TELETHON KIDS INSTITUTE
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END RHD Centre of Research Excellence

Pre-Budget Submission 2019-2020

Resourcing the beginning of the end of rheumatic heart disease in Australia

Foreword

Rheumatic heart disease (RHD) is preventable. Almost 5,000 Aboriginal and Torres Strait Islander people in Australia are living with rheumatic heart disease and a further 400,000 young Indigenous people are at risk. This represents one of the highest rates of rheumatic heart disease in the world.[1,2]

The Australian Government has a unique opportunity to close the gap in Aboriginal and Torres Strait Islander health by committing to end rheumatic heart disease in Australia. The collective experience of communities, clinicians, Aboriginal Controlled Community Health Organisations, government and non-government organisations, in addition to over 20 years of research, means the knowledge and evidence base now exists to plan and implement a comprehensive, evidence-based strategy.

Any strategy needs to focus on all levels of prevention of acute rheumatic fever (ARF) and rheumatic heart disease. The most critical element of the strategy is to work with the communities bearing the greatest burden of rheumatic heart disease; to ensure community-led solutions, based on their aspirations and priorities, can be developed and sustained.

Recommendations

1: Invest $50 million in 2019/2020 for immediate community level action

On the ground action is needed now to prevent and eliminate RHD in the highest risk communities. Funding for five communities to address primary and primordial prevention through the Rheumatic Fever Strategy in the 2017 Federal Budget has been a positive step toward this goal. Funding was allocated in late 2018[4] but is insufficient to meaningfully address the tide of new cases of ARF and RHD.

A $50 million investment would:

- Expand the number of communities supported to act on ending RHD.
- Network these communities together to share co-design approaches and outcomes.
- Enhance technical support for these communities to ensure the information needed for evidence-based action is available.
- Provide resources to primary health care services at the front line of tackling RHD.
- Establish coordination systems within and across jurisdictions, and with relevant government departments and non-government stakeholders, to support community level activites.
- Enable indicators to be set, and enable communities to access data to measure progress.
- Establish governance mechanisms to ensure accountability, as well as meaningful leadership by Aboriginal and Torres Strait Islander people.

With this investment, a solid foundation for the elimination of RHD could be established and implementation would be proportional to immediate need. Sustained long term funding of similar magnitude over the coming decade, as outlined in item 2 below, could end RHD for Aboriginal and Torres Strait Islander people in Australia.

2: Develop, fund, and implement a comprehensive, evidence-based strategy to end RHD

Funded by the National Health & Medical Research Council, the END RHD Centre for Research Excellence (END RHD CRE) is Australia's leading research collaboration in rheumatic heart disease. The END RHD CRE is developing a comprehensive, collaborative, and fully costed strategy to end RHD in Australia, known as the RHD Endgame Strategy. It will be presented to the Commonwealth Government by early 2020 and will include an 11-year plan to achieve disease control by 2031, providing a strong foundation for the implementation of a strategy to end RHD.

The RHD Endgame Strategy will be a plan to end RHD and tackle other diseases of disparity by scaling up the most effective, culturally appropriate, and impactful elements of disease control. Developing an effective, fully costed Endgame Strategy requires extensive collaboration beyond just the research community. Aboriginal and Torres Strait Islander Communities, health workers, and policy makers are central to informing the development of the strategy.

A call to action to END RHD

These recommendations align with the five priority asks of END RHD, an alliance of leading health, community, and research organisations advocating for urgent, comprehensive action on this preventable disease of inequality. Telethon Kids Institute, host organisation of the END RHD CRE, is a founding member of the alliance. These five priorities are:

1. Guarantee Aboriginal and Torres Strait Islander leadership
2. Set targets to end rheumatic heart disease
3. Fund a roadmap to end rheumatic heart disease
4. Commit to immediate action in communities at high risk of rheumatic heart disease
5. Invest in strategic research and technology to prevent and treat acute rheumatic fever and rheumatic heart disease

The END RHD CRE further calls on the Australian Government to support these priorities. Details on these priorities is attached at Appendix B.

What is rheumatic heart disease?

Rheumatic heart disease is caused by Group A Streptococcus (Strep A) bacterial infection of the throat and skin. Infection with Strep A can cause an abnormal immune reaction called acute rheumatic fever (ARF). Severe ARF and/or ARF recurrences from repeated Strep A infections can lead to rheumatic heart disease (RHD), which involves permanent damage to the heart valves.

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 patients 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. Furthermore, in Australia, 94% of new ARF cases occur among Aboriginal or Torres Strait Islander people.[2]

Strep A infections spread easily in settings of overcrowding and poor hygiene (limited access to health hardware such as running water). Primordial preventative efforts – social, environmental, and economic – should be geared towards preventing or limiting the impact of Strep A infections to reduce the burden of ARF and RHD.

Why is investment needed to end RHD?

1. Community demand

Aboriginal and Torres Strait Islander communities and their leaders are calling for action to end rheumatic heart disease.

The Australian Government has an obligation to capitalise on the previous investment and commitment to RHD control in Australia:

- Since 2009 over $30 million has been spent as part of the Rheumatic Fever Strategy.[1]
- The Commonwealth Government has committed to making RHD control a priority and taking the issue to the Council of Australian Governments' Health Council. This is in addition to broader bipartisan engagement with the issue of RHD.
- In May 2018, the Member States of the World Health Organization unanimously adopted a *Global Resolution on Rheumatic Fever and Rheumatic Heart Disease* at the World Health Assembly. Australia, as a co-sponsor of the resolution, has the opportunity to become a leader in this renewed global push to end RHD.

RHD is an avoidable inequality

- 4,539 Aboriginal and Torres Strait Islander people were living with RHD or the effects of ARF in 2016.[1]
- RHD is the leading cause of cardiovascular inequality between Indigenous and non-Indigenous people in Australia.[2]
- Young Aboriginal Australians in the Northern Territory are up to 122 times more likely to have RHD than their non-Aboriginal counterparts.[2]
- In Western Australia's Kimberley region, the average age of death from RHD is 41 years.[3]
- The RHD disability adjusted life year (DALY) rate in Indigenous Australians is 6.6 times higher than that in non-Indigenous people. This is the highest differential among all other cardiovascular diseases and the fifth highest differential of all diseases.
- To prevent further infections, people being treated for RHD must endure a penicillin injection every 28 days, usually for a minimum of ten years. This is referred to as secondary prophylaxis.[5]

2. The cost and human toll of RHD will continue to rise without action

The END RHD CRE Cost of Inaction Report on RHD identifies that if no further action is taken on RHD by 2013, more than 10,000 Aboriginal and Torres Strait Islander people will develop ARF or RHD.[1] Of these people:

- 1,370 will need heart surgery
- 563 with RHD will die
- $317 million will be spent on medical care.

RHD can lead to permanent disability and premature death, however it is a completely preventable disease. Australia has a moral obligation to address RHD as the leading case of cardiovascular disparity between Indigenous and non-Indigenous people, and a bipartisan commitment to eliminating this disease has already been made.[4] A snapshot of the burden of disease in Australia and cost of inaction is attached at Appendix A.

Ending RHD presents a unique opportunity to Close the Gap in Aboriginal and Torres Strait Islander health and move towards holistic, integrated disease control strategies. The same environmental factors responsible for ARF and RHD are responsible for numerous other health problems affecting Indigenous communities including ear disease, kidney disease, preventable blindness, and respiratory infections. By making a commitment to end RHD, not only can we eliminate this preventable disease in Australia, we can also move towards elimination of other diseases of inequality.

3. Comprehensive approaches to ending RHD are possible

Comprehensive, community-led approaches combining all four levels of preventing RHD are needed to tackle this disease:

- Primordial prevention – to address the environmental, social, and structural determinants of health which cause Strep A infection.
- Primary prevention – to identify and treat Strep A infections and prevent the development of ARF.
- Secondary prevention – to diagnose ARF and RHD early, and begin regular antibiotic treatment to prevent disease progression.
- Tertiary care – to identify people with severe RHD, provide life-prolonging care, and minimise the development of complications.

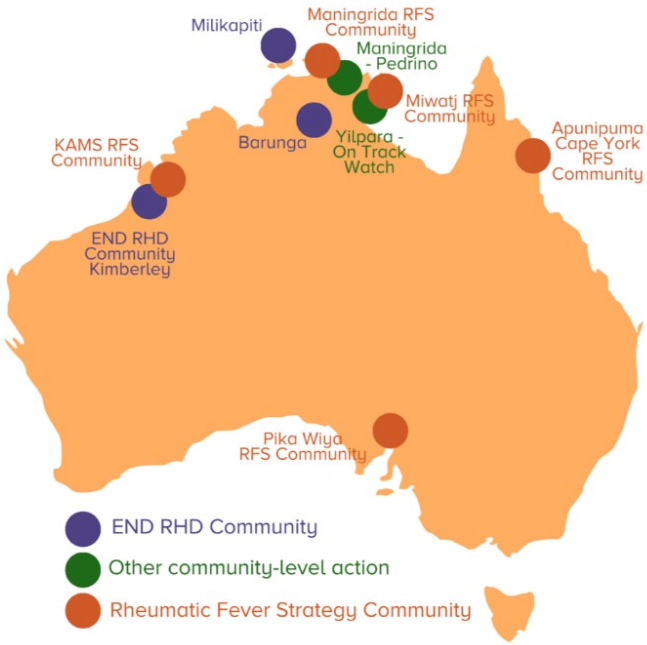
Historically, Australia has focused on tertiary care and delivering secondary prophylaxis through the Rheumatic Fever Strategy (RFS). An independent review of the RFS in 2017 recommended that the RFS be expanded to include a greater focus on early stage prevention.[6] There are good reasons to focus on primordial prevention:

- Addressing the environmental and social determinants of health will not only reduce the number of new cases of ARF and RHD, but will reduce a whole range of preventable childhood infections;
- Only primordial and primary prevention can prevent new case of ARF and RHD, and they are likely to be cost effective.

4. These effective approaches can be amplified

Community level action – through END RHD Communities and RFS Communities (see below) – is underway in at least eight sites around Australia. Other communities are also pursuing local projects with limited funding, connection to others, or technical advice. Bringing these programs of work together to support community-led activity which links in with jurisdictional RHD action plans, and is supported by substantive efforts to address the prevalence of this disease, is essential for action.

Figure 1: Community level action in 2018



END RHD Communities

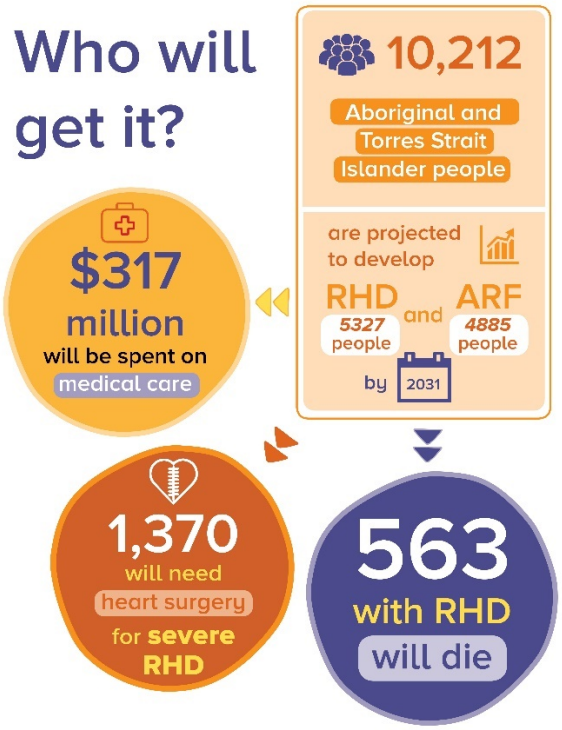
In recognition of the need for immediate, collaborative action in communities at high-risk of RHD, there are several community-led initiatives underway in Australia. The END RHD Communities approach uses community-led, research-backed prevention strategies to tackle Strep A skin and throat infections, acute rheumatic fever, and rheumatic heart disease. Central to the model is the employment of Aboriginal Community Workers who develop professional partnerships with individuals and families at highest risk and assist them to navigate the health care system, increase their self-management capacity, and manage environmental risk factors.

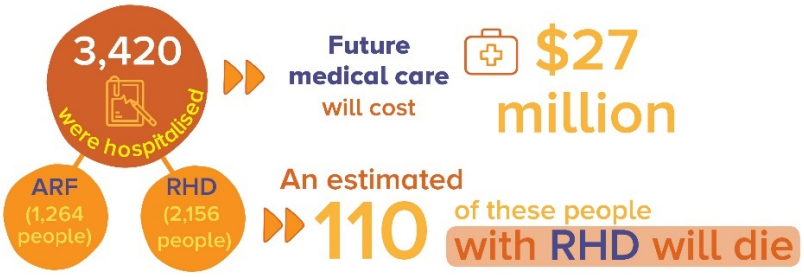
Two communities in the Northern Territory (Barunga in the Roper Gulf Region and Milikapiti in the Tiwi Islands) are already working through this adaptable, community-centric approach to act to address RHD, and Kimberley Aboriginal Medical Service, Nirrumbuk Aboriginal Corporation and Telethon Kids Institute are applying and adapting the END RHD Community approach in the Kimberley with a focus on addressing environmental health determinants.

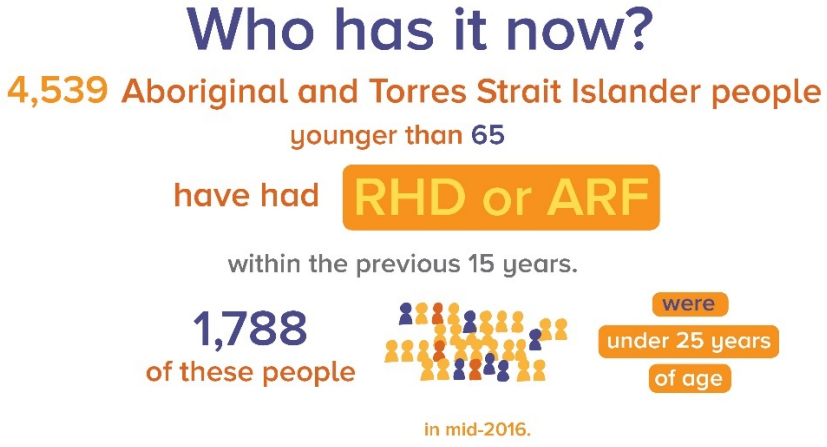
5. The knowledge and evidence exists to eliminate RHD in Australia

The END RHD CRE is a research initiative involving collaborators from 16 institutions across Australia. The CRE's investigators are working closely with individuals and communities living with the condition to fill knowledge gaps, working towards producing a costed, step-wise strategy to end RHD as a public health priority in Australia. The strategy – to be delivered to the Commonwealth as the RHD Endgame Report in 2020 – will include an 11-year plan to achieve disease control by 2031, reducing the incidence of ARF, and bringing the prevalence of RHD for Aboriginal and Torres Strait Islander Australians to the same level as non-Indigenous Australians.

The knowledge and evidence exist to eliminate RHD in Australia, what is needed now is political commitment and sustainable, long-term investment to catalyse change.


Who will get it?
10,212
Aboriginal and Torres Strait Islander people
are projected to develop
RHD 5327 people and ARF 4885 people
by 2031
$317 million
will be spent on medical care
1,370
will need heart surgery for severe RHD
563
with RHD will die


In the last ten years
3,420
were hospitalised
ARF (1,264 people)
RHD (2,156 people)
Future medical care will cost
$27 million
An estimated
110
of these people
with RHD will die


Who has it now?
4,539 Aboriginal and Torres Strait Islander people
younger than 65
have had RHD or ARF
within the previous 15 years.
1,788
of these people
were under 25 years of age
in mid-2016.

Appendix B: END RHD Priority Areas

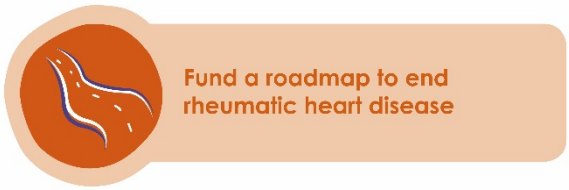
These priorities, as agreed by the founding partners of END RHD, are a starting point for the actions needed to eliminate rheumatic heart disease in Australia.

The Commonwealth Government ensures the leadership and voices of Aboriginal and Torres Strait Islander people drive the development and implementation of RHD prevention strategies, by convening an Aboriginal and Torres Strait Islander Steering Committee.

NACCHO, as the peak body for the Aboriginal Control Community Health Organisations, is the most appropriate body to provide leadership and advice on the role and composition of such a group. At a minimum, an Advisory Group should comprise Aboriginal and Torres Strait Islander leaders representing jurisdictions with a high burden of RHD, and could include experts in service delivery, clinical care, and research. It is also essential to broaden the membership beyond health to include relevant stakeholders such as housing and education bodies.

Australian Governments together commit to measurable targets for preventing new cases of acute rheumatic fever and rheumatic heart disease. Our vision is that no child born in Australia from this day forward dies of rheumatic heart disease.

Ending RHD in Australia is an achievable target. The disease meets many of the public health criteria for a disease amenable to elimination: we understand the cause and have the tools to control the disease; we have systems to measure progress; it is economically possible; and, it has recognition as a public health problem.



Australian Governments work in partnership with Aboriginal and Torres Strait Islander health bodies, experts, and key stakeholders to develop, fully fund, and implement a strategy to end rheumatic heart disease in Australia by 2031.

The RHD Endgame Report (to be finalised by the END RHD CRE in 2020) will provide a roadmap to end rheumatic heart disease in Australia by 2031. It is recommended that Australian Governments work in partnership with Aboriginal and Torres Strait Islander health bodies, experts, and key stakeholders to develop, fully fund, and implement a strategy to end rheumatic heart disease in Australia by 2031, as guided by the Endgame report.

Implementing a properly resourced national strategy will provide critical lessons in collaborative, co-designed health projects. Preventing new cases of RHD in Aboriginal and Torres Strait Islander communities by 2031 will make a critical contribution to achieving the goal of Closing the Gap in life expectancy.

Australian Governments commit to immediate action to fund comprehensive primary care and health promotion activities in Aboriginal and Torres Strait Islander communities with high rates of acute rheumatic fever, and at risk of RHD. These initiatives must be Aboriginal and Torres Strait Islander-led, and provide dedicated funding to the primary health care services in high-risk communities for both treatment and prevention.

This will also need to include: support for collaboration by peak bodies, along with increasing the number of health and community workers; service navigation and health literacy support for high-risk families; and, where appropriate, providing resources for active case finding. Initiatives must be part of a systematic approach addressing the social and environmental determinants of health: tackling inequality, overcrowding, inadequate housing infrastructure and insufficient hygiene infrastructure, and improving access to appropriate health services.

The Commonwealth Government invests in the development of a Strep A vaccine to prevent new cases of acute rheumatic fever and RHD, as well as a long-acting penicillin product to improve the lives of those already living with the disease.

A new penicillin formulation that provides longer-lasting protection would revolutionise RHD control through dramatic improvements in treatment compliance, improving health outcomes for Australian Indigenous children as well as other vulnerable children across the world.

References

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