



The RHD Endgame Strategy: A Snapshot

The blueprint to eliminate rheumatic heart disease in Australia by 2031

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The *RHD Endgame Strategy* is a product of collaboration between researchers, Aboriginal and Torres Strait Islander leaders, communities and people with lived experience.

The END RHD CRE investigators would like to thank the Aboriginal and Torres Strait Islander people who have shared their stories in the Endgame Strategy. We acknowledge that the figures outlined represent the loss of human life with profound impact and sadness for people, families, community and culture.

We thank all content experts who contributed their technical expertise, time and advice to the *Endgame Strategy*. In particular, we acknowledge the members of the *END RHD Review Working Group*, which comprised nominees from END RHD – the peak alliance leading work to eliminate RHD in Australia. Members of this working group provided invaluable insight, reviewing content for feasibility and acceptability, and including review from a cultural perspective.

Telethon Kids Institute acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the land and waters of Australia, and the lands on which this report was produced. We also acknowledge the Nyoongar Wadjuk, Yawuru, Kariyara and Kaurna Elders, their peoples and their land upon which the Institute is located, and seek their wisdom in our work to improve the health and development of all children.

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To many Australians, rheumatic heart disease is a foreign concept – a disease most will have never heard of. But for my people, RHD continues to pose a very real and present threat. Despite having been eliminated in the non-Indigenous Australian population for decades, RHD continues to devastate Aboriginal and Torres Strait Islander communities at some of the highest rates in the world. Starting with a simple Strep A infection of the throat or skin, RHD can be fatal without treatment. There is no cure and children who have the disease must endure a painful penicillin injection every 21–28 days for at least a decade or until they are 21, whichever comes first. Many, some as young as five years old, must also have open heart surgery. For these children and their families – who must be taken off country to large tertiary hospitals for months at a time – it is often the emotional scars that last the longest.

In 2016 Professor Jonathan Carapetis came to me in my capacity as the newly appointed CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO) to discuss forming END RHD – an alliance between the Aboriginal Community Controlled Health Sector and health and research bodies, all committed to ending RHD. As he outlined the plan, it became clear that we had an unprecedented opportunity to end this devastating disease.

Professor Carapetis and colleagues had been funded by the National Health & Medical Research Council to develop an *RHD Endgame Strategy*: a blueprint outlining exactly what needed to happen – and who needed to do it – to eliminate RHD for the next generation of Aboriginal and Torres Strait Islander children. But what set this research translation piece apart from previous work was that it was to be created *with* Aboriginal and Torres Strait Islander people, rather than *for* us: it was to be a research-driven strategy that had at its core the voices of those living with and impacted by RHD.

This was significant, because our people already know what needs to happen to eliminate RHD. Communities have long told us they need support to tackle the problems which contribute to the spread of Strep A infection: things like overcrowding and a lack of access to infrastructure such as hot water and running showers – basic amenities most Australians take for granted. Aboriginal Health Workers in communities with the highest RHD burden have told us they need support and resources to grow the workforce and

catch more sore throats and skin sores before they lead to acute rheumatic fever (ARF), the precursor to RHD. Most importantly, people living with ARF and RHD have told us they need better treatments and culturally safe care so they can live their lives to the fullest. The *Endgame Strategy* honours and reflects all these views, adding them to the evidence base that will underpin the work needed to eliminate RHD – work that will further ‘close the gap’ by helping to eliminate linked diseases like otitis media, trachoma and kidney disease.

In my work leading the Coalition of the Peaks – a historic partnership between the Council of Australian Governments (COAG) and Aboriginal and Torres Strait Islander leaders – we are committed to addressing the structural and systemic changes that have led to the gap in outcomes, including life expectancy, between Indigenous and non-Indigenous Australians. The *Endgame* recommendations echo this new framework and, when implemented, will go a long way to closing this gap.

The *Endgame Strategy* heralds a new chapter where ending RHD is genuinely possible. We have the Aboriginal leadership, community demand, and evidence base to support the work that can make this disease history. All we’re missing is the funding to make this a reality. If the Commonwealth Government is to meet its pledge to eliminate RHD in this decade, Australian governments must act upon this report. The *Endgame Strategy* cannot be consigned to a bookshelf to sit, gathering dust. The actions – or inaction – of today will be felt by the next generation of our people, and for generations after that. It is unconscionable to let them suffer as a result of RHD when we now have an Endgame to prevent it.

Pat Turner AM
CEO, National Aboriginal Community
Controlled Health Organisation



Introduction

The *End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE)* was established in 2014 to address the urgent need for a comprehensive, evidence-based plan to eliminate rheumatic heart disease (RHD) across Australia.

Bringing together leading experts from 16 institutions across Australia and backed by a grant from the National Health and Medical Research Council (NHMRC), the CRE has synthesised the collective experience of communities, clinicians, Aboriginal Community Controlled Health Organisations, and government and non-government organisations – as well as more than 25 years of research – to tackle this need head on.

The result is *The RHD Endgame Strategy: The blueprint to eliminate rheumatic heart disease in Australia by 2031*. This comprehensive report assesses existing and potential strategies to both prevent the next generation of Aboriginal and Torres Strait Islander children from developing RHD; and improve the quality of life and outcomes for those already living with the disease. From this extensive list of strategies came five Priority Action Areas which, collectively, have the greatest potential to bring about an end to RHD by 2031.

The *Endgame Strategy* presents the most accurate and comprehensive data on the burden of RHD in Australia to date and, using this data, estimates the health and economic impacts of implementing a range of strategies – including lives that will be saved, surgeries that will be prevented, and health expenditure which will be avoided.

With the input and endorsement of the Aboriginal and Torres Strait Islander Community Controlled Health Sector through END RHD – the peak body leading work to end rheumatic heart disease in Australia – and over 20 of Australia’s leading health and research organisations, the *Endgame Strategy* has the widespread support of those living with the disease, and working to end it.

The Endgame Strategy: A Snapshot offers a key summary of the full *RHD Endgame Strategy*, which can be accessed online at: telethonkids.org.au/rhd-endgame.

What is RHD?

Rheumatic heart disease (RHD) starts with a Strep A infection of the throat or skin. When left untreated, the infection can lead to acute rheumatic fever (ARF), which causes sore joints, rash, fevers, and heart inflammation. While the other symptoms of ARF go away, the heart damage remains – and this is known as rheumatic heart disease

Rheumatic heart disease in Australia

ARF and RHD affect people across Australia



OVER 5,000

Aboriginal and Torres Strait Islander people are living with

ARF or RHD

Two thirds of these people **are female**

Almost half have **severe disease**



Aboriginal and Torres Strait Islander people **live with ARF and RHD** at rates

60 times higher than non-Indigenous people



Initial exposure to **Strep A** can occur during the first year of life

ARF peaks in children aged **5-14 years**

The **highest rates of RHD** are among those aged **25-34 years**

The **median age at death** of Aboriginal people dying with **RHD is 50 years**

If no further action is taken to tackle RHD, it is estimated that

8,667

Aboriginal and Torres Strait Islander people

will develop **ARF or RHD by 2031**

1,356 people

will develop severe RHD (heart failure and/or valvular disease requiring a surgical procedure)

663 will die

\$273 million

will be spent on

healthcare

In 2013-17:

460 people diagnosed with RHD had to have surgery

42 of these surgeries were for **children aged 5-14 years**

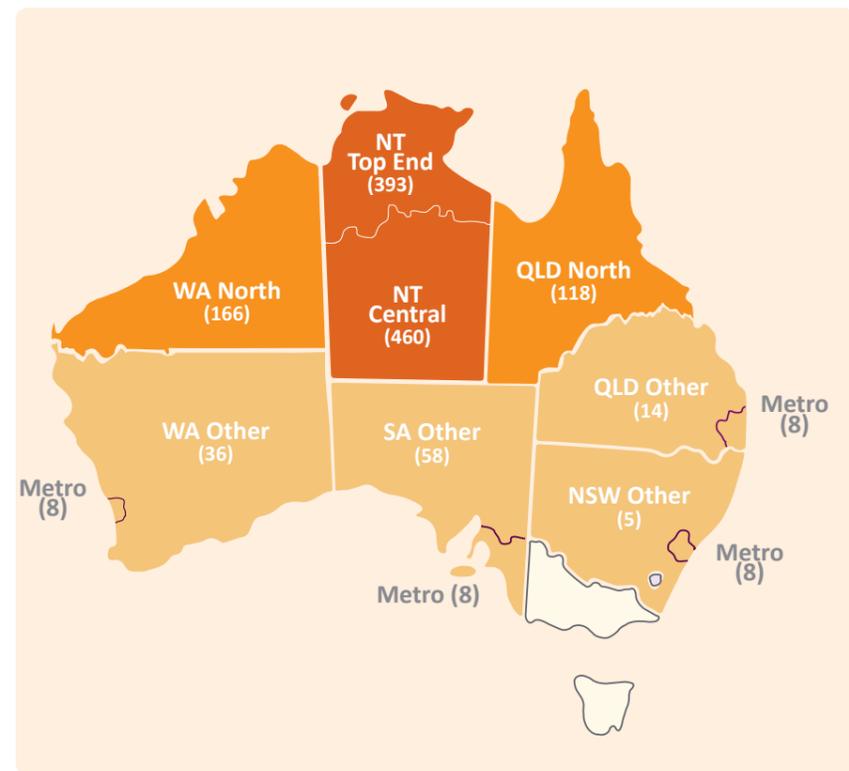
Most people had to **travel off country — often for months at a time —** to have their surgery in large tertiary hospitals

Only **36%** of people received **80% or more** of their **secondary prophylaxis injections**

4 out of 5 **new RHD diagnoses** did not have a **previous ARF episode** recorded on the register

All ARF

<100 100-200 >200

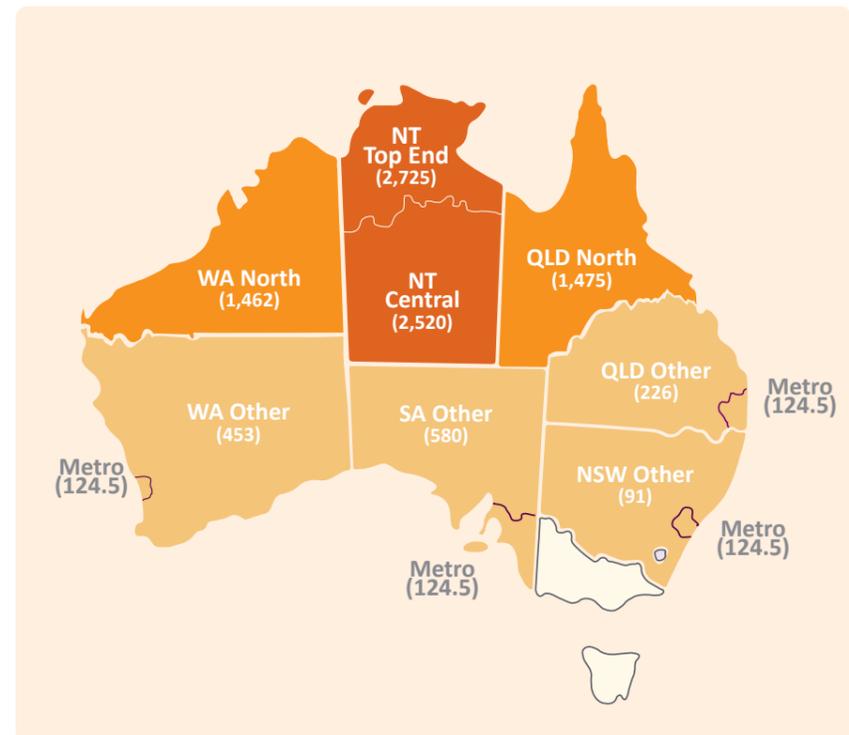


Credit: Katzenellenbogen et al., 2019

Average annual rates of ARF per 100,000 population¹

All RHD

<1,000 1,000-2,000 >2,000



Credit: Katzenellenbogen et al., 2019

Known cases of RHD in 2017, per 100,000 population¹



Tenaya's Story:

From a sore throat to open heart surgery



When Katrina Walley took her seven-year-old daughter Tenaya to the local emergency department for the fourth time within a month, she was determined she wouldn't be leaving without answers.

Tenaya had been complaining of a sore throat, stomach pains, and breathlessness. At night-time, she found it hard to lie down flat to sleep – a sign of heart failure.

“We got to the hospital around 8 or 9pm, and at this point, her oxygen levels started dropping,” Katrina says.

By 11pm, Katrina and Tenaya were being flown from their home in rural Western Australia to Perth Children's Hospital via the Royal Flying Doctor Service. On arrival, Tenaya was rushed to the intensive care unit and put on a life-support machine, where she would remain for the next two weeks.

Katrina was told her daughter's heart was failing as a result of rheumatic heart disease, and that the little girl urgently needed surgery to have one of her heart valves repaired.

— “ —

“By the second month, she started to cry every time she saw a nurse,” Katrina says.

— ” —

Tenaya was in hospital for a month before she was strong enough to have the surgery. She hated being away from her school, friends, and family, and was scared about having to have surgery.

The surgery to repair Tenaya's heart valve went well and after two months in hospital, she was finally discharged. However, just a few days later, she had to be rushed back into surgery to drain excess blood pooling around her heart.

Tenaya must now have a penicillin injection every 28 days until she is at least 21 to prevent her condition getting worse, and will likely require further surgery.



The RHD Endgame Strategy: From research to action

The END RHD CRE is committed to the translation of its research into tangible action. Experience and evidence make it clear that community-level action is crucial to eliminating RHD. The *Endgame Strategy* puts Aboriginal and Torres Strait Islander communities at the core of a holistic implementation framework, with supporting structures to ensure a nationally consistent approach.

This implementation framework comprises Five Priority Action Areas designed to operationalise the *Endgame Strategy*. The Five Priority Action Areas, implemented concurrently, have the greatest potential impact to collectively bring about a functional end to RHD by 2031. This framework was developed through an analysis of the range of strategies identified in the *Endgame Strategy* as being the most impactful, acceptable, practical and readily implementable with appropriate investment. No single one of these strategies will eliminate RHD. Instead, a comprehensive approach, applying a number of strategies across communities and jurisdictions reflecting the cultural, geographic and political context in which they operate, is needed.

Implementation Principles

The END RHD CRE supports the current reform agenda initiated by leading Aboriginal and Torres Strait Islander organisations to establish new Closing the Gap targets, which represents a new way of working to ensure meaningful improvements in outcomes for Aboriginal and Torres Strait Islander peoples. These reforms have set principles and priorities for a co-design approach. These will guide the implementation of the *Endgame Strategy* and provide a basis for the Aboriginal and Torres Strait Islander-led consultation process, which will be the first stage of implementation. In short, how the *Endgame Strategy* is implemented is as, if not more, important as which specific strategies are implemented.

Adherence to the COAG Implementation Principles (agreed in 2018)² and the reform priorities agreed by the Joint Council on Closing the Gap (in 2019)² is paramount. In addition, the END RHD CRE supports the principles agreed at the Indigenous Data Sovereignty Summit in 2018, which assert the right of Aboriginal and Torres Strait Islander people to exercise control of the data ecosystem, have readily available and accessible data, attain relevant data sustaining self-determination, and accountable data structures respecting individual and collective interests.³

Five Priority Action Areas for Implementation

Resource an Aboriginal and Torres Strait Islander-led National Implementation Unit to coordinate rheumatic heart disease elimination efforts across Australia

The RHD National Implementation Unit will:

- Work with government at the national, state, territory and local level to address the root environmental and social causes of rheumatic heart disease;
- Deliver technical support to all stakeholders involved in work to end RHD – from communities to policymakers, clinicians, and health workers;
- Support and fund communities across Australia to deliver culturally appropriate strategies to prevent RHD and ensure the best treatment for those already living with the disease;
- Develop resources and guidelines to equip communities, schools and clinicians in their work to end RHD;
- Act as the critical link between researchers and communities – setting research priorities and ensuring translation of evidence and technological advances in acute rheumatic fever and RHD diagnosis and management; and
- Monitor progress and re-evaluate strategies to ensure goals are achieved.



Aboriginal & Torres Strait Islander leadership

Fund communities to develop their own culturally appropriate programs to eliminate RHD

Ending RHD will only be successful if communities are empowered and supported to implement culturally relevant RHD elimination activities aligned to local priorities. There are currently at least 10 communities taking action to address ARF and RHD, with varying levels of funding and support.

With a network of support coordinated by the RHD National Implementation Unit, communities will be able to drive work to:

- Increase awareness about Strep A and the symptoms of ARF so that people:
 - Are diagnosed and receive the right treatment as quickly as possible to prevent RHD developing; and
 - Already living with ARF or RHD have access to culturally safe health care within their community.
- Resource peer support networks led by those living with or impacted by ARF or RHD; and
- Evaluate demand for community-based echocardiography screening, ensuring comprehensive follow-up care is available for those diagnosed.

To support this community-driven work, the Commonwealth Government should:

- Provide ongoing investment to better support and grow the Aboriginal and Torres Strait Islander health workforce; and
- Increase funding to community-based health care providers to ensure accessible, best quality care for those living with ARF and RHD.



Community-based programs

Tackle the root causes of RHD by guaranteeing communities have access to healthy housing and built environments

This will involve cross-sector collaboration between national, jurisdictional and local governments and communities to:

- Increase new housing stock and ensure proactive repair and maintenance of existing housing to reduce overcrowding and improve living conditions;
- Ensure access to essential hygiene infrastructure such as hot water, running showers and washing machines, so that people are able to achieve the Healthy Living Practices including washing hands, clothes and bodies; and
- Embed environmental health in community-based health care.



Healthy environments

Establish a comprehensive skin and throat program for high risk communities

The RHD National Implementation Unit will work with communities and their local service providers to:

- Implement comprehensive Strep A outreach activities tailored to the local context;
- Develop tools to better support health workers to diagnose and treat Strep A skin and throat infections, the precursor to ARF and RHD; and
- Explore strategies aimed at making it easier for people in high risk communities to have their skin sores and sore throats checked. For example: flexible appointment systems and after-hours services; school-based screening programs; and offering transport to and from clinics.



Early prevention

Improve the health and wellbeing of those living with ARF and RHD

Communities, researchers, service providers and the RHD National Implementation Unit will together work to:

- Make sure those already living with ARF and RHD have access to clear support pathways throughout their journey. This is especially important for transitional periods such as adolescence to adulthood and for women planning pregnancies;
- Resource positions for regional coordinators to monitor and improve treatment and health promotion activities in high risk communities; and
- Ensure people who require specialist treatment off country receive culturally safe treatment in mainstream services.



Care and support

RHD Elimination Strategies

A snapshot of potential RHD elimination strategies identified in the *Endgame Strategy* report is outlined below. These strategies were identified as having the greatest potential impact, as well as being the most acceptable, practical and readily implementable with appropriate investment. The *Endgame Strategy* emphasises the importance of community control and self-determination and therefore is not prescriptive about which strategies should be implemented. Instead, an implementation framework of Five Priority Action Areas is proposed which will support a co-design process with communities most at risk, to implement those strategies most appropriate and acceptable to them.



Prevention Opportunity	Strategies
<p>Structural and systems considerations</p> <p><i>Systemic enablers needed to reduce the burden of Strep A infections, ARF and RHD</i></p>	<ul style="list-style-type: none"> Support primary care by increased and sustained resourcing of Aboriginal and Torres Strait Islander health services, particularly in remote communities. Invest in training and employment of Aboriginal and Torres Strait Islander people in new and ongoing funded positions to deliver comprehensive primary healthcare. Use evidence-based mechanisms, including increasing Aboriginal and Torres Strait Islander staffing at all levels to reduce turnover of rural and remote staff. Embed Environmental Health within Primary Care. Prepare health providers in all disciplines to provide culturally appropriate services for Aboriginal and Torres Strait Islander people.
<p>Environmental, Social and Economic determinants</p> <p><i>Reducing the risk of Strep A transmission and infection</i></p>	<ul style="list-style-type: none"> Develop, cost and implement a National Aboriginal and Torres Strait Islander Housing and Community Environmental Health Strategy, increasing housing stock to substantially reduce overcrowding, improve housing maintenance and ensure adequate power and water supply. Assess community acceptability and value of shared community infrastructure to facilitate Healthy Living Practices, particularly washing of bodies, clothes and bedding, community swimming pools, ablution blocks and/or laundries. Support households to increase uptake of Healthy Living Practices through health promotion campaigns. Ensure Aboriginal and Torres Strait Islander governance of housing construction, management and maintenance processes through their own institutions and organisations.
<p>Primary Prevention</p> <p><i>Improving the assessment and treatment of Strep A infections</i></p>	<ul style="list-style-type: none"> Develop and evaluate resources for discussing skin sores and sore throats in primary-care settings. Develop a working definition of a 'healthy skin check' to provide guidance on the setting (privacy and environment) and components (skin areas to be examined or self-reported). Establish comprehensive healthy skin outreach programs in settings with a high burden of skin infection. Explore opportunities to increase the use of telehealth for primary prevention of ARF, and opportunities to provide healthcare or referral services from schools for sore throats and/or skin sores. Explore potential to increase access to medication for primary prevention through broader dispensing opportunities, accompanied by training and investment in the Aboriginal and Torres Strait Islander health workforce. Develop a 'look back' review of ARF notifications, with a view to scale up to major referral hospitals accounting for the majority of ARF admissions. Enhance referral systems for sore throat and skin sores, including school-based referral.
<p>Secondary Prevention</p> <p><i>Opportunities to improve prevention & management of ARF and RHD</i></p>	<ul style="list-style-type: none"> Develop training opportunities and resources to increase health worker awareness of ARF symptoms and pathways. Resource peer support programs to encourage connections and self-management. Resource primary-care providers to provide outreach secondary prophylaxis services where community demand indicates that this is a priority. Continue research to identify more sensitive and specific diagnostic tests for ARF and methods of secondary prophylaxis delivery.
<p>Tertiary Care</p> <p><i>Assisting those living with RHD to live life to its fullest</i></p>	<ul style="list-style-type: none"> Fund permanent care-coordination roles to support children and adults who are having heart surgery for RHD to ensure alignment of clinical, administrative and logistic plans alongside attention to cultural needs and communication between different levels of the health service. Enhance existing jurisdictional patient assisted travel schemes. Ensure that all people diagnosed with ARF or RHD receive high-quality, culturally relevant education in their preferred language. Establish clear clinical pathways for women of reproductive age with ARF and RHD. Improve service delivery for Aboriginal and Torres Strait Islander adolescents moving from paediatric to adult services.

Lived experience of ARF and RHD

Aboriginal and Torres Strait Islander people, families, and communities are deeply impacted by Strep A infections, ARF and RHD. The first ever systematic review of the lived experiences of people with RHD in Australia was conducted as part of the *Endgame Strategy*.⁴

This review identified three major thematic domains:

➤ **Context of living with ARF and RHD.** The context in which people live with ARF and RHD drives their experience of the disease: this includes the enduring effects of colonisation, racism, powerlessness and poverty. This social context in which people live with ARF and RHD can impede access to regular health care, make positive health practices difficult, and reduce connection to Country and culture if treatment requires travel to a distant hospital.

“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.”

5-year old female with RHD

➤ **Experiences unique to living with ARF and RHD.** The condition-specific experiences of ARF and RHD are lifelong. This includes the need for long-term, often painful, secondary prophylaxis regimen; restrictions on normal activities like school and sport; travelling long distances for surgery; and negotiating the transition from paediatric to adult care. Some parents of children living with ARF and RHD described the process of injections as traumatic, making it difficult for long-term engagement in care.

➤ **Interactions with the health system.** Experiences of interactions with the health system to prevent, treat and manage ARF or RHD were mixed. While positive engagements with healthcare providers were noted, others avoided providers due to poor past experiences and distrust of services, and identified areas for improved delivery of care.

“We don’t want our kids to have heart surgery...We want to keep the kids healthy, community healthy, look after our land.”

Aboriginal Community Researcher

The protective factors of Aboriginal and Torres Strait Islander ways of being and doing interconnected with each of these themes. Evidence demonstrated that cultural practices and strong relationships are facilitators of managing chronic illness and living with ARF and RHD.

“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.”

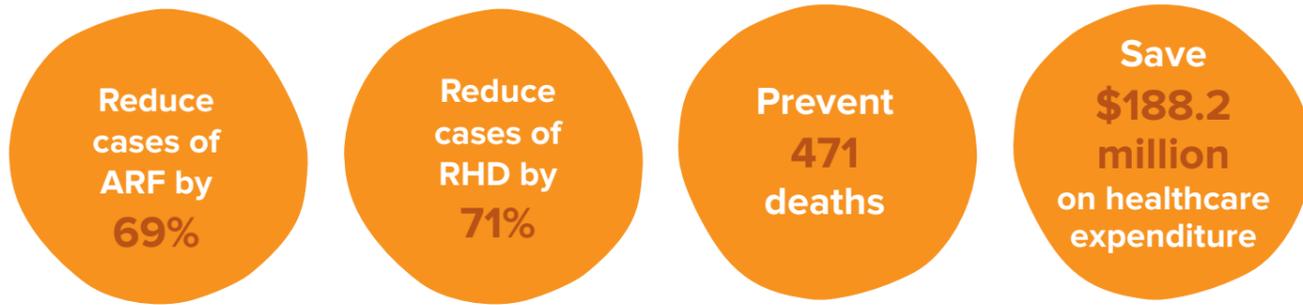
Aboriginal Community Researcher

While these themes have been evident for some time to community and professionals familiar with the challenges of living with ARF and RHD, they have yet to meaningfully influence practice or inform policy. To improve care for children, young people, families and communities living with ARF and RHD, the results of this review must be addressed, in particular, focusing on healthcare service design and operation. Such improvements will require shifts in care focus, authority and control so that services are flexible, culturally safe, adaptive to local contexts, and family and community-based.



The case for investment to end RHD

Estimates using modelling techniques showed that reducing household crowding, improving hygiene infrastructure, strengthening primary healthcare, and enhancing the delivery of secondary prophylaxis would, by 2031;



These estimates are based on conservative assumptions and therefore might represent an underestimate of the true projected impact. They do not account for the full health, economic, and social benefits of implementing equitable public health measures. For example, improving hygiene infrastructure to support Healthy Living Practices and reducing household crowding would prevent a number of health conditions beyond ARF and RHD.⁵ The potential economic benefits of preventing new cases of ARF and RHD extend beyond reductions in healthcare costs, to reduced carer time, improved school attendance and educational outcomes for children, and increased workforce participation in adults.⁶

The **cost** of implementing the *Endgame Strategy* over the next decade is **\$689 million**.

This represents the cost of the RHD-specific prevention strategies included in the Five Priority Action Areas. It should be viewed as a one-off investment to reduce diagnoses of ARF and RHD in Aboriginal and Torres Strait Islander people in line with the rest of the non-Indigenous Australian population.

However, for disease-specific strategies to succeed, investment is needed to improve the conditions in which people live, grow and work. Increasing housing stock to reduce household crowding, and ongoing improvements to, and maintenance of, living environments and infrastructure, are priorities for the overall health and wellbeing of Aboriginal and Torres Strait Islander people. This investment, while not specific to RHD, is critical to support prevention efforts.

The *Endgame Strategy* estimates 210 communities to be at high risk of RHD. If all these communities were to adopt all potential prevention strategies, the total investment through to 2031 would be **\$4.3 billion**. Actual investment costs will differ from this based on the community context, priorities and preferences. Therefore, \$4.3 billion is best considered as an indicative guide to the scale of investment needed to end RHD.

- Of this, 67% or **\$2.9 billion** is dedicated to funding for increasing remote housing stock as the most effective means to reduce overcrowding.
- A further 17% or **\$716 million** is dedicated to improving maintenance and repair of housing and other infrastructure.
- Significant positive externalities beyond ARF and RHD would be achieved with this investment.

Achieving this goal will have ongoing health and economic benefits, saving lives and preventing avoidable suffering. Importantly, Australia has a moral imperative, and agreed national goal, to prevent needless death and disability from RHD – the leading cause of cardiovascular disparity between Aboriginal and Torres Strait Islander people and non-Indigenous Australians.

The health and economic impact

The health and economic impacts of an ‘indicative bundle’ of RHD prevention strategies were modelled, allowing the prediction of the impact of the prevention strategies.

Modelled health outcomes

Modelling estimates indicate that the strategies proposed in the *Endgame Strategy* – namely reducing household crowding, improving hygiene infrastructure, strengthening primary healthcare, and increasing uptake of secondary prophylaxis – would reduce ARF and RHD cases by 69% and 71% respectively.

- The baseline risk among the Aboriginal and Torres Strait Islander population of the NT, WA, SA, QLD and NSW of an episode of ARF (including undiagnosed ARF) between birth and 64 years of age was just over two in 100 births.
- The subsequent risk of developing RHD after the application of strategies proposed in the *Endgame Strategy* was one in 100 births.
- Implementing the Healthy Living Practices and PHC improvements would **halve** (52% reduction) the total number of people living with RHD and severe RHD. The number of people dying due to RHD would also halve (320 from 663).

If all prevention strategies were implemented, the number of people living with RHD would **reduce by 71%** and **571 fewer people would die** as a result.

Modelled economic outcomes

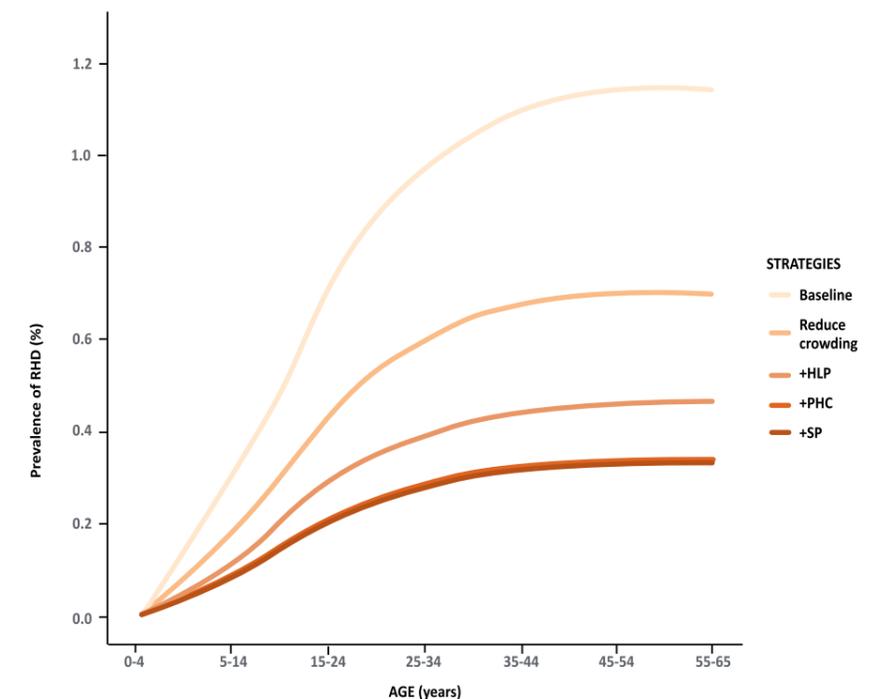
These modelled economic outcomes also account for healthcare expenditure on ARF and RHD hospitalisations, including surgical intervention and long-term management (secondary prophylaxis and specialist follow-up).

- **\$317 million** will be spent on medical care for ARF and RHD between mid-2016 and 2031 if the trend in disease rates of ARF and RHD observed over the last several years continues.⁷
- Implementing the Healthy Living Practices and PHC improvements would result in a reduction of **\$140 million** in healthcare costs.
- Reducing crowding, implementing the HLPs, and improving PHC would collectively save **\$190 million** in healthcare costs.
- If all prevention strategies were implemented, there would be a saving of **\$188.2 million** to the health system.

What is an ‘indicative bundle’ of strategies?

The *Endgame Strategy* recognises that not all strategies are applicable, appropriate or acceptable in every community. However, for the purposes of costing and modelling, a set of the most likely strategies has been selected. These can be thought of as an ‘indicative bundle’ of things to be done and provide some guidance about the potential impact and quantum of funding required.

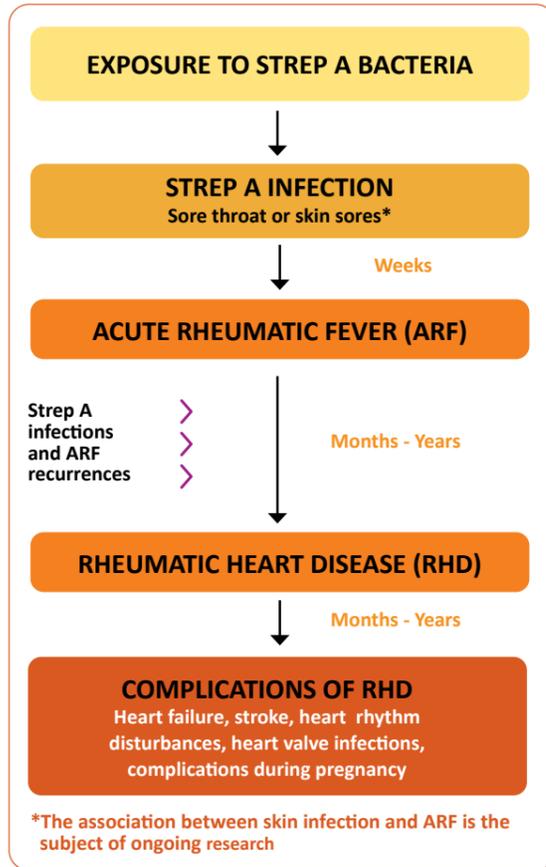
The concept is derived from the Consumer Price Index, which uses the idea of a basket or bundle of household products to estimate cost of living. Although, in reality, each household purchases a different bundle of products, an ‘indicative bundle’ of average purchases is used to make a standard estimate of living costs.



Changes in projected RHD prevalence among Aboriginal and Torres Strait Islander people born between 2019 and 2031 in the NT, SA, WA, QLD and NSW

A

Appendix A: About Strep A, ARF and RHD



Strep A to RHD causal pathway

Who has ARF and RHD now?

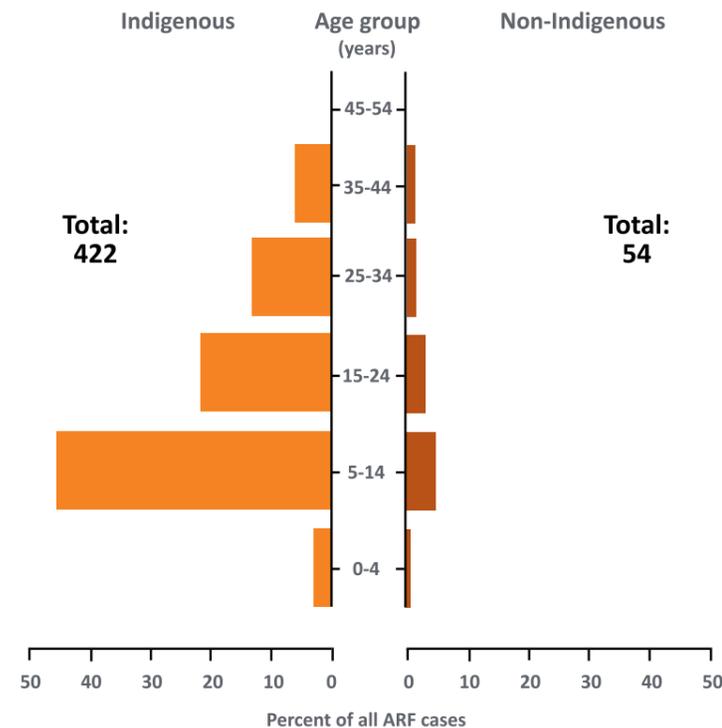
- Between 2015 and 2017 there were on average 476 diagnoses of ARF recorded each year.¹
- Of those diagnosed with ARF, 89% were Aboriginal and/or Torres Strait Islander people – meaning they are **123 times more likely** than non-Indigenous people of the same age to be diagnosed.¹
- In Australia as of mid-2017, there were 5,307 people under 55 years of age living with RHD.¹
- Two-thirds** of people living with RHD are **female** and 43% of people are living with severe disease.^{1,8}
- 71% of people with RHD are Aboriginal and Torres Strait Islander people.¹ This makes the age-standardised prevalence of RHD **60 times higher** in Aboriginal and Torres Strait Islander people.

People are exposed to Strep A bacteria through contact with other people. Strep A infection spreads easily in settings of overcrowding and limited access to health hardware such as running water.

A small number of people have an abnormal immune response to Strep A, which is known as acute rheumatic fever (ARF). ARF can cause sore joints, rashes, abnormal movements, fever and heart inflammation. Most of these symptoms resolve over a few weeks but often heart damage remains.

Severe ARF and/or ARF recurrences from repeated Strep A infections can lead to permanent scarring of the heart valves. Damage to the heart valves is called rheumatic heart disease (RHD).

There is no cure for RHD. People require an injection of long-acting penicillin every 21–28 days for at least a decade to prevent ARF recurrences. If people do not receive these injections and ARF occurs, RHD can progress, leading to heart failure or stroke. As Strep A infections are most common in those aged 5–14, those most at risk of developing ARF and RHD are children.



Age pyramid of the distribution of people with ARF (first-ever and recurrent combined), by age group and Indigenous status: NT, SA, QLD, WA and NSW (annual average of 2015-2017)*1 *WA data covers 07/2014 to 06/2017¹

B

Appendix B: Methods

The *Endgame Strategy* has been produced through a process of both traditional research methods and extensive consultation with stakeholders across sectors. This approach was taken to acknowledge the gaps in the evidence base; the significant first-hand knowledge of people working on the ground to prevent ARF and RHD; and the unique insights of those living with the disease.

Scope and Structure

The *Endgame Strategy* identifies and evaluates potential approaches to eliminate RHD in Australia by 2031. The trajectory of RHD and its causal roots within the social and environmental determinants of health necessitate a response from the health sector and beyond. Therefore, the *Endgame Strategy* includes evidence-based assessments of prevention opportunities across the spectrum: social and environmental determinants, primary prevention, secondary prevention, and tertiary care, with the structural assessment of health service and delivery within an Aboriginal and Torres Strait Islander context at the forefront. As the goal is to prevent new cases of ARF and RHD, the *Endgame Strategy* is weighted towards strategies which act early in the causal pathway from Strep A exposure to RHD. Some areas of future biomedical research have been identified as priorities, but the focus is predominantly on what can be done now, with existing knowledge, to end RHD.

Methods

The production of the *Endgame Strategy* involved the synthesis of information across the five-year lifespan of the END RHD Centre of Research Excellence. Funding was allocated to priority research projects across several disciplines of research, including epidemiology, economics, biomedical sciences, clinical practice, health services research and social sciences, with a special focus on engaging the RHD community and documenting the experiences of those living with the disease. Data and results from these smaller studies helped inform the overall *Endgame Strategy* and were complemented by literature reviews, systematic reviews, narrative reviews and the experiences of health professionals currently working in ARF and RHD control.

Evidence grading

A number of frameworks are utilised to aid decision-making in public health, particularly when the evidence base is limited or program evaluations are not available, as is common in the space of ARF and RHD.⁹ The END RHD CRE used the GRADE EtD framework for the assessment of intervention efficacy, evaluating the benefits, risks, acceptability, feasibility, costs, timeline, positive externalities and equity of strategies based on available evidence. Recommendations were then made based on a synthesis of ratings.

Review process

Technical and expert reviews were sought to evaluate each chapter in draft form, with suggestions integrated by *Endgame Strategy* authors. The END RHD Endgame Strategy Review Working Group was also established with the approval of the END RHD Advisory Committee at the request of the CRE Aboriginal Investigators who contributed to the process and, based on feedback from the Working Group, made final recommendations for consideration and document revision to the broader END RHD CRE investigator group.

Definitions

Primary healthcare	Primary healthcare is all inclusive, integrated health care and refers to the quality of health services. It is a comprehensive approach to health in accordance with the Aboriginal holistic definition of health and arises out of the practical experience within the Aboriginal community itself having to provide effective and culturally appropriate health services to its communities.
Environmental determinants	Primordial prevention is a widely used term to describe risk-reduction strategies in cardiovascular disease that prevent the development of risk factors and has been particularly used in RHD control to address the social determinants of health which drive Strep A, ARF and RHD risk.
Household crowding	Household crowding is commonly defined by the Canadian National Occupancy Standards for numbers of people sharing a bedroom. The negative health effects of crowding occur when large numbers of people are living in confined environments with limited household resources.
Health hygiene hardware	Health hardware is the physical infrastructure required for healthy living (e.g. electrical systems, toilets, showers, taps, kitchen cupboards and benches, stoves, ovens, fridges, washing machines).
Primary prevention	The assessment of skin and throat infections and treatment with appropriate antibiotics to prevent ARF in people at high risk of the disease.
Secondary prevention	Refers to comprehensive care needed for people living with ARF and RHD, including regular antibiotic delivery, immunisations, avoidance of and management of Strep A infections, and regular clinical review.
Secondary prophylaxis	Refers to the regular administration of antibiotics to reduce the risk of ARF recurrence.
Tertiary care	The surgical and medical management of RHD to prevent complications of established disease.

Endorsing Organisations



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