

Rapid Review - Acute Rheumatic Fever and Rheumatic Heart Disease in Australia

This summary and analysis of the October 2019 Australian Institute of Health and Welfare (AIHW) report into rates of acute rheumatic fever and rheumatic heart disease in Australia has been prepared by the [End Rheumatic Heart Disease Centre of Research Excellence](#). The full AIHW report can be [accessed here](#). This data extends upon a previous AIHW report released in June, 2019.

'Acute Rheumatic Fever and Rheumatic Heart Disease in Australia' is an AIHW report presenting data on acute rheumatic fever (ARF) and rheumatic heart disease (RHD). Within the report:

- All information is from data collected between 2013 – 2017;
- Data was sourced from jurisdictional RHD control program registers;
- Four jurisdictions contributed comparable data (Queensland, Western Australia, South Australia, and Northern Territory).
- Data from New South Wales is presented separately due to the short duration of the register's existence.

The burden of ARF and RHD persists in Australia

- 1,776 Aboriginal and Torres Strait Islander people and 121 non-Indigenous people in the four jurisdictions were diagnosed with ARF from 2013 – 2017.
- 1,043 Aboriginal and Torres Strait Islander people and 198 non-Indigenous people in the four jurisdictions were diagnosed with RHD from 2013 – 2017.
- 4,255 people living with RHD were recorded on state and territory registers, of whom 87% were Aboriginal and Torres Strait Islander people (3,687 diagnoses).
- ARF is generally a disease of young people, most commonly diagnosed at 5 – 14 years of age (41% of diagnoses).

Aboriginal and Torres Strait Islander people are unjustly affected by ARF and RHD

- 94% of people diagnosed with ARF were Aboriginal and Torres Strait Islander people.
- 87% of people living with RHD were Aboriginal and Torres Strait Islander people.
- Aboriginal and Torres Strait Islander people were 125 times more likely to be diagnosed with RHD than non-Indigenous Australians.

Identification of disease

- In 2013–2017, three-quarters of ARF diagnoses (74%, 1,316 diagnoses) were recorded as the first known diagnosis for that individual.
- The remaining one-quarter of diagnoses were for recurrent disease (26%, 460 diagnoses).
- Among all Aboriginal and Torres Strait Islander people with a new RHD diagnosis in 2013–2017, about 4 in 5 (838 diagnoses) did not have a previous ARF episode recorded on the registers.

Geographic burden of disease

- The vast majority of people living with the effects of ARF or RHD live in remote locations in northern regions of Australia.
- The Northern Territory has the highest burden of ARF and RHD. The rate of RHD diagnosis in the Northern Territory is three times higher than the other jurisdictions.

Management and outcomes from ARF and RHD

- Regular antibiotic injections, known as secondary prophylaxis, are recommended for people who have had ARF to prevent recurrent episodes of ARF and reduce the development of RHD.
- Across the four jurisdictions, most (37%) people received only 50 – 79% of their prescribed secondary prophylaxis injections, leaving them vulnerable to recurrent ARF episodes and worsening RHD.
- About a quarter of people received less than 25% of their recommended number of doses, and only 15% of people received the recommended number of doses.

- Reflecting difficulties in delivering secondary prophylaxis, the proportion of recurrent episodes of ARF has not changed substantially from 2013 – 2017, accounting for about a quarter of all reported ARF diagnoses.
- 350 Aboriginal or Torres Strait Islander people had heart surgery for RHD between 2013 – 2017. The vast majority of these operations occurred in people under 45 years of age, with over ten percent of operations being on children under 14 years of age.
- 275 people with RHD died in the four jurisdictions between 2013 – 2017. The median age of death was 50 years.

Limitations of this report

- Comparable information is only reported for four jurisdictions supported by the national Rheumatic Fever Strategy, with separate information provided about New South Wales. The burden of disease in Victoria, the Australian Capital Territory, and Tasmania is not reported and remains unknown. There are currently no national data on the burden of ARF and RHD in Australia.
- Data on surgical procedures are drawn from RHD registers and not from hospital admission or surgical databases. Therefore, some surgical details may be incomplete.
- The analysis of mortality data does not provide detail on cause of death, so it is not possible to know whether deaths were caused or contributed to by RHD.
- Information is not available at a community level because of concerns about small data blocks and confidentiality. This is congruent with established AIHW processes for reporting Aboriginal and Torres Strait Islander data, but does not necessarily serve the needs of those communities that want to know more about their local burden of disease.
- No information is presented on the burden of Strep A infections of the throat and skin which cause ARF. Diagnosis and management of Strep A infections is outside the scope of the RHD registers where information in this report comes from. However, understanding the causes of ARF is critical to efforts to prevent new cases.

What's new in this report?

- Information about the burden of ARF and RHD within jurisdictions has not been shared previously and provides important new information on where disease control efforts should be focused.
- The diagnoses of RHD with or without a prior presentation of ARF is previously unknown statistic.
- Detailed information about secondary prophylaxis delivery in each jurisdiction is new and offers an opportunity to support service delivery in different locations.

Main points

- The burden of ARF and RHD continues to grow among Aboriginal and Torres Strait Islander people in Australia. Modelling in the [Cost of Inaction on RHD in Australia](#) indicates that this will continue without urgent action.
- Although there have been some improvements in delivery of secondary prophylaxis, this is not reflected in a reduction of ARF recurrence rates at a population level.

What needs to happen now

- **Substantial national investment** is urgently needed to reduce the inequitable burden of ARF and RHD for Aboriginal and Torres Strait Islander people in Australia. This investment should:
 - Be focused on remote regions of northern Australia.
 - Be proportionate to existing and predicted burden of disease.
 - Be comprehensive including prevention of ARF, secondary prophylaxis, clinical management, and advanced surgical care.
 - Support comprehensive primary care to deliver services which are effective to prevent ARF and RHD.
- **Targets and monitoring** should be established to measure progress towards ending RHD. Although this report provides critical new information and is a major development in understanding RHD nationally, it offers little guidance about whether or not Australia is reducing the disparity of RHD. New disease control targets and monitoring should:
 - Provide guidance about what Australia needs to achieve in order to end RHD, and whether the country is on track to meet those targets;
 - Resource more regular and timely updates on the burden of ARF, RHD, and associated metrics;

Support local access to information about ARF and RHD, and Aboriginal and Torres Strait Islander data sovereignty.

END RHD is an alliance of peak bodies and supporters working to END RHD in Australia. Additional agreed priorities to progress this work are available online at endrhd.org.au. Contact us at end.rhd.cre@telethonkids.org.au