



THE COST OF INACTION ON  
**RHEUMATIC HEART DISEASE**  
**IN AUSTRALIA**



*The cost of Inaction on Rheumatic Heart Disease: The predicted human and financial costs of rheumatic heart disease for Aboriginal and Torres Strait Islander people 2016-2031*

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## Glossary

ARF	Acute rheumatic fever
Primary prevention	Assessment and treatment of sore throat and skin sores
Primordial prevention	Addressing the social, structural and economic determinants of health which contribute to the burden of ARF and RHD
RHD	Rheumatic heart disease
Secondary prevention	Regular antibiotics (usually monthly injections) taken by people with a history of ARF to reduce the risk of new Strep A infections
Strep A	Group <i>A Streptococcus</i>
Tertiary care	Medical and surgical care for people living with advanced RHD



## Executive Summary

Aboriginal and Torres Strait Islander communities have some of the highest rates of rheumatic heart disease (RHD) in the world.

This report outlines the trajectory of acute rheumatic fever (ARF) and RHD in Australia until 2031, assuming only the current levels of funding and attention to these diseases: *the cost of inaction*.

Using linked hospital admissions and mortality data over the last two decades, this report estimates the burden of ARF and RHD for Aboriginal and Torres Strait Islander people:

1. who were younger than 65 years and had existing disease in mid-2016 (who has it now); and
2. who are projected to develop disease between mid-2016 and 2031 at an age younger than 65 years (who will get it).

## Key findings

- **Who has it now: 4,539 people living with RHD or the effects of ARF**
- **Who will get it: if no further action is taken to address RHD, a further 10,212 Aboriginal and Torres Strait Islander people are projected to develop the disease or its precursor – ARF – by 2031. Of these people:**
  - **1,370 will need heart surgery**
  - **563 with RHD will die**
  - **\$317 million will be spent on medical care**

### Overview: Strep A, ARF and RHD

Infection with the group A *Streptococcus* (Strep A) bacterium 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.

In Australia, 94% of new ARF cases occur among Aboriginal or Torres Strait Islander people.<sup>1</sup>

A completely preventable disease, RHD can lead to permanent disability and premature death. Most at risk of developing the disease are children.

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.

# 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.

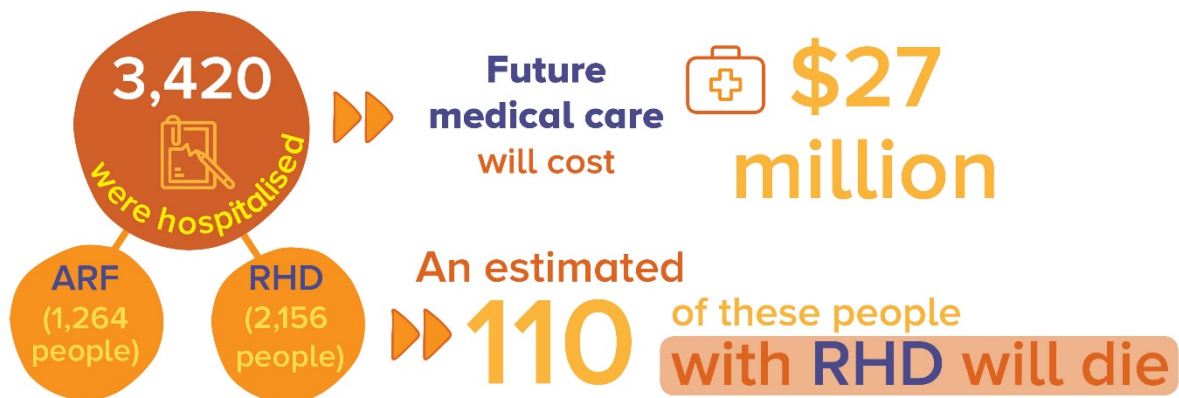
1,788  
of these people



were  
under 25 years  
of age

in mid-2016.

In the last ten years



## Who will get it?



## The cost of inaction

Eliminating RHD means preventing new cases of disease. There is a moral imperative to provide both treatment and prevention of RHD. In particular, Australia has an obligation to address RHD as the leading cause of cardiovascular disparity between Indigenous and non-Indigenous people.<sup>2</sup> A bipartisan political commitment to eliminate RHD has already been made.<sup>3</sup>

Delivering on this commitment means understanding the resources needed to deliver best-practice medical care and to address the underlying inequities that increase the risk of ARF and RHD. This report is the starting point of that process. It outlines the anticipated clinical trajectory of Aboriginal and Torres Strait Islander people who have ARF and RHD today, and those who can be expected to develop it in the future. This clinical trajectory makes it possible to estimate the cost of human life and the financial costs of medical care.

The suffering caused by RHD to individuals, families, and communities is preventable. The human and economic toll could be avoided by urgent investment by Australian governments in collaborative, community-led strategies to address the environmental and socio-economic causes of Strep A infections leading to ARF and RHD, and to improve treatment for established disease.

The future financial costs from ARF and RHD estimated in this report are expected to be absorbed by Australia's health system, with a continuing high human cost. With different kinds of investment it would be possible to shift these costs to prevention – thereby saving lives, building equity, and closing the gap in health outcomes.

## Global efforts to eliminate RHD

There is compelling international evidence that transformative action to reduce new cases of Strep A, ARF and RHD is possible. Historic examples from Cuba, the French Caribbean, and Costa Rica demonstrate that investment in comprehensive, primary care-based strategies can reduce the burden of RHD.<sup>4</sup>

In New Zealand, a 28% reduction in new cases of ARF was possible over five years as a result of school-based active case-finding, health promotion, and an enhanced health system response.<sup>5</sup> While this model is not directly replicable or appropriate in the Australian context, it is evidence that comprehensive approaches tailored to local circumstances can change outcomes.

In May 2018, Australia was a key contributor to a World Health Organization resolution for global action to eliminate RHD. This provides an opportunity for further leadership in addressing RHD at a time when the disease is being prioritised internationally.

## Introduction to Strep A, ARF and RHD

People are exposed to group A *Streptococcus* ('Strep A') through contact with other people. Infection of the throat and skin by the Strep A bacterium can cause an abnormal immune response known as acute rheumatic fever (ARF – see Figure 1).

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. Repeated Strep A infections can cause recurrent ARF and permanent scarring of the heart valves. Damage to the heart valves is called rheumatic heart disease (RHD).

Strep A infections among Aboriginal and Torres Strait Islander people usually begin in childhood. On average, Aboriginal children in remote communities have their first skin infection at seven months of age, which is predominantly caused by Strep A.<sup>6</sup> Strep A skin infections continue throughout childhood and into adolescence. Strep A throat infections begin in later childhood, peaking between 5-14 years of age.<sup>7</sup>

The incidence of ARF episodes also peaks at between five and 14 years of age and then steadily declines with increasing age, whereas the prevalence of RHD steadily increases with age. The age distribution of ARF and RHD is illustrated in Figure 2. The median age at death of Aboriginal people dying with RHD in the Kimberley region is 41 years.<sup>8</sup>

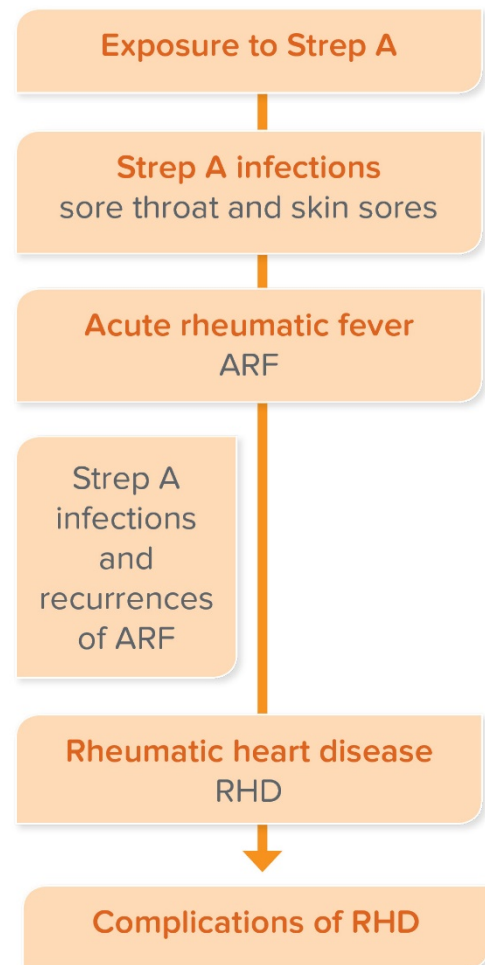


Figure 1: Causal pathway from Strep A to RHD

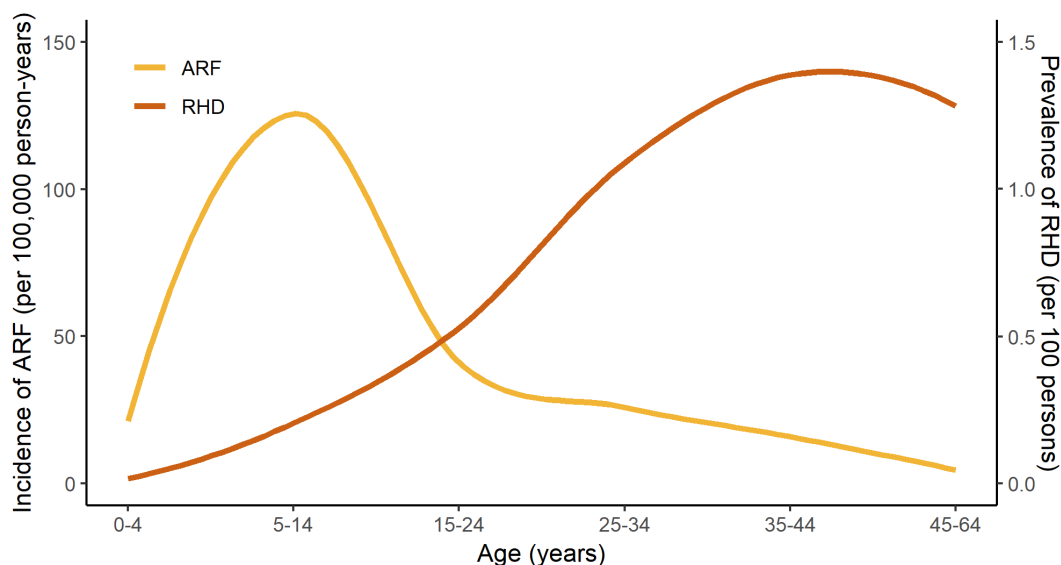
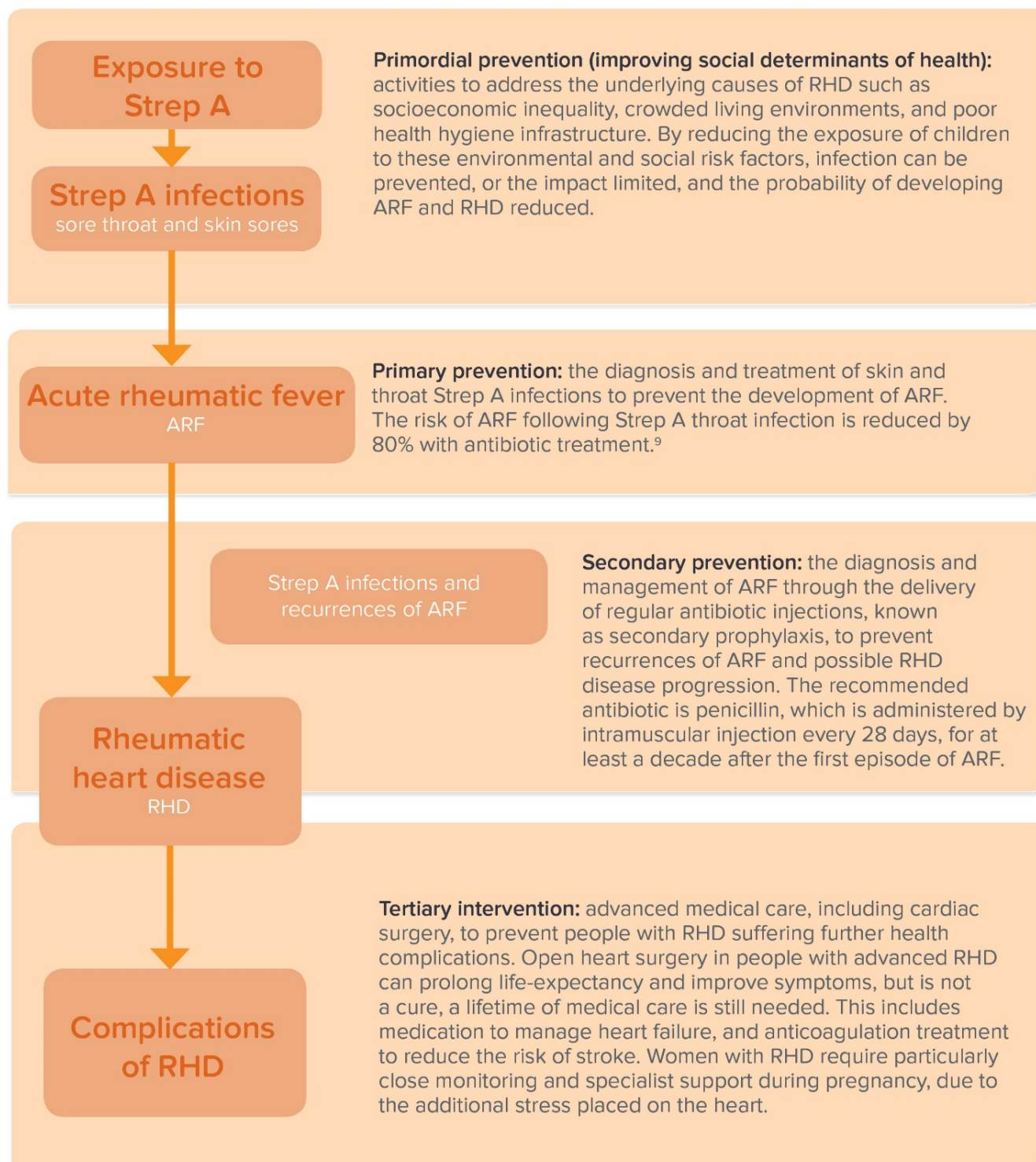


Figure 2: Incidence of ARF between 2014 and 2016 and prevalence of RHD in mid-2016, the NT, QLD, SA and WA (preliminary analysis of data from NHMRC PG 1146525)



## Current clinical action

There are many ways to intervene on the causal pathway from exposure to Strep A and development of RHD. A summary of these is presented below:





Current clinical action and health-care investment towards tackling ARF and RHD in Australia has focused on secondary prevention and tertiary intervention. This means preventing recurrent ARF and death due to RHD, rather than preventing and treating the Strep A infections which cause ARF and RHD.

The Australian Government has invested in the Rheumatic Fever Strategy since 2009.<sup>10</sup>

The Rheumatic Fever Strategy has focused on secondary prophylaxis through:

1. Improved detection, monitoring, and management of ARF and RHD via State-based registers and control programs, which exist in five jurisdictions; and
2. Developing education and training resources, supporting the register and control programs via a national coordinating body (RHDAustralia).

The delivery of secondary prophylaxis is predominately provided by primary care services. Although high-quality primary care services exist in Australia, Aboriginal and Torres Strait Islander people experience barriers to accessing primary care as well as hospital and specialist services.<sup>11,12</sup>

These barriers contribute to devastating outcomes:

- Studies in the Northern Territory have demonstrated that RHD causes an increased mortality rate compared to the general rate, and that the risk of mortality is multiple times higher for Aboriginal and Torres Strait Islander people with RHD compared to non-Indigenous people<sup>13,14</sup>
- One study in the Northern Territory found that more than one in ten (13%) children and young adults aged five to 24 years at diagnosis died within ten years of severe RHD diagnosis.<sup>15</sup>

An independent, external review of the Commonwealth Government's Rheumatic Fever Strategy recommended that, in addition to the focus on secondary prevention, the strategy broaden its mandate to also address social and environmental determinants of health and primary prevention measures.<sup>10</sup> Such a broadening of focus would prevent ARF happening in the first place.



## Results

### Who has ARF and RHD now?

4,549 Aboriginal and Torres Strait Islander people have been hospitalised with ARF or RHD and live with the consequence of the disease in the Northern Territory, Western Australia, Queensland and South Australia in mid-2016.

Almost 40% of these people were under 25 years of age; 24% had severe RHD.

- In mid-2016, there were 4,549 Aboriginal and Torres Strait Islander people who had been hospitalised for ARF or RHD since 2001 across the Northern Territory, South Australia, Queensland and Western Australia (Figure 3)
- This means more than 1% of the Aboriginal and Torres Strait Islander population under 65 years of age in these jurisdictions have a history of ARF or RHD. It is more than 2% of the population across the Northern Territory and South Australia
- The burden of disease accrues early in life. In mid-2016, almost two thirds of people who had a history of ARF were under 25 years old
- More than one third of people with RHD had severe RHD, meaning that these people had also been hospitalised for heart failure or a heart valve procedure
- 3,420 (75%) people were hospitalised for RHD (2,156 people) or ARF (1,264 people) less than ten years prior to mid-2016; and the RHD guidelines recommend that these people still receive regular medical care in the future. Their care thus has to be considered when estimating future health system demands.

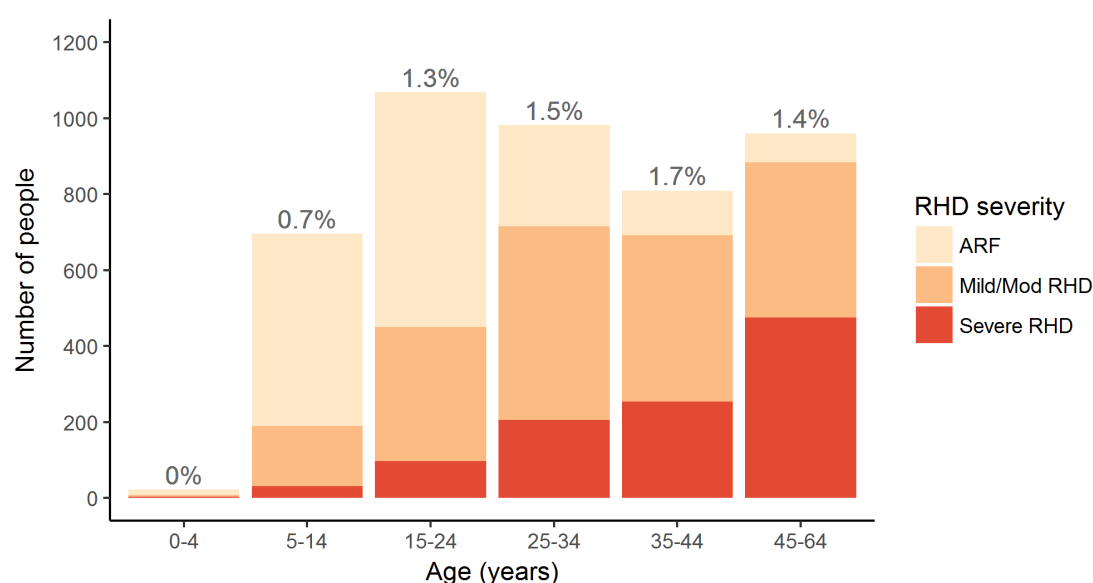


Figure 3: The prevalence of acute rheumatic fever and rheumatic heart disease, stratified by severity, among Aboriginal and Torres Strait Islander people in the Northern Territory, South Australia, Queensland, and Western Australia by age at mid-2016. 'Severe RHD' represents people who have also been admitted with heart failure or heart valve procedures. Percentage figures at the top of each bar reflect the proportion of the Aboriginal and Torres Strait Islander population in each age bracket who have ARF and RHD.

# LAQUEISHA'S STORY

Laqueisha was just five years old when she was diagnosed with rheumatic heart disease and sent on a 5,000km return trip to Perth for major heart surgery.



Surgery is a scary prospect for anyone, but for a young child, it's especially terrifying.

Coming from a remote community, the idea of leaving friends and family and relocating to a hospital in the city for an unknown amount of time, made it even harder for

Laqueisha.

Now aged ten, Laqueisha can still vividly recall her fear before being taken into surgery.

"When they put the mask on me, I was screaming. It was really hard to do it," she says.

Despite being so young, Laqueisha remembers how troubling her diagnosis and surgery was for her whole family.

"It was pretty sad for my family when they found out I had rheumatic heart disease. They didn't want me to be like this, and they didn't know rheumatic heart [disease] at the time," she says.

Fortunately, Laqueisha's surgery went well and she was able to return home.

However, having rheumatic heart disease has fundamentally altered the course of her life.

Like almost all kids living with RHD, Laqueisha must have a long-acting penicillin injection every 21-28 days, indefinitely, to ensure her condition does not deteriorate.

*"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," she says.*

Living with RHD means Laqueisha cannot be as active as her peers, and she struggles with not being able to do what other kids her age can.

"I can't run, and I can't be able to play basketball properly, which is my favourite sport," she says.

But for someone who has gone through so much, Laqueisha is a bundle of energy. She is still only young, but she has already committed to a future of helping kids going through similar situations to her.

"My dream in the future is to become a nurse and to be able to help other kids. They might have the same thing as me. I want to be able to tell them how to make it easier for them," she says.

But her ultimate dream is that, one day, RHD no longer affects kids like her.

## Who will get ARF and RHD?

**10,211 additional Aboriginal and Torres Strait Islander people will develop ARF or RHD by 2031.**

**1,370 will develop severe disease that requires heart surgery.**

In the Northern Territory, South Australia, Queensland and Western Australia from mid-2016 until the end of 2031:

- 4,885 people are projected to develop ARF, and the vast majority of new ARF cases will be under 15 years of age (Figure 4, left)
- 5,326 people are projected to develop RHD with no history of ARF (Figure 4, right).

Of the 4,885 people who are projected to develop ARF, 2,535 people will progress to RHD. This means that more than three-quarters (7,861, 77%) of the 10,211 people who are projected to develop disease between mid-2016 and the end of 2031 will experience and require medical care for RHD in their lifetime. Further, 2,260 of these people are estimated to be diagnosed with or progress to severe RHD, which includes 1,370 people who will require valvular surgery.

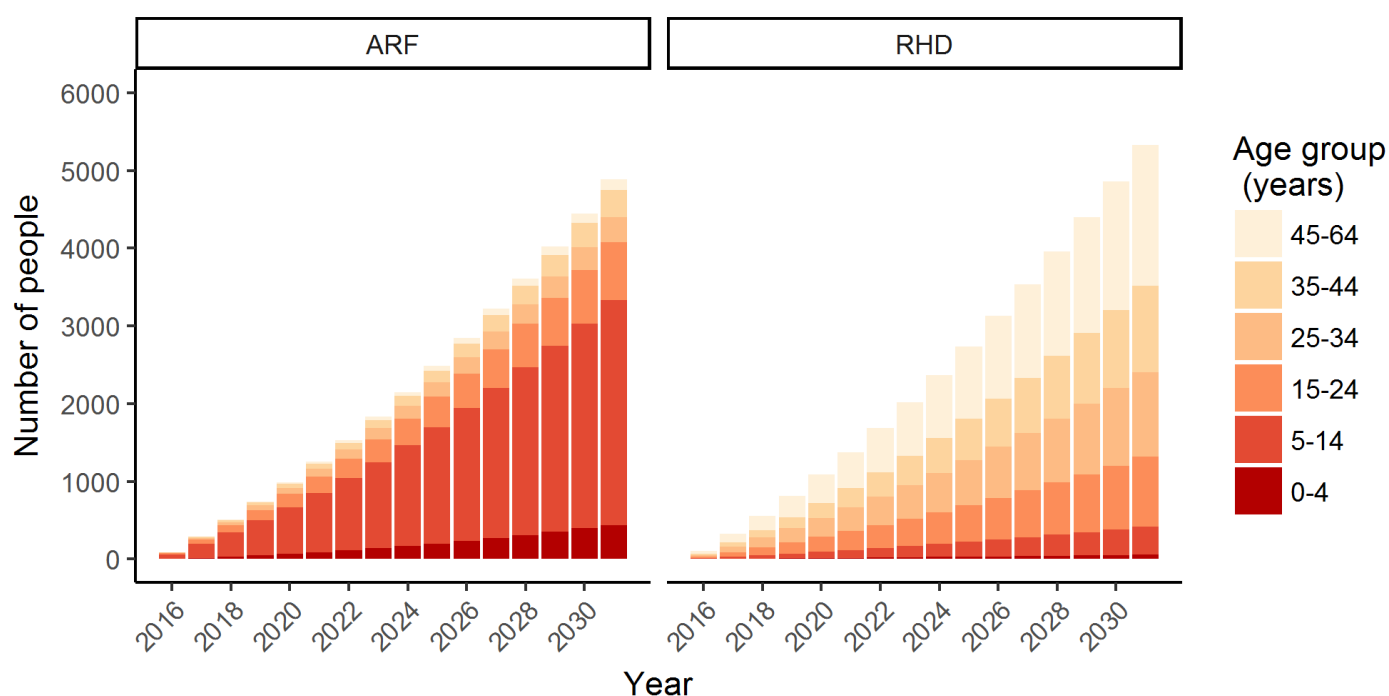


Figure 4. Number of people projected to develop ARF (left) and RHD with no history of ARF (right). With the current level of medical care delivery about half the people with new episodes of ARF will progress to RHD.<sup>13</sup>



# MARGIE'S STORY

When Liana complained of a sore foot and showed signs of a fever, her mum Margie rushed her to hospital. An X-ray of her foot revealed no obvious injury, so she was sent home and advised to take painkillers.



But Margie persisted. She took Liana to her local clinic a few days later, where the doctor ordered blood tests, suspecting acute rheumatic fever (ARF) – the precursor to rheumatic heart disease.

The results of the blood test confirmed this diagnosis, and Liana was immediately placed on a schedule of long-acting penicillin injections every 21-28 days.

She will need these injections until she is at least 21 in order to prevent further episodes of ARF.

Having worked as a health worker, Margie has seen first-hand the importance of kids living with ARF adhering to their treatment schedule, and the complications which can arise if they do not.

Because the injections are so thick and viscous, they can be very painful, which means kids and young adults often avoid going to the clinic if they can. But not receiving their treatment on time can cause their condition to deteriorate, leading to

rheumatic heart disease – which can require more serious medical interventions such as open heart surgery.

*"Initially I was stressed about how I was going to get her to have the injections every month, as I know they are very painful."*

*"The first six months were difficult. She found the injections painful during, and for a few days after, and would be upset. If she had a bad experience, it would make her anxious for the next injection," Margie says.*

For kids like Liana, it is not just the pain of the injections that can stop them receiving their treatment – it is the inconvenience of having to go to the clinic every three to four weeks. Margie says incorporating the regular injections into their life was a big adjustment for them both.

"We have to work around her schedule as she has school, and sports after school most days. We try to get into the clinic on an afternoon she has free so she can rest that night," Margie says.

Five years on from her diagnosis, Liana is now confident going to the clinic and receiving the injections herself.

"Liana reminds me when her injections are due. I find it difficult to keep track of the time but she remembers," Margie says.

For kids like Liana, a diagnosis of ARF changes the trajectory of their childhood. Having an injection every 21-28 days until adulthood is a big responsibility, but one Liana knows she must shoulder to give herself the brightest future.

## The human cost of RHD

Deaths from the disease

**673 Aboriginal and Torres Strait Islander people who develop RHD between 2016 and 2031 are predicted to die.**

**110 people**

who had RHD diagnosed before 2016 are expected to die with the disease before completing medical care

+

**563 people**

who develop RHD between 2016 and 2031 are projected to die with RHD

=

**673 people**

with RHD are predicted to die if the observed incidence rates of ARF and RHD do not change



# CAROL'S STORY

Carol Michie's mother Elizabeth was one of eight siblings born on East Arrernte (Aranda) land, near Alice Springs.



After being diagnosed with rheumatic heart disease at ten, Elizabeth had to leave country and her family for a large chunk of her childhood so she could be treated in Adelaide.

Today, the drive from Alice Springs to Adelaide takes around 16 hours thanks to modern roads and cars, but when Elizabeth was a child it took a lot longer. The long distance meant it

was hard for Elizabeth to return home between hospital stays.

Even when she was not an in-patient at the hospital, Elizabeth was a resident patient at a nearby boarding house. It was only when she was 16 that she was able to finally make the long-awaited trip back home.

Despite her serious illness, Elizabeth had her first baby at 19. But having rheumatic heart disease meant the pregnancy was high-risk, and she was very unwell throughout.

Carol was Elizabeth's third baby, and instead of being born on East Arrernte land, the severity of her mum's condition meant she had to be born in Adelaide Hospital. The long recovery time meant Carol's dad was not able to meet her until she returned home – six weeks later.

In 1970, Carol's mum had her fourth child. But the pressure of the pregnancy on her heart was all too much and as soon as her baby was born – another daughter – she was whisked away for open heart

surgery. Carol thinks she was one of the first Aboriginal women to have a plastic valve fitted.

Even after the operation, Elizabeth required ongoing medical attention.

"A lady would come and give her injections. Sometimes, when Dad wasn't there, it was my role to get on my bike and ride to get help for Mum if she needed it," Carol says.

Unfortunately, six years after her open-heart surgery, rheumatic heart disease claimed Elizabeth's life. Carol was just ten, but she says it is a day she can recall vividly.

*"I remember the day when she passed away. I sensed it. I was at school, and I looked up to the door and saw my dad standing there, with tears falling down his face. We raced down to the hospital and she was still alive, but not for much longer."*

Forty years later, Carol says the sense of loss is still very present.

"One of the biggest implications of her disease was that we were taken off country.

"Because of her condition, we lived all over Australia at different missions and communities and, sadly, my mum is buried off country."

Today, Carol can't believe RHD continues to take lives in Australia. She says urgent, collaborative action is needed to tackle the disease.

"We need to continue to work together – researchers, communities and families – to change the story of RHD in the lives of our children, families and communities that are still affected and living with the impact of RHD on a daily basis."



## The financial cost of ARF and RHD

\$344 million will be spent on the clinical management of people who currently have ARF and RHD and on those who develop ARF and RHD by 2031.

**\$27 million**

Cost of medical care for people diagnosed with ARF and RHD since 2007 and alive in mid-2016

+

**\$317 million**

Cost of medical care for people who develop ARF and/or RHD from mid-2016

=

**\$344 million**

Cost of medical care for people who have ARF or RHD or who develop the disease

*The cost of medical care for people with existing ARF and RHD (estimated in 2015 Australian dollars)*

Future medical care for people with a history of ARF or RHD occurring between 2007 and mid-2016 is estimated to cost the health system \$27 million.

This includes the annual cost of disease management (secondary prophylaxis and specialist follow-up) for a duration of up to ten years, depending on the time since last ARF or RHD hospitalisation, and the cost of hospitalisation for RHD for people predicted to progress from ARF.

However, these costs do not include the additional hospitalisation and annual disease-management costs for people who may progress from mild/moderate RHD to severe RHD requiring surgery.





## Breakdown of medical costs

Future medical care for people projected to develop ARF and RHD between mid-2016 and 2031 is estimated to cost the health system \$317 million (Figure 5). This comprises:

- \$141 million for medical care due to people projected to develop ARF
  - including those who were predicted to progress to RHD and to severe RHD requiring surgery within ten years of RHD diagnosis; and
- \$176 million due to medical care for people projected to develop RHD with no history of ARF
  - also including those who were predicted to progress to severe RHD requiring surgery within ten years of RHD diagnosis
- Children projected to develop ARF at 5-14 years of age, including their progression to RHD, will incur the highest medical cost (Figure 5).

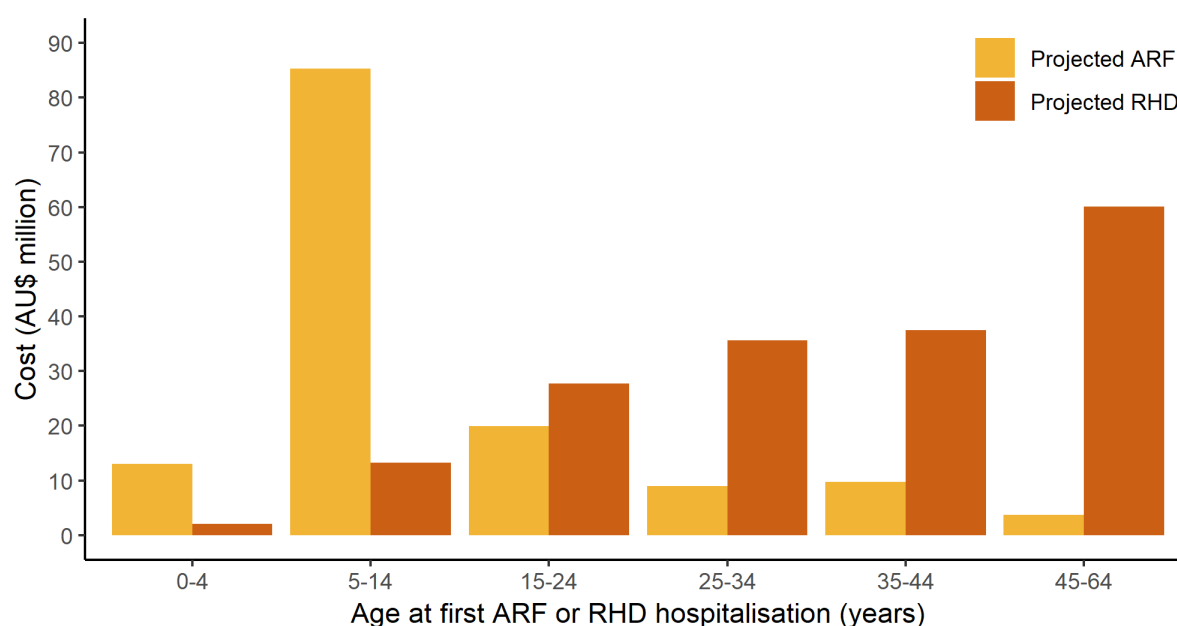


Figure 5: Medical care cost, including for disease progression, for people projected to develop ARF and/or RHD between mid-2016 and end of 2031, stratified by age at first hospitalisation captured in the data. \*Projected RHD with no history of ARF.

## Discussion and analysis

This report offers the best available data on the current and future burden of ARF and RHD in Australia, and represents the first quantification of the human and financial cost of RHD into the future.

The best data and analytic tools have been used to model and predict the future costs of ARF and RHD. However, there were several limitations:

- Using hospital data means that people with a new diagnosis of ARF who were not hospitalised will not have been counted, leading to an underestimate of both the human and financial costs
- Deaths among people with RHD are all-cause mortality, not deaths attributed directly to RHD
- Women with RHD are at risk of serious complications and require close medical supervision due to the physical demands on the heart during pregnancy and birth. Analysis has not been performed by gender, which means differences in the medical costs and experiences between men and women living with RHD are not made explicit
- The financial cost of ARF and RHD were limited to the costs of hospitalisations and annual disease management, namely secondary prophylaxis and specialist follow-ups, from the public health sector perspective. The analysis did not account for the complex and costly realities of cross-cultural communication, the cost of translators, the administrative and transport requirements of follow-up for people who move frequently, and the medical challenges of managing comorbid disease that may be worsened by ARF and RHD. Similarly, it did not account for losses in education, employment, or social contributions including childrearing or sharing cultural knowledge, all of which may far exceed direct financial expenditure and contribute to the social inequality between Aboriginal and Torres Strait Islander and non-Indigenous Australians
- Extrapolating from past events may not be a reliable means of prediction. For example, the cause of increasing rates of ARF is unclear. It is possible that greater awareness of the disease means the correct diagnosis is being made more often, and/or that more children are living in circumstances which drive ARF and RHD.

Acknowledging these limitations, the most conservative estimates have been made throughout this report. The cumulative effect of these conservative choices means that predictions are likely to represent an under-estimate of ARF and RHD costs.

Estimating the costs of ARF and RHD into the future provides a rationale for action. Since these diseases are entirely preventable, these costs are unnecessary and the financial cost can be better spent on preventative rather than reactionary measures. Measures that result in a reduction in ARF and RHD would improve health and possibly social equity for Aboriginal and Torres Strait Islander people in Australia. The relative disparity in the rates of ARF and RHD between Aboriginal and Torres Strait Islander and non-Indigenous Australians makes a compelling case for action, independent of the financial cost of disease. This report confirms what we already know: ARF and RHD cause enormous human and financial costs. The toll is inequitable between Indigenous and non-Indigenous people, but it is not inevitable. Action can be taken.

## Recommendations

Action on ARF and RHD means a comprehensive program of prevention (addressing social determinants and treatment of sore throats and skin sores) and management for people already living with the disease (secondary prophylaxis injections and advanced surgical care when needed). Action must be situated in, and led by, Aboriginal and Torres Strait Islander communities. It must be grounded in comprehensive primary care services by those communities and address the structural factors which stop people getting the care they need and the health they deserve.

END RHD ([endrhd.org.au](http://endrhd.org.au)) is an alliance of peak bodies advocating to eliminate ARF and RHD in Australia. END RHD has identified five priority next steps immediately needed to change the trajectory of this disease:



**Guarantee Aboriginal and Torres Strait Islander leadership**

**Fund a roadmap to end rheumatic heart disease**

**Set targets to end rheumatic heart disease**

**Commit to immediate action in communities at high risk of rheumatic heart disease**

**Invest in strategic research and technology to prevent and treat acute rheumatic fever and rheumatic heart disease**

The predicted growth in Aboriginal and Torres Strait Islander people living with – and dying of – ARF and RHD is avoidable. This trajectory is not inevitable and can be changed with comprehensive, community-controlled approaches.

Action on ARF and RHD has a double benefit. A wide range of other conditions are driven by similar economic, social and environmental determinants. Therefore, other childhood infections like trachoma, otitis media, scabies and respiratory infections that also contribute to the gap in health, and possibly social, outcomes between Aboriginal and Torres Strait Islander and non-Indigenous people in Australia can be tackled simultaneously. In addressing shared risk factors, outcomes can be broadly improved.

## Conclusion

At least 4,539 Aboriginal and Torres Strait Islander people are living with the effects of ARF or RHD in Australia. New cases of the disease are almost unheard of among non-Indigenous people. This inequality can be prevented.

Without immediate action, 10,212 people will have developed ARF or RHD by 2031. To provide medical care for those people Australia will need to spend at least \$317 million, which includes the cost of more than 1,000 heart operations. Tragically, 518 people will have died with RHD. Most of the people affected by ARF and RHD will be young and in the prime of their lives.

Action to address ARF and RHD can change these outcomes. Comprehensive community-controlled approaches which address the social determinants of the disease and manage the consequences are possible. These data contribute to the compelling economic, social and moral imperative to act to end RHD in Australia.

## Methods

The cost of ARF and RHD was estimated in four stages of data analysis and disease modelling, with methods summarised below and available in more detail in our companion technical report.<sup>17</sup>

**Step 1** determined the prevalence and incidence rates of ARF and RHD for a quasi-national Aboriginal and Torres Strait Islander population less than 65 years of age. These were derived from routine collections of hospitalisations\* and mortality records from the Northern Territory (NT), South Australia (SA), Queensland (QLD) and Western Australia (WA). Linked hospital and mortality data were available for the period from July 1st, 2001 to December 31st, 2016. These data were linked electronically to person-based encrypted identifiers so that a person's first admission for ARF and/or RHD could be determined and people who died before mid-2016 could be excluded from further analysis. No person or community could be identified.

**Step 2** determined the number of people who have or will develop ARF or RHD and incur the associated economic costs of ARF or RHD from mid-2016. These comprised two populations.

The first population **(A)** included all people alive at June 30th, 2016 who had been hospitalised for ARF or RHD in the previous 9.5 years. These people were defined as the sub-set of existing cases (Step 1) who had been hospitalised after January 1st, 2007. This date, being 9.5 years before mid-2016, was chosen for two reasons: (1) the ARF/RHD guidelines recommend a minimum period of ten years of medical management, meaning that these people will all be receiving secondary prophylaxis and specialist follow-up for at least half a year from mid-2016; and (2) the modelled progression of ARF or RHD was limited to ten years since diagnosis of either disease because published progression rates are limited to this amount of follow-up time.

The second population **(B)** comprised Aboriginal and Torres Strait Islander people who are projected to develop ARF or RHD under 65 years of age between July 1st, 2016 and December 31st, 2031. This projection was based on extrapolating the observed incidence rates into the future period by fitting linear trends to the age-specific incidence rates of ARF and RHD observed between Jan 1<sup>st</sup>, 2011 and December 31<sup>st</sup>, 2016 (Step 1). This projection translated into an increasing or decreasing number of people, after adjustment for population growth, developing ARF or RHD each year between mid-2016 and 2031.

Population growth was based on the Australian Bureau of Statistics (ABS)-published '*estimates and projections of the number of people identifying as Aboriginal and Torres Strait Islander Australians between 2001 and 2026*'.<sup>16</sup> As the ABS does not provide any Aboriginal projections beyond 2026, a conservative assumption of no population growth was made for the projected population between 2027 and 2031, using the ABS's projected population at 2026 for each of those years.

**Step 3** was to predict the disease trajectories for all people who have a recent history of ARF/RHD since 2007 (2A) and who are projected to develop ARF/RHD (2B). Predictions were based on a state-transition model that describes the progression (transition) between health states related to ARF and RHD in people over time. Modelled disease trajectory comprised progression from ARF to RHD, from RHD to severe RHD requiring heart surgery, and from RHD to death. The likelihood of this progression over time was based on previously published data.<sup>13,15</sup> Progression to severe RHD requiring surgery and/or mortality represented the human cost of ARF and RHD.

**Step 4** was to estimate the future medical care and associated cost for each disease trajectory. Medical care included two main components: (1) inpatient hospitalisation to acute hospitals for ARF or RHD; and (2) annual disease management, which included secondary prophylaxis and specialist follow-up over a ten-year period post-hospitalisation. Treatment costs for the estimated medical care were based on Cannon *et al.*<sup>15</sup> Medical care and the associated cost was estimated for the modelled disease trajectory occurring after mid-2016 of all people with a recent history of ARF/RHD (2A) and who are projected to develop ARF/RHD (2B). All costs estimated in this report are in 2015 Australian dollars.

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\* Public hospitalisations only for Northern Territory and South Australia



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