

Acute rheumatic fever and rheumatic heart disease in Australia, 2022

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About this report

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are preventable diseases disproportionately affecting Aboriginal and Torres Strait Islander (First Nations) people living in regional and remote areas. Prevalence rates were highest in women and children. This report provides an update on epidemiology and trends relating to ARF and RHD, and reports on the management and treatment of patients with a diagnosis of ARF and/or RHD.

Cat. no: CVD 100

Findings from this report

- [10,349 people were living with ARF and/or RHD in NSW, Qld, WA, SA, or the NT as at 31 December 2022](#)
- [272 new RHD diagnoses were made among First Nations people in Qld, WA, SA, and the NT in 2022](#)
- [Among First Nations people, the ARF diagnosis rate was highest among those aged 5–14](#)
- [1 in 4 First Nations people in Qld, WA, SA and NT prescribed BPG received at least 80% of their prescribed doses in 2022](#)

At a glance

Recorded diagnosis of
ARF and/or RHD

81%



8,448 First Nations people with a diagnosis of ARF and/or RHD were recorded on jurisdictional registers at December 2022⁽¹⁾

Northern Territory



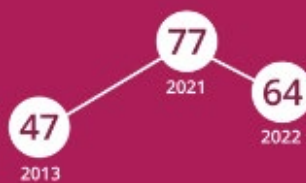
40% of First Nations people who had a diagnosis of ARF and/or RHD lived in the NT

497



497 First Nations people were diagnosed with acute rheumatic fever in 2022⁽²⁾

Annual population rate



The annual population rate of ARF diagnoses among First Nations people increased from 2013⁽³⁾ to 2021⁽⁴⁾, then decreased in 2022⁽⁵⁾

Hospital separations
with a diagnosis of ARF



In 2021–22 financial year, there was a total of 554 hospital separations with a diagnosis of ARF in NSW, Qld, WA, SA and NT⁽⁶⁾

5,424



At December 2022, 5,424 First Nations people were living with RHD⁽⁷⁾

RHD incidence rate



The incidence rate of RHD among First Nations people who were newly diagnosed with RHD increased from 2015 to 2018, then decreased over last 5 years⁽⁸⁾

7 in 10



Nearly 7 in 10 First Nations people who were newly diagnosed with RHD in 2022 were females

Prevalence rate



The prevalence rate of First Nations people living with RHD has increased since 2015⁽⁹⁾

New diagnoses of RHD



In 2022, 9 new diagnoses of RHD were recorded in people under 35 years old in NSW

Surgery for RHD



73 First Nations people had surgery for RHD in 2022

RHD register



At December 2022, 142 people living with RHD were recorded on the register in New South Wales⁽¹⁰⁾

1 in 4



Nearly 1 in 4 First Nations people in Qld,
WA, SA, and NT prescribed BPG received at
least 80% of their prescribed doses in 2022

1. Over 81% of total diagnoses of ARF/RHD in NSW, Queensland, Western Australia, South Australia and the Northern Territory
2. 95% of total diagnoses in NSW, Queensland, Western Australia, South Australia and the Northern Territory
3. 47 per 100,000 population
4. 77 per 100,000 population
5. 64 per 100,000 population
6. 85% First Nations people vs 15% non-Indigenous people
7. 78% of total of those in Queensland, Western Australia, South Australia and the Northern Territory
8. 55 persons per 100,000 population in 2015, 88 persons per 100,000 population in 2018, 55 persons per 100,000 population in 2022
9. 847 persons per 100,000 population in 2015 to 1,104 persons per 100,000 population in 2022
10. RHD is notifiable only in those aged under 35 at the time of diagnosis in NSW

Introduction

This is the 6th annual report from the [National Rheumatic Heart Disease data collection](#), collated from data provided by clinical patient registers in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory. It presents information on acute rheumatic fever (ARF) and rheumatic heart disease (RHD) cases diagnosed or receiving treatment during 2022, as well as trend data since 2013. Its aim is to provide a national overview of ARF and RHD and so it focuses mainly on data for the combined jurisdictions.

The report is comprised of 6 parts:

1. This introduction provides a background on what ARF and RHD are, and context for the data provided in the rest of the report.
2. [Acute rheumatic fever](#) provides data on the incidence (new diagnoses) of ARF.
3. [Rheumatic heart disease](#), [New rheumatic heart disease](#) and [Surgery among First Nations people with rheumatic heart disease](#) provide data on the incidence and prevalence (existing cases) of RHD, and relevant surgical treatment.
4. [Secondary prophylaxis](#) provides data on the delivery of secondary prophylaxis treatment and ARF recurrence rates.
5. [Management of acute rheumatic fever and rheumatic heart disease](#) provides an overview of the number of people being managed for ARF and/or RHD by region, and describes the jurisdictional control programs and registers.
6. [Socioeconomic and environmental factors](#) provides contextual information about some of the environmental factors associated with ARF and RHD in Australia.

At the end of the report, additional information is provided about the data collection, some technical and analytical definitions, and relevant indicator sets.

See the data tables available on the web version of this report:

- During embargo at [Acute rheumatic fever and rheumatic heart disease in Australia, 2022 – Data](#) (<https://pp.aihw.gov.au/reports/indigenous-australians/arf-rhd-2022/data>)
- When published at [Acute rheumatic fever and rheumatic heart disease in Australia, 2022 – Data](#) (<https://www.aihw.gov.au/reports/indigenous-australians/arf-rhd-2022/data>).

What is acute rheumatic fever?

Acute rheumatic fever (ARF) is an autoimmune response to an untreated infection of the throat and possibly skin by group A streptococcus (Strep A) bacteria (McDonald et al. 2004; May et al. 2016; Bennett et al. 2019; Lorenz et al. 2021; Thomas et al. 2021; Wyber et al. 2021). Not all people who have Strep A develop ARF but, in those affected, it usually develops within 2 to 3 weeks of the infection (Webb et al. 2015).

ARF can affect the heart, joints, brain, and subcutaneous tissues (the innermost layers of skin) (Parnaby & Carapetis 2010). While no lasting damage is caused to the brain, joints, or skin, ARF can cause lasting damage to the heart. There is no single diagnostic test for ARF. Australian guidelines recommend hospitalisation, so all necessary investigations are undertaken and to rule out other diagnoses.

The risk of ARF recurrence is relatively high after an initial episode. Repeated ARF increases the likelihood of long-term heart valve damage, known as rheumatic heart disease (RHD)

(Carapetis et al. 2016). As each episode of ARF can worsen the damage to the heart, the goal of treatment is to prevent ARF recurrences using long-acting penicillin treatment, which is known as secondary prophylaxis. For people who are unable to use intramuscular penicillin, oral antibiotics may be offered.

What is rheumatic heart disease?

Rheumatic heart disease (RHD) refers to damaged heart valves because of one or more episodes of ARF. An affected heart valve can become scarred and/or stiff, impacting blood flow. The mitral and aortic valves are most frequently affected. Regurgitation, the backwards flow of blood, due to damage to the mitral valve, is the most common feature of RHD.

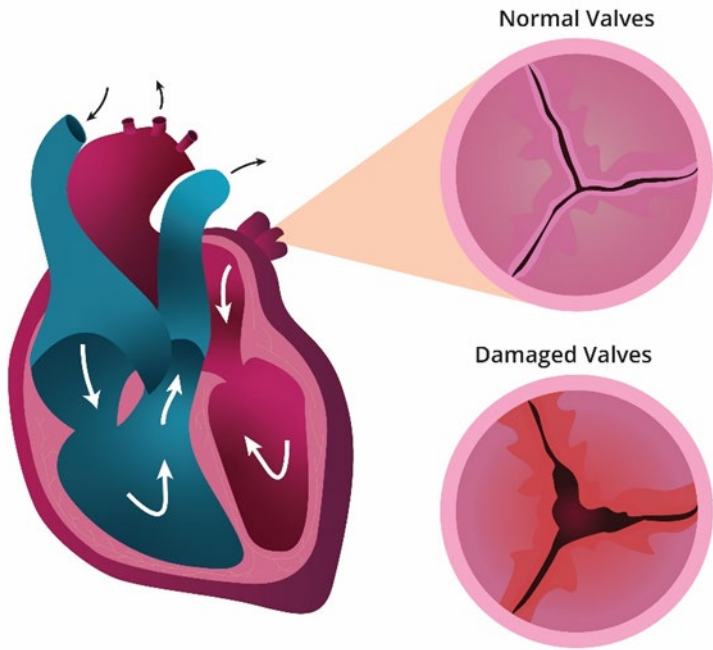
Figure 1.1 shows a diagram of the heart, comparing normal and damaged valves.

The type of valve affected and severity of damage, along with a history of ARF, are important clinical indicators for RHD diagnosis. Symptoms of RHD include fatigue, chest pain, swelling of legs, and shortness of breath. Diagnosis can be difficult as symptoms are shared with other cardiac diseases. However, many patients can remain asymptomatic despite having moderate or severe RHD.

If left untreated, RHD can cause arrhythmias (heart beats too fast, too slow, or irregularly), stroke, endocarditis (inflammation of the inner lining of the heart or its valves), and complications of pregnancy, and may be fatal.

Management of RHD includes treating symptoms and preventing worsening of disease, which requires regular medical imaging to monitor which valves are damaged and how badly. Management is complex and can involve coordination of multiple services and treatments such as primary health care, secondary prophylaxis with penicillin, and other specialist care (RHDAustralia 2020).

Figure 1.1: Diagram of the heart, comparing normal and damaged valves



Source: AIHW

Acute rheumatic fever and rheumatic heart disease are preventable

ARF and RHD are both preventable diseases. They are common in low- and middle-income countries, and among population groups living in poor socioeconomic conditions in high-income countries (Wyber & Carapetis 2015; Webb et al. 2015). ARF and RHD are caused by aspects of socioeconomic disadvantage, such as household crowding, socioeconomic deprivation, low levels of functioning 'health hardware' (for example, toilets, showers, taps) and lack of access to health care services (Webb et al. 2015; Sims et al. 2016). Improved living conditions and access to functional health hardware can reduce high rates of Strep A infections (Katzenellenbogen et al. 2017).

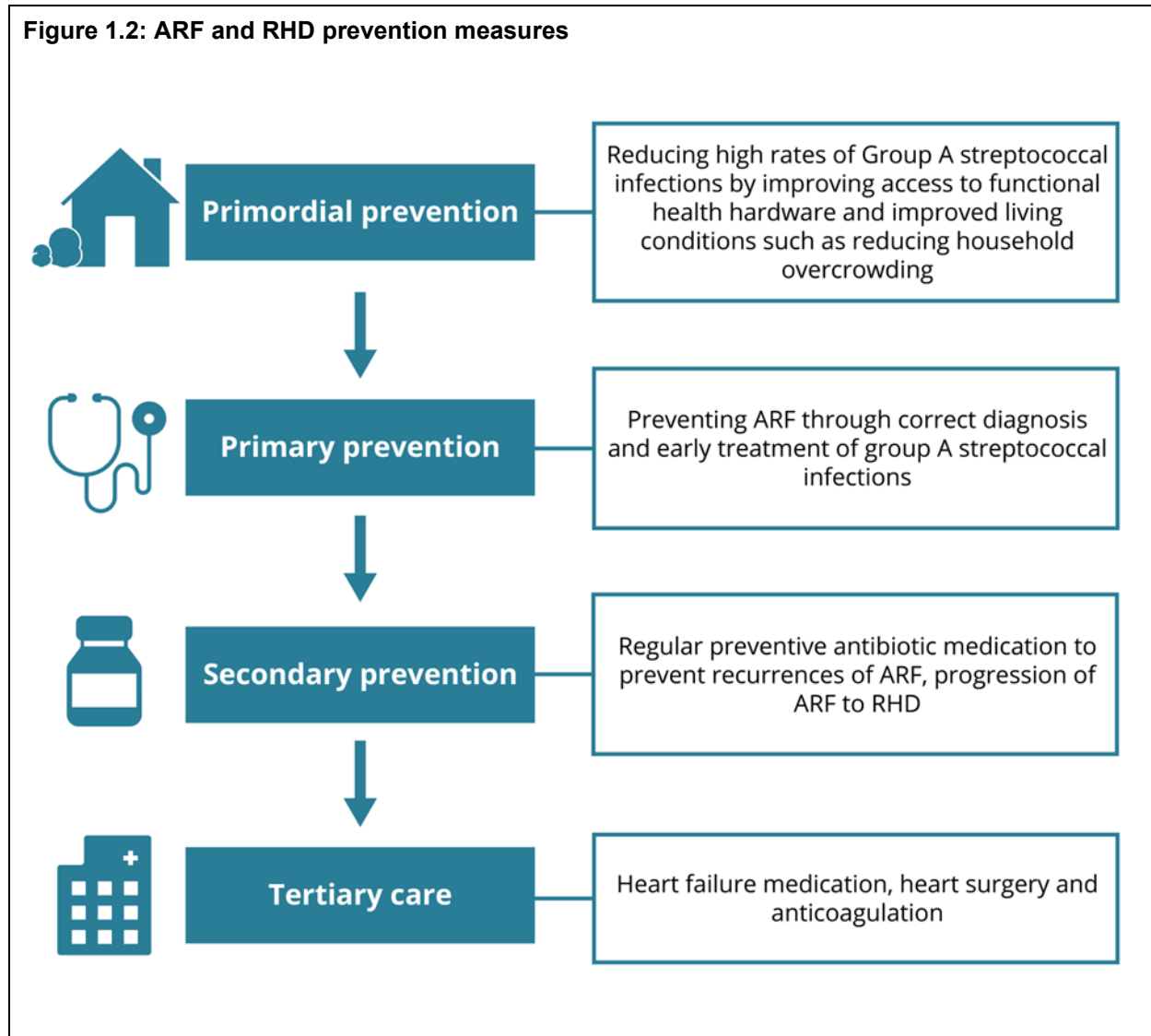
Several opportunities exist to interrupt the disease pathway from Strep A infection to ARF and then RHD (Figure 1.2). Prevention measures that improve living conditions and environmental health and address eradication of group A streptococcal infections are primordial prevention measures.

ARF is also preventable through early treatment of Strep A infections with penicillin. This is called primary prevention and relies on correct diagnosis and treatment of skin and throat infections with antibiotics as soon as possible after onset of symptoms. Timeliness of diagnosis and subsequent treatment can be negatively affected by health service access issues and delayed presentation to health services. The effectiveness of primary prevention is also compromised when the prescribed treatment does not comply with clinical guidelines (RHDAustralia 2020). Secondary prevention of the progression from ARF to RHD relies on accurate diagnosis of ARF, to enable commencement of regular antibiotic preventive medication. Correct diagnosis is challenging as there is no specific single laboratory test for ARF, and it can be misdiagnosed. Diagnosis is based on clinical criteria outlined in the Australian modification of the Jones criteria, which take into account Australia's high-risk groups (Technical notes – [Table T1](#); RHDAustralia 2020 Chapter 6).

For people with suspected or clinically confirmed ARF episodes, intramuscular injection of benzathine benzylpenicillin G (BPG) is recommended every 21 to 28 days in order to prevent further Strep A infections and thereby reduce the risk of developing recurrent ARF. Although the injection causes significant patient discomfort and inconvenience, BPG prophylaxis is by far the only clinically effective and cost-effective treatment for RHD control at both individual and community levels (Webb et al. 2015; Wyber & Carapetis 2015; RHDAustralia 2020). Tertiary care aims to slow disease progression and prevent complications associated with RHD and can include surgery to repair or replace damaged heart valves once RHD is established (Noonan 2020).

The RHD Endgame Strategy: the blueprint to eliminate rheumatic heart disease in Australia by 2031 (Wyber et al. 2020) estimated that implementing a range of strategies aimed at reducing household crowding, improving hygiene infrastructure, strengthening primary health care, and enhancing the delivery of secondary prophylaxis, would reduce ARF and RHD cases by 69% and 71%, respectively.

Figure 1.2: ARF and RHD prevention measures



This brave heart... This deadly heart... By Hayley S Kirk

I am inviting you into a story. And while it is our story, it is mostly Skout's story and how his brave heart led us on a journey to learn of a deadly heart story that just might be one of our Country's biggest, most shameful health issues.

Skout Wylie Kirk...

Skout is the youngest of my 5 children.

The day before Skout was to turn 10 years old – 7th May 2022 - he limped from school. His ankle and foot ballooning out over the top of his sock and – the ankle close to double the size of what it should normally be. When we got home, I administered ice, elevation and compression and gave him some Nurofen for the aching pain and an antihistamine just in case. By bedtime Skout's other ankle began to swell and too his wrists and hands. Within 24 hours every possible joint on his body was swollen, aching and multiple pox-wart-like bumps had appeared on his elbows. It became so overwhelming for his inflamed body that he had lost his appetite, declining even birthday cake.

Living in Sydney it can be easily taken for granted how close and accessible a world leading children's hospital is to our home. On presentation at the emergency department Skout was wheeled straight through for examination and so it began the repetition of every little detail of the, what, why, how, where, when of Skout's days was scrutinised. Calming and consoling my frightened little boy while holding my breath waiting to hear negative results to the scary stuff like lymphoma and leukemia...exhale.

"Has Skout always had a murmur in his heart?" He hadn't had a murmur...Ever. Besides recurring ear infections and tonsillitis which saw them be removed at age four and grommets in at two, my bunanay budyarra [little boy] was a healthy happy and very active child. It was a young resident doctor doing his rotation with the rheumatology team that put the pieces together. Swollen joints, rheumatic pox rash, changed heart rhythm and Strep A markers in the blood that had climbed from a usual 100 to close to 2000! After Chest x-rays, a long and detailed ultrasound on the heart, Skout was given pain relief and high dosage of anti-inflammatory medication and was admitted to hospital with suspected ARF [Acute Rheumatic Fever] – not seen at Sydney Children's Hospital for nearly 40 years!

ARF primarily affects the heart, joints, and central nervous system. Of these symptoms, the autoimmune cardiac sequelae are the most dreaded for it causes fibrosis of heart valves, leading to crippling valvular heart disease, heart failure, strokes, endocarditis, and death. To hear and comprehend this was happening to my child was highly distressing and baffling. I'm not going to lie, I had never heard of ARF and innocently asked was it an old-fashioned illness like Scarlet Fever and quote, 'like from Little House on the Prairie'?

Skout has recovered well thanks to the very fortunate access we have to preventative penicillin injections that he now has in hospital every 28 days for the next ten years. Skout has a team of doctors guiding us in his health and healing and the best news of all is that 12 months on from diagnosis and a year of monthly injections, Skout's heart has returned to being a strong and very brave heart.

Thanks to Skout and his mother Hayley for sharing their story, and to Vicki Wade for arranging its inclusion in this report.

Data collection, analysis and reporting

The Australian Institute of Health and Welfare (AIHW) is funded by the Australian Government Department of Health and Aged Care to compile and maintain the [National Rheumatic Heart Disease data collection](#), and to analyse and report annually on these data.

COVID-19 impacted both the health sector and the utilisation of health services in 2020 and 2021. This could have affected results such as diagnosis rates, BPG delivery and the number of surgeries undertaken. Further information on how the pandemic affected ARF and RHD specifically is not available.

Important notes when reading this report

The numbers in this report may not match those in previous reports

- Data in the collection are updated over time as the jurisdictional programs clean and improve their data or receive historical information.
- Service providers may not be ready to submit the data although the services have been provided in the reporting period. These data will be added in future reports when they become available.

New content in this report

- Modified the report to focus on single-year data instead of the five-year combined data of previous reports
- All statistical information for previous years has been updated as trend data in this report. Changes between years are presented in the trend analysis in each section of the report. Data in the collection are updated over time as the jurisdictional programs undertake data cleaning and quality improvement activity, so numbers in this report may not match those in previous reports. Comparisons to the results in previous versions of the report are discouraged
- In addition to regional information, the information on remoteness has been added where available. The definition of Remoteness is included in the [Glossary](#)
- Information on hospitalisations for ARF and RHD has been added
- A new chapter has been included on [socioeconomic and environmental factors](#).

Terminology

The AIHW recognises the diversity of Aboriginal and Torres Strait Islander peoples and cultures across Australia. In this report, several terms are used to refer to this population specifically based on AIHW publication guidelines, including Aboriginal and/or Torres Strait Islander, First Nations and Indigenous status. Further information on how these terms were applied in this report is available in the [Glossary](#).

About the data in this report

The data used in this report are from the [National RHD data collection](#), which is hosted and managed by the AIHW by using data from the ARF and RHD registers in the 5 jurisdictions and removing any duplications.

Throughout this report, some data from New South Wales will be incorporated with numbers from other jurisdictions and some will remain separate, depending on comparability between the jurisdictions. New South Wales data were provided directly to the AIHW from the NSW RHD register. ARF (all ages) and RHD (in persons under the age of 35 at diagnosis) became notifiable in NSW in October 2015. The register was established in May 2016. For secondary prophylaxis, the register only contains patients who consent to their information being recorded on the register. People 35 years and older at RHD diagnosis and people previously diagnosed outside New South Wales may be included on the register at the discretion of their health practitioner. Although people who were under 35 at the time of RHD diagnosis remain on the register even after turning 35, they are not included in this report as they are unlikely to be representative of people aged 35 and over with RHD in New South Wales.

Acute rheumatic fever

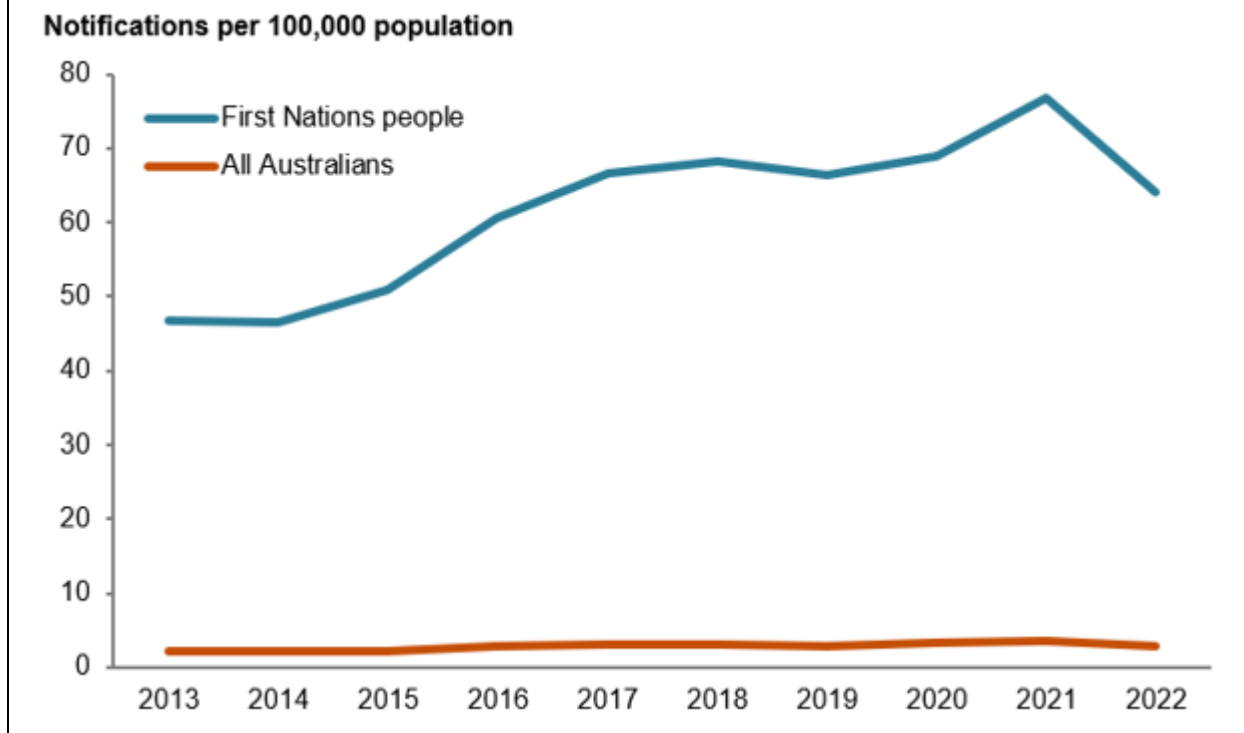
This section presents diagnoses of ARF reported by Australian RHD control programs until 2022. A person may have multiple diagnoses of ARF in their lifetime, so the number of diagnoses can be greater than the number of people affected. In this section of the report, cases are allocated to a jurisdiction and region based on where they were diagnosed.

The total number of ARF diagnoses recorded depends on the reporting practices of the various RHD registers. It is likely that ARF diagnoses are under-reported to RHD registers in all jurisdictions. A report from Agenson and others (2020) suggests that many cases of patients who attend the hospital for ARF or RHD are not reported to the jurisdictional registers.

Over 500 acute rheumatic fever diagnoses were reported in 2022

- In 2022, 533 diagnoses of ARF were recorded in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory combined. These diagnoses occurred in 525 Australians (Supplementary table 2.1)
 - 505 (95%) of the diagnoses for 497 people who were Aboriginal and Torres Strait Islander (First Nations) people, a rate of 64 per 100,000 population (Supplementary table 2.3a).
- Rates of ARF among all Australians increased from 2.1 per 100,000 in 2013 to 3.5 in 2021. There was a decrease in cases in 2022, to 2.9 per 100,000 (Figure 2.1; Supplementary table 2.2).
- From 2013 to 2022, rates of ARF among First Nations people generally increased from 47 per 100,000 in 2013 to 77 in 2021. There was a decrease in 2022 to 64 per 100,000 (Figure 2.1; Supplementary table 2.2).

Figure 2.1: Rate of ARF diagnoses, by Indigenous status and year of diagnosis, 2013 to 2022



Several factors might affect the number of cases reported in the register in each jurisdiction. Clinician awareness and reporting to the registers has likely increased in the years since the registers started and may also have been affected by the addition of ARF and RHD to the list of notifiable diseases at different times in the jurisdictions. Under-diagnosis and under-reporting to the register also means some individuals are not captured in this analysis. It is difficult to determine whether increases in the number of notifications reflect a real increase in the number of cases occurring, improved detection and diagnosis of cases, increases in the number of people being recorded on the registers, or a combination of these.

The majority of acute rheumatic fever diagnoses are in children and young adults

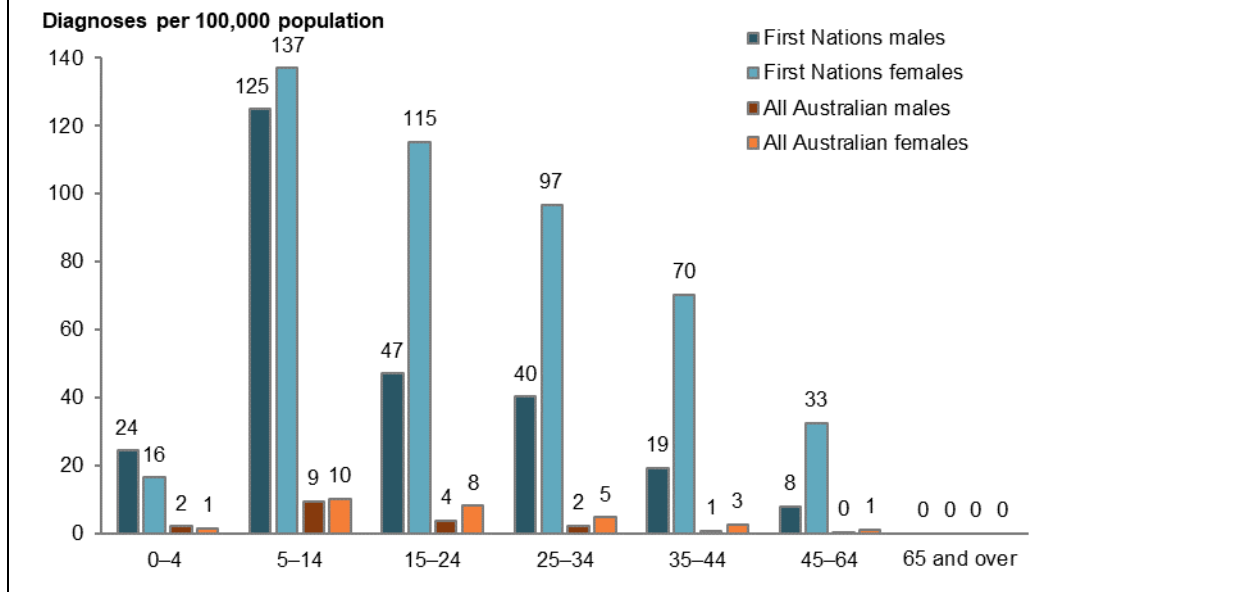
Of the 533 ARF diagnoses among all Australians in 2022:

- the most common age at diagnosis was 5–14 years
- females accounted for 61% of diagnoses
- in people aged under 15 years, ARF rates were similar among boys and girls but women 15 years and over had a higher rate than men (Figure 2.2; Supplementary table 2.3b).

Of the 505 ARF diagnoses among First Nations people in 2022:

- the highest rate of diagnosis was among those aged 5–14 years, accounting for 43% of all diagnoses
- females accounted for 62% of diagnoses
- ARF rates per 100,000 population among females were higher than those among males (Figure 2.2; Supplementary table 2.3a).

Figure 2.2: Rate of ARF diagnoses, by Indigenous status, age, and sex, 2022



Diagnoses of acute rheumatic fever are more common in remote areas

In 2022:

- the rate of ARF diagnoses among First Nations people increased as remoteness increased (Figure 2.3; Supplementary table 2.5).
- the Northern Territory had the highest rate of diagnoses per 100,000 population for all Australians (Supplementary table 2.4b) followed by Western Australia, Queensland, South Australia and New South Wales (Figure 2.4; Supplementary table 2.4a). A similar order was found among First Nations people, except the diagnoses rate was slightly higher in South Australia than in Queensland.

Figure 2.3: Percent of ARF diagnoses among First Nations people, by remoteness, 2022

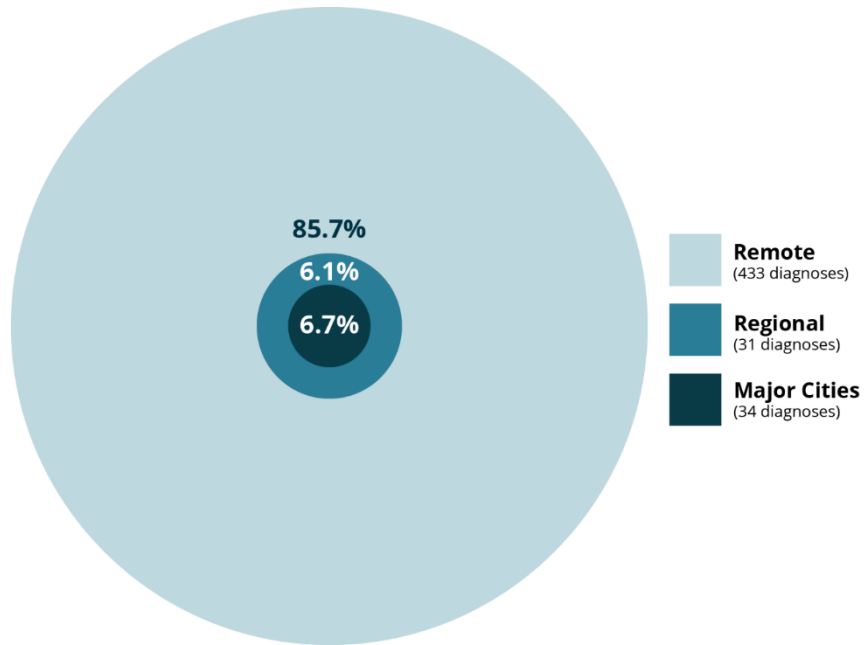
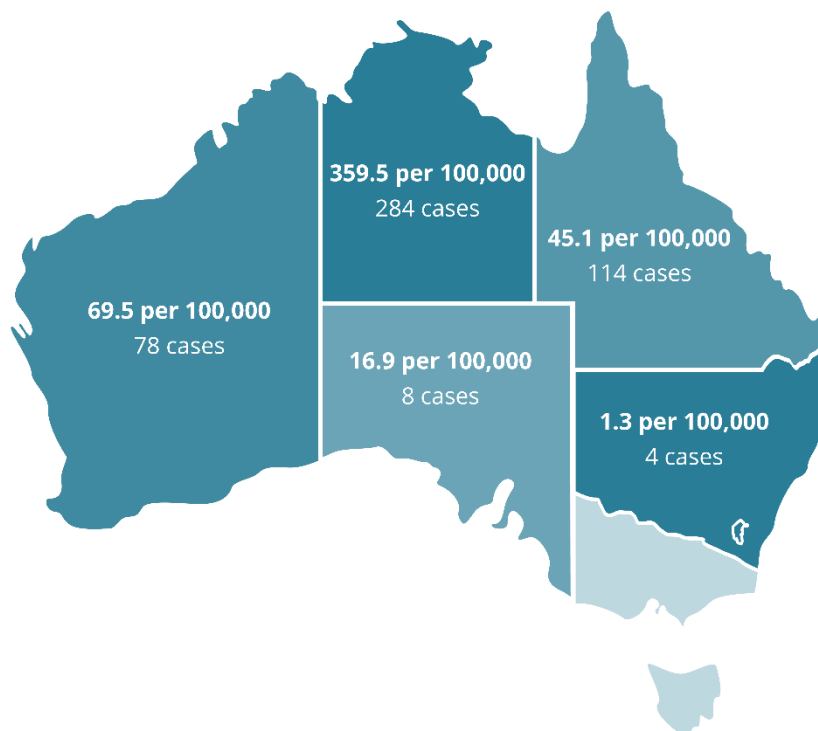


Figure 2.4: Rate of ARF diagnoses (per 100,000 people) among First Nations people, by state or territory, 2022



Symptoms of acute rheumatic fever

Diagnosing ARF can be challenging as there is no single diagnostic laboratory test – diagnosis is based on clinical decisions plus supporting laboratory evidence. The Jones diagnosis criteria was introduced in 1944 and has been periodically modified and updated in the Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (RHDAustralia 2020). Specific manifestations occurring in ARF that are reliably collected by jurisdictions and are related to an increased risk of RHD are presented in this report. These manifestations are:

- carditis
- prolonged P-R interval
- Sydenham chorea (Box 2.1).

People with carditis, a prolonged P-R interval and/or atrioventricular (AV) junctional arrhythmias are more likely to sustain heart damage (and hence to develop RHD) than those without.

Box 2.1: ARF manifestations associated with an increased risk of RHD

Carditis: inflammation of the heart muscle and heart tissue, including the membrane which lines the chambers of the heart and forms the surface of the heart valves (endocardium). It causes a rapid heart rate, fatigue, shortness of breath and exercise intolerance, and in ARF is associated primarily with the mitral valve. Carditis occurs in about 40% to 50% of people with ARF.

Prolonged P-R interval and/or AV junctional arrhythmias: detected through electrocardiography (ECG). Refers to when the time between specific electrical features of a heartbeat is longer than expected. Often the person has no symptoms.

Sydenham chorea: a neurological disorder, most commonly seen in childhood, resulting from infection with group A beta-haemolytic streptococcus, the bacterium that causes rheumatic fever. It is characterised by involuntary movements of the hands, feet, tongue and face, which stop during sleep. This is more common in females – globally it affects up to 36% of cases, and is associated with carditis.

A complete list of major and minor manifestations of ARF is provided in the Australian guideline for prevention, management and diagnosis of ARF and RHD and in [Table T1](#) of this report.

Source: RHDAustralia 2020.

In 2022, of the 505 ARF diagnoses among First Nations people, 33% had at least one manifestation of carditis, prolonged P-R interval, or Sydenham chorea (Supplementary table 2.6). The inclusion of Sydenham chorea in this value may cause an overestimation of the number of cases at higher risk of progressing to RHD, as it is most often associated with the development of carditis rather than directly with RHD.

Diagnostic categories for acute rheumatic fever

In 2022, of all 505 ARF diagnoses among First Nations people:

- 213 (42%) diagnoses were definite diagnoses
- 151 (30%) diagnoses were probable diagnoses
- 141 (28%) were possible diagnoses (Box 2.2; Supplementary table 2.7).

Box 2.2: ARF diagnostic categories

There is no one specific diagnostic test for ARF. Instead, it is diagnosed based on medical history and a pattern of clinical features ('manifestations') as follows:

Definite ARF, first episode: 2 major or one major and 2 minor manifestations plus evidence of preceding Strep A infection.

Definite ARF, recurrent episode: 2 major or one major and 2 minor manifestations or 3 minor manifestations plus evidence of preceding Strep A infection. (Prior to the 2020 RHD Australia guidelines, the manifestation requirement was one major and one minor manifestation plus preceding Strep A to confirm diagnosis.)

Probable ARF: clinical presentation falls short by either one major or one minor manifestation, or the absence of streptococcal serology results, but where ARF is the most likely diagnosis.

Possible ARF: Strong clinical suspicion of ARF, but insufficient signs and symptoms for diagnosis of definite or probable ARF.

The new guidelines were released in 2020 and may have been implemented at different times in different jurisdictions. The definitions prior to 2020 have been added in parentheses where they differ.

For more information on types of manifestations, see [Technical notes](#).

Source: RHD Australia 2020.

Acute rheumatic fever can recur, especially if left untreated

Box 2.3: ARF recurrence status definitions

First known episode: a reported ARF episode (definite, probable, or possible) in an individual with no known past ARF or RHD.

Recurrent episode: a reported ARF episode (definite, probable, or possible) in an individual with known past ARF or RHD.

First known and recurrent ARF episodes are preventable (Figure 1.2). After the first known ARF episode, adherence to secondary prophylaxis reduces the likelihood of recurrence.

Of the 533 ARF diagnoses in 2022 among all Australians in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory combined, 157 (30%) were recurrent cases.

Of the 505 ARF diagnoses among First Nations people in these jurisdictions, 152 (30%) were recurrent cases (Supplementary table 2.8).

Further analysis on recurrence rates among First Nations people on prophylaxis can be found in 'Secondary prophylaxis'.

Hospitalisations for ARF

To present a more complete picture of treatment journey for ARF patients, hospitalisation data is included here. The 2020 Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease recommend that people with suspected ARF be admitted to hospital to support timely and accurate diagnosis and prompt treatment (RHDAustralia 2020).

The data are drawn from the AIHW National Hospital Morbidity Database. This database includes data on all hospital separations in Australia, in both public and private hospitals. Further information on how hospitalisation data are collected can be found in [Appendix C](#).

In the 2021–22 financial year, there was a total of 554 hospital separations in NSW, Qld, WA, SA and NT where a diagnosis of ARF was recorded, of which 85% (471) were identified as people of Aboriginal and/or Torres Strait Islander origin.

Among these 471 hospital separations:

- there were more females (55%) than males (45%)
- almost half occurred among children aged under 15 years (Supplementary tables 2.9a and 2.9b).

Over time, the number and rate of ARF hospital separations among First Nations people increased, from 319 separations (49 per 100,000) in 2012–13 to 532 (69 per 100,000) in 2020–21, before dropping to 471 (60 per 100,000) in 2021–22. The number and rate for non-Indigenous Australians both decreased over this period (Supplementary table 2.10).

Note: The data used for this analysis are de-identified, and so reflect the number of separate hospitalisation events occurring in each year, rather than the number of people admitted.

Rheumatic heart disease

The [National Rheumatic Heart Disease \(RHD\) data collection](#) includes information about diagnoses of RHD recorded in each jurisdiction ([Table 5.1](#)). It is important to note the following:

- The total number of RHD diagnoses recorded depends on each state and territory's reporting practices, both historically and at present.
- The commencement year of each register varies, and RHD has become notifiable at different times in each jurisdiction.
- A person can have only one diagnosis of RHD, though they may be registered in more than one jurisdiction as they can receive care in different places. For the national data collection, each diagnosis was assigned to only one jurisdiction, based on location for primary health care at the time the data were submitted.

In New South Wales, RHD is notifiable only in those aged under 35 at the time of diagnosis, but it is notifiable for all ages for the other 4 jurisdictions. As New South Wales uses different inclusion criteria it is not comparable to the other 4 jurisdictions and so results for New South Wales are shown separately.

Rheumatic heart disease is more common in First Nations people

At 31 December 2022, 6,954 people were recorded as having RHD on registers in Queensland, Western Australia, South Australia, and the Northern Territory (Supplementary table 3.1b). Of these:

- 78% (5,424) were First Nations people
- most non-Indigenous Australians were not from a high-risk country of origin
- 29% were under 25 years old – with 5 being under 5 years old
- 66% were female
- the Northern Territory and remote areas had the highest prevalence rate
- the median age on the register at the end of 2022 was 37 years (Figures 3.1, 3.2 and 3.3; Supplementary tables 3.1b, 3.2, 3.3b and 3.4)
- the prevalence of RHD increased for First Nations people and all Australians over time (Figure 3.4; Supplementary tables 3.5a and 3.5b).

Figure 3.1: Prevalence of RHD, by Indigenous status and age, as at 31 December 2022

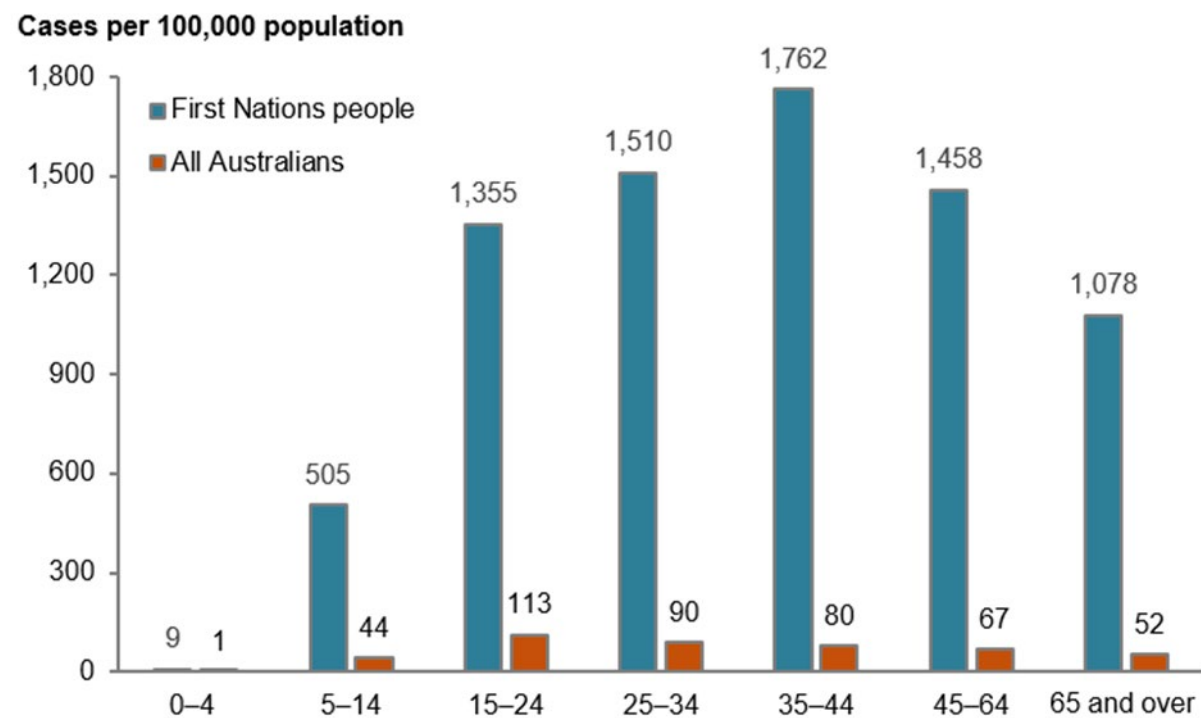


Figure 3.2: Prevalence of RHD among First Nations people, by state or territory of management, 2022

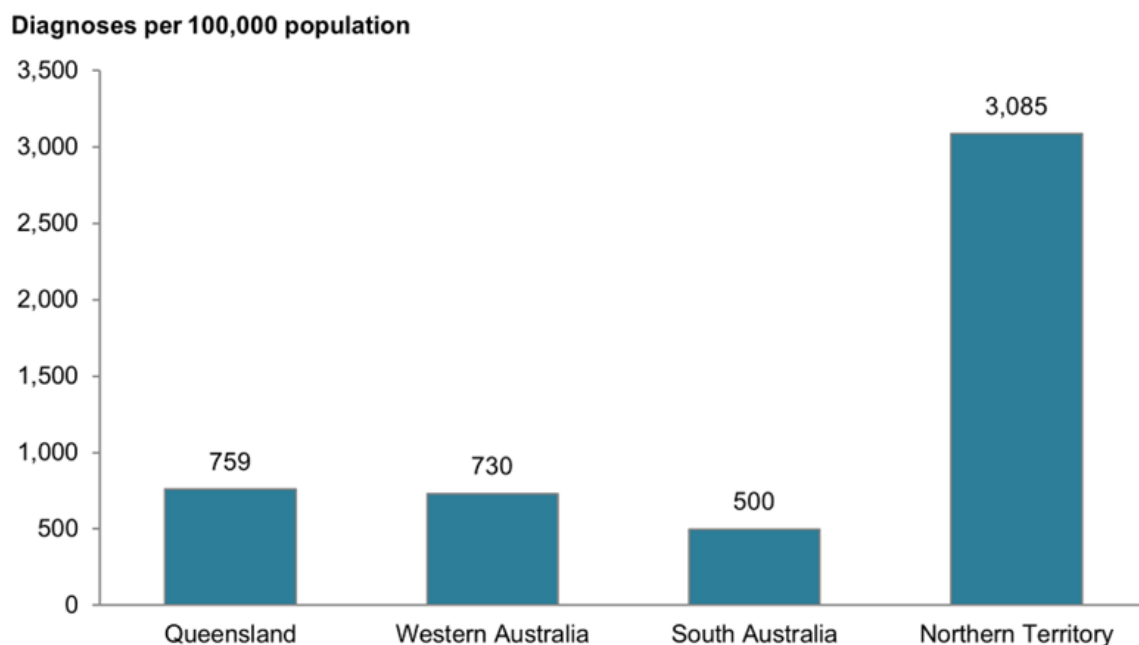


Figure 3.3: Per cent of prevalent RHD among First Nations people in Qld, WA, SA, and NT, by remoteness of management, 2022

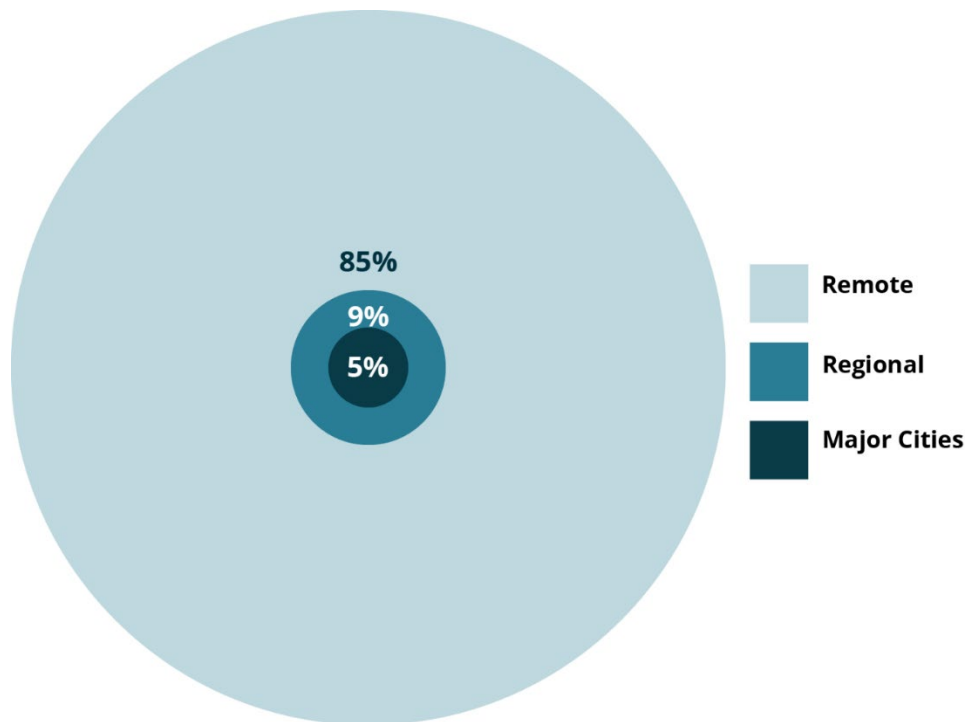
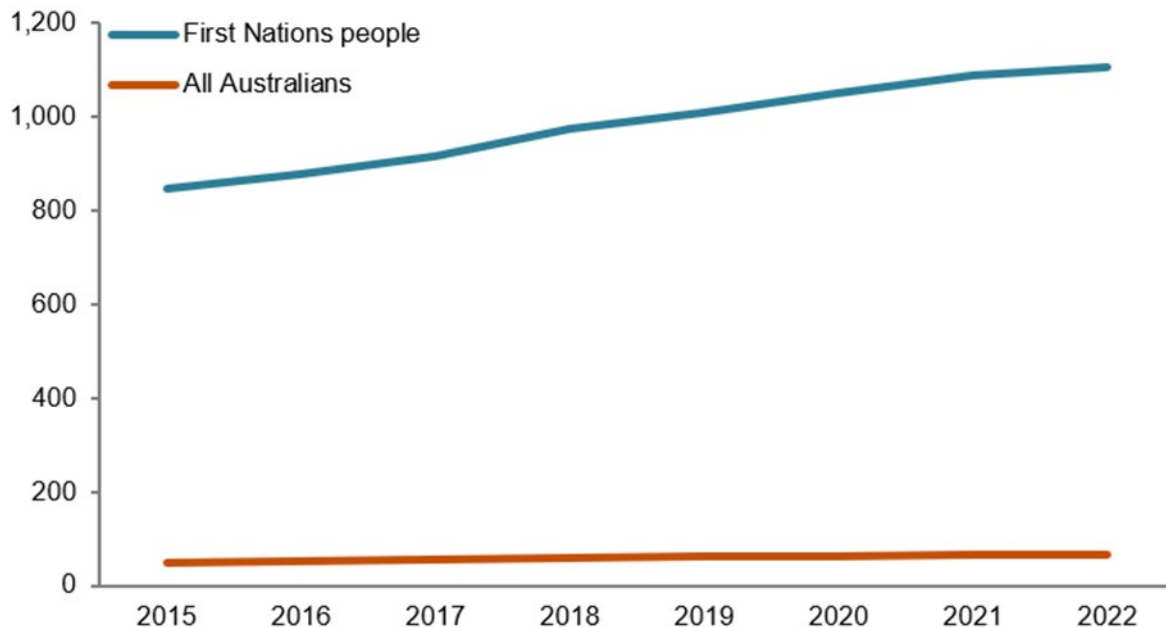


Figure 3.4: Prevalence of RHD diagnoses, by Indigenous status and year, 2015 to 2022

Diagnoses per 100,000 population



At 31 December 2022, 142 people were recorded on the New South Wales register. This is unlikely to be representative of all Australians with RHD in New South Wales as RHD is notifiable only in those under 35 at the time of diagnosis. Of these:

- 37% (53 people) were First Nations people and 63% (89) were non-Indigenous
- most non-Indigenous people with RHD were Pacific Islanders (44)
- 7.7% (11) were under 15 years old
- 55% (78) were female
- the median age on the register at the end of 2022 was 24 years (Supplementary tables 3.1b, and 3.4)
- the prevalence of RHD generally increased for First Nations people and all Australians over time, with slight fluctuations for First Nations people due to small numbers (Supplementary tables 3.5a and 3.5b).

RHD priority status at most recent assessment

A person's priority status (Table 3.6) determines the recommended care plan to meet their medical and personal needs. This status may change over time as their condition and needs change. Priority definitions changed from the 2012 guidelines to the 2020 guidelines. Some people now require ongoing management that was not previously recommended. Both definitions are explained in Table 3.6. The time of application of these changes may vary between jurisdictions.

Priority 1 is assigned to people at greatest risk of disease recurrence/ exacerbation, and requires the most frequent follow up. Priority 4 is assigned to people with the lowest risk disease, and involves the least frequent follow up.

Table 3.1: Priority definitions

Priority level	2012 Guideline	2020 Guideline
Priority 1	<ul style="list-style-type: none"> • Severe valvular disease or • Moderate/severe valvular lesions with symptoms or • Mechanical prosthetic valves; tissue prosthetic valves & valve repairs including balloon valvuloplasty 	<ul style="list-style-type: none"> • Severe RHD of any valve or • High risk post-valve surgical patients or • ≥ 3 episodes of ARF within the last 5 years or • Pregnant women with RHD (of any severity) may be considered Priority 1 for the duration of the pregnancy or • Children ≤ 5 years of age with ARF or RHD
Priority 2	<ul style="list-style-type: none"> • Any moderate valve lesion in the absence of symptoms and with normal LV function 	<ul style="list-style-type: none"> • Moderate RHD of any valve or • Mild RHD involving both aortic and mitral valves or • Moderate risk post-valve surgical patients
Priority 3	<ul style="list-style-type: none"> • ARF with no evidence of RHD or • Trivial to mild valvular disease 	<ul style="list-style-type: none"> • Mild RHD involving only a single valve or • ARF (probable or definite), currently prescribed secondary prophylaxis or • Borderline RHD currently prescribed secondary prophylaxis or • Low risk post-valve surgical patients

Priority level	2012 Guideline	2020 Guideline
Priority 4	<ul style="list-style-type: none"> Patients with a history of ARF (no RHD) for whom secondary prophylaxis has been ceased 	<ul style="list-style-type: none"> History of ARF (possible, probable or definite) and completed secondary prophylaxis or Borderline RHD not on secondary prophylaxis or Resolved RHD and completed secondary prophylaxis

Source: Adapted from The Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease 2020.

At the end of 2022, of the 5,424 First Nations people diagnosed with RHD and living in Qld, WA, SA or NT, 4,384 (81%) had a priority status recorded at their most recent evaluation. Of the 4,384 people, 24% (1,054 people) were priority 1, 22% (944) were priority 2, 47% (2,061) were priority 3, and 7.4% (325) were priority 4 (Supplementary tables 3.5a and 3.6).

There were 24 people living in NSW with a diagnosis of RHD and who had a current priority status recorded. Priority 3 was the most common priority status (Supplementary table 3.6).

New rheumatic heart disease

In this report, a 'new' RHD diagnosis (incidence) is defined as one that was newly diagnosed. In most cases, it is not possible to identify a year of onset for RHD as the condition may be asymptomatic initially. The analysis is based on year of diagnosis.

One in 3 diagnoses are in children

In Queensland, Western Australia, South Australia and the Northern Territory:

- there were 344 reports of new RHD diagnoses for all Australians in 2022
- four-fifths (272 cases) of new RHD diagnoses were among First Nations people (Supplementary table 3.9)
- new RHD was diagnosed mostly in children under 15 (32%) and women (68%) for all Australians and First Nations people (38% and 68%, respectively) (Figure 3.5; Supplementary tables 3.7a and 3.7b)
- Queensland had the most diagnoses (121 and 173, respectively) and the Northern Territory had the highest rate (138 and 45 per 100,000, respectively) among First Nations people and all Australians (Figure 3.6; Supplementary tables 3.8a and 3.8b)
- for all Australians, diagnosis rates increased between 2015 and 2018 from 3.6 to 5.7 diagnoses per 100,000 and then decreased to 3.4 in 2022 (Figure 3.7; Supplementary table 3.10b)
- for First Nations people, the rate fluctuated between a low of 55 in 2015 and 2022 and a high of 88 in 2018. It is possible that the decrease since 2020 is related to reduced access to medical services due to COVID-19 restrictions, and is not necessarily reflective of a true reduction in new RHD (Figure 3.7; Supplementary table 3.10a)

Figure 3.5: Incidence of new RHD diagnoses by Indigenous status, age, and sex, 2022

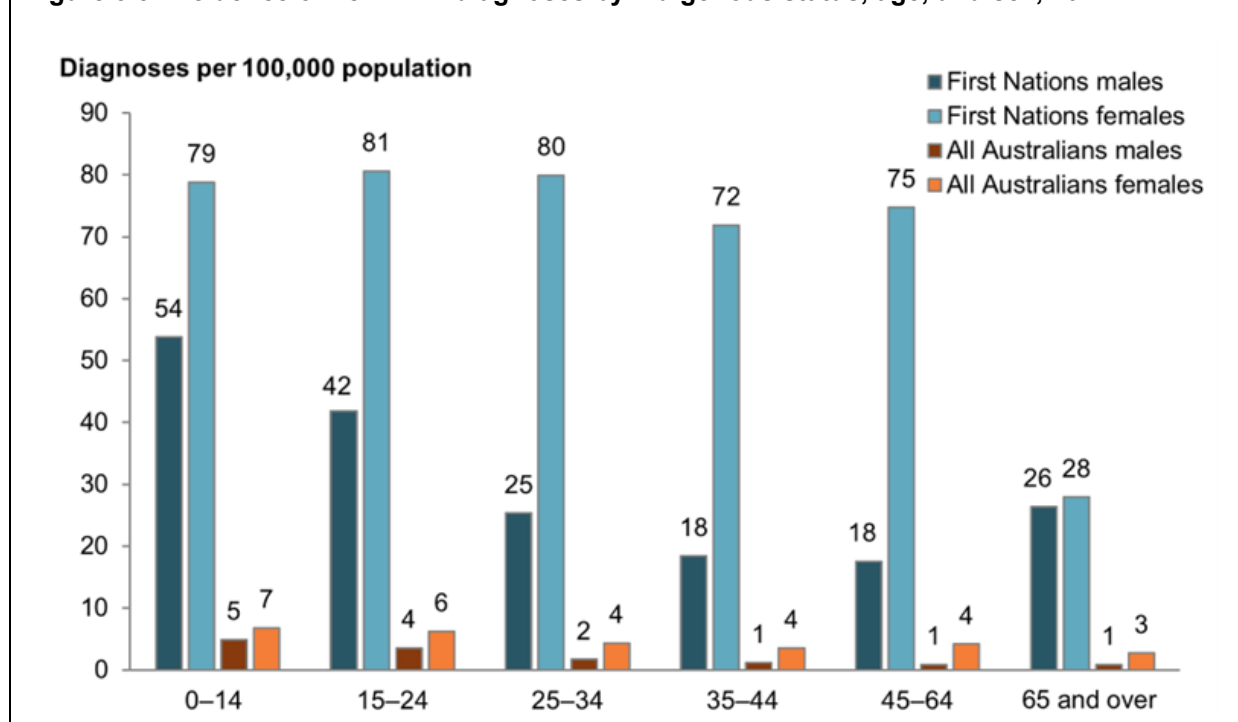


Figure 3.6: Incidence of new RHD diagnoses among First Nations people, by state or territory, 2022

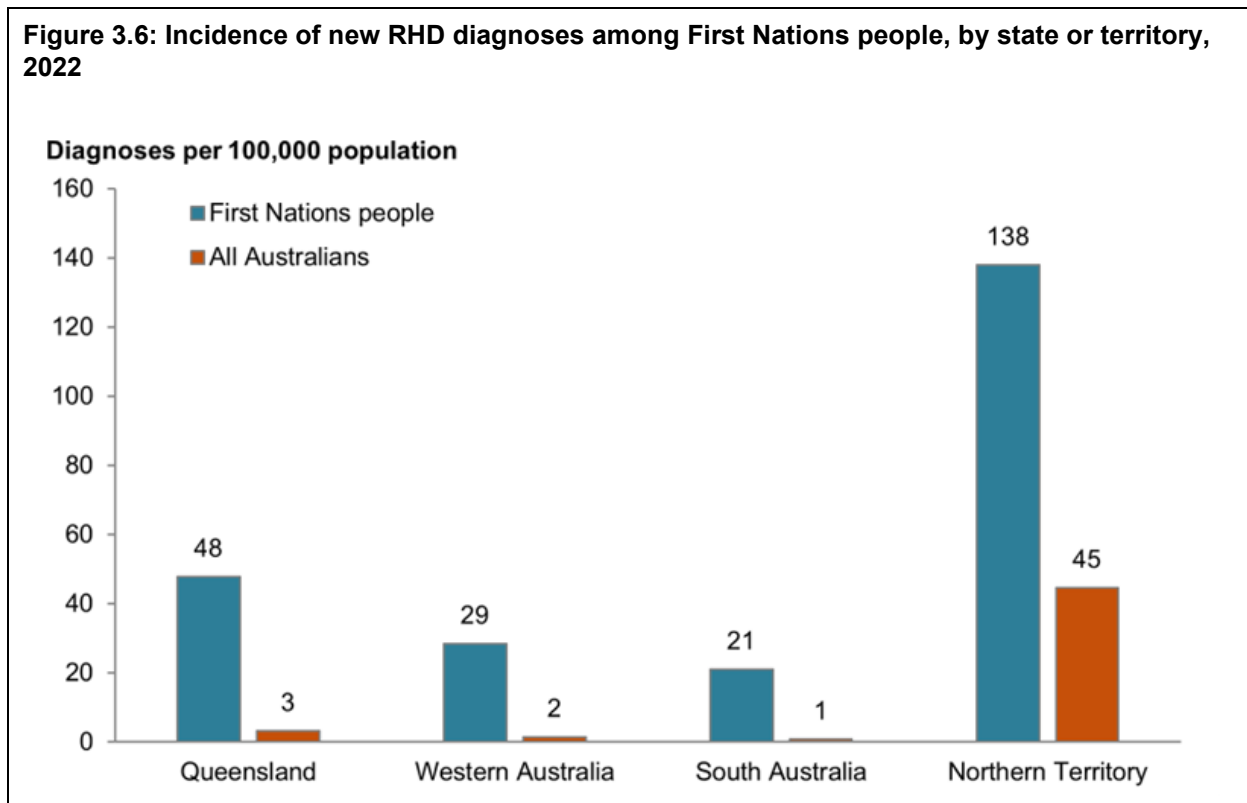
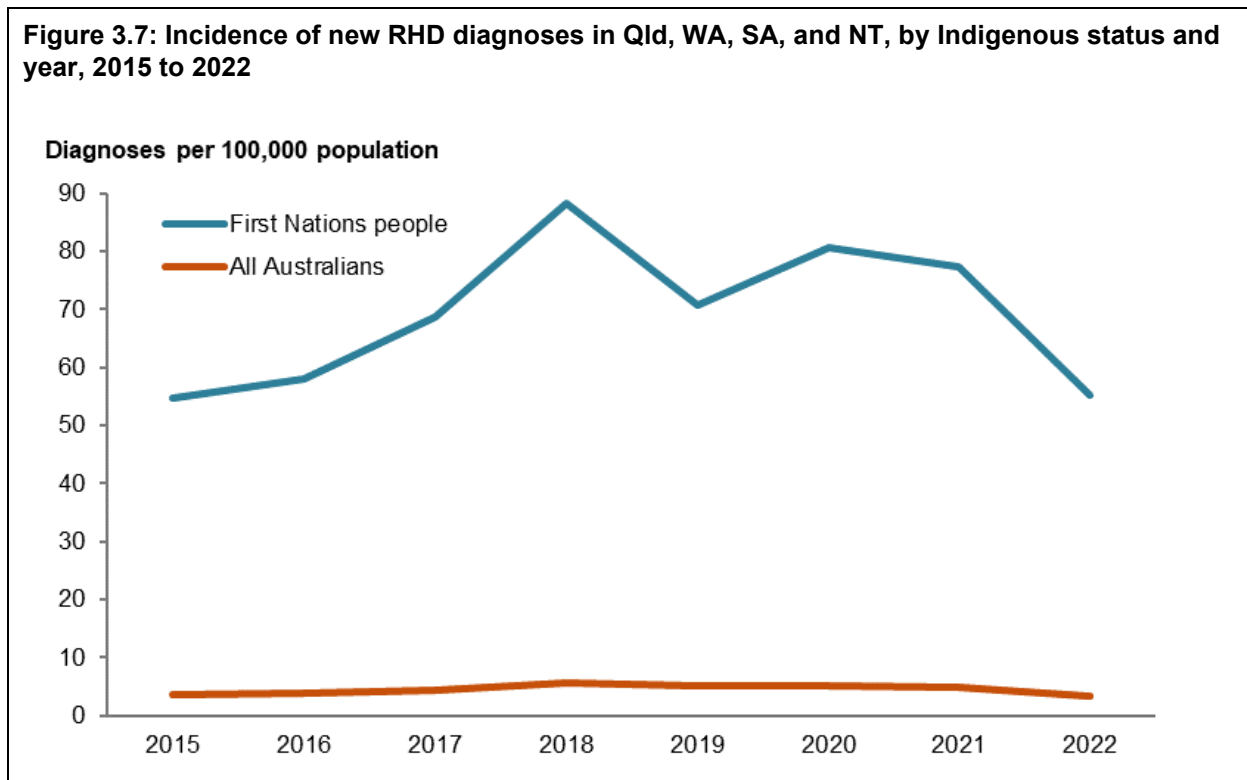


Figure 3.7: Incidence of new RHD diagnoses in Qld, WA, SA, and NT, by Indigenous status and year, 2015 to 2022



Severity of rheumatic heart disease is recorded at the time of diagnosis

Severity is collected at the time of diagnosis and can be categorised as severe, moderate, mild, or borderline, as determined by a specialist. Table 3.2 lists the definitions of each status. In reports published prior to 2023, severity and priority were combined to reflect the patient's current status and that was called severity. As such, previous reports do not have comparable data related to severity. Borderline RHD data were not available from all registers for this report.

Table 3.2: Definitions of RHD severity status

Severity status	Definitions
Severe	Severe valvular disease Or moderate/severe valvular lesions with symptoms Or mechanical prosthetic valves; tissue prosthetic valves & valve repairs including balloon valvuloplasty
Moderate	Any moderate heart valve damage without symptoms, and with normal left ventricle function.
Mild	ARF with no evidence of RHD Or trivial to mild valvular disease
Borderline	Individual ages equal to or less than 20 years at diagnosis And at least one of the following: <ul style="list-style-type: none"> • At least 2 morphological features of RHD of the MV without pathological MR or MS • Pathological MR • Pathological AR
ARF only/No RHD	ARF with no evidence of RHD

AR = Aortic regurgitation

LA = left atrium

LV = left ventricle

MS = mitral stenosis

MR = Mitral regurgitation

MV = mitral valve

In 2022, of the 211 First Nations people with severity recorded at a new RHD diagnosis in Qld, WA, SA or NT:

- 42% (88 people) had mild RHD
- 36% (76) had moderate RHD
- 22% (47) had severe RHD (Supplementary table 3.11).

No previous documented acute rheumatic fever

RHD occurs only in someone who has had ARF. Timely and accurate diagnosis of ARF is critical to reducing the risk of RHD as it will allow sufficient time for secondary prophylaxis to be effective. This also relies on timely diagnosis and treatment of Strep A infections.

Among the 272 First Nations people with a new RHD diagnosis in 2022, 78% (213) did not have a previous ARF episode recorded on the registers or were diagnosed with RHD within 90 days of their recorded first ARF episode (Supplementary table 3.12). These data show that in many cases, RHD could not have been prevented by secondary prophylaxis, and highlight the importance of primordial and primary prevention.

ARF might not be recorded on a register for various reasons, such as being diagnosed before the relevant register began; being diagnosed prior to the condition being notifiable; the person being diagnosed in a jurisdiction that does not have a register, or the episode was never diagnosed.

New diagnoses of rheumatic heart disease in NSW

In NSW, RHD is notifiable only in those aged under 35 at the time of diagnosis. In New South Wales in 2022:

- there were 9 reports of new RHD diagnoses (Supplementary table 3.7b)
- RHD diagnosis rates have remained steady between 2013 to 2022 around 0.3 per 100,000 cases (Supplementary table 3.10b).

Surgery among First Nations people with rheumatic heart disease

For analysis purposes, a surgical event was included regardless of the year of RHD diagnosis, acknowledging that the years for which jurisdictions have been collecting data vary.

Refer to [Table 5.1](#) for more information.

RHD leads to structural damage to the heart valves – most commonly the mitral valve. The aortic, pulmonary and tricuspid valves can also be affected. Surgery may be needed to replace or repair valves. Surgery may include prolonged hospitalisation, isolation from family, and ongoing regular monitoring. A person may have surgical events more than once on damaged valves and may have multiple procedures in one surgical event – that is, multiple valves repaired or replaced in a single surgery.

These figures reflect only those surgeries that were recorded in the registers and may not include all RHD-related surgery undertaken. However, comparison with data from the National Hospital Morbidity Database suggests that most RHD surgeries among First Nations people in Queensland, Western Australia, South Australia, and the Northern Territory are recorded on the registers (AIHW unpublished analysis). NSW was not included in this analysis.

RHD-related surgery in Qld, WA, SA, and the NT

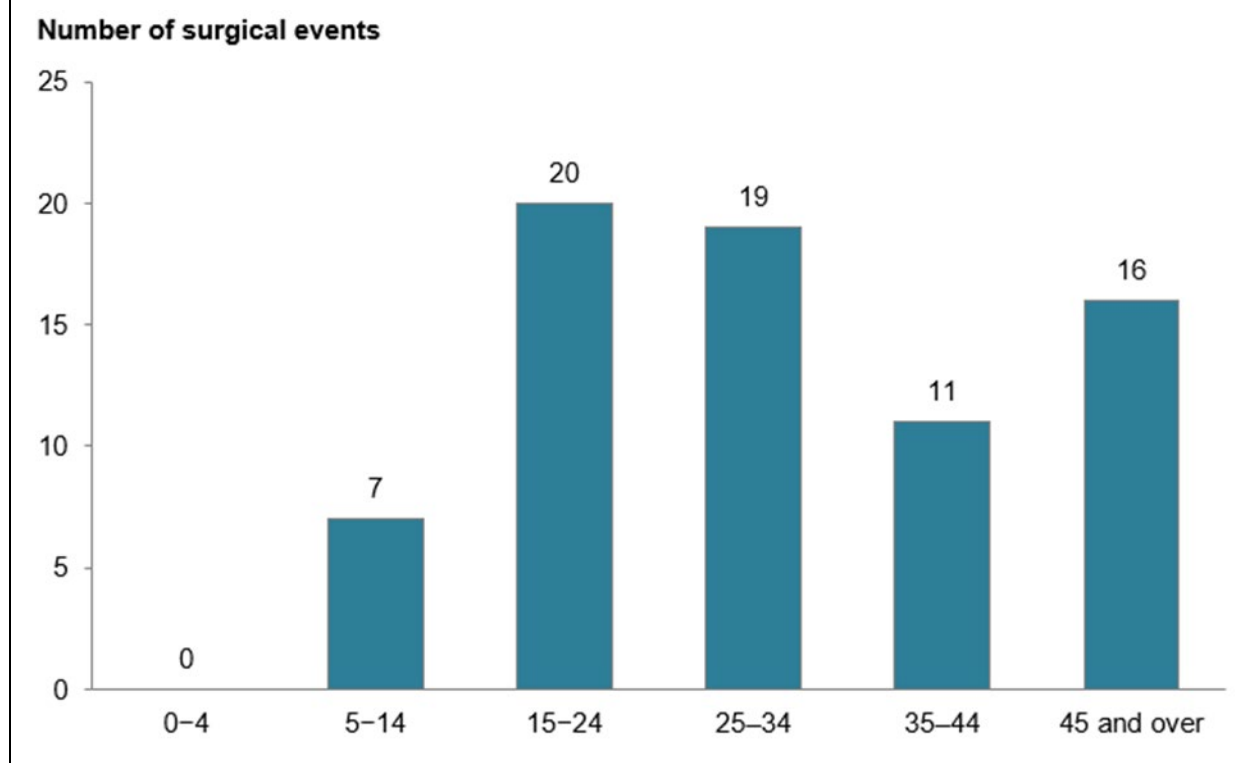
In 2022, 92 people diagnosed with RHD and living in Queensland, Western Australia, South Australia, or the Northern Territory had surgery. Of those, 73 people were First Nations people who underwent 73 surgical events (Supplementary table 3.13). Of these First Nations people:

- All people (73) had only one surgical event in that year (Supplementary table 3.14)
- 59% were female (Supplementary table 3.15)
- On average, people had their first surgery 2.4 years after RHD diagnosis (Supplementary table 3.16).

In 2022, of the 73 surgical events among First Nations people:

- most surgical events occurred among those aged 15–24, who had 20 surgical events
- No children aged under 5 years had surgery for RHD (Figure 3.8; Supplementary table 3.15)

Figure 3.8: Surgical events among First Nations people with RHD, by age group, 2022



RHD-related surgery in NSW

In New South Wales in 2022, fewer than 5 people underwent RHD surgical events. As such, there are too few cases to draw any meaningful statistical conclusions (Supplementary table 3.13).

Hospitalisations for RHD

People with RHD may be admitted to hospital for several reasons, including for diagnostic investigations, for treatment and care of symptoms or complications, or for surgery to repair or replace affected valves.

The data presented in this section are drawn from the AIHW National Hospital Morbidity Database. This database includes data on all hospital admissions in Australia, in both public and private hospitals. Further information on how hospitalisation data is collected can be found in [Appendix C](#).

In the 2021–22 financial year, there was a total of 1,823 hospital separations in Qld, WA, SA and NT where a diagnosis of RHD was recorded. Among these 1,823 hospital separations:

- The majority were in females (66%)
- Over one-third occurred among patients aged 45 to 64
- 50% (906) were for First Nations people (Supplementary tables 3.17a and 3.17b).

The number of hospital separations among all Australians ranged between around 1,700 and 2,000 separations per year between 2012–13 and 2021–22, with the rate showing a slightly decreasing trend over the period. For First Nations people the number of separations increased a little over time (from 731 in 2012–13 to 906 in 2021–22) but the rate was relatively stable at around 200 separations per 100,000 people (Supplementary table 3.18).

Note that the data used for this analysis are de-identified, and so reflect the number of separate hospitalisation events occurring in each year, rather than the number of people admitted.

Secondary prophylaxis

People with ARF and/or RHD are given regular antibiotics to prevent future Strep A infections. This is referred to as 'secondary prophylaxis'. This reduces the risk of developing ARF again and prevents developing or worsening RHD. The most effective antibiotic is BPG which is administered as an intramuscular injection. For people who are unable to use intramuscular penicillin, oral antibiotics may be offered. Secondary prophylaxis with regular BPG is the only RHD control strategy shown to be both clinically and cost effective at community and individual levels (Webb et al. 2015; Wyber & Carapetis 2015; RHD Australia 2020) and needs to be complemented with other primordial and primary prevention activities to eliminate RHD.

Benzathine benzylpenicillin G treatment recommendations

BPG is routinely recommended every 28 days to maintain prolonged, low-level benzylpenicillin concentrations. A 21-day antibiotic regimen may be considered by a medical specialist for a small proportion of patients who have breakthrough ARF despite receiving the 28-day regimen, or are at high risk of adverse consequences if ARF reoccurs. The regimen lasts 5-10 years, depending on cardiac involvement or not, or until age 21, whichever comes later (RHD Australia 2020).

In New South Wales, details of patients prescribed or administered prophylaxis are recorded on the register only if they have consented to be included. At 31 December 2022, 44% (37 people) of First Nations patients had consented to have their prophylaxis data recorded on the register (Supplementary table 4.6a). This means the NSW data are not comparable to data from the other 4 jurisdictions and are reported separately below. Due to the COVID-19 pandemic, NSW was not able to consistently follow-up with all providers of secondary prophylaxis in 2021 and 2022, so adherence in those years may be under-reported.

Delivery of benzathine benzylpenicillin G to First Nations people

Proportion of doses delivered is calculated as the proportion of the scheduled 13 doses per year for patients on a 28-day BPG regime, and 17 doses for patients on a 21-day regime. Patients who commenced part-way through the year have been included with an adjusted expected number of doses. Patients who should have been on BPG but did not receive a dose in 2022 were also included in the analysis.

Benzathine benzylpenicillin G delivery in Qld, WA, SA, and the NT in 2022

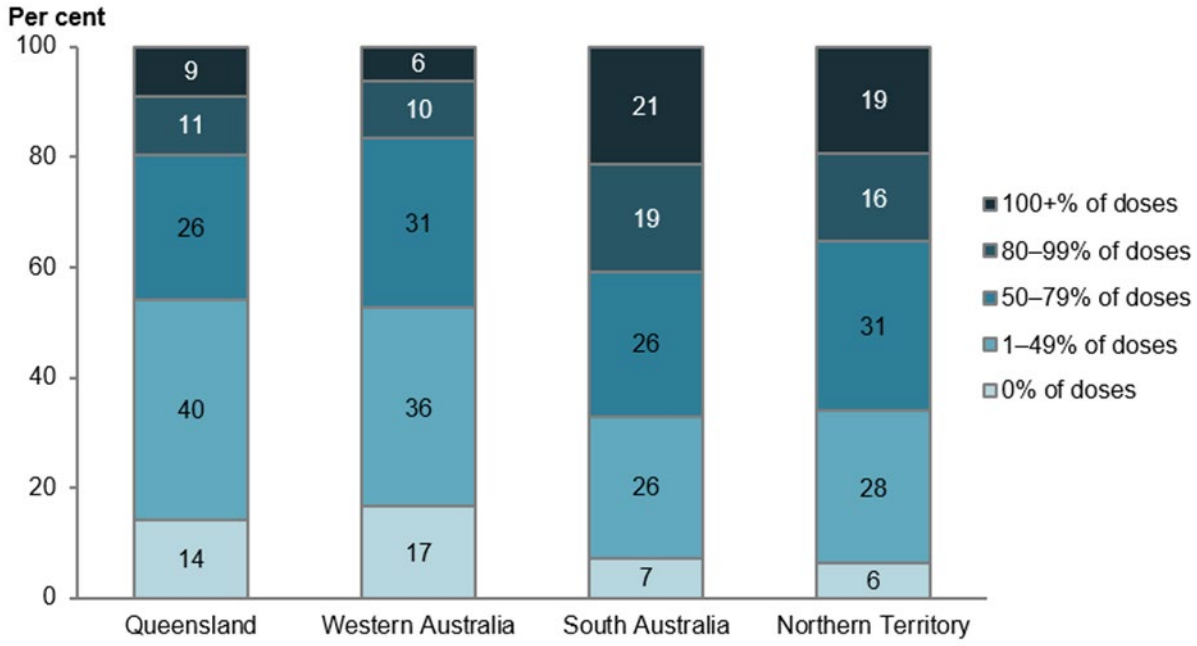
There were 4,957 First Nations people eligible for inclusion in calculations about BPG delivery in 2022. Of these:

- 14% (704 people) received 100% or more of their prescribed doses
- 14% (671) received 80% to 99% of their prescribed doses
- 29% (1,457) received 50% to 79% of their prescribed doses
- 43% (2,125) received less than 50% of their prescribed doses, including 10% (513) who did not receive any doses (Supplementary table 4.1).

In 2022, 28% (1,375 people) of First Nations people received at least 80% of doses. The proportion of people who received at least 80% of prescribed doses in each jurisdiction was:

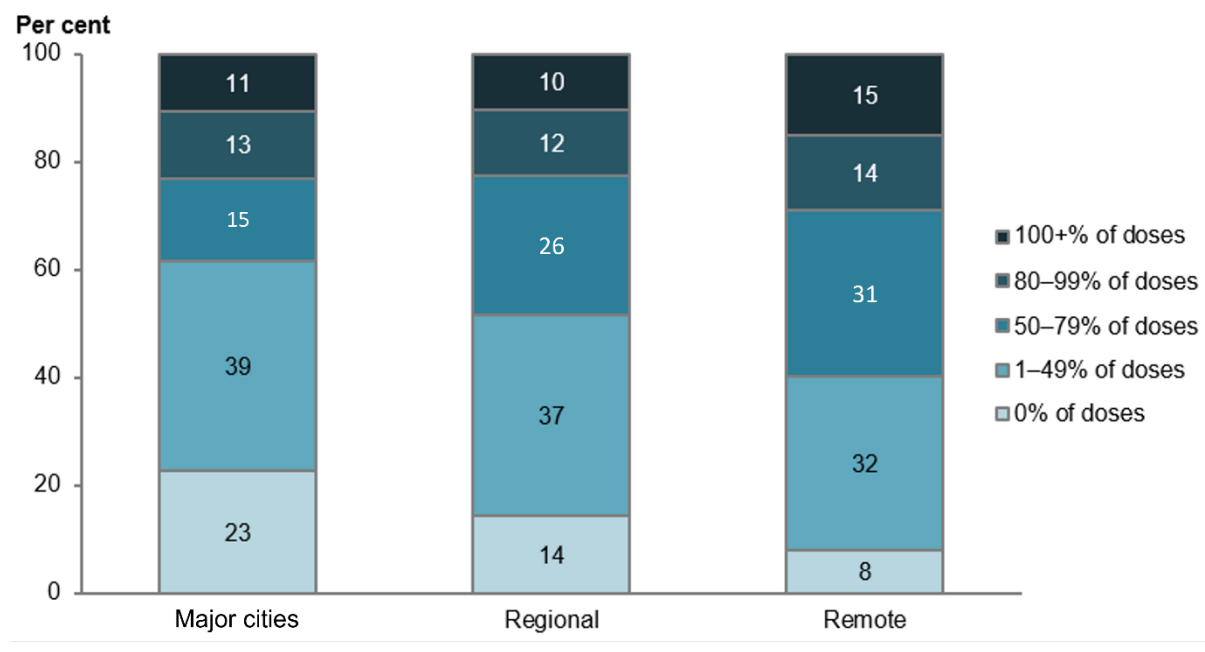
- 41% (84 people) in South Australia
- 35% (875) in the Northern Territory
- 20% (270) in Queensland
- 17% (146) in Western Australia (Figure 4.1; Supplementary table 4.1).

Figure 4.1: Proportion of doses received by First Nations people with acute rheumatic fever (ARF) and/or rheumatic heart disease (RHD) on a BPG regime, by state and territory, 2022



The proportion of people who received at least 80% of prescribed doses increased as remoteness increased (Figure 4.2; Supplementary table 4.2).

Figure 4.2: BPG delivery level of First Nations people in Qld, WA, SA, and NT with ARF and/or RHD on a 21-day or 28-day BPG regime during 2022, by remoteness



Women and children had the most doses of benzathine benzylpenicillin G delivered

In 2022, among First Nations people prescribed prophylaxis:

- more males received fewer than 40% of their prescribed doses than females and more females received at least 80% of doses than males (Figure 4.3; Supplementary table 4.3).
- delivery was highest among people aged 5–14, with 41% receiving at least 80% of doses (Figure 4.4; Supplementary table 4.4).

Figure 4.3: Proportion of doses received by First Nations people with ARF and/or RHD on a BPG regime, by sex, 2022

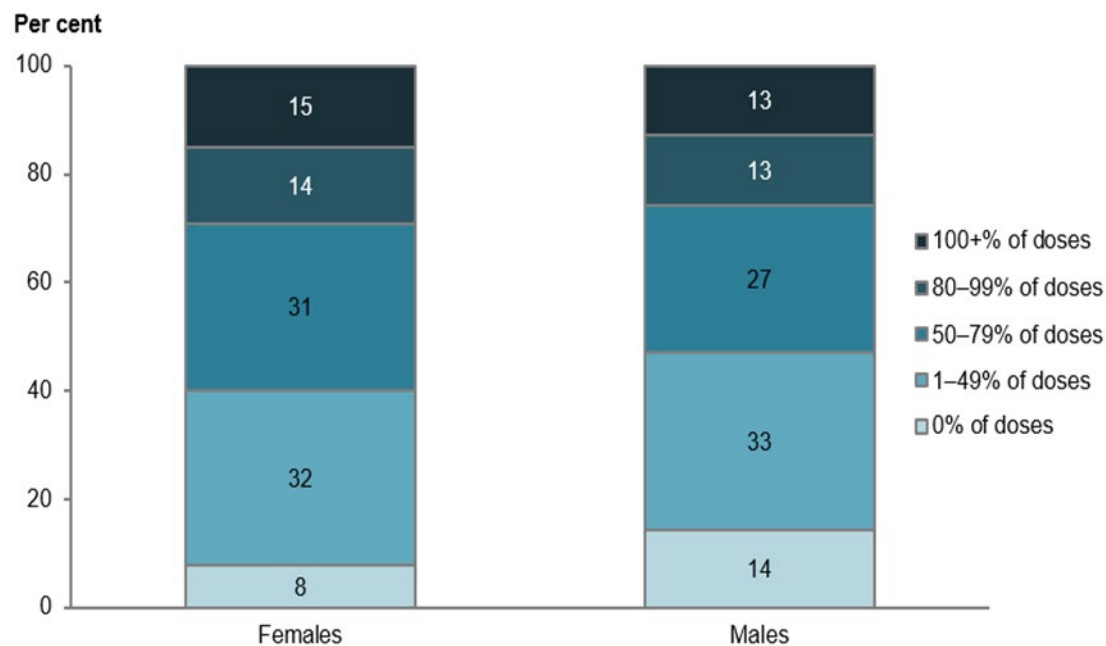
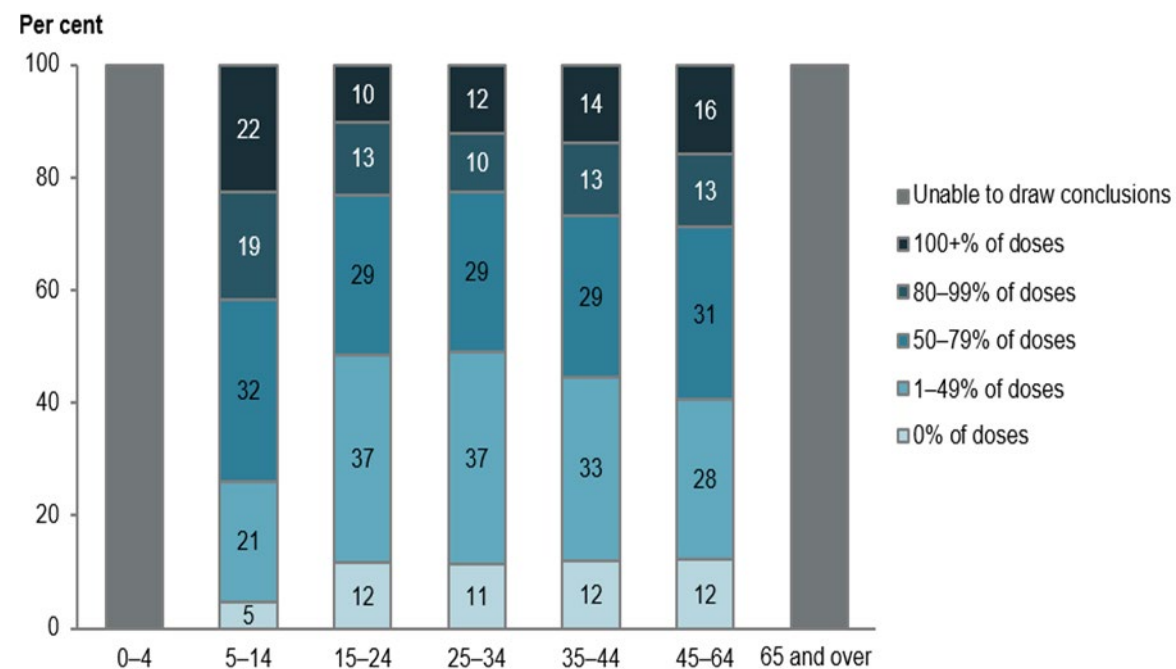


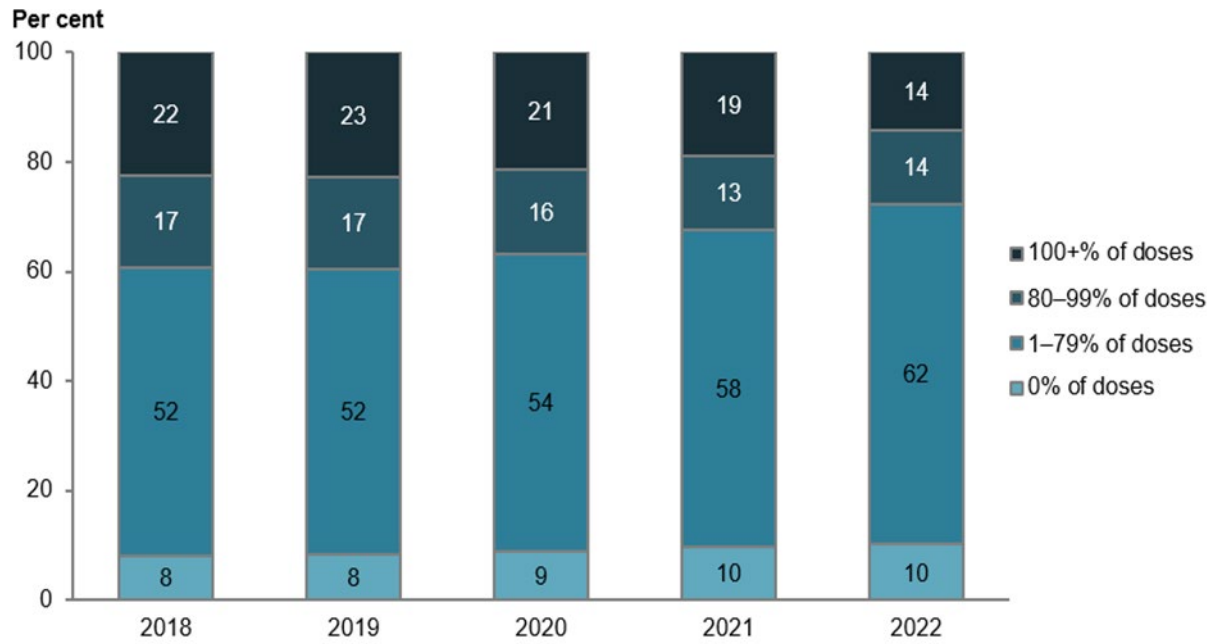
Figure 4.4: Proportion of doses received by First Nations people with ARF and/or RHD on a BPG regime, by age group, 2022



Delivery of benzathine benzylpenicillin G has decreased since 2019

The proportion of First Nations people receiving at least 80% of their prescribed doses decreased from 39% in 2019 to 28% in 2022 (Figure 4.5). In 2022, 10% of First Nations people prescribed BPG did not receive any of their prescribed doses (Supplementary table 4.5). The decrease in those receiving at least 80% of their prescribed doses could be due to the adverse impact of COVID-19 on individuals and health services.

Figure 4.5: Proportion of doses received by First Nations people with ARF and/or RHD on a BPG regime, by year, 2018 to 2022



Benzathine benzylpenicillin G delivery in NSW

As noted above, information on secondary prophylaxis in New South Wales is only available for patients who consent to share information with the AIHW. This information was available for 37 First Nations people during 2022, 31 of which should have been receiving BPG. Of these, 32% had 80% or more doses recorded (Supplementary table 4.6b).

ARF recurrence rates among First Nations people who were prescribed benzathine benzylpenicillin G

Adherence to secondary prophylaxis reduces the likelihood of recurrence. Trends in the number of recurrent ARF episodes among people prescribed secondary prophylaxis may be used to monitor the effectiveness of ARF and RHD program implementation. Recurrence rates are calculated using the rate per 100 patient-years. Further information on patient-years can be found in [Appendix B](#).

ARF recurrence rates in Qld, WA, SA, and the NT

In 2022:

- 141 ARF recurrences were reported among those prescribed BPG (3.7 recurrences per 100 patient-years)
- most recurrences were in the Northern Territory (93 recurrences)
- the rate of ARF recurrences per 100 patient-years was highest in the Northern Territory and lowest in Western Australia
- the rate of recurrence per 100 patient-years fluctuated with age, with the highest risk among those aged 45–64. There were no recurrences in those under 5 or 65 and over (figures 4.6 and 4.7; Supplementary table 4.7).
- From 2018 to 2022, the ARF recurrence rate per 100 patient-years among First Nations people prescribed BPG fluctuated between 3.7 and 4.7 (Figure 4.8; Supplementary table 4.8).

Figure 4.6: ARF Recurrences per 100 patient-years among First Nations people who have received at least one dose of BPG by state or territory, as at 31 December 2022

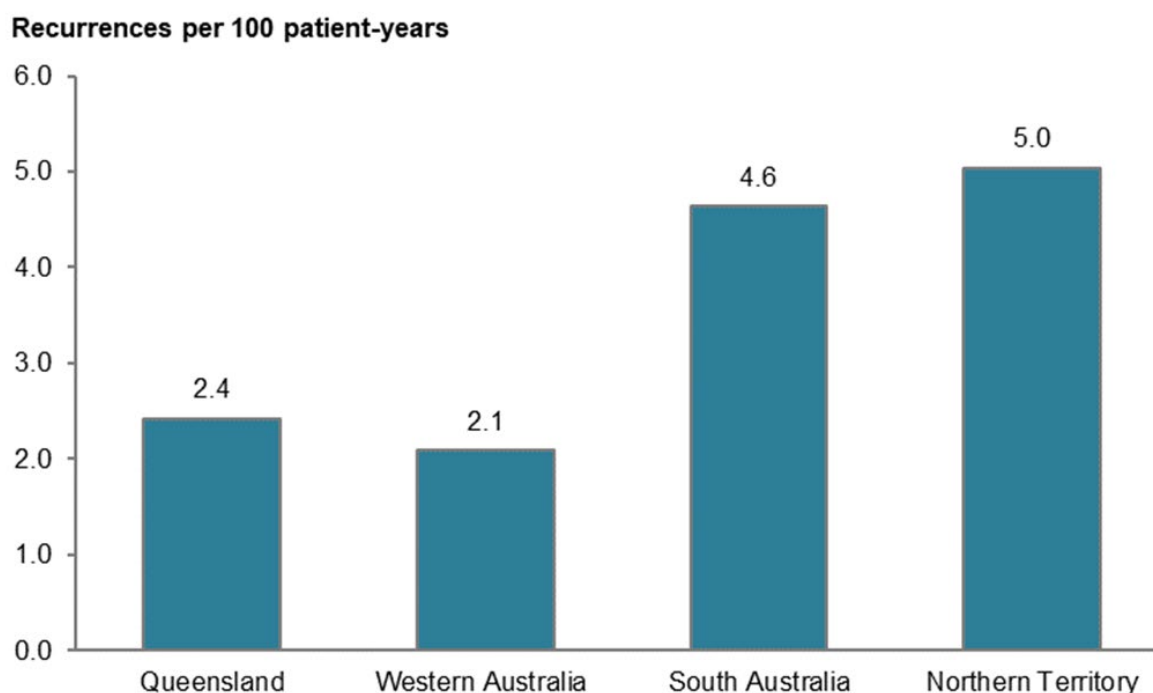


Figure 4.7: ARF Recurrences per 100 patient-years among First Nations people who have received at least one dose of BPG by age, as at 31 December 2022

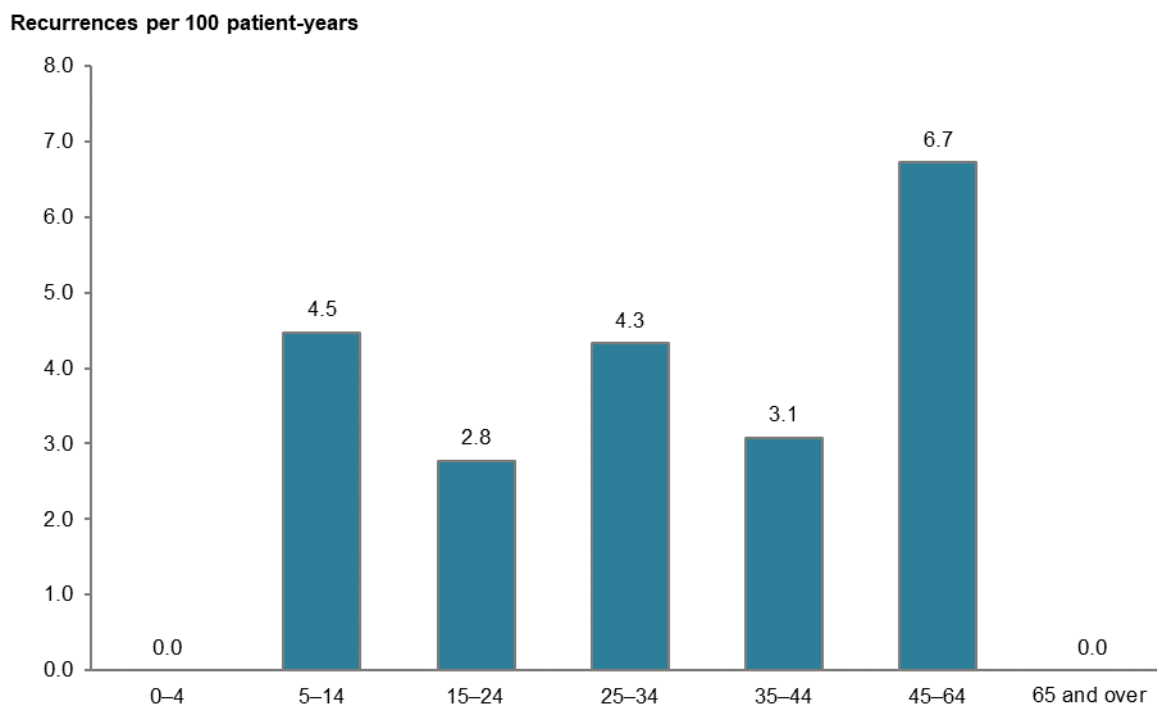
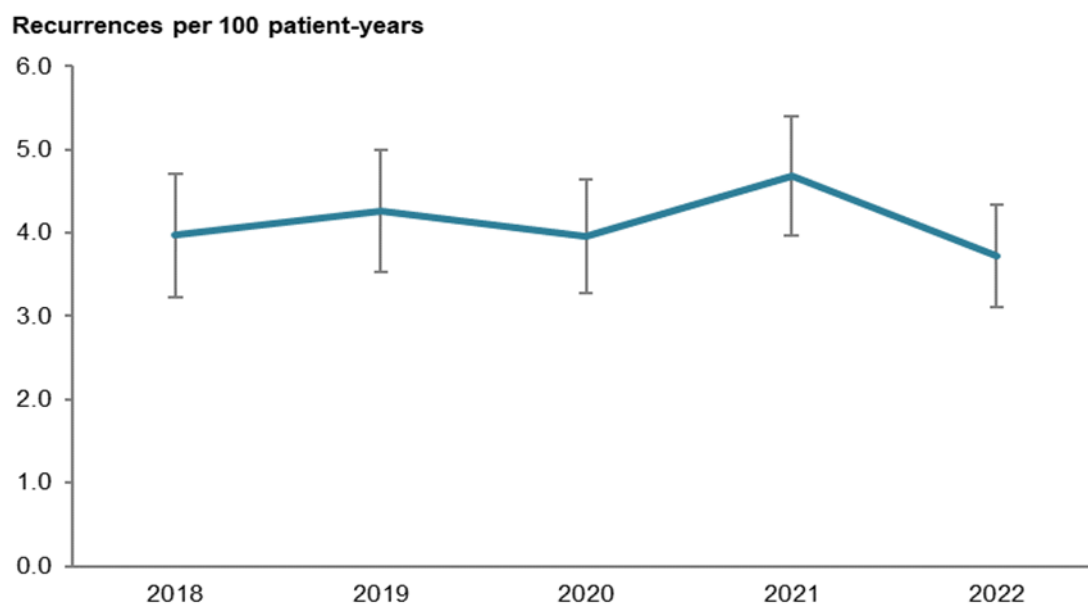


Figure 4.8: ARF Recurrences per 100 patient-years among First Nations people who have received at least one dose of BPG in Qld, WA, SA, and NT, 2018 to 2022



ARF recurrence rates in NSW

Secondary prophylaxis data are provided in New South Wales only if an individual consents to be included. In 2022, 44% (37) of people with ARF and/or RHD consented to being included (Supplementary table 4.6a).

In 2022, among 31 First Nations people who were currently prescribed BPG, there were no reported ARF recurrences (Supplementary table 4.7). The number of recurrences each year is too small to draw meaningful conclusions about change over time.

Management of acute rheumatic fever and rheumatic heart disease

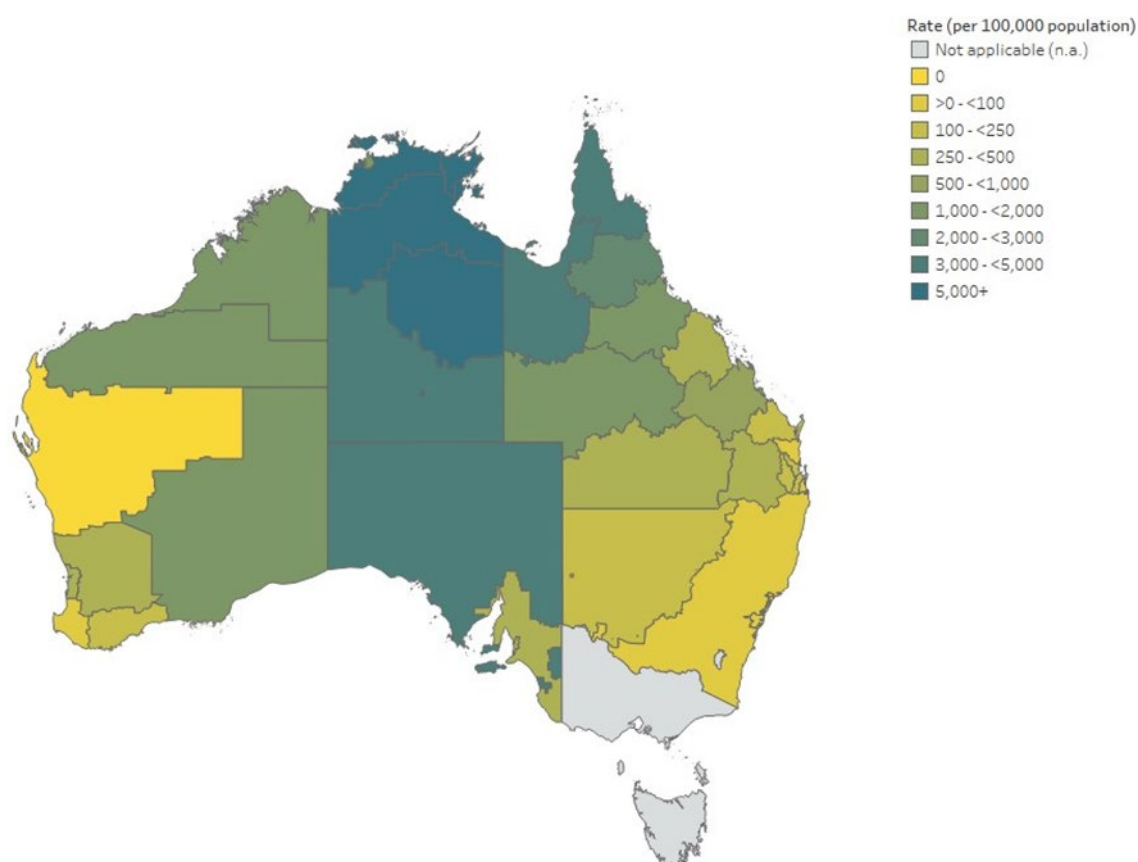
At 31 December 2022, there were 10,349 people on the RHD registers living with a diagnosis of ARF and/or RHD in New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory. Of these:

- 31% people had ARF only recorded; 30% had only RHD recorded; and 38% had both ARF and RHD recorded (Supplementary table 5.1)
- the Northern Territory had the highest number of people living with ARF and/or RHD, followed by Queensland, Western Australia, South Australia, and New South Wales (Supplementary table 5.2)
- First Nations people accounted for 82% (8,448) of the diagnoses (Supplementary table 5.2)
- more females than males were living with a diagnosis of ARF and/or RHD (Supplementary table 5.3).
- the rate of people being managed for ARF and/or RHD increased as remoteness increased (Supplementary table 5.5)

The region of management is recorded for everyone reported to the register. This is the region where the health service which is responsible for the coordination of their primary health care for ARF or RHD is located. The region of management may differ from where they were diagnosed with or developed ARF or RHD. The regions with the highest rates of management for First Nations people were:

- Rural Darwin (NT), with 7,859 cases per 100,000 population
- Barkly (NT), with 6,636 per 100,000
- East Arnhem (NT), with 6,488 per 100,000 (Figure 5.1; Supplementary table 5.4).

Figure 5.1: ARF and/or RHD diagnoses among First Nations people, by region of management, at 31 December 2022



Notes

1. Crude rates (per 100,000 population) are calculated using the number of diagnoses, divided by the regional population. The state or territory totals are from the Australian Bureau of Statistics (ABS). The remoteness populations from NSW and SA are derived from ABS data. The other regional populations are provided by each state or territory. Due to constraints in the jurisdictions, previous populations were used when new populations were unable to be supplied. Qld uses 2020 data as a proxy. WA uses 2021 data as a proxy. NT is up to date.
2. Includes all First Nations people managed for ARF and/or RHD in 2022.
3. The data excludes any ARF and/or RHD diagnoses nationally that had an unknown or other region of management.

Source: AIHW analysis of [National Rheumatic Heart Disease data collection](#).

Control programs and registers vary by jurisdiction

Under the Rheumatic Fever Strategy, the Australian Government supports RHD control programs in 4 jurisdictions: Queensland, Western Australia, South Australia and the Northern Territory (HPA 2017).

These programs are funded to support:

- improved clinical care, including improved delivery of and adherence to secondary prophylaxis antibiotics
- provision of education and training for health care providers, individuals, families and communities

- collection and provision of agreed data annually to the Australian Institute of Health and Welfare (AIHW) for national monitoring and reporting of ARF and RHD and measuring program effectiveness in the detection and management of ARF and RHD
- maintenance of a dedicated state-wide patient register and recall system for ARF and RHD.

Although an RHD control program and register operates in New South Wales, this program is not currently covered under the Rheumatic Fever Strategy.

Information from the ARF/RHD registers in these 5 jurisdictions is compiled by the AIHW to provide information about ARF and RHD in Australia.

Box 5.1: Acute rheumatic fever/rheumatic heart disease registers

All jurisdictions with RHD registers have different notification and data collection practices and therefore the numbers, data quality and completeness in the RHD registers are variable. Table 5.1 summarises the program and register establishment across the jurisdictions.

Table 5.1: Timeline of program and register establishment

Type of register or notification	NSW	Qld	WA	SA	NT	Vic	Tas, ACT
RHD control program	2015	2009	2009	2010	1997 ^(a)	–	–
ARF/RHD register	2016	2014 ^(b)	2009	2012	1997	–	–
Definite ARF notifiable	2015	1999	2007	2016	1996	2023 ^(e)	–
Probable ARF notifiable	2015	1999	2015	2016	2019	2023	–
Possible ARF notifiable	2015	1999	2015	2016	–	2023	–
Confirmed RHD notifiable	2015 ^(c)	2018 ^(d)	2015	2016	2019	2023	–
Borderline RHD notifiable	–	2018	2015	2016	–	2023	–

(a) The Top End Control Program was established in Darwin in 1997 and expanded in 2000 to include the whole Northern Territory.

(b) Prior to the current register, Queensland utilised the FERRET electronic patient record system for North Queensland Health facilities from 2009-2014.

(c) In NSW, RHD is notifiable only in persons aged under 35.

(d) In Queensland, RHD became a notifiable condition on 1 September 2018.

(e) In Victoria, both ARF and RHD became routine notifiable conditions on 31 July 2023.

Source: RHD Australia (ARF/RHD writing group) 2020.

Socioeconomic and environmental factors

Poor living conditions increase the risk of ARF and RHD. This section draws on data from the 2021 Census of Population and Housing and the 2018–19 National Aboriginal and Torres Strait Islander Health Survey to provide information on 2 key risk factors associated with ARF and RHD:

- household overcrowding
- dwelling standards.

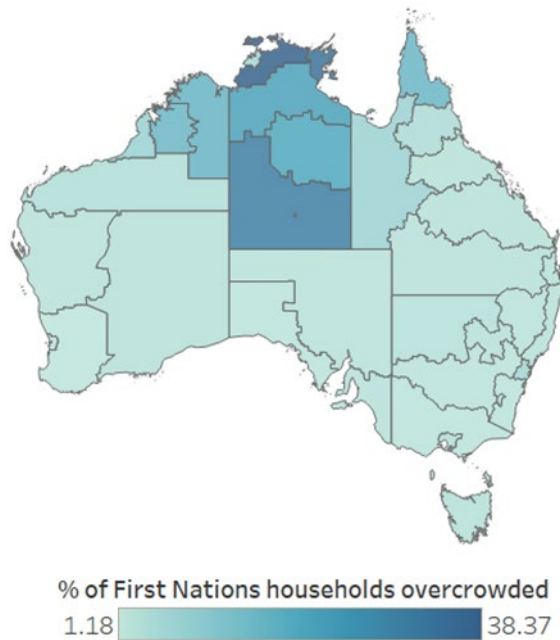
Household overcrowding

Household overcrowding is a risk factor that is associated strongly with Strep A. An overcrowded dwelling is defined here using the Canadian National Occupancy Standard (CNOS) as one that requires at least one additional bedroom to accommodate the people who usually live there, given their ages, sex and relationships to each other (CMHC 2022). Although the concept of overcrowding can be a subjective one, influenced by cultural and personal factors, the CNOS-type standard generally underpins housing design across Australia.

In 2021, about 1 in 5 (19%) First Nations people lived in overcrowded households. Households in Very remote and Remote areas were more likely than those in non-remote areas to be overcrowded (31% and 16%, respectively, compared with 8%). Among those jurisdictions where ARF/RHD data are available, the proportion of First Nations people living in overcrowded households was highest in the NT (57%), followed by WA (21%), Qld (19%), SA (17%) and NSW (13%) (AIHW 2023a and 2023b).

About 66% of all ARF and/or RHD cases are diagnosed or managed in regions that have high rates of household overcrowding (all Northern Territory regions, the Kimberley in Western Australia, and Torres Strait and Cape York in Queensland) (Figure 6.1).

Figure 6.1: Map of overcrowded First Nations households by Indigenous Region, 2021



Dwelling standards

Apart from adequate size of houses, a house in acceptable condition, with working facilities that support healthy living, is important in reducing the risk of Strep A. A house is considered to be in acceptable condition if it has no more than 2 structural problems and has the following facilities:

- Working facilities for washing people
- Working facilities for washing clothes or bedding
- Working facilities for preparing food
- Working sewerage facilities.

In 2018-19 (the most recent data available for this measure), about 69,000 (19.7%) First Nations households lived in a house that was not in acceptable condition according to the above definition. About 87% of these households were in NSW, QLD, WA, SA and NT.

In 2018–19, about 43% of First Nations households in *Very remote* areas were living in houses that were not in acceptable condition, compared with 26% in *Remote areas*, 23% in *Outer regional* areas, 14% in Inner regional areas and 17% in Major cities ([AIHW analysis of ABS 2020](#)).

More detail on the association between the 9 Healthy Living Practices and Strep A, ARF and RHD is provided in Chapter 4 of The 2020 Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease ([RHDAustralia 2020](#)).

Technical notes

Table T1: The 2020 Australian guideline for the diagnosis of ARF (modified Jones criteria)

Diagnosis or manifestation type	High-risk groups ^(a)	All other groups
Definite initial episode of ARF	2 major or one major and 2 minor manifestations plus evidence of a preceding Strep A infection ^(b)	2 major or one major and 2 minor manifestations plus evidence of a preceding Strep A infection ^(b)
Definite recurrent episode of ARF in a patient with known past ARF or RHD	2 major or one major and 2 minor or 3 minor manifestations plus evidence of a preceding Strep A infection ^(b) In the 2012 guidelines- 2 major or one major and one minor or 3 minor manifestations plus evidence of a preceding Strep A infection ^(b)	2 major or one major and 2 minor or 3 minor manifestations plus evidence of a preceding Strep A infection ^(b) In the 2012 guidelines, 2 major or one major and one minor or 3 minor manifestations plus evidence of a preceding Strep A infection ^(b)
Probable ARF (first episode or recurrence)	A clinical presentation that falls short by either one major or one minor manifestation, or the absence of streptococcal serology results, but one in which ARF is considered the most likely diagnosis. Such diagnoses should be further categorised according to the level of confidence with which the diagnosis is made: <ul style="list-style-type: none"> Highly suspected ARF Uncertain ARF 	A clinical presentation that falls short by either one major or one minor manifestation, or the absence of streptococcal serology results, but one in which ARF is considered the most likely diagnosis. Such diagnoses should be further categorised according to the level of confidence with which the diagnosis is made: <ul style="list-style-type: none"> Highly suspected ARF Uncertain ARF
Major manifestations	<ul style="list-style-type: none"> Carditis (including subclinical evidence of rheumatic valvulitis on echocardiogram) Polyarthritis^(c) or aseptic mono-arthritis or polyarthralgia Chorea^(d) Erythema marginatum^(e) Subcutaneous nodules 	<ul style="list-style-type: none"> Carditis (including subclinical evidence of rheumatic valvulitis on echocardiogram) In the 2012 guidelines, Carditis (excluding subclinical evidence of rheumatic valvulitis on echocardiogram) Polyarthritis^(c) Chorea^(d) Erythema marginatum^(e) Subcutaneous nodules
Minor manifestations	<ul style="list-style-type: none"> Monoarthralgia Fever^(f) ESR ≥30mm/h or CRP ≥30 mg/L Prolonged P-R interval on ECG^(g) 	<ul style="list-style-type: none"> Fever^(f) Polyarthralgia or aseptic mono-arthritis ESR ≥60 mm/h (ESR ≥30 mm/h in the 2012 guidelines) or CRP ≥30 mg/L Prolonged P-R interval on ECG^(g)

CRP = C-reactive protein
ECG = electrocardiogram
ESR = erythrocyte sedimentation rate
Strep A = group A streptococcus

- (a) High-risk groups are those living in communities with high rates of ARF (incidence >30/100,000 per year in 5–14 year olds) or RHD (all-age prevalence >2/1000). First Nations people living in rural or remote settings are known to be at high risk. Data are not available for other populations, but First Nations people living in urban settings, Maoris and Pacific Islanders, and potentially immigrants from developing countries, may also be at high risk.
- (b) Elevated or rising antistreptolysin O or other streptococcal antibody, or a positive throat culture or rapid antigen test for Strep A.
- (c) A definite history of arthritis is sufficient to satisfy this manifestation. Note that if polyarthritis is present as a major manifestation, polyarthralgia or aseptic mono-arthritis cannot be considered an additional minor manifestation in the same person.
- (d) Chorea does not require other manifestations or evidence of preceding Strep A infection, provided other causes of Chorea are excluded.
- (e) Care should be taken not to label other rashes, particularly non-specific viral exanthemas, as erythema marginatum.
- (f) Oral, tympanic or rectal temperature $\geq 38.5^{\circ}\text{C}$ ($\geq 38^{\circ}\text{C}$ in the 2012 guidelines) on admission, or a reliably reported fever documented during the current illness.
- (g) If carditis is present as a major manifestation, a prolonged P-R interval cannot be considered an additional minor manifestation.

Source: RHD Australia 2020.

Abbreviations

Term	Meaning
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ARF	acute rheumatic fever
BPG	benzathine benzylpenicillin G
CNOS	Canadian National Occupancy Standard
ECG	electrocardiography
NSW	New South Wales
NT	Northern Territory
Qld	Queensland
RHD	rheumatic heart disease
SA	South Australia
Strep A	group A streptococcal infection
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Symbols

Symbol	Definition
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data
\geq	greater than or equal to
\leq	less than or equal to
..	not applicable
—	nil or rounded to zero

Glossary

Aboriginal and/or Torres Strait Islander: A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander. See also [First Nations person](#)

acute rheumatic fever (ARF): An acute, serious disease that affects mainly children and young adults, and can damage the heart valves, the heart muscle and its lining, the joints, and the brain. It is brought on by a reaction to a throat or skin infection by group A streptococcal bacteria. Now very rare in the non-Indigenous population, it is still at unacceptably high levels among First Nations people living in remote areas. Also referred to as rheumatic fever.

aortic valve: Valve between the left ventricle and the aorta in the heart.

bioprosthetic valve: A prosthetic valve made from human or animal donor tissue. Used in patients with rheumatic heart disease who require surgery.

First Nations person: A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander. Used interchangeably with Aboriginal and/or Torres Strait Islander in this report. See also [Aboriginal and/or Torres Strait Islander](#).

group A streptococcus (Strep A) infection: Caused by bacteria known as group A (beta-haemolytic) streptococcus, a common infection that can cause sore throats (pharyngitis), scarlet fever or impetigo (skin sores).

health hardware: The physical equipment necessary for healthy, hygienic living within homes or communities. The term has been used to describe safe electrical systems, toilets, showers, taps, kitchen cupboards and benches, stoves, ovens and fridges collectively.

mechanical valve: A long-lasting valve made of durable materials. Used in patients with rheumatic heart disease who require surgery. Requires lifelong anticoagulant medication.

mitral valve: Valve between the left atrium and the left ventricle in the heart.

Non-Indigenous Australians: People who have declared that they are not of Aboriginal or Torres Strait Islander descent. Compare with [First Nations person](#) and [Aboriginal and/or Torres Strait Islander](#).

pulmonary valve: Valve between the right ventricle and the pulmonary artery in the heart.

region of management: The regional health boundaries are defined by each jurisdiction. For some jurisdictions, the regions align with other standard geographic classifications such as remoteness categories but for other jurisdictions the regions are state-specific areas.

rheumatic fever: see [acute rheumatic fever](#)

rheumatic heart disease (RHD): An acquired chronic disease referring to damaged heart valves caused by earlier episode(s) of [acute rheumatic fever](#).

tricuspid valve: Valve between the right atrium and the right ventricle in the heart.

valvotomy: An operation that opens up a stenosed (unnaturally narrow) heart valve and allows it to function properly. Used in patients with rheumatic heart disease who require surgery.

Valve repair: Reconstruction, restoration of diseased native valve tissue. An alternative to valve replacement and used in patients with rheumatic heart disease who require surgery.

valve replacement: Replacement of one or more of the heart valves with either an artificial valve or a bioprosthesis. Used in patients with rheumatic heart disease who require surgery. See also [bioprosthetic valve](#).

Terminology used to refer Aboriginal and Torres Strait Islander people in this report

Table G1: Table of terminology used in this report

Term	Use in this report
Aboriginal and/or Torres Strait Islander	<p>Within AIHW publications, 'Aboriginal and Torres Strait Islander (First Nations) people' is always used for initial references in a report. In longer reports, this may also be repeated at the start of each new section.</p> <p>Proper nouns remain unchanged (for example, the <i>National Aboriginal and Torres Strait Islander Health Survey</i> or the National Indigenous Australians Agency).</p>
Indigenous status	This term is only used for data directly derived from the Indigenous Status Standard question, and any relevant text, figures, graphs, or tables.
First Nations	The preferred and subsequent term for Aboriginal and Torres Strait Islander people in reports.
All Australians	'All Australians' is used when comparing First Nations people with the total population (<i>including</i> First Nations people).
Non-Indigenous	This term is used for comparing First Nations people with non-Indigenous people.

Appendix A: Calculations of ARF recurrences per 100 patient-years

ARF recurrence rate per 100 patient-years is the number of ARF recurrent events per 100 patient-years during the period that a person is prescribed prophylaxis and, therefore, at risk of ARF recurrence. The time prescribed prophylaxis is used to determine time at risk of ARF recurrence because a person is prescribed prophylaxis if they have been previously diagnosed with ARF and/or RHD and could therefore have an ARF recurrence. The numerator is the number of recurrences. The denominator of the rate is calculated by adding the time prescribed prophylaxis of all patients, where each patient's exposure time is defined as days spent in a pre-determined time period (that is, a year), ended only by events such as death or the end of the prescription period. The rate is then divided by the total number of days per year to get the value for each patient-year and then multiplied by 100.

Appendix B: Hospitalisations

The data used in this report for hospitalisation are drawn from the AIHW National Hospital Morbidity Database. This database includes data on virtually all hospital admissions in Australia, in both public and private hospitals. Data are collected for each episode of hospital care (called a hospital separation), which starts when a patient is admitted to hospital and ends when the hospital stay ends, or there is change in the type of care (for example, from acute care to rehabilitation hospital care).

Most diseases or conditions are recorded as a diagnosis following these criteria:

- Diseases are recorded as principal diagnosis when they are considered to be the primary reason for the patient being hospitalised.
- Diseases that coexist with principal diagnosis, or arise during the episode of care, are recorded as additional diagnoses when they affect the management of patients in terms of requiring therapeutic treatment, diagnostic procedures, or increased nursing care and/or monitoring (IHPA 2022).

Algorithm for identifying ARF and RHD in hospital data

The algorithm for identifying ARF and RHD in hospital data is adopted from the ABDS 2015, where the ICD-10-AM code allocations for identifying RHD and non-rheumatic valvular disease (nRVD) in hospitals data were developed (Katzenellenbogen et al. 2019). Based on this algorithm:

ICD-10-AM codes I05.0, I05.1, I05.2, I06 and I09 are counted under RHD. This includes principal (PDx) and additional (ADx) diagnoses.

However, if the PDx or ADx is I05.8, I05.9, I08.0, I08.1 or I08.3 then:

- if the person is under 60 years of age, does not have nRVD codes (I34–I39) and no congenital heart disease codes (Q20–Q28) then they are classified under RHD
- otherwise, they are counted under nRVD.

ICD-10 codes I07, I08.2, I08.8 and I08.9 are counted under nRVD.

ARF is identified by the ICD-10-AM codes I00–I02.

Appendix C: Key reporting Indicators

Table A1: 2020 Rheumatic heart disease guidelines key reporting indicators

	Indicator	Data availability (yes/no)
ARF	Yearly ARF incidence by episode type, age group, sex and Ethnicity	Yes
	Yearly ARF recurrences	Yes
	(a) as a proportion of all ARF episodes (b) rate per 100 patient-years for patients prescribed BPG (both oral and BPG)	
Rheumatic heart disease	Yearly RHD point prevalence by age group, sex, ethnicity, severity	Yes
Secondary prophylaxis	Proportion of people receiving secondary prophylaxis each year	Yes
	(a) 80-100% of doses	
	(b) 40-79% of doses	
	(c) <40% of doses	

Source: RHD Australia (ARF/RHD writing group) 2020 (3.2 edition, March 2022)

Table A2: Potential indicators from the RHD Endgame Strategy

	Indicator	Data availability (yes/no)
Primary prevention	Proportion of sore throat and skin sore infections in children assessed and treated by a trained healthcare professional.	No
ARF	Number and rate of new cases of (definite) ARF notified per time period – by age and sex, Indigenous category, region of onset.	Yes
	Proportion of ARF episodes which are recurrence.	Yes
	Number and proportion of patients with ARF recurrence.	Yes
	Number of deaths recorded with ARF as a cause (either underlying cause or associated cause of death)	No
RHD	Number and rate of incident cases of RHD, by age and sex, Indigenous category, valve involved. Severity of RHD at time of diagnosis.	Yes, except valve involvement.
	What proportion of people with mild RHD remain mild over 12-month period.	No
Secondary prophylaxis	Number of people indicated to receive secondary prophylaxis by age, sex and Indigenous category. Proportion of patients who received 100%, >80%, 50-79%, and less than 40% of doses in 12-month period.	Yes
Intervention	Provision of echos to Priority 1,2 and 3 as per current Australian Guideline	No
Mortality	Number of maternal deaths coded (or attributed, or coronial investigations) associated with RHD.	No
	Number of deaths recorded with RHD as a cause, underlying cause or associated cause of death.	No

Source: Wyber, et al. 2020

Notes

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The Australian Government Department of Health and Aged Care funds the AIHW to report on rheumatic heart disease control strategies for Queensland, Western Australia, South Australia and the Northern Territory. The New South Wales Government funds that state's control program.

Data quality statement

The [National Rheumatic Heart Disease data collection](#), held by the AIHW, contains data on diagnoses of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in Australia. It is a collation of data from ARF/RHD clinical registers held by certain states and territories in which ARF and/or RHD are notifiable diseases. In 2022, ARF and RHD were notifiable in 5 jurisdictions (New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory), although these became notifiable at different times in different jurisdictions. In New South Wales, RHD cases are notifiable only in people aged under 35 years. Diagnoses of notifiable diseases are required by law to be reported to state and territory health authorities, to enable ongoing monitoring and support public health responses.

This is the sixth annual report from the National RHD data collection. It presents information on ARF and RHD in Australia drawn from the established jurisdictional registers. Data in the collection are updated over time as the jurisdictional programs undertake data cleaning and quality improvement activity, so numbers in this report may not match those in previous reports.

In Western Australia, South Australia and the Northern Territory, the ARF/RHD control programs are funded by the Australian Government Department of Health and Aged Care. In Queensland, the ARF/RHD control programs are funded by both the Australian Government Department of Health and Aged Care and the Queensland Government. A state-funded ARF/RHD register commenced in New South Wales in 2016, with notifications starting in late 2015. ARF and RHD were made notifiable in Victoria from 31 July 2023. Data about ARF and RHD diagnoses are not currently collected by jurisdictional health departments in the Australian Capital Territory, Victoria or Tasmania.

The current Northern Territory RHD register has been collecting data since 1997. Queensland register commenced in 2009, as did the West Australian register, and the South Australian RHD register commenced in 2012. The Queensland register incorporates information from 1999 onwards, from the prior collection in the Ferret database, and transitioned to the current register in 2012. The Northern Territory register also incorporates information from a prior collection. All states have different notification and data collection practices and therefore the numbers, data quality and completion in the RHD registers are variable. In particular, in South Australia, only RHD cases aged under 50 are recorded on the register, except when they are from a high-risk population group. For some jurisdictions, consent must be sought from a patient before they are included in the register. Generally, notification and register data are maintained in separate systems and are not linked.

The registers include demographic and clinical information about people with ARF and/or RHD. Records are made of the first known ARF episode and recurrent episodes and diagnoses are classified as definite, probable or possible diagnoses. Data are collected about diagnoses' preventive treatment and episode type, level of confirmation, level of severity at diagnosis and when clinical monitoring activities or surgery are performed.

While the registers have comprehensive data, gaps remain in the availability, quality and collection. Some key performance indicators on echocardiograms, ethnicity, detection methods, wait times for surgery and deaths due to surgery could not be reported due to poor data quality or variation in collection across state and territories. Risk factor information about people in the registers, such as adverse events and living conditions, are not currently collected in any register. These data would assist in monitoring ARF and RHD epidemiology and program evaluation.

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