END RHD Election Platform 2019
No child born in Australia today should die of rheumatic heart disease:
A proposal for immediate action to prevent disease and save lives
Foreword
Rheumatic heart disease (RHD) is preventable. Over 4,500 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

What is rheumatic heart disease?
Rheumatic heart disease is caused by a 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, which results in 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. 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.

The facts about RHD
• 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 for people with RHD is 41 years.3

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

Any strategy needs to focus on all levels of prevention of Strep A infection, acute rheumatic fever, and RHD. 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.

Development of a costed, step-wise approach to ending RHD is underway. A sustained and substantial funding commitment will be needed. This immediate funding ask is critical to be able to address immediate needs and build on the work already happening across Australia.
END RHD

END RHD is a national partnership of health and community organisations calling for a commitment from the government to prioritise the end of RHD in Australia. END RHD is the first time such a broad-based alliance has come together to pool their collective expertise around what needs to be done to address the disparities in RHD.

The founding members of END RHD are the National Aboriginal Community Controlled Health Organisation (NACCHO), Aboriginal Medical Services Alliance Northern Territory (AMSANT), Aboriginal Health Council of Western Australia (AHCWA), Queensland Aboriginal and Islander Health Council (QAIHC), Aboriginal Health & Medical Research Council of NSW (AH&MRC), Aboriginal Health Council of South Australia (AHCSA), Australian Medical Association, Heart Foundation, Menzies School of Health Research, and the Telethon Kids Institute.

In October 2018, END RHD identified five key priority areas to begin the end of RHD in Australia.

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

Six months later, substantial progress towards these priorities has been achieved:

- END RHD, through NACCHO, was commissioned by the Commonwealth Department of Health to develop a Roadmap to eliminate RHD in Australia. The Roadmap was accepted at the COAG Health Council meeting on the 8th March 2019, and has been referred to AHMAC to report back to the Health Council in November 2019.

- $160 million was committed under the Medical Research Future Fund (MRFF) to establish the Indigenous Health Research Fund, with ending rheumatic heart disease as one of its priorities. Of this funding, $35 million was allocated to the development of a Strep A vaccine. Investment in a more acceptable long-acting penicillin product to improve the lives of those living with the disease remains a priority.

- $3.7 million from the existing $6 million in Commonwealth funding for primary prevention activities under the Rhematic Fever Strategy was allocated to five Aboriginal medical services across Australia, new funding was allocated for an additional location in Western Australia, to increase community level action in communities with a high burden of disease.

- A growing number of health, not-for-profit organisations, corporate partners, and peak bodies pledged their support for END RHD by becoming END RHD Charter signatories. Advocacy efforts and government investment has contributed to END RHD being able to secure philanthropic funding for some community based projects.
With these priorities in mind, END RHD is calling for the following investments to be considered between 2019-2023:

$1.5 million per year, per community, for 15 communities to support immediate community level action

On the ground action is needed urgently to prevent and eliminate RHD in the fifteen highest risk communities. A commitment to address primary and primordial prevention, announced as part of $6 million in funding to the Rheumatic Fever Strategy in the 2017 Federal Budget, was a positive step towards this goal, however the funding allocated in late 2018 has been insufficient to meaningfully address the tide of new cases of ARF and RHD.

Starting now, this investment would:

- **Triple** the number of communities supported to act on ending RHD from five to fifteen.
- **Provide** resources to primary health care services at the frontline of tackling RHD – including health workforce.
- **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, including best practice science on environmental health and clinical practice.
- **Establish** coordination systems within and across jurisdictions, and with relevant government departments and non-government stakeholders, to support community level activities.
- **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.

$3.25 million per year for each of the five jurisdictions with the highest burden of RHD to guide state and territory level prevention and control initiatives

Western Australia, the Northern Territory, South Australia, Queensland and New South Wales all at present have a varying level of commitment to controlling and preventing ARF and RHD in their respective states and territories. Committing $3.25 million per jurisdiction across the four-year period would:

- **Fund** the development of jurisdictional action plans and governance structures to connect relevant government departments and stakeholders.
- **Support** legislation and training programs to facilitate housing maintenance by Aboriginal and Torres Strait Islander people and organisations.
- **Develop** adaptable training resources for best practice management of skin sores and sore throats – the precursors to ARF and RHD.
- **Continue funding** RHD register-based control programs to support training and secondary prophylaxis delivery.
- **Employ** staff to coordinate cardiac care, particularly for Aboriginal and Torres Strait Islander people who live rurally or remotely, and need to travel interstate for surgery.
$3.75 million per year to support national actions to end RHD

RHD and ARF are not contained by jurisdictional borders – a national approach is required to support individual state and territory efforts. The following actions require an annual commitment of $3.75 million:

- **Appoint and resource** an Aboriginal and Torres Strait Islander-majority RHD Steering Committee to oversee national approaches, monitor data, and ensure synergy with health strategies.
- **Provide** technical support for communities and jurisdictions.
- **Connect**, through the RHD Steering Committee, departments of health, housing, education and Prime Minister and Cabinet.
- **Support** the implementation of the national Aboriginal and Torres Strait Islander Health Workforce plan.
- **Develop** a network of best practice clinical centres to provide dedicated support for people with severe RHD.
- **Progress** a national RHD research strategy, identifying priority areas for investment by the Medical Research Future Fund, and encouraging investigators to seek funding through other avenues including the National Health and Medical Research Council.
What is needed now is political commitment and sustainable, long-term investment to catalyse change

Why is investment needed to end RHD?

1. Community demand
Aboriginal and Torres Strait Islander communities and their leaders are calling for funding to expand community-led initiatives already up and running across Australia, in order to end rheumatic heart disease. The Australian Government has an obligation to capitalise on the previous investment and commitment to RHD control in Australia.

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 to address RHD, more than 10,000 Aboriginal and Torres Strait Islander people will develop ARF or RHD by 2031.1 Of these people:
- 1,370 will need heart surgery
- 563 with RHD will die
- $317 million will be spent on medical care.

RHD is a completely preventable disease that is not usually seen in high-income countries. Australia has a moral obligation to address RHD as the leading case of cardiovascular disparity between Indigenous and non-Indigenous people.

3. Comprehensive approaches to ending RHD are possible
Comprehensive, community-led approaches combining all four levels of prevention are needed to tackle this disease. Historically, Australia has focused on late-stage 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

4. These effective approaches can be amplified
Community level action – through END RHD Communities and RFS Communities – 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.

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 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.
<table>
<thead>
<tr>
<th>Communities: 15 communities</th>
<th>Social determinants of health (per annum)</th>
<th>Primary prevention (per annum)</th>
<th>Secondary prevention (per annum)</th>
<th>Tertiary care (per annum)</th>
<th>Strategic investments (per annum)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fund community level governance structures to determine local priorities, review local data, seek technical support, and set program direction</td>
<td>Resource communities and invest in environmental health services to improve the nine Healthy Living Practices</td>
<td>Employ more Aboriginal and Torres Strait Islander people in comprehensive primary care services to manage sore throats and skin sores and to improve delivery of secondary prophylaxis to prevent RHD. Explore new opportunities for early diagnosis and active case finding</td>
<td>Resource primary care services to provide care coordination to people with severe RHD to maximise access to speciality services and surgery</td>
<td>Resource primary care structures to determine local priorities, review local data, seek technical support, and set program direction</td>
<td></td>
</tr>
<tr>
<td>$100,000 per community</td>
<td>$800,000 per community</td>
<td>$500,000 per community</td>
<td>$100,000 per community</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Jurisdictions: 5 jurisdictions</th>
<th>Systems and structural support (per annum)</th>
<th>Social determinants of health (per annum)</th>
<th>Primary prevention (per annum)</th>
<th>Secondary prevention (per annum)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support legislation and training programs to facilitate housing maintenance by Aboriginal and Torres Strait Islander people</td>
<td>Develop adaptable training resources for best practice management of skin sores and sore throats</td>
<td>Continue funding for RHD register based control programs to support training and secondary prophylaxis delivery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$1,000,000 per jurisdiction</td>
<td>$500,000 per jurisdiction</td>
<td>$500,000 per jurisdiction</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nationally: Over 4 years</th>
<th>Systems and structural support (per annum)</th>
<th>Social determinants of health (per annum)</th>
<th>Primary prevention (per annum)</th>
<th>Secondary prevention (per annum)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appoint and resource an Indigenous-majority RHD Steering Committee to oversee national approaches, data, and articulation with national health strategies. Provide technical support for communities and jurisdictions</td>
<td>Resource the RHD Steering Committee to connect across health, housing, education, and Prime Minister and Cabinet</td>
<td>Support the implementation of the national Aboriginal and Torres Strait Islander Health Workforce Plan</td>
<td>Develop a network of best practice clinical centres to provide dedicated support for people with severe RHD</td>
<td></td>
</tr>
<tr>
<td>$3,000,000</td>
<td>$250,000</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total annual costs (all sites) | $9.5 million | $17.25 million | $12.5 million | $3.25 million | $170 million over 4 years

No child born in Australia today should die from rheumatic heart disease: A proposal for immediate action to prevent disease and save lives.
References


