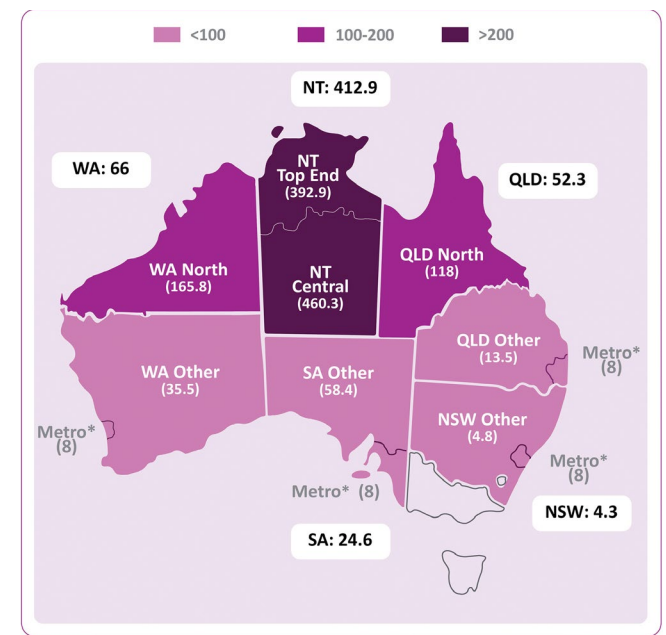
**Burden of RHD**

Between 2013 and 2017, 1261 people on an RHD register were newly diagnosed with RHD in Australia.<sup>32</sup> Of these, 1041 (83%) were Aboriginal or Torres Strait Islander people at a rate of 49.9 diagnoses 100 000 population over this period.<sup>32</sup> This compares to 0.4 diagnoses 100 000 population over the period for non-Indigenous Australians.<sup>32</sup> By far, the highest prevalence and incidence of RHD in Aboriginal or Torres Strait Islander people occur in the NT (Box 5).<sup>32</sup>

As of mid-2017, 5307 people younger than 55 years were living with RHD in the five jurisdictions studied.<sup>4</sup> Two-thirds of them were female.<sup>4,32</sup> More than 2200 (43%) of people living with RHD have severe disease, defined as having a history of heart failure or heart valve procedure. Despite representing 5% of the total Australian population younger than 55 years, 71% of people with RHD were Aboriginal and Torres Strait Islander people.<sup>4</sup> This makes the age-standardised prevalence of RHD 61.4 times higher in Aboriginal and Torres Strait Islander people (674 per 100 000 population) than in non-Indigenous people (11.1 per 100 000 population).

In the age groups 15–24 years and 25–34 years, Aboriginal and Torres Strait Islander people are about 100 times more likely to have RHD than non-Indigenous people of the same age (Box 6).<sup>4</sup>

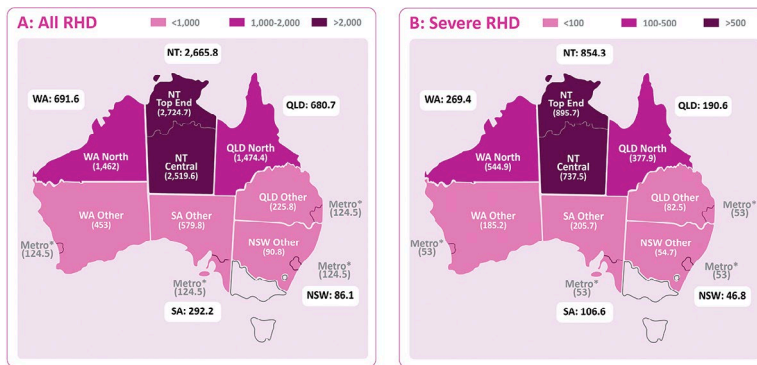
**4 Map of age-standardised rates of acute rheumatic fever per 100 000 Aboriginal and Torres Strait Islander people younger than 45 years, by Indigenous region group and jurisdiction (2015–2017)\***



\* Reproduced with permission from Wyber et al, 2020<sup>10</sup> based on data from Katzenellenbogen et al, 2020<sup>4</sup> and the ERASE Project (Box 2). Jurisdictional age-standardised rates (combined urban, rural and remote) are presented in white boxes for NSW, NT, QLD, SA and WA only. Metro age-standardised rates are presented in grey text and include combined Australian Bureau of Statistics-defined Indigenous regions comprising the metropolitan and surrounding areas of Perth, Adelaide, Sydney and Brisbane. Metro = metropolitan. NT = Northern Territory. NSW = New South Wales. QLD = Queensland. SA = South Australia. WA = Western Australia.



### 5 Age-standardised prevalence of all RHD and severe RHD per 100 000 Aboriginal and Torres Strait Islander people younger than 55 years, by Indigenous region group and jurisdiction (2015–2017)\*



\* Reproduced with permission from Wyber et al, 2020<sup>10</sup> based on data from Katzenellenbogen et al, 2020<sup>4</sup> and the ERASE Project (Box 2). Jurisdictional age-standardised rates (combined urban, rural and remote) are presented in white boxes for NSW, NT, QLD, SA and WA only. A single consolidated metro age-standardised prevalence is presented in grey text and includes combined Australian Bureau of Statistics-defined Indigenous regions comprising metropolitan and surrounding areas of Perth, Adelaide, Sydney and Brisbane. Metro = metropolitan. NT = Northern Territory. NSW = New South Wales. QLD = Queensland. RHD = rheumatic heart disease. SA = South Australia. WA = Western Australia.

experienced by Aboriginal and Torres Strait Islander people with RHD and is seen even in young people. In total, 663 of the 4013 Aboriginal and Torres Strait Islander people aged < 55 years with RHD in 2017 (17%) had been hospitalised with heart failure (Box 7).

Women with RHD have an increased risk of complications during pregnancy owing to increased circulating blood volume and cardiac effort.<sup>33</sup> In the setting of RHD, pregnant women with moderate or severe RHD are at risk of complications such as preterm birth and fetal growth restriction.<sup>34</sup> In addition, anticoagulation may be needed in patients with mechanical valves to prevent stroke, but anticoagulation therapy is associated with increased risks to both mother and foetus. A recent prospective study of 150 pregnant Aboriginal and Torres Strait Islander women with RHD found that 78% of these women lived in a remote location and 72% were from the most socioeconomically disadvantaged quintile. In the NT, 74.2 per 10 000 women giving birth had RHD.<sup>33</sup> Nearly a quarter required admission to intensive care facilities during pregnancy.<sup>33</sup>

### Consequences and complications of RHD

Severe and untreated RHD can lead to a range of complications, which can in turn cause disability, reduced quality of life and premature death. Heart failure is the most common complication

### Comorbidities

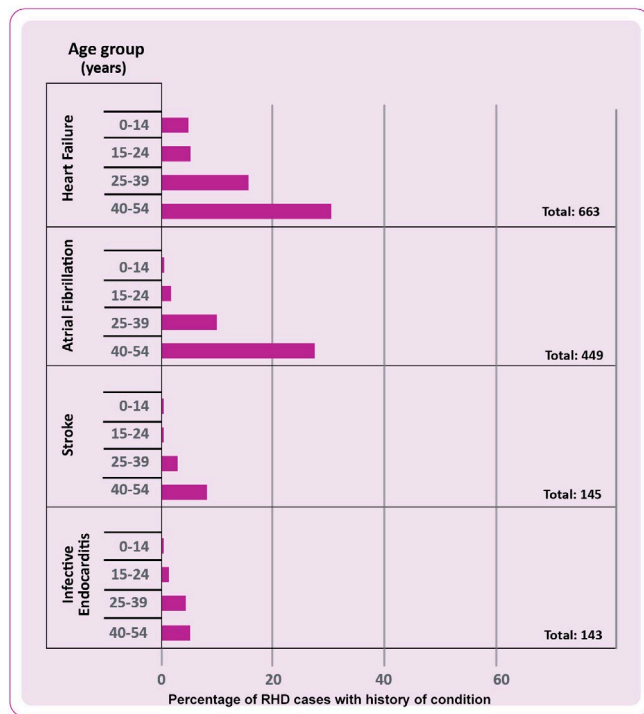
The burden of comorbid disease for Aboriginal and Torres Strait Islander people with RHD is high.<sup>10</sup> Of the 3379 Aboriginal and Torres Strait Islander people aged < 55 years with RHD, 20%

### 6 Annual average prevalence counts and proportions of RHD and severe RHD,\* by age and Indigenous status<sup>†4</sup>

	All RHD			Severe RHD		
	Indigenous	Non-Indigenous	Total	Indigenous	Non-Indigenous	Total
<b>Average count per year</b>						
0–4 years	< 5	< 5	5	< 5	< 5	< 5
5–14 years	356	55	411	76	28	104
15–24 years	907	116	1023	190	67	257
25–34 years	978	224	1202	301	135	436
35–44 years	850	398	1248	310	265	575
45–54 years	684	734	1418	329	557	886
All age groups (0–54 years)	3779	1528	5307	1207	1053	2266
<b>Prevalence per 100 000 population</b>						
0–4 years	4.4	0.1	0.4	1.2	0.1	0.2
5–14 years	223.1	2.8	19.1	47.4	1.4	4.8
15–24 years	663.2	5.6	46.0	139.2	3.2	11.6
25–34 years	972.6	9.3	47.9	299.2	5.6	17.4
35–44 years	1089.7	18.1	54.8	397.2	12.0	25.3
45–54 years	963.5	33.9	63.7	462.9	25.8	39.8
Crude prevalence, 0–54 years	601.2	12.9	42.5	191.9	8.9	18.1
ASP, 0–54 years	674.0	11.1	40.0	223.1	7.5	16.3
ASPR	60.6	–	–	29.6	–	–

\*Defined as heart failure and/or receipt of a valvular intervention as documented in hospital data, RHD register data or in the Australian and New Zealand Society of Cardiac and Thoracic Surgeons database or Melbourne Royal Children's Hospital paediatric surgery database; severe RHD is counted as a subset of all RHD. † Data represent New South Wales, Northern Territory, Queensland, South Australia (2015–2017) and Western Australia (mid 2014–mid 2017), and are derived from Katzenellenbogen et al, 2020.<sup>4</sup> ASP = age-standardised prevalence (world standard population). ASPR = age-standardised prevalence ratio. RHD = rheumatic heart disease.

### 7 History of admissions for RHD-associated complications among Aboriginal and Torres Strait Islander people living with RHD at 30 June 2017 — percentages of RHD cases with history of condition by age group and total numbers of patients with each comorbidity\*



\*Adapted with permission from Wyber et al, 2020<sup>10</sup> based on data from Katzenellenbogen et al, 2020<sup>4</sup> and the ERASE Project (Box 2). Data represent New South Wales, Northern Territory, Queensland, South Australia and Western Australia. RHD = rheumatic heart disease.

had previously been admitted to hospital for diabetes or chronic kidney disease. In adulthood, the burden of comorbid ischaemic heart disease increases with at least 449 people (13%) having both RHD and ischaemic heart disease. A history of alcohol-related

admissions (including for conditions caused by alcohol) was also common (959 people, 28%), and was highest in the 40–54 years age-group.<sup>10</sup> More than a quarter (25.8%) of Aboriginal and Torres Strait Islander people aged 15–24 years with RHD had a history of smoking, with markedly higher smoking rates in those aged 25–54 years (65.8%).<sup>10</sup> Preventing complications and supporting people living with RHD and other diseases requires a robust, responsive health system.

#### Severe RHD requiring surgery

People with severe RHD may require surgical intervention to repair or replace damaged valves.<sup>34</sup> Surgery is often needed early in life. In one cohort of young people in the NT diagnosed with RHD between 5 and 24 years of age, more than 40% of people with severe RHD underwent valvular surgery within 1 year of diagnosis, and 60% had undergone valvular surgery within 5 years of diagnosis.<sup>35</sup>

Between July 2002 and June 2017, 3205 valvular interventions were performed on 2725 people aged 50 years or younger who were living with RHD in NSW, NT, QLD, SA and WA — an average of 214 per year. A total of 112 of those who had surgery (3.8%) died within a year of the intervention. The 1-year mortality rate varied across age groups, from 2% for those aged 0–14 years to 4% for those aged 35–50 years.

#### Mortality among people with RHD

Of the 275 all-cause deaths of people with RHD on the RHD registers between 2013 and 2017, 80.3% were Aboriginal and Torres Strait Islander.<sup>32</sup> The median age of death was 50 years and females accounted for about two-thirds of deaths (145 deaths).<sup>32</sup> This is likely to be an underestimate, as not all people with RHD are recorded on RHD registers. In the period 1997–2005, the death rate ratio was 55 in the NT and 13 in the other four jurisdictions once age and sex were considered. Aboriginal and Torres Strait Islander people with RHD are dying young as a direct consequence of their disease. In contrast, non-Indigenous people with RHD are living longer with their disease and are dying from other or associated causes.<sup>36</sup>

## Chapter 3

# The lived experience of RHD: why Aboriginal and Torres Strait Islander knowledges, perspectives and experiences underpin RHD elimination

Emma Haynes, Alice Mitchell, Stephanie Enkel, Rosemary Wyber, Dawn Bessarab

**T**he impact of *Streptococcus pyogenes* (Strep A) infections, acute rheumatic fever (ARF) and rheumatic heart disease (RHD) is a function of both epidemiologic burden and the experiences of people living with disease.

A recent systematic review collated publications addressing the lived experiences of Aboriginal and Torres Strait Islander people living with ARF and RHD.<sup>37</sup> The authors (one senior Aboriginal and Torres Strait Islander research leader and two non-Indigenous researchers with extensive experience in Aboriginal and Torres Strait Islander health) analysed 24 publications (15 focused on Australia<sup>2,38–51</sup> and nine on New Zealand<sup>52–60</sup>) using a critical decolonising lens, drawing on both postcolonial theory and critical race theory. In addition to the inductive thematic analysis of the identified publications, a sociolinguistic analysis was undertaken of Aboriginal and Torres Strait Islander research participants' direct quotes extracted from the 15 Australian publications. This prioritised direct Aboriginal and Torres Strait Islander voices over publication authors' analysis and reporting of interview data. This provides a very comprehensive overview of the lived experience of ARF and RHD in the Australian context.

This review revealed that biomedical issues are dwarfed by the impact of circumstances in which people live, including the enduring effects of colonisation, racism, powerlessness and poverty. Limited access to culturally safe, high quality health care and sociocultural/linguistic shortcomings in health communication have negative impacts and influence willingness and capacity to seek care. The factors affecting the lived experience of RHD interact cumulatively, magnifying the difficulties of life with RHD. An overwhelming sense of collective trauma relating to RHD experiences in Aboriginal and Torres Strait Islander families was revealed. These themes are outlined in Box 8.

### Reducing the impact of living with ARF and RHD

Action on the broad social, cultural and economic determinants of health and wellbeing for Aboriginal and Torres Strait Islander people is necessary to address key contributors to adverse lived experiences with ARF and RHD. Concurrently, targeted action is needed to address specific health system factors identified by Aboriginal and Torres Strait Islander people as contributing to the collective trauma of living with ARF and RHD. Improvements in health care service design and operation will require shifts in care focus, authority and control so that services are flexible, culturally responsive, adaptive to local contexts, and family and community based.

Given that the average age at ARF diagnosis is 5–14 years,<sup>3</sup> early engagement with the health system establishes lifelong

patterns for young people and their families. This makes optimum early management essential for reducing disease effects. However, the systematic review identified gaps in knowledge relating to children's and adolescents' lived experiences. Addressing this gap would build on Aboriginal and Torres Strait Islander recognition of the importance of children in the continuity of Indigenous society, as young people grow up to be adults with the responsibility to care for their culture and country.<sup>61</sup> This requires different resourcing and co-design of health systems to prioritise local community input and recruit health care providers who have training in child and adolescent health.

Providing good quality care requires health service providers to overcome the issues of inequity, cultural inappropriateness, complexity and institutional racism. Consequently, "A decolonising approach to primary health care in remote services is needed in order to improve shared decision making and alleviate power imbalances between clinicians and Aboriginal patients".<sup>51</sup> This requires changes to standard biomedical approaches. The collective trauma revealed by analysing participant quotes points to the need for recognition of ongoing trauma experiences and for this to be addressed in care models for families such as trauma-informed care (unpublished data).

The dominant biomedical lens also predisposes service providers to uncritically make assumptions about the information provided by patients or not ask how things might be different. This was reflected in the tendency of the reviewed publications to reinforce negative stereotypes and hold a problematised view of Aboriginal and Torres Strait Islander people and issues. For example, the review found commonly reinforced perceptions that non-compliance was a failure of families to provide care, particularly for young people. This is despite strong evidence to suggest that non-compliance is rather more about families' lack of understanding about RHD and failure of health care providers to provide a clear explanation.<sup>49</sup>

The protective factors of Aboriginal and Torres Strait Islander ways of knowing, being and doing interconnected with each of the major thematic domains that emerged from the review. Evidence shows that cultural practices and strong relationships are facilitators of managing chronic illness and positively influence the experience of living with ARF and RHD.

While the themes identified through the systematic review have been evident for some time to communities and professionals familiar with the challenges of living with ARF and RHD, they have only just started to meaningfully influence practice and inform policy.<sup>62</sup> The results of the review should be addressed through systemic changes to influence the context in which people are living with ARF and RHD. This not only

8 Lived experience themes identified among Aboriginal and Torres Strait Islander people living with ARF and RHD<sup>37</sup>

Major thematic domain	Themes	Summary	Illustrative quotes
<b>Sociological:</b> the context in which people live and how this drives their experience of living with ARF and RHD; this includes the enduring effects of colonisation, racism, powerlessness and poverty	<ul style="list-style-type: none"> <li>■ Lived realities</li> <li>■ Experiences of power differences and racism</li> <li>■ Aboriginal and Torres Strait Islander culture, knowledge and strengths</li> </ul>	The lived reality of those affected by RHD is driven by entrenched disadvantage expressed in terms of the practical, pressing issues of everyday life (transport, food security) and an intersection of inequalities. People consistently experienced racism and a sense of powerlessness in connecting with, and attempting to access, primary health care. These experiences, and therefore the difficulties of living with RHD, may be mitigated by the protective factors of Aboriginal and Torres Strait Islander ways of knowing, being and doing.	No car to go hunting, an intermittent supply of food, no phone, no money for a bus fare were all mentioned as impacting either on the patient's wellbeing, or on their ability to access medical services—Harrington et al, 2005 <sup>43</sup>
<b>Disease-specific:</b> experiences unique to living with ARF and RHD as a complex, lifelong condition	<ul style="list-style-type: none"> <li>■ Collective trauma (sociolinguistic analysis)</li> <li>■ Experience of medications and adherence</li> <li>■ Experiences of pain</li> </ul>	Analysis of the combined quotes extracted from publications revealed an overwhelming sense of collective trauma in families relating to experiences of living with RHD. A constant shifting of locus of responsibility for adherence to secondary prophylaxis regimens creates tension often described in terms of blame (service provider attitudes) and powerlessness (community perceptions). The pain associated with injection delivery is a central issue for many families, impacting on adherence and influenced by the clinical management and attitudes of health care providers.	The hardest part of living with rheumatic heart [disease] is to keep having the injections. It makes me feel really sad and sometimes mad. It's really, really, hard— 10-year-old girl who had heart surgery when aged 5 years, quoted in Wyber et al, 2018 <sup>2</sup>
<b>Health sector:</b> experiences of interactions with health systems, often influenced by past experiences	<ul style="list-style-type: none"> <li>■ Inadequate delivery of health care services</li> <li>■ Health communication</li> <li>■ Factors contributing to positive experiences of health care</li> </ul>	The reviewed publications reflected a view that access to primary health care was considered inadequate and culturally unsafe. Limitations, due to insufficient resources and policy decisions, result in gaps in comprehensive care. Fragmented transition from paediatric to adult care, in primary and tertiary care, was particularly notable. Poor communication, often due to sociocultural/linguistic disconnections, was found to compromise ongoing engagement with health care and was the most frequently cited theme in the publications. Holistic approaches to care, involving families and the broader community, were described as factors which can contribute to positive experiences and high quality care delivery.	We have our own ways of understanding illness and health. Only by using our own words, metaphors that are meaningful to us, and a communication style that is respectful, can we hear the messaging from health professionals. This means the health messages need to be made with us rather than for us— Aboriginal participant quoted in Haynes et al, 2019 <sup>44</sup>  "Good care" for patients with RHD was often discussed using the terms <i>djaka</i> , meaning to care for physically, and <i>gungga'yun</i> , translated as to encourage or to nurture— Harrington et al, 2006 <sup>42</sup>

ARF = acute rheumatic fever. RHD = rheumatic heart disease.

necessitates prioritising the knowledge, perspectives and experiences of Aboriginal and Torres Strait Islander cultures, but also needs to ensure the active engagement and participation of

Aboriginal and Torres Strait Islander people and their communities in the development of all future interventions to address ARF and RHD.

## Chapter 4

# Critical elements of a comprehensive approach to end RHD

Rosemary Wyber, Katharine Noonan, Catherine Halkon, Stephanie Enkel, Alex Brown, Anna Ralph, Asha Bowen, Jonathan Carapetis

The protracted causal pathway of rheumatic heart disease (RHD) means there are many opportunities to intervene and reduce incident disease. A framework for classifying these strategies — beginning with action on the indirect causes of disease and moving to action on direct biomedical causes through primary, secondary and tertiary approaches — is shown in Box 9. Within each of the domains shown in this figure, a range of strategies to avert or ameliorate RHD are possible. *The RHD Endgame Strategy: the blueprint to eliminate rheumatic heart disease in Australia by 2031* (the Endgame Strategy) collates a comprehensive list of these potential strategies and analyses them according to considerations derived from the GRADE Evidence to Decision (EtD) framework.<sup>10,63</sup> The EtD framework is intended for use in population-level decisions and incorporates a range of considerations including acceptability, feasibility and externalities. This chapter summarises major RHD control strategies, associated evidence and key considerations from the EtD framework.

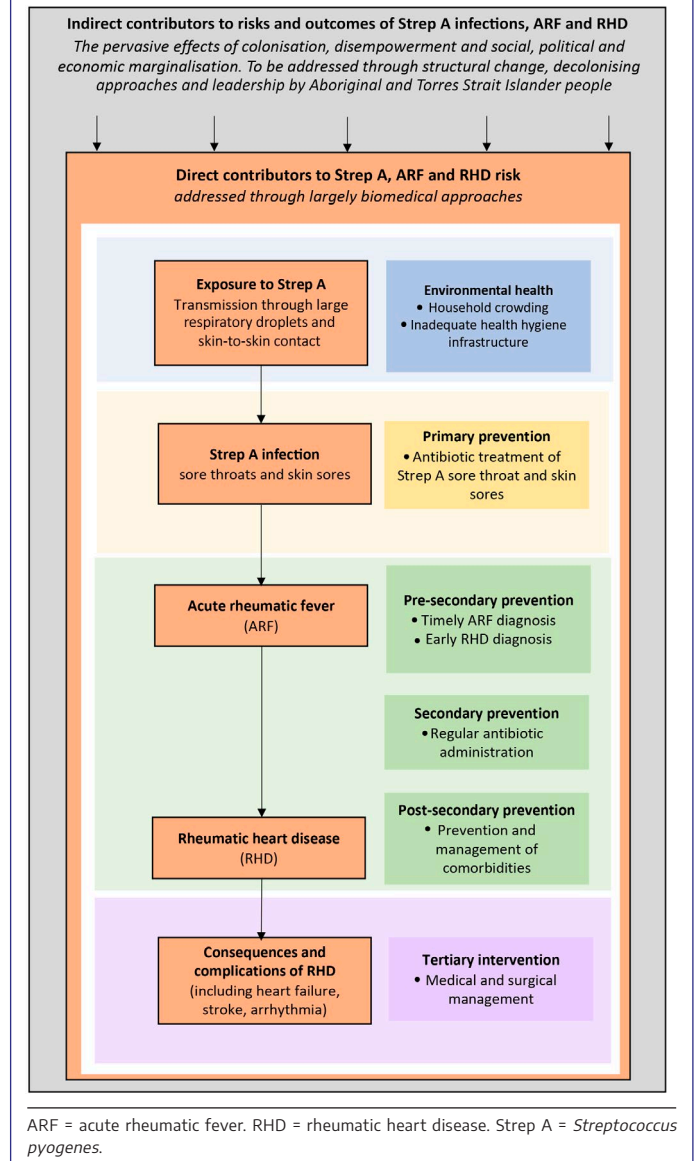
### Reducing structural drivers of Strep A infections, ARF and RHD for Aboriginal and Torres Strait Islander people

Colonisation, racism and policy failures drive the ongoing burden of RHD in Australia by concentrating indirect risk factors — including poverty, inadequate housing and insufficient access to effective health care — among Aboriginal and Torres Strait Islander people.<sup>8,64,65</sup> These effects are compounded because the people at greatest risk of these diseases have inadequate opportunities to identify and implement solutions.<sup>66</sup> In addition, the services, infrastructure and local capacity needed to prevent new diagnoses of acute rheumatic fever (ARF) and RHD are fragmented and split between policy silos of health, housing, education, justice and other departments. RHD is too often addressed as a biomedical diagnosis rather than a symptom of pervasive social injustice.<sup>9</sup>

While preventing and treating *Streptococcus pyogenes* (Strep A) infections has the potential to reduce new diagnoses of ARF and RHD, only by addressing the indirect causes of disease can the inequity of RHD be brought to an end. This necessarily involves including decolonisation, self-determination and political power for Aboriginal and Torres Strait Islander people.<sup>67</sup> Structural shifts towards these goals include the *Uluru statement from the heart* and the four reform priorities identified in the Closing the Gap Refresh consultation process.<sup>68,69</sup> As the process of truth-telling and reconciliation takes place in Australia, specific strategies are needed to remediate drivers of ill health. Clinically, this means addressing the critical under-resourcing of primary health care,<sup>70</sup> expanding the health workforce (eg, by progressing the National Aboriginal and Torres Strait Islander Health and Medical Workforce Plan<sup>71</sup>) and improving access to culturally responsive care.

Action on the political, economic, social, colonial and power structures which drive ARF and RHD burden would have a

### 9 Causal pathway of RHD with opportunities for prevention<sup>10</sup>



wide impact on a range of other conditions that disproportionately affect Aboriginal and Torres Strait Islander people. Direct action on housing, primary care and culturally responsive health care are also inexorably linked to rates of otitis media, trachoma, scabies, respiratory tract infections and gastrointestinal infections. A systems approach that addresses these root causes will help avoid fragmented, disease-specific programs which contribute to duplication and unnecessary complexity.<sup>66</sup>

## Environmental and social determinants of Strep A prevention

Strep A spreads through large airborne droplets and skin-to-skin contact.<sup>72</sup> Therefore exposure, transmission and infection are inextricably tied to the environment in which people live and interact, particularly in households.

Several environmental health strategies could reduce Strep A transmission and infection at a household level. Nine Healthy Living Practices (HLPs) were developed by Nganampa Health Council and have become a community-initiated framework for considering housing and health issues in Aboriginal and Torres Strait Islander communities.<sup>73</sup> HLPs are widely used by communities and governments to consider the conditions relating to housing, the built environment and the natural environment, and to help guide priorities for action, including in the *National Indigenous housing guide* and the Aboriginal and Torres Strait Islander Health Performance Framework.<sup>74,75</sup> Evidence for associations between each of the nine HLPs and Strep A infections is shown in Box 10. HLPs with the strongest evidence of association with Strep A infections (HLPs 5, 1 and 2) are addressed in more detail but are indivisible from each other in a comprehensive approach to healthy homes.

### Healthy Living Practice 5: Reduce the negative impacts of household crowding

Reducing the negative effects of household crowding is consistently identified as one of the major health priorities for Aboriginal and Torres Strait Islander people and peak bodies.<sup>87,88</sup> The term “household crowding” is considered distinct from “overcrowding” — a term which has been criticised for failure “to recognise the cultural strengths of multigenerational close living” potentially including support, connection, and protective influence of

extended family.<sup>37,89</sup> However, these benefits accrue when people have sufficient control over the people and the numbers of people who they choose to live with, and when there is adequate housing design and infrastructure to support household size.<sup>89</sup> Household crowding with a negative effect on health is often the result of culturally and climatically inappropriate housing design.

Of all the environmental risk factors for Strep A infection, ARF and RHD, household crowding has the strongest evidence of causal association.<sup>65</sup> A 2018 systematic review found that, across a variety of occupancy measures, household crowding increased the risk of ARF/RHD (risk ratio, 1.7–2.8) and that this relationship was consistent, dose-responsive and biologically plausible.<sup>65</sup> However, understanding the exact magnitude of the association in Australia is hampered by the lack of culturally appropriate tools for describing household crowding and widespread use of the Canadian National Occupancy Standard as a blunt measure.<sup>90</sup> Three main approaches could reduce the harmful effects of household overcrowding: building new houses, modifying and maintaining existing houses, and changing household use patterns to minimise the risks of household crowding.

Few attempts have been made to explore the health effects of new-build housing. One study examined health outcomes in 10 Northern Territory communities where an average of 11 new houses were built (range, 7–15) in 2005.<sup>91</sup> Building new houses did not reduce household crowding and did not reduce skin infections. This lack of impact was attributed to the scale of the program, with far larger investments in housing and environmental health likely to be needed to change outcomes.<sup>91</sup> In addition, building new housing can perversely exacerbate household crowding if people move from several houses with inadequate infrastructure to live in one new house with functioning

### 10 Healthy Living Practices and their association with Strep A infections

Healthy Living Practice	Evidence of association with Strep A infection	Strength of evidence
1: Washing people	A study from Pakistan suggests that daily handwashing is associated with a 34% reduction in skin infections. <sup>76,77</sup>	Strong
2: Washing clothes and bedding	Strep A bacteria are generally not transmitted person to person via clothes or bedding unless heavily contaminated. <sup>78</sup> Using appropriate washing practices can kill scabies mites and lice which may contribute to skin damage and subsequent Strep A infection. <sup>79,80</sup>	Medium
3: Removing wastewater safely	There is no evidence that Strep A is transmitted through contaminated water or human faecal matter. <sup>81</sup>	Weak
4: Improving nutrition and the ability to store, prepare and cook food	Outbreaks of Strep A pharyngitis have been associated with contaminated foods. <sup>82</sup> However, this does not appear to be a major driver of infection for Aboriginal and Torres Strait Islander people in remote locations.	Weak
5: Reducing the negative impacts of overcrowding	A 2018 systematic review found evidence of a causal association between household crowding and increased risk of ARF/RHD (risk ratio, 1.7–2.8). <sup>65</sup>	Strong
6: Reducing the negative effects of animals, insects and vermin	There is no evidence that Strep A can be transmitted between animals and humans. <sup>81,83</sup> However, biting insects can cause scratching and skin damage which can be subsequently infected with Strep A.	Medium (indirect)
7: Reducing the health impacts of dust	Strep A is not transmitted through environmental dust outside of houses. Inside houses, dust may be contaminated by Strep A bacteria but it is not clear whether desiccated Strep A in dust can cause infection. <sup>84</sup>	Weak
8: Controlling the temperature of the living environment	The association between climate and skin sores is unclear, and there is conflicting evidence about seasonal changes in disease burden. <sup>25,85</sup> Low household temperatures may be associated with functional crowding as people gather for warmth, and this could potentiate Strep A spread.	Weak
9: Reducing hazards that cause trauma	Crowded, poorly maintained homes can increase the risk of minor skin damage due to cuts and abrasions which may become infected with Strep A. <sup>86</sup>	Medium

ARF = acute rheumatic fever. RHD = rheumatic heart disease. Strep A = *Streptococcus pyogenes*.

utilities.<sup>92</sup> Therefore, new builds should be coupled with repair and maintenance programs of existing houses. Repair programs also improve health in their own right. For example, in New South Wales, a Housing for Health program was established to undertake repairs and maintenance of Aboriginal community housing.<sup>93</sup> From 2000 to 2010, people participating in this approach had 40% fewer hospital separations for infectious diseases (including skin infections) and a twofold improvement in the ability to wash people, bedding and clothes.<sup>93</sup>

Modification of existing houses may also offer scope to increase physical space between people, reducing the close physical contact which is associated with Strep A and scabies transmission.<sup>94,95</sup> For example, housing with an enclosed yard as surge accommodation for visitors has been identified as a preference in several communities.<sup>96</sup> A variety of programs have attempted to increase functional living space in remote community housing, including addition of more bedrooms, more verandas and more functional yard space.<sup>97</sup> However, our literature review did not identify any evaluations of the health impact of expanding functional space.

It may also be possible to reduce the risk of Strep A infection by adopting protective living practices in crowded houses. Although increasing the space between beds in military barracks reduced Strep A infections in historic studies, our literature review did not identify any contemporary examples of distancing within households.<sup>98</sup> Further, to our knowledge, there is no compelling evidence for reducing the risk of Strep A infection by respiratory hygiene measures<sup>99,100</sup> or by providing or elevating mattresses.<sup>101,102</sup>

The impact of household crowding is widely acknowledged, although there is little evidence about the efficacy of different crowding reduction strategies. Common themes in relevant studies and consultations suggest that a comprehensive approach, under the leadership of Aboriginal and Torres Strait Islander people, is needed. This should include: building sufficient new, fit-for-purpose houses; repairing and refurbishing existing houses; supporting tenants to report faults; carrying out local maintenance; and supporting community-controlled housing management programs. To achieve this, the Australian Government should develop, cost and implement a national Aboriginal and Torres Strait Islander housing and community environmental health strategy in partnership with Aboriginal and Torres Strait Islander people.<sup>103,104</sup>

### Healthy Living Practice 1: Washing people

A randomised control trial completed in Pakistan showed that daily handwashing with soap by children reduces skin infections.<sup>76</sup> A recent systematic review concluded that daily handwashing is recommended for prevention of skin sores in remote Australia.<sup>77</sup> However, many people in remote Aboriginal and Torres Strait Islander communities have insufficient access to functioning health hardware (including shower heads, taps and sinks), consumables (including soap and clean towels), and water for effectively washing hands and bodies.<sup>105–107</sup>

These health hardware limitations are only some of the barriers to hand and body washing. A broad array of social, structural, educational, mechanical and cultural practices contribute to washing behaviours, as outlined in Box 11.<sup>107,108</sup> Underlying determinants can include household crowding,

climatic and structural disruptions to consistent water supply, and social norms.<sup>109–111</sup> A comprehensive, multiple-exposure, multiple-effect approach to addressing these determinants is needed before handwashing becomes routine.<sup>107</sup>

Several health promotion programs have been run in Aboriginal and Torres Strait Islander communities to increase washing of hands, faces and bodies.<sup>112–117</sup> There has been limited evaluation of these programs and there is little evidence of changes in washing behaviour.<sup>107</sup> At least some programs appear to be acceptable when well implemented in partnership with Aboriginal and Torres Strait Islander people, in relevant languages and local contexts.<sup>107</sup> However, health promotion campaigns conducted in isolation, without addressing household infrastructure and maintenance or affordable access to consumables, are unlikely to be effective and may be stigmatising or harmful.<sup>111,118</sup>

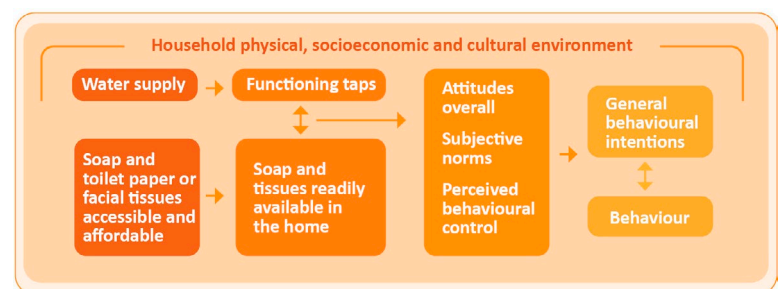
Hygiene consumables in remote communities may be unavailable or prohibitively expensive.<sup>107</sup> A small number of programs have been established to distribute or improve access to hygiene products, the largest of which is Squeaky Clean Kids.<sup>119</sup> Evaluation of this approach is planned and further understanding about the role of soap provision in preventing skin sores may emerge following the COVID-19 pandemic response in remote communities.

Hygiene hardware in houses and communities is a key determinant of washing opportunities. Houses which have been poorly designed, constructed and maintained are more likely to have plumbing problems, which limit capacity for washing people.<sup>120</sup> Proactive household maintenance approaches and implementation of an updated *National Indigenous housing guide* are likely to be needed to reduce barriers relating to plumbing.<sup>121</sup>

Community infrastructure may also offer washing opportunities. For example, swimming pools may offer similar benefits in some Aboriginal and Torres Strait Islander communities. Although there are no high quality studies with a control group, 10 observational studies in remote communities have found that swimming pools were associated with reduced prevalence and severity of skin sores.<sup>122</sup> Positive externalities of pools may include social cohesion, drowning prevention and community capital.<sup>122–126</sup> However, pools require funding, governance and sustainability to be addressed to achieve these benefits. Alternatively, some communities have built or suggested ablution blocks to improve access to showers, although the health effects of this approach have not been evaluated.<sup>127,128</sup>

Schools also provide an important setting to increase handwashing practices. Historically, anecdotal reports suggested that

### 11 Conceptual model of factors influencing opportunities for handwashing and face cleaning\*<sup>107</sup>



\*Reproduced with permission from Wyber et al, 2020.<sup>10</sup>

access to soap and water, sinks and functional washing facilities in remote schools was limited.<sup>105,106</sup> The COVID-19 pandemic has contributed to a rapid increase in hand hygiene facilities in schools and this should be maintained through funding, training and policy instruments.<sup>129</sup>

**Healthy Living Practice 2: Washing clothes and bedding**

Ensuring that people have facilities to wash clothes and bedding may reduce the rates of Strep A skin infection by reducing the risk of transmission (particularly from heavily contaminated clothing) along with scabies and crusted scabies.<sup>78-80</sup> However, facilities for people to wash clothing and bedding are limited in many remote Aboriginal and Torres Strait Islander communities. For example, in 2013 the East Arnhem Spin Project (Washing Machine Djäma) found that only 49% of 450 households in five communities had a functional washing machine.<sup>130</sup> Heavy machine use, in conjunction with poor installation, mineralised water and limited maintenance, mean that the lifespan of a domestic washing machine in remote communities is about 2 years.<sup>130</sup> Soap and detergent required to wash clothes and bedding may also be prohibitively expensive.<sup>131</sup> Strategies to increase washing of clothes generally focus on household washing machines or community laundromats.

Functional plumbing is needed to be able to use domestic washing machines, along with facilities to dry clothes and dispose of used wastewater.<sup>132</sup> Maintenance issues are a major contributor to plumbing problems but can be mitigated by a comprehensive approach including: proactive scheduled maintenance programs which do not rely solely on the tenant reporting faults;<sup>133</sup> decentralised maintenance services that employ local people to undertake these activities;<sup>118</sup> and tenancy management to support household members to report housing maintenance issues and provide education about batching of non-urgent repairs and the importance of prompt reporting.<sup>111,118</sup> Communities, councils and retailers can also support access to functional household washing machines by stocking a small range of quality machines, stocking spare parts, and facilitating washing machine repairs and maintenance (by arranging access to such services, or training community members to perform them).<sup>130</sup>

A stable supply of power and water at low cost is essential for running health-related infrastructure and implementing many HLPs. In many remote Aboriginal and Torres Strait Islander communities, power supplies are accessed via card-operated,

pre-payment meters.<sup>134,135</sup> While popular, these pre-payment meters are expensive and not equipped to provide information about electricity use, faults or disconnections.<sup>135</sup> Household power outages are therefore common in remote communities, owing to insufficient funds to purchase power or because of central outages or faults. Inadequate quantity and quality of water for washing also hampers use of washing machines.<sup>136,137</sup>

Lack of access to household washing machines has prompted construction of several community laundries in remote communities.<sup>138-141</sup> A contemporary laundromat program has recently been initiated by the Aboriginal Investment Group in an NT community.<sup>140</sup> Large shipping containers have been converted to fit four washers and dryers linked to soap and water, with room for laundry preparation and folding.<sup>140</sup> Although community laundromats have been built over several decades, there has been little evaluation of their use or health effects.

**Primary prevention of ARF**

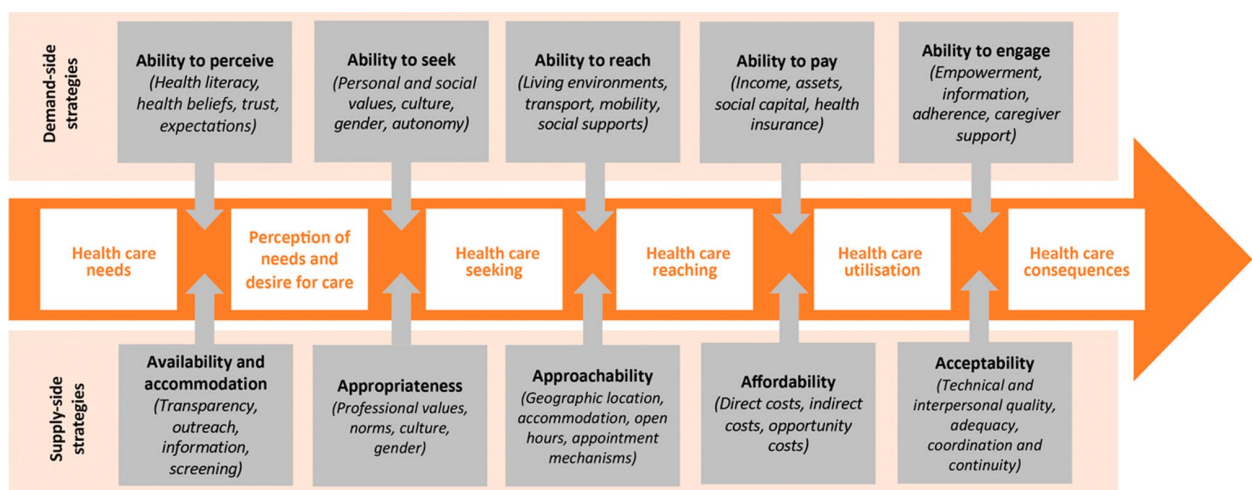
Antibiotic treatment of Strep A pharyngitis can significantly reduce the risk of ARF subsequently developing. Treatment with oral penicillin can reduce the attack rate of ARF by about 70%, and this increases to 80% if a single intramuscular injection of benzathine benzylpenicillin is given.<sup>142</sup> Therefore, many episodes of ARF are preventable if Strep A pharyngitis can be promptly diagnosed and appropriately treated. In Australia, primary prevention extends to treatment of Strep A skin infections, based on evidence outlined in Box 1. Therefore, primary prevention in Australia is the diagnosis of skin and throat infections and treatment with appropriate antibiotics to prevent ARF in people at high risk of the disease.

Strategies to improve primary prevention of ARF can be considered according to the model of access to health care shown in Box 12.<sup>143</sup> This model outlines supply-side and demand-side contributors to whether or not people are able to access and engage with health services, in conjunction with additional cultural and contextual determinants for Aboriginal and Torres Strait Islander people.<sup>144</sup>

**Supply-side strategies**

Supply-side considerations relate to how health services provide care and whether those services are available, appropriate,

12 Model of patient-centred access to health care developed by Levesque and colleagues<sup>143</sup>





approachable, affordable and acceptable.<sup>143,144</sup> In remote Aboriginal and Torres Strait Islander communities, a range of supply-side barriers are likely to affect whether people can access care for skin sores and sore throats.

Strategies to increase availability and accommodation of services may include outreach and screening. In particular, active screening for skin sores may increase detection and treatment. This could occur opportunistically given that Aboriginal and Torres Strait Islander children in remote communities have regular contact with the primary health care system through child health checks, immunisations, and high rates of presentation with infections and non-infectious diseases.<sup>145–147</sup> These clinical encounters may offer opportunities for active identification of skin sores, particularly the annual Aboriginal and Torres Strait Islander Peoples Health Assessment (Medicare Benefits Schedule Item 715). The *National guide to a preventative health assessment for Aboriginal and Torres Strait Islander people* — produced by the National Aboriginal Community Controlled Health Organisation and the Royal Australian College of General Practitioners — recommends opportunistic screening for skin sores for children who have high rates of skin disease.<sup>148</sup> However, further clinical guidance is needed to define the components of a “healthy skin check” (including areas to be examined or self-reported) and appropriate environments for screening (including privacy considerations if conducted outside of clinic settings).<sup>149</sup>

Outreach services beyond the clinic — to homes, schools or homelands — may also support availability and accommodation. Providing access to health care through schools may be an important opportunity for outreach. Theoretically, this could include: direct service provision at school via school nurses; support for schools to identify skin sores and refer children to the clinic; or provision of first aid and basic care by school staff. However, there are few examples of this approach in practice, reflecting the difficulties of already substantial responsibilities on schools, complexities of providing care without guardians present, and the need for integration with local primary care services.<sup>149</sup>

Several health system issues contribute to capacity for outreach service delivery. For example, telehealth facilities for outreach staff in homes or homelands to communicate with clinicians at the clinic could potentiate outreach.<sup>150</sup> Similarly, increasing capacity for Aboriginal and Torres Strait Islander health practitioners to dispense medication for primary prevention could improve access. For example, a system of “standing orders” exists in New Zealand for registered nurses to provide antibiotics for sore throat, which has reduced waiting times for clinic assessments.<sup>151,152</sup> Similar arrangements for dispensing medication in remote parts of Australia — by harmonising this approach, and increasing workforce investment and training — could maximise the benefits.<sup>153,154</sup>

At a community level, availability and accommodation of services can also be addressed through proactive outreach-based skin health programs.<sup>155–160</sup> There is good evidence that these programs can be effective in reducing the prevalence of scabies and skin sores.<sup>77,161</sup> Comprehensive, community-led, healthy skin outreach programs should be incorporated into strategies for primary prevention of ARF in settings with a high burden of skin infection.<sup>77,161</sup>

Approachability issues include limited after-hours services in some remote communities and lengthy waiting times.<sup>162,163</sup>

Expanding the range of places and times at which people can have sore throat and skin assessments may improve access. For example, in New Zealand, dedicated drop-in sore throat clinics at pharmacies, shopping centres and primary care clinics were a major component of the Rheumatic Fever Prevention Programme from 2014.<sup>164</sup> However, focused sore throat services are unlikely to be appropriate in remote Aboriginal and Torres Strait Islander communities where populations are small, and symptomatic sore throats are rare.<sup>17</sup> Skin and throat assessments, as part of comprehensive primary health care through local clinics, are more likely to be effective in the Australian context.

Appropriateness includes professional norms and culture within clinics. There has been little evaluation of the knowledge, attitudes and behaviour of primary care staff regarding sore throat and skin sore management. Normalisation of skin sores by hospital staff suggests professional attitudes and training may be an issue.<sup>165</sup> Appropriate care delivery could be supported by improved use of clinical guidelines and provision of education and training for assessment and treatment of sore throat and skin sores. Several guidelines, protocols and clinical recommendations for managing skin infections in Aboriginal and Torres Strait Islander people have been developed in Australia, streamlined by the *National healthy skin guideline* in 2018.<sup>161,166–168</sup> A similarly consistent approach to sore throat treatment is yet to be developed, with seven pharyngitis guidelines in use across Australia.<sup>169</sup> Application of clinical guidelines may be increased if they are coupled with quality improvement processes, clinical audits and decision support tools embedded in primary care patient information systems.<sup>148,170,171</sup>

Affordability issues include the costs of primary health care, medications and consumables. In remote Aboriginal and Torres Strait Islander communities, clinical consultations and medication are generally free at point of care. Funding is provided through Medicare subsidies, the Indigenous Australians’ Health Programme and Pharmaceutical Benefits Scheme Section 100 provisions for remote clinics. However, in urban settings, costs for clinical consultation and medications may be a barrier to access.<sup>172</sup> The Closing the Gap Pharmaceuticals Benefits Scheme Co-Payment Measure (CTG PBS) is intended to support Aboriginal and Torres Strait Islander people in non-remote areas to access subsidies for prescription medication.<sup>173</sup> Despite this, barriers to the use of CTG PBS scripts are widespread: some prescribers are not aware of the provisions, some primary care services are not eligible to provide CTG scripts, and hospital-generated scripts are usually ineligible. Several improvements identified by the National Aboriginal Community Controlled Health Organisation should be implemented to improve equity, and increase access and uptake, of CTG PBS measures.<sup>174</sup> Similarly, Pharmaceutical Benefits Scheme Section 100 provisions could be enhanced by implementing recommendations from a 2011 Senate report, including that Section 100 provisions be made available to all Aboriginal medical services irrespective of geographic location.<sup>175</sup>

Acceptability of services includes the technical adequacy of care delivered. Improvement mechanisms may include training, clinical audit, review processes and technical innovation. Diagnosis of ARF may offer a sentinel opportunity to look back at missed opportunities for primary prevention. By identifying events where people had signs or symptoms of Strep A infection but did not receive the recommended antibiotic therapy, it may be possible to identify systemic barriers, provide feedback to clinical staff and improve future care delivery. This approach

has provided useful insights in New Zealand and a “look back review meeting” of ARF notifications could be trialled in Australian settings that have a high burden of ARF.<sup>152</sup>

Technical innovations may also improve acceptability and quality of services. For example, diagnosis of Strep A skin infections can usually be made by trained clinicians on the basis of typical wound appearance and confirmed with microbial swabs if needed.<sup>161</sup> However, distinguishing Strep A throat infections from viral infection on clinical appearance is more difficult.<sup>15,176</sup> New generation point-of-care tests using polymerase chain reaction to identify Strep A in remote Aboriginal and Torres Strait Islander settings may be a useful diagnostic adjunct, and this warrants further research.<sup>176</sup>

### Demand-side strategies

Demand-side considerations reflect opportunities for people to perceive their need for health care, seek and reach care, and pay for and engage with the services delivered.

Perception of health need is likely to be a barrier to access because community awareness of the risk of Strep A skin and throat infections preceding ARF and RHD is generally limited.<sup>51,172</sup> There is some evidence that childhood skin infections are both normalised and stigmatised by families and health care professionals.<sup>172,177</sup> This may mean that people do not seek treatment or are not offered it when attending a clinic.<sup>165</sup> In New Zealand, health promotion campaigns using local champions increased knowledge about sore throats, ARF and heart damage, and increased health-seeking behaviour.<sup>178,179</sup> However, some New Zealand campaigns appear to have contributed to stigma about sore throats and ARF, which highlights the importance of carefully co-designed health promotion resources.<sup>180</sup> Culturally meaningful health promotion campaigns to increase awareness of the risks of skin sores and sore throats and ARF should continue to be developed, implemented and evaluated in Australia. (Box 13 and Box 14).

The ability to engage with care has many determinants. At an individual level, providing relevant information during clinical consultations may improve engagement and capacity for self-management. This can be supported by development of culturally and linguistically appropriate resources to discuss skin sores and sore throats.<sup>181,182</sup> Engagement may also be increased through peer support and care navigation initiatives (Box 13 and Box 14).<sup>183,184</sup> At a community level, ability to engage in sore throat and skin sore management is likely to be determined by community ownership of skin health initiatives.<sup>185–189</sup> There is evidence that local community-driven programs are

### 14 Activity domains of END RHD Communities\*



\*Reproduced with permission from Wyber et al, 2020.<sup>10</sup>

more effective than externally implemented programs.<sup>190</sup> Local burden of disease data to inform planning and prioritising of these activities, in line with data sovereignty principles, should be available to communities and their clinics.<sup>191</sup>

### Secondary prevention of RHD

Secondary prevention focuses on people who are at risk of recurrent ARF, because they have had ARF or they live with RHD. The spectrum of secondary prevention includes early and accurate ARF diagnosis, accurate RHD diagnosis and secondary prophylaxis using antibiotics.

Antibiotic therapy with intramuscular injections of benzathine benzylpenicillin has been the global standard of care for ARF prevention since the drug's development in the 1950s. The aim is preventing Strep A infections to prevent recurrent episodes of ARF.<sup>192</sup> Receiving more than 80% of scheduled injections appears to be protective against recurrent episodes of ARF.<sup>193</sup> Prevention of ARF recurrences is strongly associated with better clinical outcomes, including reduced overall mortality.<sup>193–196</sup> RHD registers are generally used to support delivery of these secondary prophylaxis injections.

The delivery of secondary prophylaxis and RHD registers has been the focus of RHD control strategies in Australia over the past 20 years. However, despite investment over many years, delivery of injections remains low, with only 42% of people on RHD registers in Australia receiving more than 80% of scheduled injections in 2018.<sup>3</sup> Improved service delivery for the full spectrum of secondary prevention activities, as well as enhanced secondary prophylaxis injection delivery, are needed to improve outcomes for people already on the trajectory towards severe RHD.

### Delivering early and accurate diagnosis of ARF

Early and accurate ARF diagnosis is a critical opportunity to prevent RHD because it allows for disease-altering secondary prophylaxis to be initiated as soon as possible. The diagnosis of RHD among people without prior ARF can be explained by several potential factors: ARF symptoms are absent or mild and people do not seek medical care; symptoms are present but people do not seek care; symptoms are not recognised as ARF by health practitioners; there are delays in making the diagnosis; or the diagnosis is not adequately documented.<sup>197</sup> As more people are diagnosed with RHD through echocardiographic screening,

### 13 Summary of the END RHD Communities approach

- The END RHD Communities model is a collaborative approach to reducing rheumatic heart disease (RHD) in high risk Aboriginal and Torres Strait Islander communities. Qualitative research indicates that Aboriginal people want help, such as help to navigate health systems, help to understand their health (and their family's health), and support that could mitigate the effects of high health care staff turnover.<sup>177</sup>
- Central to the model is the employment of Aboriginal community workers who develop partnerships with individuals and families who are at highest risk of acute rheumatic fever (ARF) and RHD, and then assist them to navigate the health care system, increase their self-management capacity and manage environmental risk factors. The project is designed to allow the community to control how the project is implemented and governed at a community level while retaining core evidence-based components (ie, strategies that are known to reduce ARF and RHD incidence) illustrated in Box 14.

it is likely that more cases without documented ARF will also be found.

Early diagnosis of ARF is likely to require increased health-seeking behaviour and enhanced primary health care capacity to respond. This includes resourcing and staffing, in addition to technical support to develop and disseminate diagnostic pathways. Clinical innovations to improve diagnosis have included revisions to the Jones criteria for ARF diagnosis, to increase specificity for high risk groups, along with better health worker training.<sup>62,198</sup> Ongoing training and resources are needed to address high workforce turnover and frequent use of fly-in/fly-out health professionals in high risk areas. A range of training and education resources are available to improve knowledge and management of ARF.<sup>62</sup> This includes online modules and resources, workshops, and the RHD Australia diagnosis calculator app.<sup>199–201</sup> These resources should continue to be developed and evaluated alongside work to ensure integration and consistency with other clinical guidelines that are commonly used in high risk settings, such as the Central Australian Rural Practitioners Association's standard treatment manual.<sup>166</sup> This may be supported by improving technical capacity for ARF diagnosis — for example, by improving access to Strep A serological testing and developing a diagnostic test for ARF.<sup>202</sup>

The proportion of people diagnosed with RHD who have had a documented episode of ARF is a reasonable indicator of whether ARF is being diagnosed or missed. A variety of data sources indicate that about 55–80% of patients are diagnosed with RHD without preceding evidence of ARF, although some data suggest that this proportion reduces to about 25% in patients younger than 25 years.<sup>4,32,197</sup> A standard approach to monitoring metrics may provide an opportunity for quality and process improvement. ARF is notifiable in five jurisdictions in Australia, but the notification process, data reporting and links to RHD registers vary substantially across jurisdictions. Efforts to simplify the ARF notification process should continue and suitability of ARF as a nationally notifiable disease should be revisited.<sup>203</sup>

### Increasing early diagnosis of RHD

Early diagnosis of RHD, before heart valve damage becomes severe, may provide an opportunity to begin secondary prophylaxis sooner. This reduces the risk of progressive heart damage and may enable some regression, or even complete resolution, of RHD. Echocardiography can detect asymptomatic RHD. Echocardiography screening has benefits for people detected with definite RHD if high quality secondary prophylaxis is then delivered and cardiac care, including appropriately timed surgery if needed, is instituted. However, RHD does not meet all the standard public health criteria for community screening, and population-level screening is not currently recommended in Australia except in population subgroups such as pregnant women who are at high risk of RHD.<sup>62</sup>

Echocardiography screening for RHD may be considered in communities with high rates of ARF and RHD, or in the context of ARF outbreak investigation or follow-up.<sup>26,204</sup> When echocardiography screening is undertaken, community support and input are essential, and systems and resources should be available for providing education, secondary prophylaxis and follow-up. Ideally, screening would form part of a comprehensive health response to RHD in select communities, which would require the collaborative development of criteria and thresholds

for screening. Further research should address the role of echocardiography screening in different population groups, the use of non-expert operators, and incorporation of screening into routine health checks.<sup>205</sup>

### Improving delivery and uptake of secondary prophylaxis

There are multiple, well documented barriers to delivery of secondary prophylaxis, including the frequency and duration of the treatment regimen, the pain associated with the injections and the under-resourcing of primary health care services that are responsible for care.<sup>206–208</sup> The determinants of adherence to long term medication can be described using a World Health Organization framework that includes people and culture, the health system, socioeconomic context, and condition- and therapy-specific factors.<sup>209</sup> Each presents an opportunity to improve delivery and uptake of secondary prophylaxis, and the most feasible and acceptable recommended strategies are presented in Box 15.

Secondary prevention has become synonymous with antibiotic secondary prophylaxis in Australia. While this prophylaxis is critical, and the associated RHD register-based control programs should remain a core component of a comprehensive prevention strategy, the continuing rising rates of ARF and RHD in Australia<sup>3</sup> demonstrate that prophylaxis is not achieving its aim. Secondary prevention for ARF and RHD needs to meet its broadest definition, delivering the full spectrum of prevention activities for people and communities impacted by ARF and RHD. These activities must focus on the early and accurate diagnosis of ARF and RHD, and address the systemic factors that influence adherence to secondary prophylaxis.

### Tertiary care for people living with ARF and RHD

People already living with RHD require a range of medical and allied health services, collectively termed tertiary care. Tertiary care involves monitoring valve function through echocardiography and clinical review, providing advanced medical and surgical management, and providing other primary and specialist health services which prevent complications.<sup>34,62</sup> Effective tertiary care should reduce symptoms, improve quality of life and extend life expectancy. However, there is good evidence that these complex medical needs are not always being met.<sup>221</sup>

The focus of the Endgame Strategy is preventing new diagnoses of ARF and RHD. Detailed review of options to improve tertiary care in quaternary settings is outside of the scope of this supplement. However, several clear priorities for improving care delivery have been identified in other publications and should be incorporated into a comprehensive approach.<sup>222,223</sup>

People with RHD should have access to high quality, patient-centred tertiary care close to home or via telehealth where available. Strategies to achieve this include: improving access to regular specialist review; investing resources to ensure that women who have (or are at risk of) RHD receive specific specialist care during pregnancy; optimising transition from paediatric to adult services; improving medical management such as enabling access to safe anticoagulation therapy and monitoring; and ensuring access to dental care. Access to timely valvular procedures and/or surgery, serviced only by specialised hospitals, is a priority for those with severe disease.

Designated care hubs should have the required level of qualified staff and appropriate facilities to meet the population needs,

## 15 Opportunities to improve uptake of secondary prophylaxis against RHD, structured according to the World Health Organization framework for long term medication adherence<sup>209,210</sup>

Factors	Strategies	Recommendations
People and culture	<ul style="list-style-type: none"> <li>Provide resources and support to peer-support programs</li> </ul>	A range of complex factors influences adherence to secondary prophylaxis, including culture, age and sex. <sup>37</sup> Peer-support programs have been shown to be beneficial for young people living with chronic disease, and there is reasonable evidence that peer-support programs can improve the lived experience of ARF and RHD for young Aboriginal and Torres Strait Islander people. Resourcing to aid peer-support programs and encourage connections and self-management should be provided, and a range of peer-support models iterated by people living with ARF/RHD and their communities should be used.
Health system — registers	<ul style="list-style-type: none"> <li>Improve function of RHD registers</li> </ul>	Optimising the effectiveness of RHD registers is critical to successful delivery of secondary prophylaxis. A range of possible options includes: ensuring that register details are accessible to clinicians at point of care; aligning register data fields across jurisdictions; creating a single national register; and integrating secondary prophylaxis with My Health Record. <sup>4,211</sup> A review of the RHD registers should be undertaken. A national updated review of RHD register function should be conducted, and should include the perspectives of Aboriginal and Torres Strait Islander people enrolled on RHD registers. Treating clinicians should be consulted, and recommendations should be made to optimise register function jurisdictionally and nationally.
Health system — clinics	<ul style="list-style-type: none"> <li>Provide resources and support to outreach services</li> <li>Appoint RHD focused staff in primary care clinics</li> </ul>	Primary health systems can have a significant impact on secondary prophylaxis delivery. <sup>49</sup> Overseas evidence and expressed preferences from Australian stakeholders suggest that increasing capacity for outreach secondary prophylaxis is a priority, <sup>45,49,56,212</sup> Primary care providers should be resourced to provide outreach secondary prophylaxis services where community demand indicates that this is a priority. There is also reasonable evidence to suggest that appointing staff members with responsibility for delivery and follow-up of secondary prophylaxis is likely to improve uptake, but primary health care services need dedicated resources to facilitate this.
Condition- and therapy-related	<ul style="list-style-type: none"> <li>Support people to remember to have their injections</li> <li>Minimise pain</li> </ul>	Although evidence varies, reminder systems collectively appear to be associated with increased delivery of timely secondary prophylaxis compared with no-reminder systems. <sup>213-217</sup> Communities and clinics should be resourced to develop and deliver locally relevant reminder systems for secondary prophylaxis injections. Efforts to reduce pain are a clinical imperative. Reducing the pain of injection delivery may also increase secondary prophylaxis adherence for some people. There is a range of biomedical and non-biomedical strategies for reducing the pain of benzathine benzylpenicillin injections, with low and moderate level evidence of effectiveness. <sup>47,218,219</sup> Administration guidelines have been developed to reduce the pain associated with secondary prophylaxis injections in Australia, although these have not been evaluated. <sup>220</sup> National stakeholders should review strategies to reduce pain of secondary prophylaxis injections, develop clinical practice guidelines and disseminate these approaches.

ARF = acute rheumatic fever. RHD = rheumatic heart disease.

including the required access to echocardiography, cardiology services, surgical care, psychological and social support, and expertise in adolescent health and transition care.<sup>46,62</sup> Most people requiring specialist care for RHD live in rural and remote Australia. Current patient assistance travel schemes are inconsistent across jurisdictions, resulting in inequities for rural and remote patients. Implementing recommendations to improve the schemes — including streamlining of bureaucratic processes, increasing financial benefits, and broadening the definition of and provision for carers — could improve access to specialist review. Larger numbers of comprehensive, specialist cardiology outreach services, plus telehealth options for rural and remote communities, should also be provided.<sup>224,225</sup>

Until early prevention strategies are implemented, there will be a continued need for surgery for people with RHD. Currently, in the NT, 60% of people diagnosed with RHD between the ages of 15 and 24 years will require heart valve surgery within 5 years of diagnosis.<sup>4</sup> Most RHD patients in remote communities, whether in NSW, NT, Queensland, South Australia or Western Australia, must travel great distances if they require cardiac surgery — they often travel thousands of kilometres, under stressful circumstances, for their operations. This is because the major tertiary centres are all in capital cities. Care for people requiring surgery could be improved by implementing strategies to enhance preoperative care, perioperative

care and handover to primary care. For example, people with RHD should have regular dental reviews to minimise the risk of bacterial endocarditis. However, these reviews are often missed and the need for preoperative dental optimisation is a frequent cause of surgical delay. Primary health care providers should be resourced and supported to educate people with RHD on the importance of dental hygiene and ensure that routine care plans for people living with RHD include regular dental reviews.<sup>226,227</sup>

Women with RHD are at increased risk of complications during pregnancy. The Australasian Maternity Outcomes Surveillance System's study on RHD in pregnancy identified care delivery that was inadequate for women's needs and, consequently, adverse outcomes.<sup>33</sup>

Educational resources to support discussions with women of reproductive age about the potential implications of ARF and RHD for pregnancy should be tailored to local settings and contexts,<sup>62</sup> with information provided to women in both primary care and tertiary care settings. Primary care services must be enabled to provide this support to Aboriginal and Torres Strait Islander women with RHD, who receive the vast majority of their pregnancy care in primary care clinics; this should include appropriate training and resources for health workers.<sup>228-230</sup>

A large proportion of Aboriginal and Torres Strait Islander women living with RHD are diagnosed with the condition during their pregnancy.<sup>33,231</sup> To address this issue, the RHD Australia 2020 clinical guidelines now recommend echocardiography as part of routine antenatal care for pregnant women who are at high risk of RHD.<sup>62</sup>

Another population group with specific care needs is adolescents who have ARF and RHD. Improving service delivery for young Aboriginal and Torres Strait Islander people transitioning from paediatric to adult services should be a priority.<sup>46</sup> Structures that enable coordinated transition of care should be put in place. Strengthening primary care involvement at the core of this transition — with strong, patient-centred, bidirectional communication — would aid this. This model should include default referral pathways, shared access to records, and combined multidisciplinary team meetings for patients who have complex care needs. Aboriginal and Torres Strait Islander youth leaders should work in partnership with cardiology services and other service delivery agencies to develop a model of care for transition programs.

Aboriginal and Torres Strait Islander people with cardiac disease face significant barriers to accessing health care, often associated with services which do not meet their needs, do not foster therapeutic relationships, or do not account for language differences and variation in health literacy.<sup>232</sup> Dedicated RHD care coordination roles, to support children and adults who are having heart surgery, would align administrative and logistic plans with cultural needs and ensure communication between different levels of the health service.<sup>226,233</sup> Hospitals need to work to improve current cultural safety frameworks. They also need to implement strategies that increase recruitment and retention of Aboriginal and Torres Strait Islander health staff (doctors, nurses, allied health practitioners and liaison officers) in acute care settings. An example of a strategy that could be implemented immediately is making high quality, culturally appropriate education on RHD available to patients, in their preferred language. Hospitals should work to improve current cultural safety frameworks and training.<sup>234</sup>

National standards of care for centres providing cardiac surgery for people with RHD should be developed, and tertiary centres should share and adapt successful models of enhanced discharge planning and clinical handover.<sup>235–237</sup> Increasing access to and participation in culturally safe cardiac rehabilitation programs could prevent subsequent RHD-related complications and readmissions. Increased resourcing for cardiac

rehabilitation in rural and remote areas is likely to improve long term outcomes. Jurisdictional agencies should explore potential models to improve cardiac rehabilitation, including outreach and on-site programs.<sup>238,239</sup> Improving access to safe anticoagulation and monitoring on return to communities must also be a priority. Community care providers should be resourced and supported to provide culturally appropriate education on the importance of anticoagulation, and increase the capacity for self-management of anticoagulation using point-of-care international normalised ratio testing machines.<sup>235–237</sup> Finally, the safety and effectiveness of novel anticoagulants for use in RHD should be explored.

## Conclusion

The Endgame Strategy identifies strategies for addressing the causes of ARF and RHD that have the greatest potential impact and are the most acceptable, feasible, and readily implementable with appropriate investment. While it is not prescriptive about which strategies should be implemented, it identifies critical elements of a comprehensive approach. Following the biomedical model, these must include:

- reducing the environmental risks of Strep A transmission and infection by ensuring that all communities have safe, functional housing and health hardware;
- establishing comprehensive skin and sore throat prevention and treatment programs for high risk communities;
- expanding secondary prevention activities to meet the broadest definition; and
- improving access to and quality of tertiary care for those already living with ARF and RHD.

However, there are prerequisite structural and systemic changes needed for any of these strategies to be effective. Aboriginal and Torres Strait Islander health services need increased and sustained resourcing, which includes support to train and employ Aboriginal and Torres Strait Islander people to deliver holistic primary health care. In tandem, improvements in cultural safety in the mainstream health system must be elevated as a priority. There is compelling evidence that a high functioning, well resourced and culturally outstanding health workforce, including the environmental health workforce, is essential to reduce the burden of Strep A infection, ARF and RHD.

## Chapter 5

# Health and economic impacts of particular RHD prevention strategies

Katharine Noonan, Rosemary Wyber, Jonathan Carapetis, Jeffrey Cannon

The Endgame Strategy aims to offer communities and decision makers with a menu of potential strategies for addressing *Streptococcus pyogenes* (Strep A) infections, acute rheumatic fever (ARF) and rheumatic heart disease (RHD) that can be tailored to local needs and contexts. We aimed to estimate the costs and the population-level health and economic benefits of implementing each potential strategy. Strategies were selected based on strength of evidence, likely acceptability, and feasibility of implementation, and compared with a scenario of inaction. This work is intended to support communities and governments to explore the effects of different decisions relating to RHD, and augment place-based, community-led decision making. Local decision making and strategy engagement will be critical determinants of the success of selected strategies.

The health and economic benefits of implementing each strategy were estimated using a state transition model (Box 16). The model predicts the proportions of a cohort that develop ARF, RHD and RHD-related complications, and the associated health and economic outcomes. For the inaction scenario (ie, continuing the status quo), the proportions of the cohort that are predicted to experience ARF and RHD are based on the epidemiological data presented in Chapter 2 and described in Box 1. The proportions used for the scenario of inaction are modified for the other strategies based on their expected impact on the risks of ARF and RHD, outlined in Box 17. As a result, the associated health and economic outcomes also change at the cohort level.

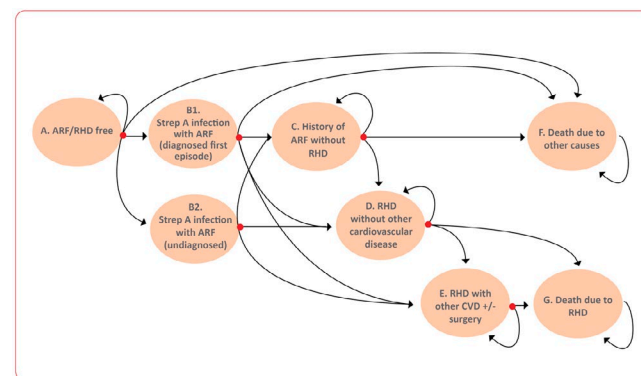
The model focuses only on the disease trajectory for people born after 2019, rather than including the trajectory for people who have established disease, to demonstrate how the outcomes for a new generation can be changed with interventions that take effect from early in life. Further, focusing on a new generation will allow time to fully implement some of the strategies given that the peak age bracket for ARF onset is 5–14 years.

The model then predicts the change in health and economic burdens using the expected effects that the prevention strategies would have on the epidemiology of ARF and RHD. Detailed modelling undertaken for the 2018 cost of inaction report showed the projected impact of RHD on the current Aboriginal and Torres Strait Islander population.<sup>2,240</sup>

### Cost of inaction

If nothing different is done, 5832 of the Aboriginal and Torres Strait Islander people born between 2019 and 2031 ( $n = 251\,267$ ) will develop ARF and 2835 will develop RHD (Box 18).<sup>31</sup> From the latter group, 1356 people will develop severe RHD (heart failure and/or valvular disease requiring a surgical procedure) and 663 people will die prematurely as a result of RHD. At the current rates of ARF and RHD incidence, \$273 million will be spent on medical care. These modelled financial outcomes account for only direct health care expenditure on ARF

16 State-transition model of RHD used to estimate health and economic effects of implementing RHD prevention strategies\*



\* Reproduced with permission from Wyber et al, 2020.<sup>10</sup> ARF = acute rheumatic fever. RHD = rheumatic heart disease. CVD = cardiovascular disease.

and RHD hospitalisations, including surgical intervention and long term management (ie, secondary prophylaxis and specialist follow-up).<sup>31</sup>

### Cost of alternative strategies

A range of RHD prevention strategies were identified in the Endgame Strategy using the GRADE Evidence to Decision framework and in consultation with the End Rheumatic Heart Disease Centre of Research Excellence investigators, the END RHD Advisory Committee and other stakeholders.<sup>10,63,148</sup> These strategies showed the greatest promise in terms of preventing new cases of RHD over the next decade, and appear to be acceptable, practical, and readily implementable with appropriate investment.<sup>10</sup>

From these strategies, a selection of the most feasible, acceptable and impactful strategies was identified for further economic and effectiveness modelling, summarised in Box 17. Indicative costs for these strategies were derived from publicly available sources and are outlined in Appendix Eight of the Endgame Strategy.<sup>10</sup>

The estimated reductions in RHD prevalence and RHD-related deaths projected to occur in Aboriginal and Torres Strait Islander people born between 2019 and 2031 in New South Wales, Northern Territory, Queensland, South Australia and Western Australia if several key strategies are implemented are shown in Box 19. The cumulative effects of each of these strategies are compared with a baseline scenario, whereby existing measures to control RHD continue but no additional actions are taken.

## 17 Summary of modelled prevention strategies for RHD and estimated effect sizes

Potential strategy	Estimated effect size for modelling purposes
<b>Reduce household crowding</b>	
<ul style="list-style-type: none"> <li>Building new housing or extending existing housing</li> </ul>	<ul style="list-style-type: none"> <li>39% reduction in risk of Strep A infection*<sup>65</sup></li> </ul>
<b>Implementing HLPs</b>	
<ul style="list-style-type: none"> <li>Improving capacity to undertake the nine HLPs — would include improvements in health hygiene infrastructure and health promotion campaigns</li> </ul>	<ul style="list-style-type: none"> <li>34% reduction in risk of skin sores<sup>76</sup> (note that HLPs encompass a range of measures beyond handwashing, so this reduction may be an underestimate of the true effect size)</li> </ul>
<b>Primary health care</b>	
<ul style="list-style-type: none"> <li>Strengthening capacity in primary health care — could improve timely treatment of Strep A infections (including co-infection with scabies) and improve diagnosis of first episode of ARF</li> <li>Three main approaches in primary care include:               <ul style="list-style-type: none"> <li>clinic-based health engagement and education to increase care-seeking behaviour for Strep A infections and possible ARF</li> <li>strep A outreach programs to identify skin sores and sore throats at a household level</li> <li>strengthened primary health care management of Strep A and ARF through staff training and increased staffing</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Although empiric evidence about health-seeking behaviour and the effect of strategies is limited, a conservative estimate is:               <ul style="list-style-type: none"> <li>currently 20% of people with a skin sore or sore throat are assessed and treated in a clinic, but this could be increased to 50% with education and outreach, so an additional 30% of people with skin sores or sore throats in the population would receive antibiotics for primary prevention</li> <li>in addition, increased health-seeking behaviour and strengthened primary health care management of ARF would result in an estimated additional 10% of people with ARF being diagnosed, which would facilitate secondary prevention and thereby reduce progression from undiagnosed ARF (now diagnosed) to RHD</li> </ul> </li> </ul>
<b>Improve delivery of secondary prophylaxis</b>	
<ul style="list-style-type: none"> <li>Secondary prophylaxis could reduce progression from ARF to mild RHD and from mild RHD to severe RHD; approaches would include:               <ul style="list-style-type: none"> <li>improving primary health care quality and staffing</li> <li>increased RHD register-based control program capacity</li> <li>empowering self-management and peer support</li> <li>increasing the capacity of health clinics to have greater connection and engagement with families and people living with RHD and ARF</li> <li>strengthening transitional care (ie, from paediatric to adult services)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>In the absence of studies showing the direct effect of high delivery of secondary prophylaxis, an effect has been estimated by combining independent data from the Northern Territory and Brazil†</li> <li>Based on these data, achieving at least 80% delivery of secondary prophylaxis would result in a 16% reduction in progression from ARF to mild RHD and a 33% reduction in progression from mild RHD to severe RHD</li> <li>These effects were applied to the proportion of the population estimated to reach at least 80% adherence, which we assumed would increase to 60% of people (currently about 30%)<sup>241</sup></li> </ul>

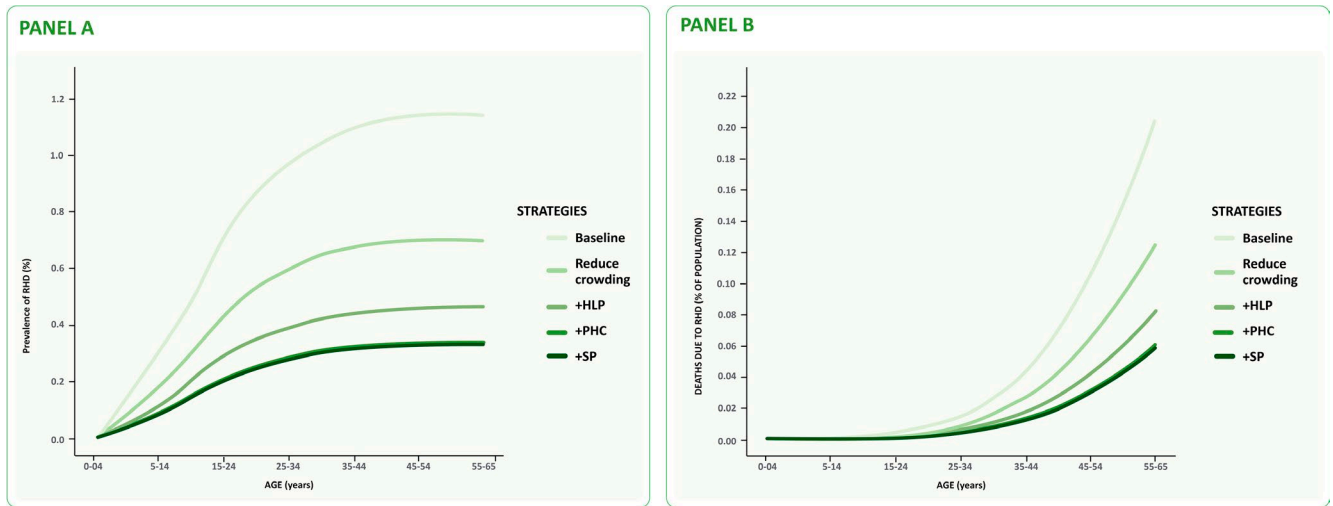
\*The proposed 39% reduction has been deduced from internal meta-analysis of the appropriate studies assessed in Coffey et al.<sup>65</sup> †A study from the NT showed that a recurrence of ARF occurred in about 14% of people with at least 80% adherence to secondary prophylaxis and 38% of those with less than 80% adherence;<sup>193</sup> data from Brazil showed that the prevalence of significant carditis was 30% in people with primary ARF and 58% in those with recurrent ARF, and that the prevalence of significant valve disease was 10% in people with primary ARF and 40% in those with recurrent ARF.<sup>194</sup> ARF = acute rheumatic fever. HLP = Healthy Living Practice. RHD = rheumatic heart disease. Strep A = *Streptococcus pyogenes*.

## 18 Predicted lifetime (0–64 years of age) health and economic outcomes of RHD experienced by Aboriginal and Torres Strait Islander people born in New South Wales, Northern Territory, Queensland, South Australia and Western Australia from 2019 to 2031 (n = 251 267), by prevention strategy implemented

Strategy	Number of first ARF cases	Number of RHD cases	Number of severe RHD cases*	Number of deaths†	DALYs	Health care costs‡ (\$m)	Cost savings‡ (\$m)
<b>No strategies implemented (baseline)</b>	5832	2835	1356	663	12 932	273.4	NA
<b>Independent implementation of strategies</b>							
Crowding	3573	1737	831	406	7921	167.5	105.9
HLPs	3864	1878	898	439	8566	181.1	92.3
PHC	4444	2066	984	483	9450	204.3	69.1
SP	5832	2787	1250	652	12 696	281.6	+ 8.2
<b>Combined implementation of strategies</b>							
Crowding + HLPs	2364	1149	549	269	5239	110.8	162.6
Crowding + HLPs + PHC	1799	836	398	195	3823	82.7	190.7
HLPs + PHC	2942	1367	651	320	6254	135.3	138.1
HLPs + PHC + SP	2942	1343	599	314	6132	139.4	134.0
All four strategies	1799	821	366	192	3748	85.2	188.2

\*Comprises people with RHD which is severe at diagnosis and those progressing from mild RHD over time. † Number of people who die with RHD but not necessarily because of RHD. ‡ Health care expenditure on ARF and RHD hospitalisations, including costs of surgical interventions and long term management (ie, SP [based on the RHD Australia guidelines<sup>62</sup>] and specialist follow-up), but not including the costs of treating *Streptococcus pyogenes* infection or implementing the prevention strategies. ARF = acute rheumatic fever. DALYs = disability-adjusted life years. HLP = Healthy Living Practice. NA = not applicable. PHC = primary health care. RHD = rheumatic heart disease. SP = secondary prophylaxis.

### 19 Changes in projected RHD prevalence (panel A) and RHD mortality (panel B) in Aboriginal and Torres Strait Islander people born between 2019 and 2031 in New South Wales, Northern Territory, Queensland, South Australia and Western Australia\*



\*Reproduced with permission from Wyber et al, 2020.<sup>10</sup> HLP = Healthy Living Practice. PHC = primary health care. RHD = rheumatic heart disease. SP = secondary prophylaxis.

Implementing all RHD prevention strategies would reduce both RHD prevalence and related deaths by 71%, avoiding 471 premature deaths due to RHD. This would also save \$188.2 million in health care costs outlined in Box 18. Reducing household crowding alone would reduce the prevalence of RHD and associated deaths by 39%. Supporting communities to implement the Healthy Living Practices would reduce the prevalence of RHD and related deaths by a further 21%, equating to a 59% reduction compared with the current rates. Smaller but important gains would be realised by optimising primary health care for the prevention and treatment of Strep A infections and ARF, and for improved delivery of secondary prophylaxis.

The estimates modelled in this chapter are based on conservative assumptions at all steps, and therefore underestimate the true expected impact of the package of strategies. They also do not account for the full health, economic and social benefits of implementing equitable public health measures. For example, implementing the Healthy Living Practices would prevent several health conditions beyond Strep A infections. Specifically concerning ARF and RHD, the potential economic benefits of preventing new diagnoses extend beyond reductions in health care costs. Such benefits include reduced carer time, improved school attendance by children, improved educational outcomes, and increased participation in the workforce.<sup>242</sup>



## Chapter 6

# Getting it done: a new approach will end RHD

Catherine Halkon, Katharine Noonan, Stephanie Enkel, Rosemary Wyber, Jonathan Carapetis

The Australian Government has set itself ambitious targets to end rheumatic heart disease (RHD) — “eradication” of RHD by 2030 is a priority in its long term national health plan.<sup>1</sup> Similarly, the *Implementation plan for the National Aboriginal and Torres Strait Islander health plan 2013–2023* calls for the elimination of RHD over the course of this decade.<sup>8</sup> In addition, in 2018, Australia played a leading role at the World Health Assembly in a resolution recognising the control of RHD as a global health priority.<sup>243</sup> Despite these public commitments, rates of acute rheumatic fever (ARF) and RHD continue to rise among Aboriginal and Torres Strait Islander people.<sup>3</sup> It is clear that a new approach is needed if Australia is to eliminate RHD.

### What has been done to prevent and manage RHD in Australia?

In the first half of the 20th century, ARF was common among almost all children in Australia.<sup>244</sup> By the end of the 1950s, as economic development led to improved living conditions, ARF virtually disappeared among non-Indigenous people in Australia.<sup>244</sup> However, ARF and RHD persisted among Aboriginal and Torres Strait Islander people.<sup>245,246</sup> Endemic rates of ARF and RHD among Aboriginal and Torres Strait Islander people have now been publicly reported for a quarter of a century. In 2004, the Australian Institute of Health and Welfare produced the seminal report *Rheumatic heart disease: all but forgotten in Australia except among Aboriginal and Torres Strait Islander peoples*, which provided a detailed overview of ongoing disease burden.<sup>247</sup> However, few effective policy responses followed; an arbitrary disease reduction target was established but not resourced.<sup>248</sup> The Northern Territory was the first jurisdiction to act on the continuing burden in Aboriginal communities, implementing formal policies for RHD control in 1996, with legislation to make ARF a notifiable condition, and establishing Australia’s first register-based control program in 1997.<sup>249</sup> Since then, RHD registers have been implemented in four states, with associated notifiable disease legislation enacted. In 2009, the Australian Government adopted the first funded national approach to prevent RHD, with the launch of the Rheumatic Fever Strategy (RFS).<sup>250</sup>

The RFS provides Commonwealth funding for register-based RHD control programs in four jurisdictions (NT, Queensland, South Australia and Western Australia), with the Government of New South Wales independently funding its RHD register (Box 20). The RFS also funds RHD Australia to provide evidence-based clinical guidelines,<sup>62</sup> develop and implement education and training resources, and support health systems to achieve best practice for focused prevention activities in high risk communities.<sup>251</sup> In recent years, RHD Australia has increasingly invested its efforts in working with patients, families and communities and applying a cultural lens to its work.<sup>252</sup>

The Australian Institute of Health and Welfare also receives funding to support monitoring and reporting of register data.

The limitations of the RFS, as the keystone policy for RHD control, are evident given the continued high rates of ARF and RHD.<sup>2</sup> The RFS is a strategy in name only. There is no policy framework or implementation plan; disease reduction targets and evaluation measures were never agreed to. Output metrics, rather than improved health outcomes, are used to assess the performance of jurisdictional control programs. There is an over-riding focus on secondary prophylaxis delivery, which has hampered other prevention activities earlier in the course of disease.<sup>211</sup> States and territories have, to varying degrees, attempted to augment the RFS by broadening prevention efforts. The most comprehensive policy approach is Queensland’s RHD action plan.<sup>253</sup>

Evidence increasingly shows that a focus on secondary prevention will not achieve sustained disease control. Over half of the Aboriginal and Torres Strait Islander people younger than 55 years who were living with RHD in Australia in 2017 had no prior diagnosis of ARF, reflecting a missed opportunity for secondary prophylaxis to prevent progression to RHD.<sup>4</sup> The only evaluation of the RFS to date recommended expanding activities to include primordial and primary prevention and strengthening the role of primary care.<sup>211</sup> In response, additional funding was committed in 2017 for community-led primary care projects.<sup>250</sup> While these projects are assisting communities to implement their chosen initiatives, the time-frame for implementation (3–4 years) is insufficient to demonstrate impact on ARF rates and there is no evident plan for sustainable funding beyond 2021.

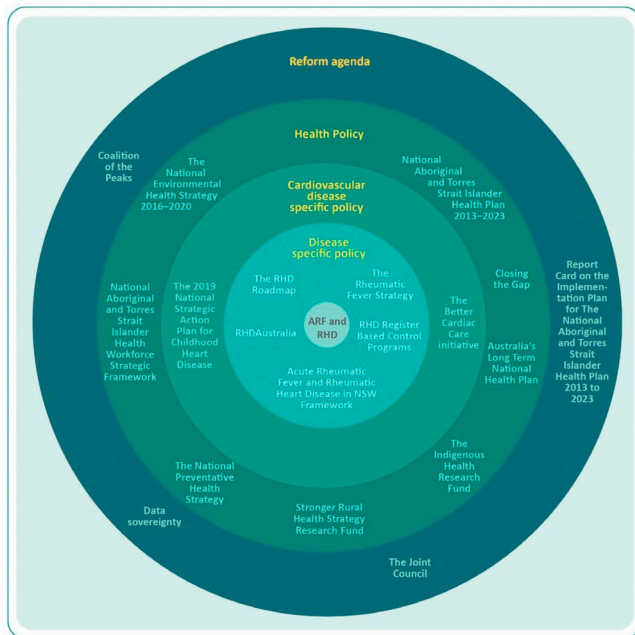
### 20 History of ARF and RHD notification and RHD control programs in Australia\*<sup>62</sup>

	NT	QLD	WA	SA	NSW	VIC, TAS, ACT
RHD Control Program established	1997 <sup>†</sup>	2009	2009	2010	2015	X
ARF/RHD Register established	1997	2006	2009	2012	2016	X
Confirmed ARF notifiable	1996	1999	2007	2016	2015	X
Probable ARF notifiable	2019	X	2015	2016	2015	X
Possible ARF notifiable	X	X	2015	2016	X	X
Confirmed RHD notifiable	2019	2018	2015	2016	2015 <sup>§</sup>	X
Borderline RHD notifiable	X	2018	2015	2016	X	X

<sup>†</sup> The Top End Control Program was established in Darwin 1997, and expanded in 2000 to include the whole NT.  
<sup>§</sup> Notification of RHD only in persons aged less than 35 years.

\*Reproduced with permission from Wyber et al, 2020.<sup>10</sup> ACT = Australian Capital Territory. ARF = acute rheumatic fever. NT = Northern Territory. NSW = New South Wales. QLD = Queensland. RHD = rheumatic heart disease. SA = South Australia. VIC = Victoria. WA = Western Australia. X = approach not available.

## 21 The policy context of ARF and RHD in Australia\*



\*Reproduced with permission from Wyber et al, 2020.<sup>10</sup> ARF = acute rheumatic fever. RHD = rheumatic heart disease.

The Australian Government has invested about \$54 million under the RFS over 12 years (from 2009 [its inception] to 2021 [when the current budget commitment ends]). While the RFS has resulted in some positive process and system improvements, there have been no measurable reductions in the rates of ARF and RHD.<sup>211,254</sup> This indicates a clear need for a more comprehensive approach, grounded in preventive activities, under Aboriginal and Torres Strait Islander leadership with longer funding horizons and better intersectoral collaboration.

Register-based RHD control programs are recognised as an effective approach to disease control.<sup>62,255</sup> However, maintenance of a register and recall system for secondary prophylaxis is just one element of what should be a comprehensive strategy. The disease trajectory and opportunities for prevention of *Streptococcus pyogenes* infection, ARF and RHD necessitate a policy response, and practice changes, across a range of sectors. The social and environmental conditions in which people are born, grow, live, work and age account for at least 34% of the health gap for Aboriginal and Torres Strait Islander people and contribute to the high rates of ARF and RHD.<sup>256</sup> Prevention strategies to achieve RHD elimination are complex and inter-related, which means a comprehensive approach will be enabled, or hindered, by policies across multiple portfolios and jurisdictions (Box 21).

### Critical enabling policies

Improvements in living conditions are acknowledged as key drivers of RHD elimination in developed countries,<sup>9,257</sup> including the elimination of the disease for most of Australia's non-Indigenous population. Housing and environmental health policies should be considered to be critical enablers for any RHD elimination strategy. Despite adequate housing standards for health and wellbeing as a basic human right, enshrined in Article 25 of the United Nations Universal Declaration of

Human Rights, housing in many remote Aboriginal and Torres Strait Islander communities — those communities most at risk of ARF and RHD — consistently fails to meet these standards. The separation into silos of health, housing and education without cross-collaboration and integration continues to contribute to the problem of ARF. To achieve collaboration, these siloed approaches need to be broken down.

Remote area housing policy<sup>258,259</sup> has been mired in political debate since before the expiration of the keystone *National partnership agreement on remote Indigenous housing (2008–18)* in 2018.<sup>260</sup> Failures in housing policy to meet the needs of Aboriginal and Torres Strait Islander communities coupled with a lack of consistent, adequately resourced environmental health services nationally, are barriers to ARF and RHD prevention.

### The way forward

It is widely acknowledged that a new way of working is needed if there are to be meaningful improvements in outcomes for Aboriginal and Torres Strait Islander people. Leading Aboriginal and Torres Strait Islander organisations are driving a reform agenda in Aboriginal and Torres Strait Islander–government relations.

Recognition of the need for solutions tailored to communities, and of the critical role of local resident knowledge, is growing.<sup>261</sup> There are numerous community-based and community-led initiatives across Australia (including the community-led ARF primary prevention projects) which demonstrate an increasing demand for community control and decision making.<sup>261</sup> Critical to community empowerment is the governance and sovereignty of data, which means the right of Indigenous people to govern the creation, collection, ownership and application of their data.<sup>262</sup>

The Closing the Gap Refresh process, emerging from the findings of the Closing the Gap strategy, established a new partnership between governments and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations (Coalition of Peaks).<sup>263,264</sup> Their principles and priorities, which will guide the Closing the Gap Refresh process, should also underpin any RHD elimination strategy. The implementation principles (shared decision making; place-based responses and regional decision making; evidence, evaluation and accountability; and targeted investment and integrated systems) can be effectively mapped to the critical elements of a comprehensive RHD elimination strategy.<sup>264</sup> The recommendations of *The RHD Endgame Strategy: the blueprint to eliminate rheumatic heart disease in Australia by 2031* (hereafter referred to as the Endgame Strategy) are also concurrent with the four priority reforms arising from the Closing the Gap Refresh process (Box 22).<sup>69</sup> It may also be possible to accelerate progress towards RHD elimination through priority biomedical research initiatives, outlined in Box 23.

### 22 Coalition of Peaks priority reforms<sup>69</sup>

- Ensuring that Aboriginal and Torres Strait Islander people's own governance and decision-making structures are supported
- Recognising that community-controlled organisations are an act of self-determination, where Aboriginal and Torres Strait Islander people deliver services to their communities based on their own needs, cultures and relationship to land
- Confronting institutionalised racism in mainstream government institutions and agencies to ensure that Aboriginal and Torres Strait Islander people can access the services they need in a culturally safe way
- Sharing data and information with Aboriginal and Torres Strait Islander people to ensure that Aboriginal and Torres Strait Islander people have more power to determine their own development

## 23 Outstanding research priorities to accelerate RHD elimination

It is possible to substantively reduce rates of ARF and RHD with existing knowledge. Concurrent research to address outstanding knowledge gaps may provide avenues to accelerate reduction in incidence of ARF.

Biomedical research priorities include:

- improving our understanding of how housing and environmental health contributes to ARF risk and how this can be mitigated;
- exploring contributors to ARF susceptibility and opportunities for an improved ARF diagnostic test;
- developing a new long acting prophylactic agent for secondary prophylaxis to reduce the need for frequent painful injections;
- conducting a randomised trial to determine whether people with borderline RHD detected on echocardiography screening benefit from secondary prophylaxis; and
- developing a Strep A vaccine, supported by funding to the Strep A Vaccine Global Consortium to coordinate international vaccine development, and \$35 million of Commonwealth funding to establish the Australian Strep A Vaccine Initiative to take a leading vaccine candidate into an efficacy trial by 2024.<sup>265,266</sup>

ARF = acute rheumatic fever. RHD = rheumatic heart disease. Strep A = *Streptococcus pyogenes*.

Declarations about eliminating RHD have not yet been matched by a political commitment to do the work needed to achieve that goal. *An RHD roadmap: a plan for elimination of RHD by 2031* was commissioned by the Honourable Ken Wyatt, MP (then Federal Minister for Indigenous Health). Written by END RHD and the National Aboriginal Community Controlled Health Organisation in 2019, it stalled in the review process following initial consideration at the Council of Australian Governments (COAG) Health Council in March 2019.<sup>267</sup> With the dissolution of the COAG structure in June 2020 by the Morrison government, it is unclear how this work will be progressed.<sup>268</sup>

## Measuring impact

The ultimate marker of success of the Endgame Strategy is RHD elimination. Specifically, this would be a rate of RHD for young Aboriginal and Torres Strait Islander people equal to the very low rate among non-Indigenous people. Progress towards RHD

elimination, defining and measuring success and ensuring accountability will require longitudinal monitoring capacity as strategies are put into practice.

Key performance indicators and datasets already exist to inform jurisdictional data collection, reporting and practice.<sup>62,269</sup> However, these do not include disease control targets and they do not clearly link with environmental or primary prevention goals. The Endgame Strategy proposes metrics, for further consultation, which encompass and enhance existing measures. This includes the addition of primary prevention indicators and national targets. It also acknowledges the current limitations in capacity to collect population-level data and ensure data integrity.<sup>10</sup> Collecting, analysing and sharing data requires human and financial resources and consideration of this must be factored into improvements to current metrics.

Measuring impact needs to go beyond establishing targets and KPIs and improving data systems. Data should be used as a tool to support decision making at national, jurisdictional, regional and community levels, with control and use of data informed by contemporary data sovereignty policies.<sup>88,191</sup>

## Conclusions and recommendations

The end of RHD in Australia is possible. A precipitous decline in ARF among non-Indigenous people in Australia occurred over half a century ago.<sup>244</sup> Persistence of the disease among Aboriginal and Torres Strait Islander people is testament to the pervasive effects of colonisation, disempowerment, and social, political and economic marginalisation. Australia has a moral imperative and agreed national goal to eliminate RHD. Achieving this will require structural and systemic change on indirect drivers of disease, and focused action on direct contributors through health care, housing and environmental health initiatives. Current funding under the RFS ends in 2021. Now is the opportunity to move on to a different, comprehensive strategy with increased long term investment and enshrined Aboriginal and Torres Strait Islander leadership.

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