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Rheumatic heart disease and acute rheumatic fever in Australia: 1996–2012

CARDIOVASCULAR DISEASE SERIES NO. 36

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Authoritative information and statistics to promote better health and wellbeing

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Number 36

Rheumatic heart disease and acute rheumatic fever in Australia: 1996–2012

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Abbreviations

ABS	Australian Bureau of Statistics
ACHI	Australian Classification of Health Interventions
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
AR	aortic regurgitation
ARF	Acute rheumatic fever
ASR	Age-standardised rate
BPG	benzathine penicillin G
CKD	chronic kidney disease
CRP	C-reactive protein
CVD	cardiovascular disease
ECG	electrocardiogram
ERP	estimated resident population
ESR	erythrocyte sedimentation rate
GAS	group A streptococcus
GRIM	General Record of Incidence of Mortality
ICD-10	International Classification of Diseases, 10th revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification
METeOR	Metadata Online Registry
MR	mitral regurgitation
MS	mitral stenosis
NCCH	National Centre for Classification in Health
NHMD	National Hospital Morbidity Database
NSW	New South Wales
NT	Northern Territory
Qld	Queensland
RHD	Rheumatic heart disease

SA	South Australia
Tas	Tasmania
Vic	Victoria
WA	Western Australia
WHO	World Health Organization

Symbols

–	nil or rounded to zero
. .	not applicable
n.a.	not available
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data

Summary

Acute rheumatic fever (ARF) is rare in most developed countries, but rates among Aboriginal and Torres Strait Islander people are among the highest in the world based on available data. Rheumatic heart disease (RHD), which can be prevented by adequate treatment of ARF, also occurs at very high rates among Aboriginal and Torres Strait Islander people.

In 2009, the Australian Government's Rheumatic Fever Strategy was established to improve detection, monitoring and management of ARF and RHD through register-based control programs in the Northern Territory, Western Australia and Queensland.

Key findings

Jurisdictional incidence of ARF and prevalence of RHD:

Data on the jurisdictional incidence of ARF and prevalence of RHD come from the Northern Territory, Queensland and Western Australian Rheumatic Heart Disease registers. It is not possible to directly compare these data as the registers are at different stages of establishment and coverage.

- There were 317 recorded cases of ARF in the Northern Territory between 2005 and 2010, 178 in Queensland between 2009 and 2011, and 21 in Western Australia between 1 July 2010 and 30 June 2011.
- There were 1,479 recorded cases of RHD in the Northern Territory (at 31 December 2010), 939 in Queensland (at 27 August 2012), and 158 in Western Australia (at 30 June 2011).

Large inequalities exist between Indigenous and other Australians:

- Almost all cases of ARF recorded in the Northern Territory between 2005 and 2010 were for Aboriginal and Torres Strait Islander people (98%), with 58% in 5–14 year olds.
- In the Northern Territory in 2010, the prevalence rate of RHD among Aboriginal and Torres Strait Islander people was 26 times the rate for non-Indigenous people.
- Between 2007–08 and 2009–10, Aboriginal and Torres Strait Islander people had hospitalisation rates for ARF/RHD that were more than 6 times as high as for other Australians, but were less likely to have heart valve surgery if hospitalised.
- The death rate from RHD among Aboriginal and Torres Strait Islander people was 5 times as high as that of non-Indigenous Australians between 2004 and 2007.

RHD is a serious disease and has a substantial impact on individuals:

- Regular, long-term antibiotic treatment is recommended for people with ARF or RHD. The proportion of patients in the Northern Territory who received more than 80% of their required doses improved from 23% in 2005 to 28% in 2010, though it still remains quite low.
- Heart surgery may be required to repair heart valve damage resulting from RHD. This is likely to explain why 68% of the hospitalisations for ARF/RHD in 2009–10 occurred in people aged 55 and over.

1 Introduction

1.1 Background

What is acute rheumatic fever?

Acute rheumatic fever (ARF) is the body's autoimmune response to an untreated group A streptococcus (GAS) bacterial infection of the upper respiratory tract and possibly of the skin. The immune-mediated damage caused by ARF can affect the heart, joints, brain, skin and subcutaneous tissues (Parnaby & Carapetis 2010). While the acute episode of ARF can be extremely painful and sometimes requires hospitalisation, it causes no lasting damage to the brain, joints or skin. However, it can cause permanent damage to the heart, particularly the mitral and aortic valves, and when this occurs it is known as rheumatic heart disease (RHD). The risk of ARF recurrence is relatively high after an initial episode and repeated episodes increase the chance of long-term heart valve damage (RHD Australia 2012).

ARF most commonly occurs in children aged 5–14 but recurrent cases can occur in people aged in their mid-forties and older (Carapetis et al. 2005a). Not everyone is susceptible, with some evidence to suggest that less than 6% of people in any population have an inherent susceptibility (Carapetis et al. 2000). Further, not all strains of GAS are able to cause ARF in a susceptible host (RHD Australia 2012). In Australia, ARF is a significant cause of disease among Aboriginal and Torres Strait Islander people but occurs very rarely in other populations (RHD Australia 2012).

Correct diagnosis and early treatment of GAS pharyngitis can prevent some cases of ARF that may otherwise have developed. To date, a swab test of the throat is usually viewed as the gold standard for diagnosing GAS pharyngitis. One limitation of this method is that it takes more than 24 hours to confirm the diagnosis if traditional culture techniques are used, although rapid tests that can be used at the point of swabbing may improve the timing (although they have yet to be used widely in Australia). Although research suggests that many cases of ARF could be prevented if people with sore throats due to GAS are treated with antibiotics within 9 days of onset, it is not clear that this strategy would reduce the risk of ARF in high-risk populations (RHD Australia 2012) because most cases of ARF do not follow a sore throat due to GAS infection.

There is no specific laboratory test for diagnosing ARF so diagnosis is based on clinical criteria—the Jones criteria and more recently the World Health Organization (WHO) criteria (RHD Australia 2012). The 2012 Australian guidelines for diagnosing ARF are based on a modified version of the Jones and WHO criteria that takes into account Australia's high-risk groups, particularly Aboriginal and Torres Islander people. These updated Australian guidelines are described in Appendix D (Table D1).

Once a diagnosis of a first episode or recurrence of ARF is suspected, the patient should be admitted to hospital to ensure that all investigations are performed and to confirm the diagnosis (RHD Australia 2012). One of the main aims of the management of ARF is to prevent further recurrences by use of regular secondary prophylaxis (that is, secondary prevention) with benzathine penicillin G (BPG), which has been shown to be the only clinically effective and cost-effective RHD control strategy at both community and population levels (RHD Australia 2012). More information about secondary prophylaxis for ARF and RHD control is in Chapter 5.

What is rheumatic heart disease?

RHD manifests as permanent damage to the heart muscle or heart valves as a result of ARF. Such damage can reduce the ability of the heart to pump blood effectively around the body, leading to symptoms such as shortness of breath after exercise and feelings of fatigue and weakness. Severe forms of the disease can result in serious incapacity or even death. The diagnosis guidelines for RHD are described in Appendix D Table D2.

Heart valve damage is a common presentation of RHD, often in the form of stenosis or regurgitation. Stenosis occurs when a heart valve becomes smaller and stiffer, obstructing the flow of blood. Regurgitation occurs when a valve fails to close properly and some blood flows back into the heart instead of around the body, increasing the workload of the heart and reducing its output. Symptoms of both stenosis and regurgitation include shortness of breath on exertion, weakness and fatigue. Mitral regurgitation is the most common occurring valve lesion in RHD.

These symptoms of RHD can also occur with other heart conditions, making a definitive diagnosis more difficult. Signs of damage detected by echocardiography and a history of ARF are both important clinical indicators for RHD diagnosis.

The best practice guidelines for managing RHD include access to culturally appropriate primary care services; secondary prophylaxis with penicillin; adequate monitoring of anticoagulation therapy in patients with atrial fibrillation and/or mechanical prosthetic valves; access to oral healthcare; access to echocardiography; access to a specialist physician, paediatrician and/or cardiologist, preferably the same specialist, for regular follow-up visits; and access to cardiothoracic and interventional cardiology services (RHD Australia 2012).

Risk factors and prevention of acute rheumatic fever and rheumatic heart disease

GAS infection is a major risk factor for the development of ARF and any factors that would increase individual exposure to these bacteria contribute to the risk of ARF. Both untreated ARF and the recurrence of ARF are major risk factors for RHD. In addition to GAS throat infection, it has been suggested that pyoderma (a GAS skin infection that is often secondary to scabies) may also be a risk factor for ARF, particularly among Indigenous communities living in a tropical climate (McDonald et al. 2004). Exposure to GAS is closely related to overcrowded housing, a low level of hygiene and poor sanitation.

Socioeconomic and environmental factors play an important, but indirect role, in the magnitude and severity of ARF and RHD. A shortage of resources for providing good quality health-care services, inadequate knowledge and experience of health-care providers, and a low level of awareness of ARF in the community can have a significant impact on the early detection of ARF and the development of further complications (WHO 2004).

Poor socioeconomic conditions, overcrowding and poor sanitation exist in some Aboriginal and Torres Strait Islander communities, contributing to the spread of GAS bacterial infections and scabies, and so potentially to the development of ARF (Australian Health Ministers' Advisory Council 2011). In addition, the lack of access to medical care, such as in some remote communities, increases both the likelihood of recurrent episodes of ARF and of ARF progressing to RHD.

ARF has almost disappeared in the non-Indigenous populations of developed countries, mainly due to improvements in living conditions (Quinn 1989). The cases of RHD that

remain in these populations occur mostly among the elderly—a legacy of the higher childhood rates of ARF in developed countries before the 1960s. However, high rates of RHD still exist in many developing countries, and in Australia the prevalence of RHD is very high among Aboriginal and Torres Strait Islander people.

Implementing the intensive treatment regimens required for long-term prevention of ARF and RHD has proven difficult in Australia's remote Indigenous communities. Current guidelines recommend that secondary prevention of RHD requires a 4-weekly injection of penicillin to be given for at least 10 years (RHD Australia 2012). In communities where socioeconomic disadvantage and lack of access to medical services are commonplace, effective prevention, diagnosis and treatment of the disease remain ongoing challenges.

How Australia compares

Most of the international studies documenting the incidence of ARF and prevalence of RHD have been conducted in school-age children aged 5–14 (Carapetis et al. 2005b). Rates of ARF and RHD are high in Aboriginal and Torres Strait Islander children aged 5–14 compared with other Australian children and non-Indigenous children of the same age from other developed countries (Carapetis et al. 2005b). For more information, see Chapter 6.

Why is it important to understand acute rheumatic fever and rheumatic heart disease?

ARF and RHD are important to understand and investigate because they are preventable diseases. There are two patterns of ARF and RHD observed that are relevant to the health of the Australian community. The first, and most important, is that large inequalities exist in the occurrence of ARF between Aboriginal and Torres Strait Islander people and other Australians. The second consequence is that health problems related to RHD remain among our older population (that is, those aged 65 and over) for both Indigenous and other Australians, due to higher rates of ARF across the whole population when that generation was younger. This can result in the need for significant medical procedures, including heart valve replacements for a considerable number of people each year. For example, about 1,200 people aged 15 and over who were hospitalised with a principal diagnosis of ARF or RHD in 2009–10 had at least one heart valve procedure performed.

There has been recent investment in ARF and RHD as a result of the Australian Government's 2008-09 Budget measure 'New Directions: An equal start in life for Indigenous children' that included funding for a Rheumatic Fever Strategy. The strategy aims to improve detection, monitoring and management of ARF and RHD in Aboriginal and Torres Strait Islander communities through register-based control programs in the Northern Territory, Western Australia and Queensland. The control programs provide education and training for health-care providers, families and communities and support improved delivery of secondary prophylaxis and clinical care. A national coordination unit—RHD Australia—was also established under the strategy to develop a data collection and reporting system, and to support improvements in the diagnosis and clinical treatment of ARF and RHD.

Demographics of Aboriginal and Torres Strait Islander people

As ARF and RHD are more common in the Indigenous population in Australia, it is important to understand the demographics of this population. In 2010, it was estimated there were about 563,100 Aboriginal and Torres Strait Islander people in Australia, representing

2.6% of the Australian population (AIHW 2011a). The Northern Territory had the highest proportion of Indigenous Australians (29.8%) in 2010, followed by Tasmania (4.0%), Queensland (3.6%) and Western Australia (3.3%), while Victoria had the lowest (0.7%). However, the majority of Aboriginal and Torres Strait Islander people live in New South Wales (29% of the total Australian Indigenous population), Queensland (29%), Western Australia (14%) and the Northern Territory (12%).

As a population group, Indigenous Australians are significantly younger than other Australians. For example, Aboriginal and Torres Strait Islander people aged under 15 constitute 35% of the total Indigenous population, whereas this age group represents about 19% of the total Australian population. Conversely, those aged 65 and over comprise only 3% of the Indigenous population, compared with 14% of the total Australian population (AIHW 2011a).

1.2 Aims

The aims of this report are to present the latest available data on the incidence of ARF (the number of new and recurrent cases reported for a given period), the prevalence of RHD (the number of existing cases at a given time), and hospitalisations and deaths for ARF and RHD in Australia. In particular, this report examines and presents data on:

1. The incidence of ARF and the prevalence of RHD in Australia.
2. The demographic characteristics (age, sex and Indigenous status) of those hospitalised with, and who die from, ARF and RHD.
3. Hospitalisation rates for ARF and RHD, and death rates for RHD, by state and territory.
4. The main hospital procedures performed for ARF and RHD.
5. International comparisons of hospitalisation and death rates for ARF and RHD.

1.3 Data sources and methods

The main data sources used in this report are the AIHW National Hospital Morbidity Database; the AIHW National Mortality Database and AIHW GRIM (General Record of Incidence of Mortality) Books; Northern Territory, Queensland and Western Australian ARF notifications data; data from the Northern Territory, Queensland and Western Australian Rheumatic Heart Disease registers; and the AIHW Disease Expenditure Database. Further information about the national data sources analysed in this report is in Appendix B. Further information about ARF notifications data and the Northern Territory, Queensland and Western Australian Rheumatic Heart Disease registers is in Chapter 2. The statistical methods used in this report are described in Appendix C.

What's missing from the picture?

Consistent national data on the incidence of ARF and the prevalence of RHD are not available. The majority of data currently available are drawn from the Northern Territory, Queensland and Western Australia where ARF is a notifiable disease and where register and control programs have been established. The development of specifications for a minimum data set and a data collection system by RHD Australia in partnership with the jurisdictional RHD programs will further support detection and management of ARF and RHD.

2 Acute rheumatic fever

2.1 Incidence

It is not possible to give a complete picture of ARF in Australia as no national incidence data exist. However, jurisdictional data are available from the Northern Territory, Queensland and Western Australian Rheumatic Heart Disease registers. In addition, ARF has been a notifiable disease in the Northern Territory since 1994 (RHD Australia 2012), and it became a notifiable disease in Queensland in 1999 (Queensland Health: Sweeny & Beard 2009) and in Western Australia in September 2007 (Western Australia Department of Health 2012). ARF is not a notifiable condition in any other jurisdiction in Australia (RHD Australia 2012).

Acute rheumatic fever notifications

In the Northern Territory, all new and recurrent cases of ARF are notified to the Centre for Disease Control by doctors and the data are published quarterly in *The Northern Territory Disease Control Bulletin*. In Queensland, confirmed new and recurrent cases of ARF are notified to, and published by, Queensland Health. Similarly, all new and recurrent cases of ARF in Western Australia are notified to the Western Australian Department of Health's Notifiable Infectious Disease Database and published regularly.

Northern Territory

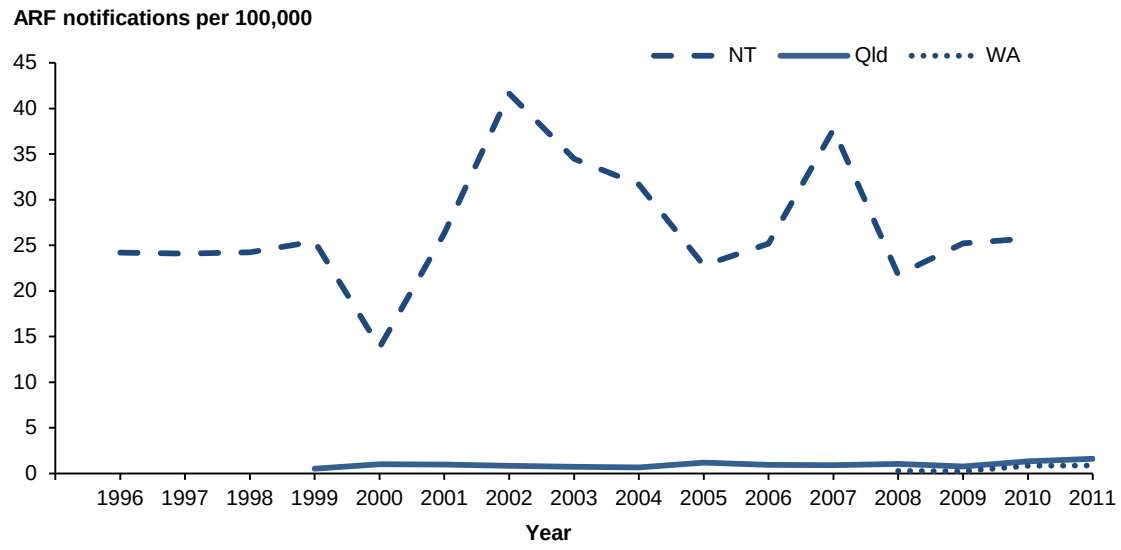
Over the 15 years from 1996 to 2010, there were 823 cases of ARF notified in the Northern Territory, at an average rate of 26 notifications per 100,000 population per year. However, the annual rate of notifications varied considerably over this period. Notification rates were reasonably stable at 24 to 25 notifications per 100,000 population between 1996 and 1999 before dropping to their lowest level over the 15 years in 2000 (14 notifications per 100,000 population) (Figure 2.1). There was a sharp increase in notification rates between 2000 and 2002 (42 per 100,000) followed by a fall between 2002 and 2005 (23 per 100,000). Another sharp increase in rates occurred between 2005 and 2007 (38 per 100,000) but rates then fell again in 2008 (22 per 100,000). Notification rates have risen slightly since 2008, with the rate in 2010 being 26 per 100,000 population.

Dr Keith Edwards from the Northern Territory Rheumatic Heart Disease Control Program, at the Centre for Disease Control, Northern Territory Department of Health, suggested that one explanation for the peak in notification rates in 2007 is that an audit in that year found 30 to 40 clients who were not on the RHD register and these patients were all added at once (K Edwards 2012, pers. comm., 5 May). If the date of onset of ARF of most of these patients was actually before 2007 then the notification rate in 2007 would be lower than 38 per 100,000 population.

Dr Edwards also advised that the penicillin Bicillin® L-A, which is used in the secondary prevention of ARF, was temporarily out of stock in 2007. Although patients with ARF and RHD were protected by receiving a different form of benzathine penicillin instead, patients with skin sores who did not have ARF or RHD may not have received benzathine penicillin, and this may have caused an increase in GAS skin disease that, in turn, may have caused more cases of ARF (K Edwards 2012, pers. comm., 5 May).

It is possible that the sharp increase in notification rates between 2000 and 2002 coincided with increased awareness of ARF in the Northern Territory after the establishment of the

RHD register in Central Australia. Educational campaigns by clinicians at various times over the 15 years might also explain fluctuations in ARF notification rates over time.



Sources: Western Australia Department of Health 2012; Queensland Health 2006, 2008, 2012; Queensland Health: Sweeny & Beard 2009; Northern Territory Centre for Disease Control 1998, 2002, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011; Queensland Health 2012; Territory Health Services 1999, 2000, 2001.

Figure 2.1: Acute rheumatic fever notifications, Northern Territory, Queensland and Western Australia, 1996–2011

Queensland

Between 1999 and 2011, there were 502 cases of ARF notified in Queensland at an average rate of 1.0 per 100,000 population per year. ARF notification rates in Queensland between 1999 and 2011 based on the total Queensland population were much lower than the corresponding rates in the Northern Territory (Figure 2.1). However, it should be noted that, over this period, Aboriginal and Torres Strait Islander people accounted for about 3% of the Queensland population, compared with 30% in the Northern Territory. Therefore, given that most cases of ARF occur in Aboriginal and Torres Strait Islander people, notification rates in Queensland would be considerably higher if calculated based on the Aboriginal and Torres Strait Islander population.

While there has been some fluctuation in ARF notification rates in Queensland over the 13 years, overall the rate increased from 0.5 to 1.5 notifications per 100,000 population (Figure 2.1). As with the fluctuations in the Northern Territory, the rise in Queensland after 2009 might be explained by increased awareness of ARF after the establishment of the Queensland Rheumatic Heart Disease Register and Control Program register in 2009, while the fluctuations before this might be explained by educational campaigns by clinicians at various times. Further, Queensland Health introduced a process for routinely looking for missed cases of ARF at the end of 2004 and, in 2006, a North Queensland Rheumatic Heart Disease Program Coordinator was recruited. These initiatives are likely to have contributed to the 41% increase in the number of ARF notifications in North Queensland between 1999–2004 and 2004–2009 (Hanna & Clark 2010).

Western Australia

Since September 2007 when ARF became a notifiable disease in Western Australia, 50 cases have been notified. Between 2008 and 2011, the ARF notification rate increased from 0.3 to 0.9 per 100,000 population (Figure 2.1). ARF notification rates in Western Australia between 2008 and 2010 were much lower than the corresponding rates in the Northern Territory and were also lower than the corresponding rates in Queensland (Figure 2.1).

Northern Territory, Western Australian and Queensland Rheumatic Heart Disease Control Program registers

The Northern Territory Rheumatic Heart Disease Control Program register was established in the Top End of the Northern Territory (Darwin) in 1997 and in Central Australia (Alice Springs) in 2000 (Noonan et al. 2001; Parnaby 2011). In 2007, the two registers were amalgamated into a single register for the Northern Territory. The Northern Territory register includes data related to ARF and RHD diagnosis, hospitalisations, compliance with prophylactic antibiotic treatment, clinical progress, surgery and deaths. The register is run by the Northern Territory Department of Health. Confidentialised data from the register were provided to the Australian Institute of Health and Welfare (AIHW) for analysis.

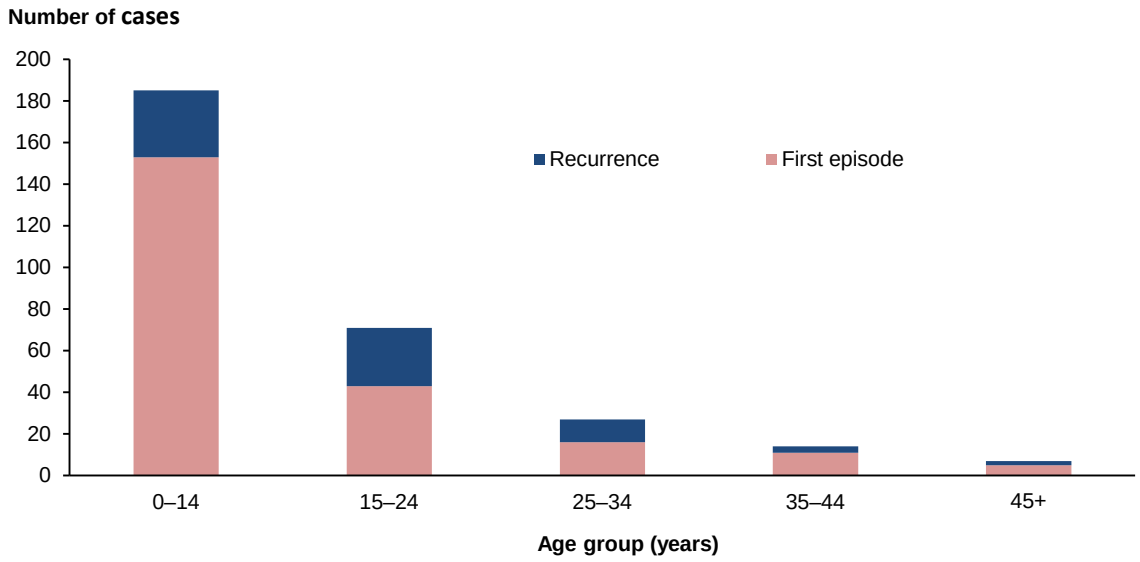
Queensland and Western Australia collect similar data. The Queensland Rheumatic Heart Disease Control Program register started in early 2009 but the register mainly covers North and Far North Queensland; therefore, most of the cases reported to the register are from the northern districts. Confidentialised data from the register were provided to the AIHW. The Western Australian Rheumatic Heart Disease Control Program register also started in early 2009 and now covers all of Western Australia. Confidentialised summary data were provided to the AIHW.

As the Northern Territory RHD register has been operating in the Top End since 1997 and in Central Australia since 2000, it is currently the strongest jurisdictional source of data on the incidence of ARF and prevalence of RHD in Australia. In contrast, the RHD register and control programs in Queensland and Western Australia are at different stages of establishment. Therefore, caution should be exercised when interpreting and comparing ARF incidence and RHD prevalence data across the three jurisdictions. RHD Australia has developed a recommended data set for ARF and RHD registers in Australia (RHD Australia 2012). If collection of this recommended dataset is adopted, comparable data from the jurisdictional RHD registers may be available in the future.

Northern Territory Rheumatic Heart Disease Control Program register

In the Northern Territory, 317 cases of ARF were recorded on the Rheumatic Heart Disease Control program register between 2005 and 2010. All but six of these were in Indigenous people. Of the 317 cases, most (228) were new, while 76 (24% of all episodes) were recurrent. For the remaining 13 episodes it was unknown whether they were new or recurrent. There are several reasons why it might not be possible to determine whether a case of ARF is new or recurrent. First, if the initial episode was only diagnosed as possible ARF then a further episode would be difficult to define as new or recurrent and a decision may not have been made. Second, an episode of ARF can improve and then flare up again a few months later and so it may be difficult to decide whether the flare-up is a recurrence or resurgence. Finally, it may be due to data omission.

New cases of ARF outnumber recurrent cases in all age groups (Figure 2.2). The number of recurrent cases among those aged under 25 suggests that the long-term prevention of ARF may not have been effective for a large number of people who have been treated for the disease. To treat ARF successfully and prevent its recurrence, antibiotics must be taken every 4 weeks for 10 years. Such a treatment regimen relies on the provision of continuous medical and other locally appropriate support strategies that may not always be available in remote Indigenous communities. Another factor that might have an impact on effective treatment is a lack of adherence by the patient. Factors that could improve ongoing adherence to secondary prophylaxis in Australia include improving the availability of culturally appropriate health services for Aboriginal and Torres Strait Islander people and having a routine review and management plan (RHD Australia 2012).

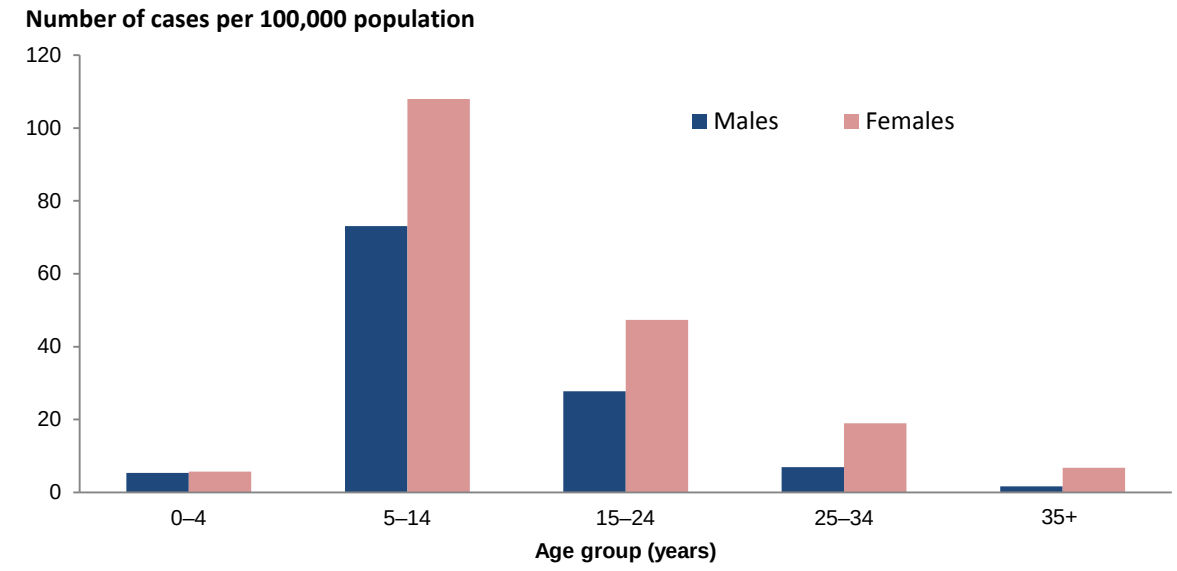


Note: Excludes cases of unknown status.

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Control Program register data.

Figure 2.2: Acute rheumatic fever incidence, Northern Territory, by age and episode type, 2005–2010

In the Northern Territory between 2005 and 2010, there were 183 cases of ARF in children aged 5–14, accounting for 58% of all new and recurrent cases, and 76 cases in 15–24 year olds, accounting for a further 24% of cases (Table A1.1). Among those aged 5 and over, incidence rates were higher among females than males (Figure 2.3).



Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Control Program register data.

Figure 2.3: Acute rheumatic fever incidence rates, Northern Territory, by age and sex, 2005–2010

Between 2005 and 2010, the age-adjusted incidence rate for ARF in the Northern Territory based on the registry data peaked in 2007 for both males (20.3 cases per 100,000 population) and females (42.3 cases per 100,000 population) (Table 2.1). Incidence rates fell between 2007 and 2008 but have increased again since then for both sexes. Similarly to the peak in ARF notifications in the Northern Territory in 2007, the peak in ARF incidence rates in that year may be related to the temporary shortage in supply of Bicillin® L-A in that year. Dr Keith Edwards confirmed that another factor that might affect the identification and diagnosis of ARF from year to year is that there is evidence that some cases of ARF are sub-clinical as they present with established RHD and, if they do not score highly enough on the modified Jones criteria for the diagnosis of ARF, will not be diagnosed as ARF (K Edwards 2012, pers. comm., 5 May).

Table 2.1: Incidence of acute rheumatic fever, Northern Territory, 2005–2010

Sex group	2005	2006	2007	2008	2009	2010
			Number of new and recurrent cases			
Males	16	23	26	14	21	23
Females	26	26	50	28	31	33
Persons	42	49	76	42	52	56
			Number of cases per 100,000 population[(a)]			
Males	12.7	18.7	20.3	10.6	15.9	17.6
Females	22.7	23.3	42.3	23.1	25.3	27.6
Persons	17.5	20.9	31.0	16.7	20.5	22.4

(a) Age-standardised to the 2001 Australian population.

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Control Program register data.

Queensland Rheumatic Heart Disease Control Program register

As at 27 August 2012, there were 1,385 patients registered on the Queensland Rheumatic Heart Disease register.

There were 200 ARF notifications in the 3 years from 2009 to 2011, but 22 of these cases were subsequently ruled out, leaving a total of 178. Of these 178 notifications, 61% were new cases, 10% were recurrent, and for the remaining 29% it was not known whether they were new or recurrent. The majority (90%) of cases of ARF occurred in Indigenous people. Just over 60% of cases occurred in 5–14 year olds and another 19% in 15–19 year olds. In contrast to the picture in the Northern Territory, there was no gender differential in the incidence of ARF in Queensland, with half of the cases occurring in females and half in males (49% versus 51%).

Western Australian Rheumatic Heart Disease Control program register

Between 1 July 2010 and 30 June 2011, there were 21 new and recurrent cases of ARF notified to the newly established Western Australia Rheumatic Heart Disease register (Table 2.2). All 21 cases occurred in Aboriginal and Torres Strait Islander people, with 57% in males (12 cases).

Table 2.2: New and recurrent cases of acute rheumatic fever, Western Australia, 2010–11

Age group (years)	Males	Females	Persons
		Number of cases	
0–14	7	5	12
15+	5	4	9
Total	**12**	**9**	**21**

Source: Western Australia Rheumatic Heart Disease Control Program register.

2.2 Deaths

Between 2007 and 2009, there were 12 deaths in Australia where ARF was the underlying (main) cause of death. This suggests that it is uncommon for ARF to be recorded as the underlying cause of death.

The small number of deaths from ARF also means that it is difficult to confidently determine the proportion of ARF deaths that occur among Indigenous Australians. Further, the latest year for which unit record mortality data by Indigenous status were available for analysis for this report was 2007. Between 2004 and 2007, 13 deaths with an underlying cause of death of ARF were recorded among the jurisdictions for which Indigenous identification was considered reliable for mortality data (New South Wales, Queensland, Western Australia, South Australia and the Northern Territory), and less than one-third of these deaths occurred in people who identified as being of Aboriginal and Torres Strait Islander origin.

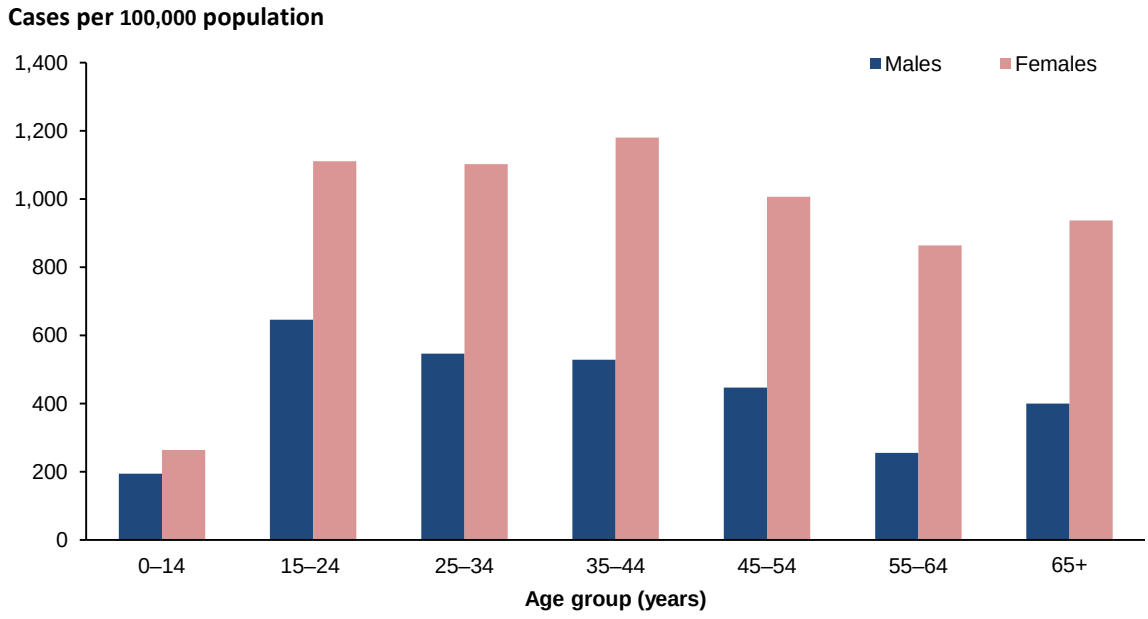
3 Rheumatic heart disease

3.1 Prevalence

It is not possible to give a complete picture of RHD in Australia as no national prevalence data exist. However, jurisdictional data are available from the Northern Territory, Queensland and Western Australian RHD registers.

Northern Territory

As at 31 December 2010, there were 1,479 cases of RHD in the Northern Territory—969 cases in females and 510 in males. RHD prevalence rates were lowest among 0–14 year olds. Among those aged 15 and over, the prevalence of RHD was higher among 15–44 year old females than among females aged 45 year and over, while prevalence rates in males declined between the ages of 15 and 64 before increasing slightly again in those aged 65 and over (Figure 3.1). Prevalence rates were higher among females than males in all age groups.

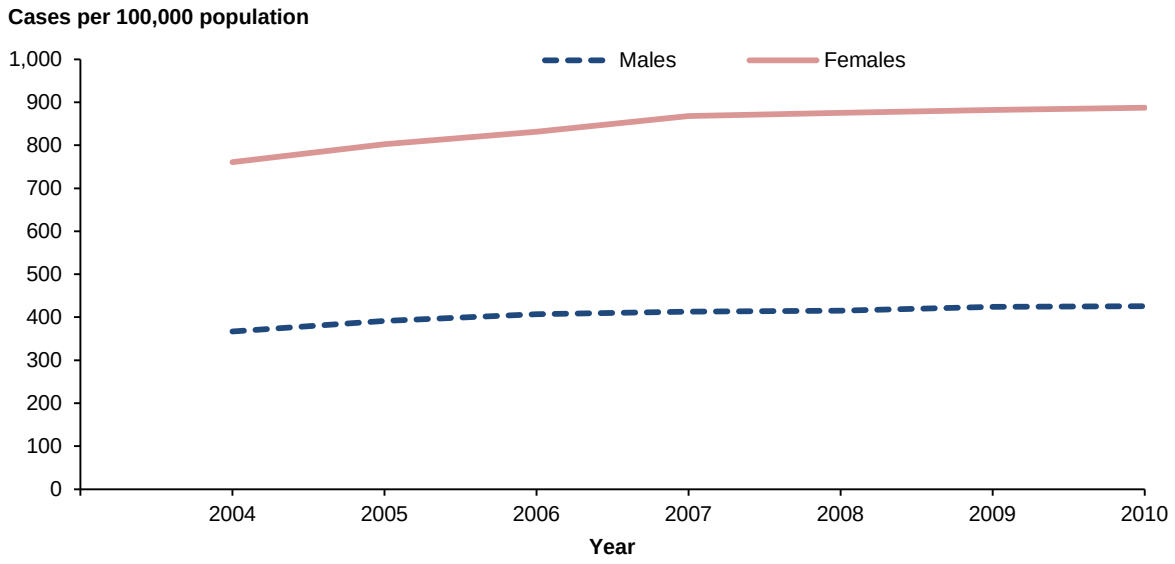


Note: Age-specific rates calculated using the 2010 estimated resident population for the Northern Territory.

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Control Program register data.

Figure 3.1: Rheumatic heart disease prevalence rates in the Northern Territory, by age and sex, 2010

The prevalence of RHD in the Northern Territory appears to be increasing. Between 2004 and 2010, the age-standardised prevalence rate increased from 555 cases per 100,000 population to 647, an increase of 17%. The biggest increase occurred in persons aged 65 and over, for whom the rate increased by 50% from 433 cases per 100,000 population in 2004 to 650 cases per 100,000 in 2010 (Table A2.1). This increase in older persons may be due to the ongoing ascertainment of existing cases rather than development of new disease. Over the 7 years, females had consistently higher rates than males (Figure 3.2). It is possible that this increase is the result of improved diagnosis and data collection rather than a true increase in the prevalence of the disease.



Note: Age-standardised to the 2001 Australian population.

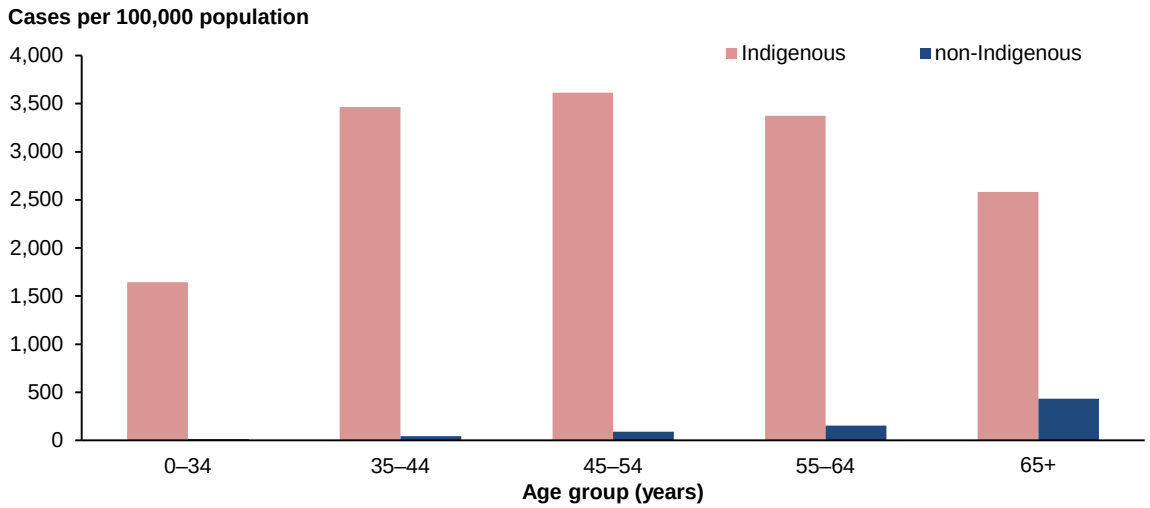
Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Control Program register data.

Figure 3.2: Prevalence of rheumatic heart disease in the Northern Territory, by sex, 2004 to 2010

In 2010, RHD was much more prevalent among Indigenous people in the Northern Territory (1,379 cases) than it was among non-Indigenous Australians (100 cases). After adjusting for the different age structures of the populations, the prevalence rate among Indigenous Australians was 26 times as high as for non-Indigenous Australians —2,474 per 100,000 population (that is, 2.5% of the total Indigenous population in the Northern Territory) compared with 94 cases per 100,000 population (that is, 0.1% of the total non-Indigenous population in the Northern Territory).

Among Indigenous Australians in the Northern Territory, RHD prevalence rates were high across all age groups, with the highest among those aged 35–64 (Figure 3.3). In contrast, prevalence rates among non-Indigenous Australians increased steadily with age, with the highest in those aged 65 and over.

The most marked difference between Indigenous and non-Indigenous Australians in the prevalence of RHD occurred in those aged under 35, where Indigenous Australians had a 122–fold greater prevalence than non-Indigenous Australians. This suggests that RHD is rare in young non-Indigenous Australians in the Northern Territory. While the differential between Indigenous and non-Indigenous Australians fell with increasing age, Indigenous Australians aged 65 and over in the Northern Territory still had a prevalence rate of RHD that was 6 times as high as that of their non-Indigenous counterparts. The shorter life expectancy of Indigenous Australians may also account for some of these changes in ratio.



Note: Age-specific rates calculated using the 2006 estimated resident Indigenous and non-Indigenous populations for the Northern Territory.

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Control Program register data.

Figure 3.3: Rheumatic heart disease prevalence rates in the Northern Territory, by age and Indigenous status, 2010

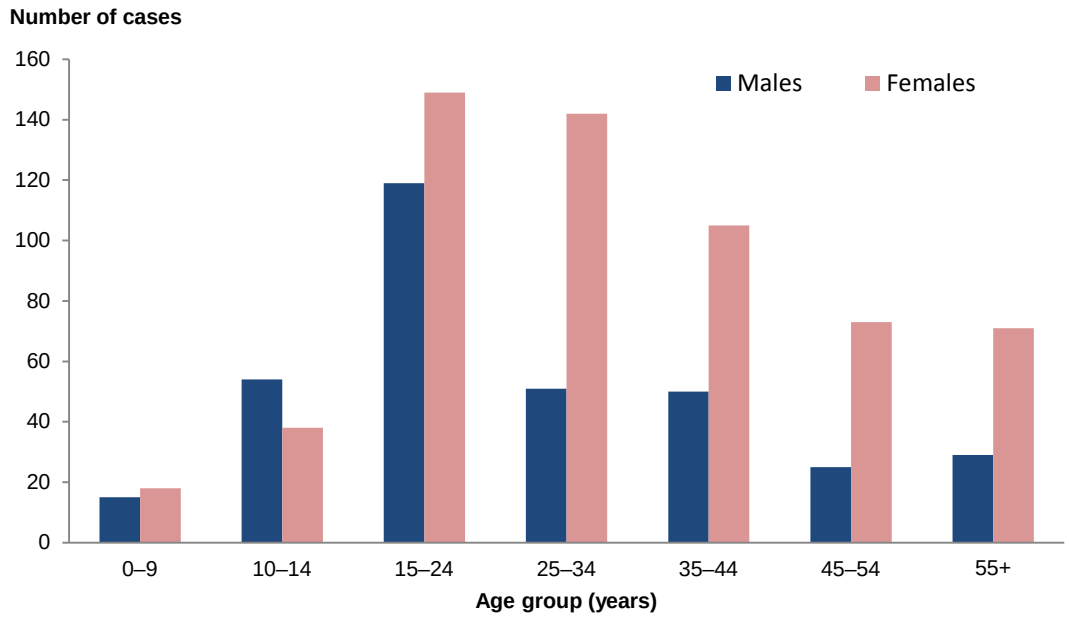
Queensland

Of the 1,385 patients registered on the Queensland Rheumatic Heart Disease Control Program register as at 27 August 2012, there were 939 patients who had progressed to RHD, 166 patients who did not have RHD and 280 cases yet to be reviewed or whose RHD status was unknown.

Of the 939 patients with RHD, 90% were Aboriginal or Torres Strait Islander people, 9% were not Indigenous and 1% were of unknown Indigenous status. Almost two-thirds of those with RHD were female (596 cases) but most of these cases occurred in females who were aged 25 years and over (66%) (Figure 3.4). In contrast, the majority of cases of RHD in males (55%) occurred in those aged under 25.

Western Australia

As at 30 June 2011, there were 158 patients with confirmed RHD registered on the Western Australia Rheumatic Heart Disease register. Of these RHD patients, all were Aboriginal and Torres Strait Islander people and the majority (61%) were female (97 cases). Just over two-fifths (42%) of those with RHD were aged 0–24 (67 cases), while 36% were aged 25–44 (57 cases) and 22% were aged 45 and over (34 cases).



Source: AIHW analysis of Queensland Rheumatic Heart Disease Control Program register data.

Figure 3.4: Number of cases of rheumatic heart disease in Queensland, by sex and age as at 27 August 2012

3.2 Deaths

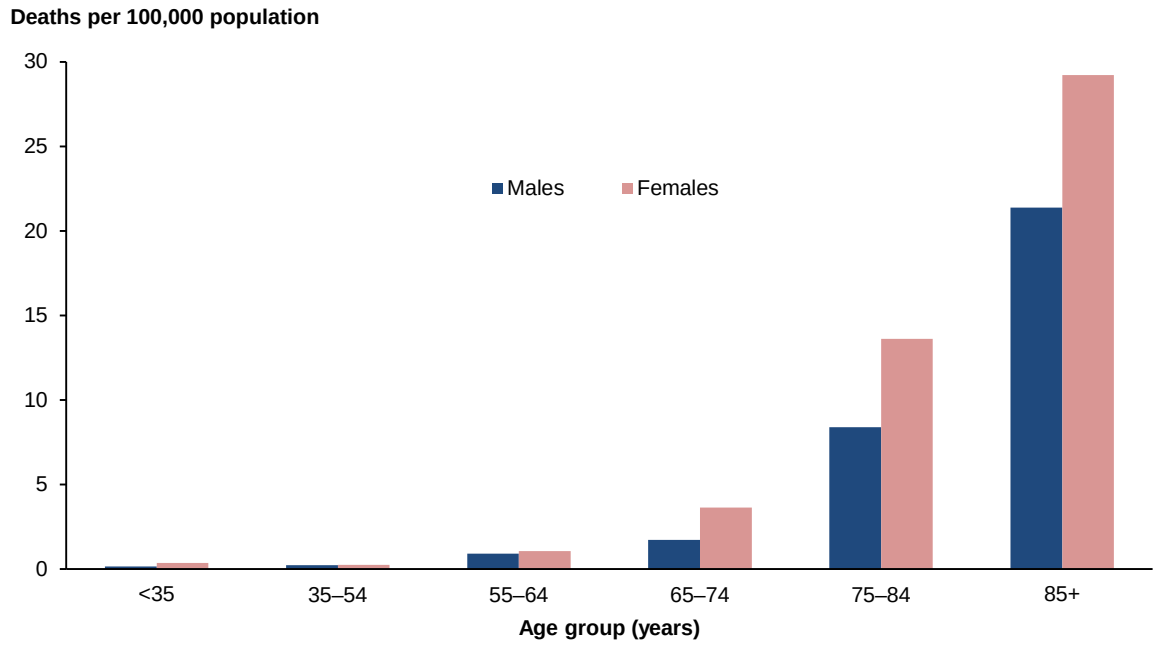
Between 2007 and 2009, there were 897 deaths recorded nationally with RHD as the underlying cause of death. This equates to 0.6% of all cardiovascular disease (CVD) deaths (141,819) and 0.2% of all deaths (422,560) over this period. The average death rate over the 3 years was 1.4 per 100,000 population (Table A2.2).

Sex and age

Unlike other forms of CVD, more females die from RHD than males. Between 2007 and 2009, females accounted for more than two-thirds of RHD deaths—606 compared with 291 for males. The age-adjusted death rate for females (1.5 per 100,000 population) was 50% higher than the male rate (1.0 per 100,000) (Table A2.2; Figure 3.5). The higher RHD death rate in females compared with males is consistent with the higher RHD prevalence and hospitalisation rates in females.

Death rates increased rapidly with age, with the greatest rates among those aged 85 and over (Figure 3.5). More than 80% of deaths occurred among people aged 65 and over.

In contrast to ARF, RHD predominately affects older Australians, with more than 80% of deaths occurring in those aged 65 and over. Consistent with the hospitalisation rates for RHD, death rates are higher among older Australians.



Note: Cause of death data for 2009 are preliminary and are subject to further revision.

Source: Analysis of the AIHW National Mortality Database.

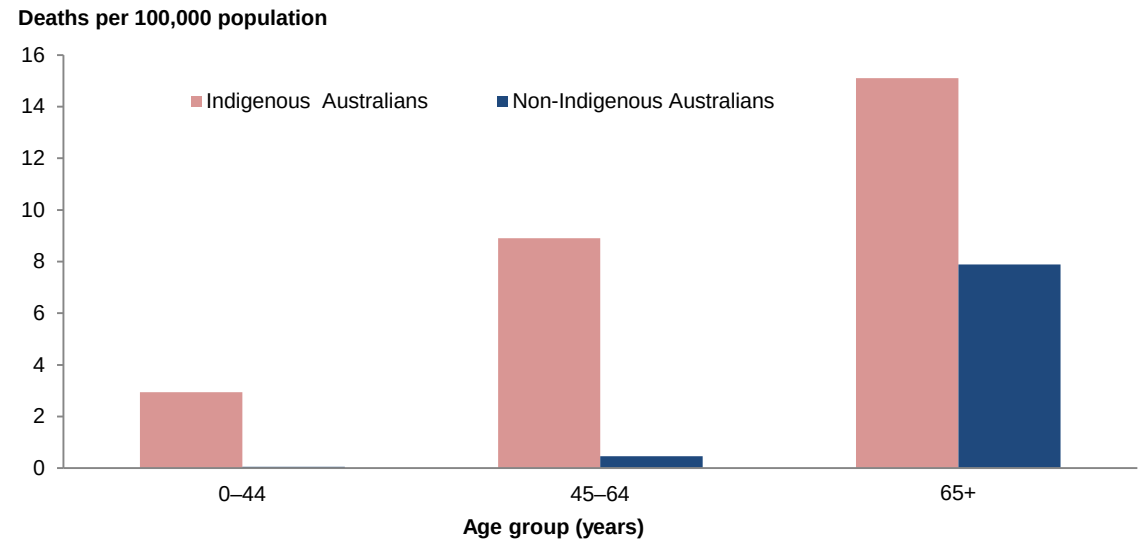
Figure 3.5: Rheumatic heart disease death rates, underlying cause, by age and sex, 2007–2009

Aboriginal and Torres Strait Islander people

Between 2004 and 2007, there were 63 deaths from RHD among Indigenous Australians (Table A2.3). The age-standardised death rate for Indigenous Australians (5.8 per 100,000 population) was 5.2 times as high as the rate for non-Indigenous Australians (1.1 per 100,000 population). Across all age groups, Indigenous Australians consistently had higher death rates than non-Indigenous Australians (Figure 3.6). However, it is interesting to note that the magnitude of the difference is lower in those aged 65 and over.

State and territory

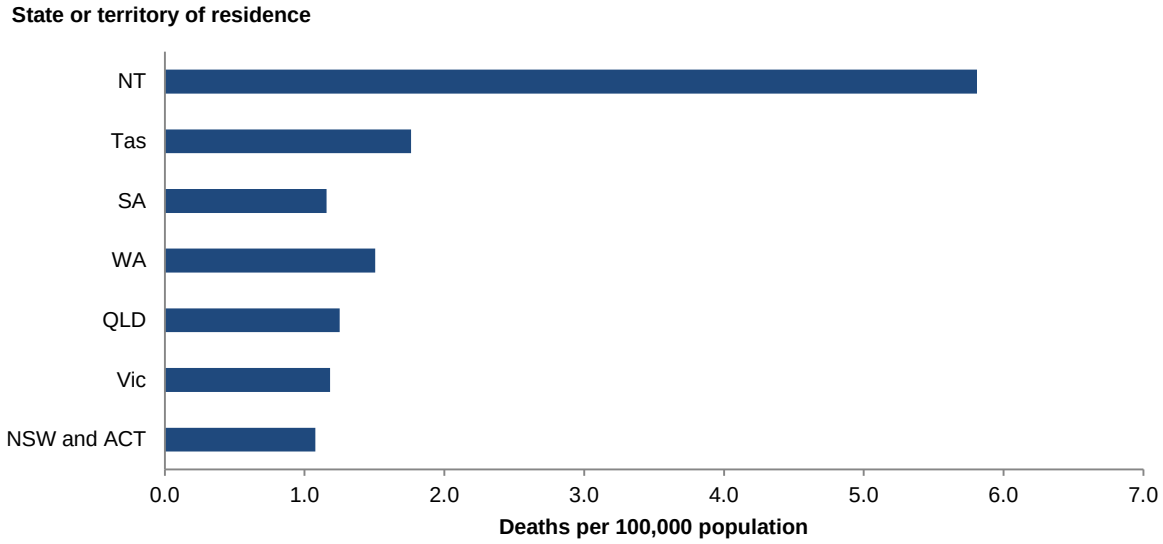
Between 2005 and 2007, the Northern Territory had the highest age-standardised RHD death rate (5.8 per 100,000 population) of any state or territory (Table A2.4; Figure 3.7). This rate was 4.7 times as high as the national average. Among the other jurisdictions, there was not a great deal of variation in the RHD death rates over the 3 years, with the age-adjusted rates ranging from 1.1 per 100,000 population in New South Wales and the Australian Capital Territory to 1.8 per 100,000 in Tasmania.



Note: Data from NSW, QLD, WA, SA, NT only.

Source: Analysis of the AIHW National Mortality Database.

Figure 3.6: Rheumatic heart disease death rates, underlying cause, by Indigenous status and age, 2004–2007



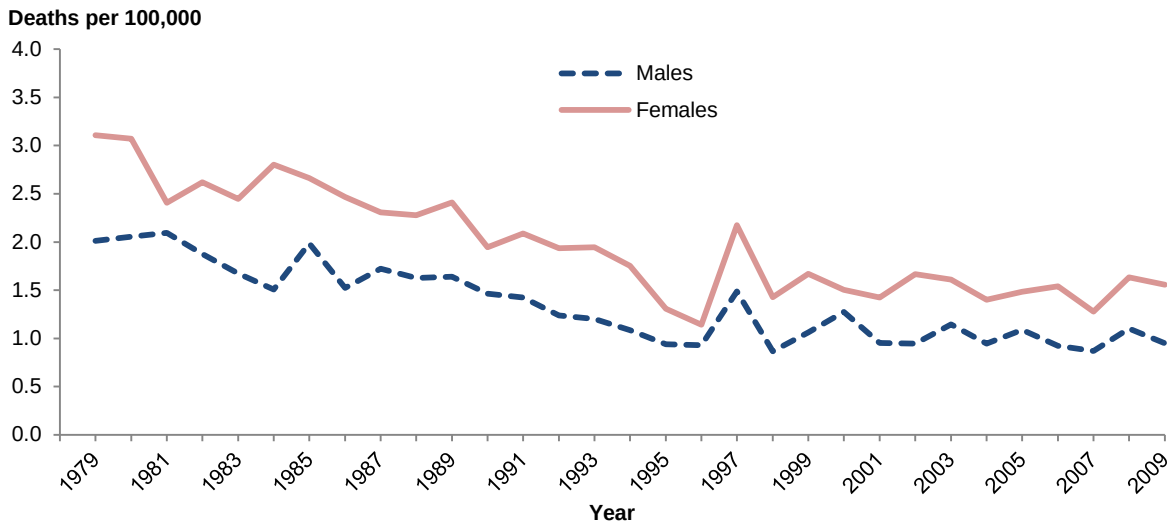
Note: Age-standardised to the Australian population as at 30 June 2001.

Source: Analysis of the AIHW National Mortality Database.

Figure 3.7: Rheumatic heart disease death rates, underlying cause, by state and territory of residence, 2005–2007

Trends

Between 1979 and 1996, death rates for RHD in Australia more than halved, falling from 2.0 to 0.9 deaths per 100,000 population for males and 3.1 to 1.1 deaths per 100,000 population for females (Table A2.5; Figure 3.8). Death rates increased again between 1996 and 1997 by an average of 0.8 deaths per 100,000 population, but have stabilised since 1998. Over the 31 years to 2009, the age-standardised death rates were consistently higher for females than males, reflecting the higher prevalence of rheumatic heart disease in females.



Notes

1. Age-standardised to the Australian population as at 30 June 2001.
2. Death rates for 1979–1996 have been adjusted to ICD-10 standards using a comparability factor of 0.69.
3. Cause of death data for 2009 are preliminary and are subject to further revision.

Source: Analysis of the AIHW National Mortality Database.

Figure 3.8 Rheumatic heart disease death rates, underlying cause, by sex, 1979–2009

Contribution of other cardiovascular diseases, chronic kidney disease and diabetes to deaths involving RHD

In addition to the 897 deaths registered between 2007 and 2009 where RHD was the underlying cause of death, there were another 1,185 deaths where RHD was recorded as an associated cause of death. An associated cause of death is a disease or condition, other than the underlying cause, that was instrumental in causing death (AIHW 2012).

It is common for people who die with RHD to have another CVD listed on the death certificate as having contributed to the death. Of the 2,082 deaths registered between 2007 and 2009 that involved RHD, 90% had at least one other CVD listed as a cause of death (Table 3.1). Chronic kidney disease (CKD) was listed as contributing to the death for 19% of deaths involving RHD, while diabetes was listed for 11% of deaths involving RHD. Only 7% of deaths involving RHD did not have another CVD, CKD or diabetes contributing to the death. This suggests that it is not only the RHD that adversely affects health, but also its interaction with other vascular diseases.

Table 3.1: Contribution of other cardiovascular diseases, chronic kidney disease and diabetes to deaths where RHD was the underlying or an associated cause of death, 2007–2009

Causes of death	Number of deaths	Per cent
RHD (without other CVDs, diabetes or CKD)	151	7.3
RHD and CKD (without diabetes or other CVDs)	32	1.5
RHD and diabetes (without other CVDs or CKD)	11	0.5
RHD and other CVDs (without diabetes and CKD)	1,371	65.9
RHD, diabetes and CKD (without other CVDs)	6	0.3
RHD, other CVDs and CKD (without diabetes)	291	14.0
RHD, other CVDs and diabetes (without CKD)	155	7.4
RHD, other CVDs, diabetes and CKD	65	3.1
Total deaths where RHD was the underlying or an associated cause of death	**2,082**	**100.0**

Note: Cause of death data for 2009 are preliminary and are subject to further revision.

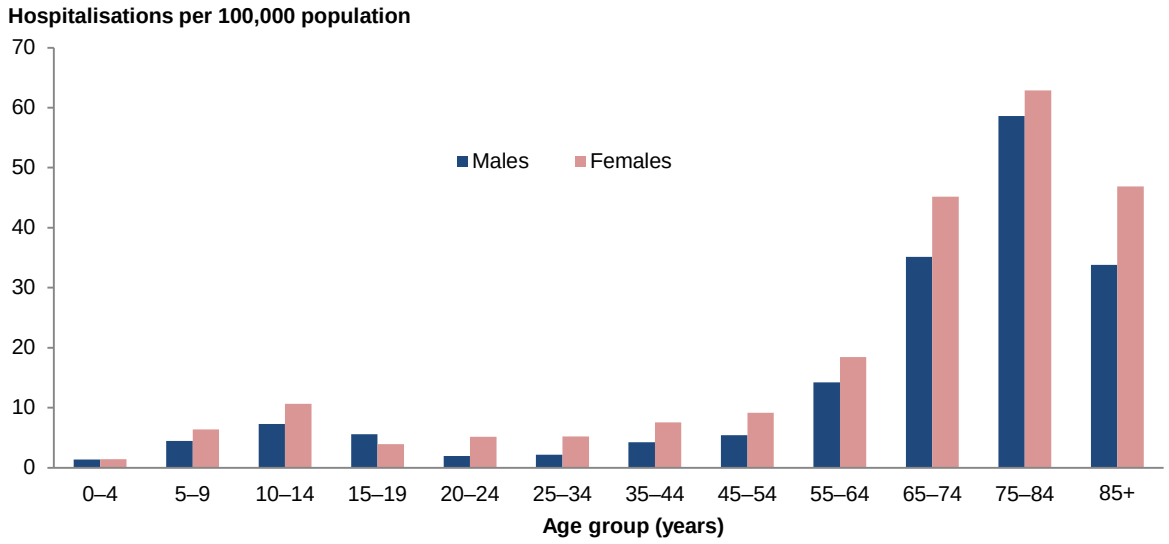
Source: AIHW National Mortality Database.

4 Hospitalisations for acute rheumatic fever and rheumatic heart disease

In this chapter ARF and RHD have been grouped together because age patterns for hospitalisations where ARF was the principal diagnosis suggest that hospital records may not always accurately distinguish between ARF and RHD. In 2009–10, there were 2,666 hospitalisations with a principal diagnosis of ARF or RHD in Australia—0.6% of all cardiovascular disease hospitalisations (482,252 hospitalisations). This equates to a crude rate of 12 hospitalisations per 100,000 population (Table A3.1). The principal diagnosis is the diagnosis established to be the problem that was chiefly responsible for the patient's episode of care in hospital (AIHW 2011a).

Sex and age

With the exception of 15–19 year olds, females had higher rates of hospitalisation with ARF or RHD than males in 2009–10 (Figure 4.1). Overall, the age-standardised hospitalisation rate for females (13 per 100,000 population) was 1.3 times as high as that for males (10 per 100,000).



Note: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.

Source: AIHW National Hospital Morbidity Database.

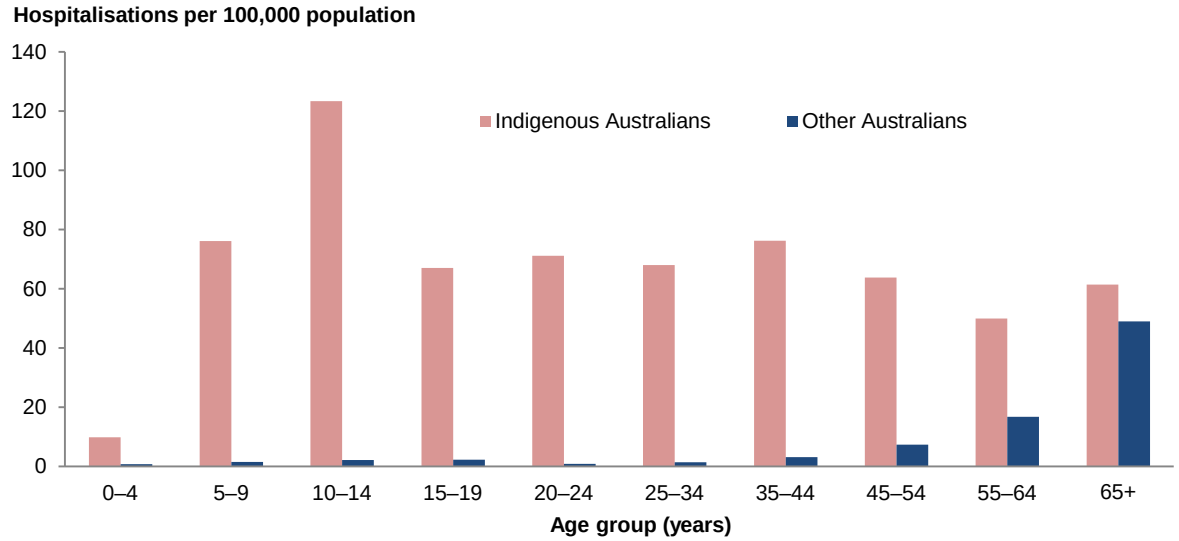
Figure 4.1: Rates for hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by sex and age, 2009–10

Hospitalisation rates increased sharply with age between the ages of 55 and 84, with the rate among 65–74 year olds being 2.5 times as high as that among 55–64 year olds. The highest rates were in those aged 75–84 years—59 hospitalisations per 100,000 population for males and 63 per 100,000 for females (Table A3.1). Among children aged 0–14, the increase in hospitalisation rates for ARF or RHD with age is likely to be due to exposure to ARF. However, among people aged 15 and over, the increase in hospitalisation rates from the age of 55 is likely to be due to RHD and its treatment.

Aboriginal and Torres Strait Islander people

Between 2007–08 and 2009-10, in jurisdictions with adequate Indigenous identification, there were 1,065 hospitalisations with a principal diagnosis of ARF or RHD for Aboriginal and Torres Strait Islander people and 6,519 hospitalisations for other Australians (Table A3.2).

After adjusting for age, the overall rate of hospitalisation with ARF or RHD for Indigenous Australians (67 per 100,000 population) was 6.7 times as high as that of other Australians (10 per 100,000). Aboriginal and Torres Strait Islander people had higher age-specific rates than other Australians in all age groups, although the rates for the two groups were closer for the 65 and over age group (Figure 4.2).



Notes

1. Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.
2. Based on patients usually resident in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory; excludes private hospitals in the NT.
3. Other Australians include peoples whose Indigenous status was 'Not stated'.

Source: AIHW Hospital Morbidity Database.

Figure 4.2: Rates for hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by Indigenous status and age, 2007–08 to 2009–10

State and territory

In 2009–10, the Northern Territory had the highest age-adjusted rate of hospitalisations with a principal diagnosis of ARF or RHD (86 hospitalisations per 100,000 population) (Table A3.3). This was followed by Queensland (15 hospitalisations per 100,000 population) and Western Australia (12 hospitalisations per 100,000 population).

Among people aged under 65, the Northern Territory had a much greater rate of hospitalisations for ARF or RHD than any other jurisdiction in 2009–10 (Figure 4.3).

Notes

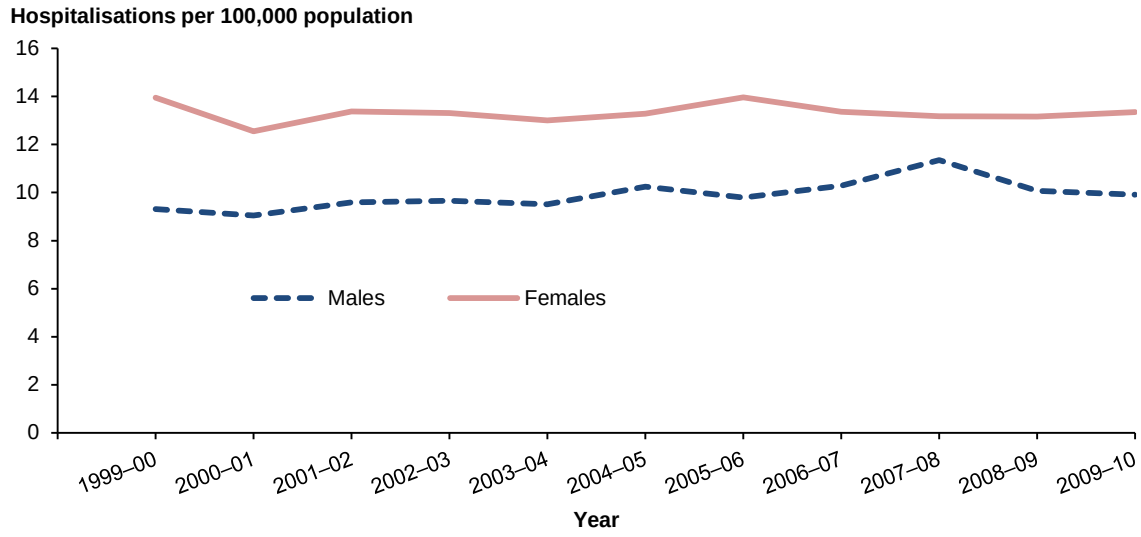
1. Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.
2. Age-standardised to the 2001 Australian population.

Source: AIHW National Hospital Morbidity Database.

Figure 4.3: Rates for hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by age and state and territory of residence, 2009–10

Trends

Between 1999–00 and 2009–10, the number of hospitalisations with a principal diagnosis of ARF or RHD increased from 2,191 to 2,666. Overall, there was little change in the age-standardised hospitalisation rate over this period. However, for males the rate increased slightly between 1999–00 and 2007–08, from 9.3 to 11.3 hospitalisations per 100,000 population, but has since fallen (Table A3.4). Females had consistently higher hospitalisation rates than males over the 11 years (Figure 4.4). The pattern of higher hospitalisation rates in females is consistent with the higher ARF incidence and RHD prevalence rates in females from the Northern Territory Rheumatic Heart Disease Control Program register. Also, as mentioned earlier, the gender difference might be the result of higher use and exposure to health services by the female population, but to date no evidence can substantiate these results.



Notes

1. Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.
2. Age-standardised to the 2001 Australian population.

Source: AIHW National Hospital Morbidity Database.

Figure 4.4: Rates for hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by sex, 1999–00 to 2009–10

Contribution of other cardiovascular diseases, chronic kidney disease and diabetes to hospitalisations involving ARF or RHD

In addition to the 2,666 hospitalisations with a principal diagnosis of ARF or RHD in 2009–10, there were another 8,581 hospitalisations with an additional diagnosis of ARF and/or RHD. The additional diagnosis is a condition or complaint either coexisting with the principal diagnosis or arising during the episode of care (AIHW 2011a).

It is common for people hospitalised with ARF or RHD to have a principal or additional diagnosis of another CVD associated with the hospitalisation. In 2009–10, 84% of the 11,247 hospitalisations with any diagnosis of ARF or RHD also had a diagnosis of another CVD (Table 4.1). Almost one-fifth (18%) of hospitalisations involving ARF or RHD also had another diagnosis of CKD, while 15% had a diagnosis of diabetes. Only 15% of hospitalisations involving ARF or RHD did not have a diagnosis of another CVD, CKD or diabetes recorded.

Table 4.1: Contribution of other cardiovascular diseases, chronic kidney disease and diabetes contributing to hospitalisations with a principal or an additional diagnosis of acute rheumatic fever or rheumatic heart disease, 2009–10

Diagnosis	Number of hospitalisations	Per cent
ARF or RHD (without other CVDs, diabetes or CKD)	1,659	14.8
ARF or RHD and CKD (without diabetes or other CVDs)	46	0.4
ARF or RHD and diabetes (without other CVDs or CKD)	41	0.4
ARF or RHD and other CVDs (without diabetes and CKD)	6,644	59.1
ARF or RHD, diabetes and CKD (without other CVDs)	19	0.2
ARF or RHD, other CVDs and CKD (without diabetes)	1,156	10.3
ARF or RHD, other CVDs and diabetes (without CKD)	829	7.4
ARF or RHD, other CVDs, diabetes and CKD	853	7.6
Total hospitalisations with a principal or additional diagnosis of ARF or RHD	**11,247**	**100.0**

Source: AIHW National Hospital Morbidity Database.

Heart valve surgery for RHD

Valve surgery and interventional cardiology such as balloon valvuloplasty are the most common types of therapeutic procedures performed in hospital for people with RHD. Whether or not such interventions are required for an individual with RHD depends on the presence of symptoms and the severity of the heart valve damage and, if an intervention is indicated, the type performed depends on the type of heart valve damage.

Note that all heart valve procedures reported here relate to hospitalisations with a principal diagnosis of ARF or RHD among people aged 15 and over. While it would be rare for a person with ARF to have heart valve surgery, hospitalisations with a principal diagnosis of ARF have been included with those for RHD to ensure that any conflation of RHD as ARF is accounted for.

In 2009-10, there were 2,449 hospitalisations with a principal diagnosis of ARF or RHD among people aged 15 and over and, of these hospitalisations, 49% had at least one heart valve procedure performed (Table 4.2). Replacement of the mitral and aortic valves were the most common heart valve procedures performed for these hospitalisations, accounting for 23% and 22% respectively.

Table 4.2: Heart valve procedures performed for hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease among people aged 15 and over, 2009–10

Heart valve procedures	Number of heart valve procedures	Per cent of all heart valve procedures	Number of hospitalisations with a principal diagnosis of ARF or RHD that had at least one heart valve procedure performed[(a)]	Per cent of all hospitalisations with a principal diagnosis of ARF or RHD (n=2,449)
Replacement of mitral valve	581	28.8	581	23.7
Replacement of aortic valve	562	27.8	558	22.8
Tricuspid valve annuloplasty	256	12.7	256	10.5
Repair of mitral valve	236	11.7	229	9.4
Mitral valve annuloplasty	212	10.5	211	8.6
Other heart valve procedures[(b)]	173	8.6	166	6.8
All heart valve procedures	**2,020**	**100.0**	**1,208**	**49.3**

(a) Components do not add to total because a patient may have had more than one type of heart valve procedure.

(b) Includes repair, replacement, incision and other procedures on the pulmonary valve; repair, replacement, incision and other procedures on the tricuspid valve; reconstruction, incision and other procedures on the mitral valve; repair, incision and other procedures on the aortic valve.

Source: AIHW National Hospital Morbidity Database.

Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people are more likely to be hospitalised than other Australians, however, they are less likely to undergo a procedure once admitted to hospital (AIHW 2011a). The results of multivariate analysis reported in *Aboriginal and Torres Strait Islander Health Performance Framework 2010: detailed analyses* (AIHW 2011a) showed that for both Indigenous and other Australians some of the most important factors contributing to whether a patient received a procedure related to their principal diagnosis once hospitalised were: the number of additional diagnoses, the hospital sector (that is, public or private), the principal diagnosis, remoteness of usual residence, state of usual residence, age and sex. After controlling for these variables, the odds of receiving a procedure for Indigenous Australians was about 40% less than the odds for other Australians.

Between 2007–08 and 2009–10, there were 675 hospitalisations with a principal diagnosis of ARF or RHD among Indigenous Australians aged 15 and over and 6,348 among other Australians of the same age. After adjusting for age, the rate of these hospitalisations in Aboriginal and Torres Strait Islander people (65.9 per 100,000 population) was 5.4 times as high as the corresponding rate in other Australians (12.2 per 100,000 population). However, over the 3 years, Indigenous Australians were less likely than other Australians to have had at least one heart valve procedure performed when hospitalised with a principal diagnosis of ARF or RHD (28% compared with 49%) (Table 4.3).

Replacement of the mitral valve was the most common heart valve procedure for Aboriginal and Torres Strait Islander people aged 15 and over (15% of hospitalisations with a principal diagnosis of ARF or RHD) (Table 4.3). This was also a common procedure among other

Australians aged 15 and over (23% of hospitalisations with a principal diagnosis of ARF or RHD) as was replacement of the aortic valve (23%).

Table 4.3: Heart valve procedures performed for hospitalisations[(a)] with a principal diagnosis of acute rheumatic fever or rheumatic heart disease among people aged 15 and over, by Indigenous status, 2007–08 to 2009–10

	Number of hospitalisations with a principal diagnosis of ARF or RHD that had at least one heart valve procedure performed		Per cent of all hospitalisations with a principal diagnosis of ARF or RHD	
Heart valve procedures	**Indigenous Australians[(a)]**	**Other Australians[(b)]**	**Indigenous Australians (N =675)**	**Other Australians (N= 6,348)**
Replacement of mitral valve	100	1,450	14.8	22.8
Replacement of aortic valve	50	1,437	7.4	22.6
Tricuspid valve annuloplasty	46	732	6.8	11.5
Repair of mitral valve	37	614	5.5	9.7
Mitral valve annuloplasty	30	588	4.4	9.3
Other heart valve procedures[(c)]	23	417	3.4	6.6
All heart valve procedures[(d)]	**188**	**3,096**	**27.9**	**48.8**

(a) Based on patients usually resident in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory; excludes private hospitals in the NT.

(b) Other Australians include peoples whose Indigenous status was 'Not stated'.

(c) Includes repair, replacement, incision and other procedures on the pulmonary valve; repair, replacement, incision and other procedures on the tricuspid valve; reconstruction, incision and other procedures on the mitral valve; repair, incision and other procedures on the aortic valve.

(d) Components do not add to total because a patient may have had more than one type of heart valve procedure.

Source: AIHW National Hospital Morbidity Database.

For both Indigenous and other Australians, the proportion of hospitalisations between 2007–08 and 2009–10 with a principal diagnosis of ARF or RHD that had at least one heart valve procedure was higher among those aged 55 and over than those aged 15–54 (Table 4.4). Just over one-quarter (26%) of these hospitalisations among Aboriginal and Torres Strait Islander people aged 15–54 had at least one heart valve procedure performed, compared with 41% among those aged 55 and over. For other Australians, the proportion that had a heart valve procedure was 44% for those aged 15–54 and 50% for those aged 55 and over. Thus, in both age groups, hospitalisations for ARF or RHD among Aboriginal and Torres Strait Islander people were less likely to have had a heart valve procedure recorded than other Australians.

Table 4.4: Proportion of hospitalisations[(a)] with a principal diagnosis of acute rheumatic fever or rheumatic heart disease among people aged 15 and over that had at least one heart valve procedure performed, by Indigenous status, 2007–08 to 2009–10

	Hospitalisations with a principal diagnosis of ARF or RHD		Number of hospitalisations with a principal diagnosis of ARF or RHD that had at least one heart valve procedure performed		Per cent of all hospitalisations with a principal diagnosis of ARF or RHD	
Age group (years)	**Indigenous Australians**	**Other Australians[(b)]**	**Indigenous Australians**	**Other Australians[(b)]**	**Indigenous Australians**	**Other Australians[(b)]**
15–54	604	1,167	159	518	26.3	44.4
55+	71	5,181	29	2,578	40.8	49.8
All ages	**675**	**6,348**	**188**	**3,096**	**27.9**	**48.8**

(a) Based on patients usually resident in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory; excludes private hospitals in the NT.

(b) Other Australians include peoples whose Indigenous status was 'Not stated'

Source: AIHW National Hospital Morbidity Database.

5 Adherence to secondary prophylaxis in the Northern Territory

People who develop ARF are at a relatively high risk of developing recurrent episodes and, to prevent recurrences, should be treated with antibiotics after their first attack. The current Australian guidelines state that secondary prophylaxis with benzathine penicillin G (BPG) injections is recommended in all people with a history of ARF or RHD (RHD Australia 2012). For patients not considered to be at high risk, the current treatment of choice is 4-weekly BPG injections. However, 3-weekly BPG administration is recommended for patients considered to be at high risk. The guideline also states that all people with ARF or RHD should continue secondary prophylaxis for at least 10 years after the last episode of ARF or until the age of 21, whichever is the longer. People with mild RHD who have completed 10 years of secondary prophylaxis do not need to continue treatment after that time. People with moderate RHD should continue secondary prophylaxis until the age of 35, while those with severe RHD should continue treatment until the age of 40, or longer if they wish.

The length of time over which secondary prophylaxis needs to be administered is a major challenge in ensuring compliance with the recommended protocol (that is, adherence) particularly for Aboriginal and Torres Strait Islander people (Parnaby & Carapetis 2010). Other factors that affect adherence with secondary prophylaxis in remote Australian Aboriginal and Torres Strait Islander communities are the availability and acceptability of health services. A study from the Northern Territory has shown that patients had better adherence to treatment when they felt that their care was more personalised and that they had a sense of belonging to the clinic (Harrington et al. 2006). Other studies have also shown that adherence to secondary prophylaxis was improved by active follow-up of patients who missed an injection and where monthly injections were given by a dedicated staff member (RHD Australia 2012). RHD control programs are the most effective way of improving adherence to secondary prophylaxis of ARF and clinical follow-up of people with RHD (RHD Australia 2012). For this reason, the RHD control programs are a key focus of the Government's Rheumatic Fever Strategy.

The number of people registered for secondary prophylaxis in the Northern Territory increased from 758 in 2005 to 1,116 in 2010 (Table 5.1). One factor that is likely to have contributed to this increase is the introduction, in 2007, of an automated process for identifying and reporting back to health centres those patients requiring secondary prophylaxis (Parnaby 2011).

Of the 5,816 patients receiving treatment over the 6 years, 57% (3,340) had a diagnosis of RHD, 35% (2,052) had a diagnosis of ARF and the rest (7%, or 424) had a diagnosis of either possible ARF or possible RHD. Note that not all people with RHD who are registered on the Northern Territory RHD register will also be registered for secondary prophylaxis as prophylactic treatment ceases after a period of time depending on the severity of the RHD.

The proportion of patients receiving more than 80% of their required doses has improved over time from 23% in 2005 to 28% in 2010, though still remains quite low. Since 2007, there has also been an increase in the proportion of patients receiving 50–80% of required doses and a decrease in the proportion receiving less than 50% (Table 5.1).

A contributing factor to this increase is the development of automated master charts that are sent through to health centres. In the past, staff at health centres were required to identify

patients for secondary prophylaxis. The automated master charts have taken over this task of going through individual charts to identify patients and this has reduced the likelihood of patients 'falling through the cracks'.

Table 5.1: Adherence to secondary prophylaxis in the last 12 months for persons registered on the Northern Territory ARF/RHD Control Program, 2005–2010

	Treatment year						
Percentage of required doses received in the previous 12 months	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2005–2010**
	Number of people						
< 50%	303	380	417	399	365	337	2,201
50-80%	283	319	329	364	439	465	2,199
> 80%[(b)]	172	203	230	231	266	314	1,416
Total people registered	**758**	**902**	**976**	**994**	**1,070**	**1,116**	**5,816**
	Coverage (per cent)						
< 50%	40.0	42.1	42.7	40.1	34.1	30.2	37.8
50-80%	37.3	35.4	33.7	36.6	41.0	41.7	37.8
> 80%[(a)]	22.7	22.5	23.6	23.2	24.9	28.1	24.3

(a) Includes people who received one or more doses when none were required.

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Program data.

6 Expenditure on acute rheumatic fever and rheumatic heart disease

This chapter presents the most recent (2008–09) health-care expenditure estimates for ARF and RHD in Australia. The estimates include expenditure by the Australian Government, state, territory and local governments and the non-government sector (such as private health insurance and individual contributions).

Estimates are sourced from the AIHW Disease Expenditure Database (see Appendix B). Health expenditure comprises recurrent and capital spending on hospital services, medical services, dental services, other health practitioner services, patient transport services, medicines, community and public health services, aids and appliances, health administration and health research.

It is important to note that only estimates of direct health expenditure are included in this report. Direct health expenditure relates to preventing, diagnosing and treating health problems. These estimates do not include costs that are not accrued by the health system, such as travel costs of patients, costs associated with the social and economic burden on carers and family, and costs relating to lost quality and quantity of life. Therefore, the estimates reported here do not represent the total economic impact of ARF and RHD in the Australian community.

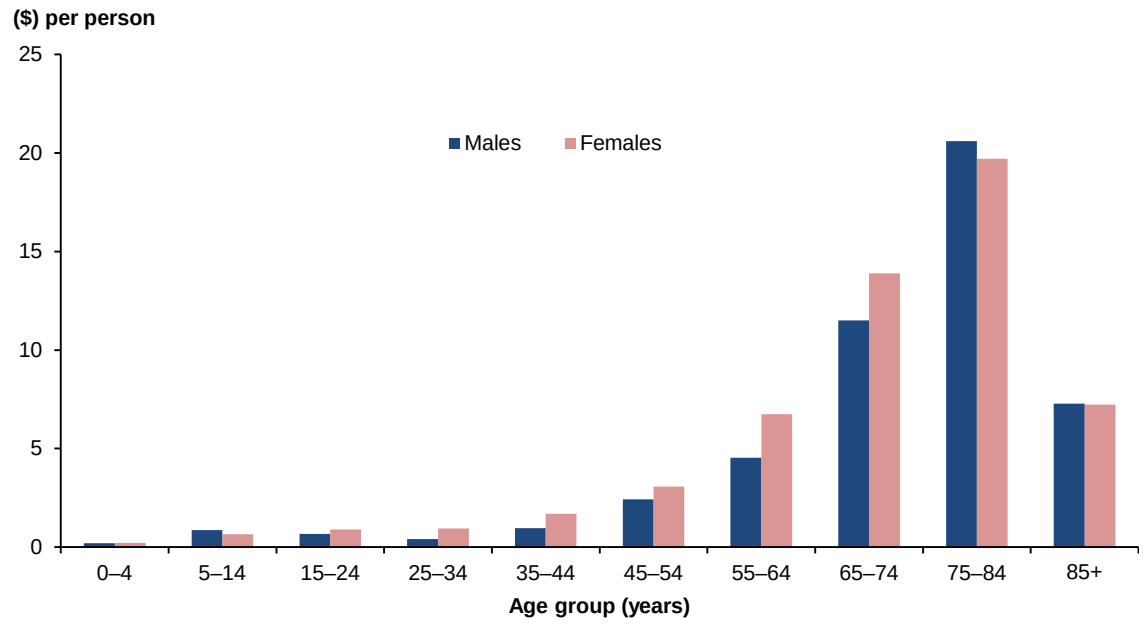
It is not possible to allocate all expenditure on health goods and services by disease. Expenditure on most community and public health programs, for instance, support the treatment and prevention of many conditions and cannot be allocated to one specific disease or injury. This is also true of capital expenditure on health facilities and equipment, which has the added problem of being characterised by large outlays that fluctuate greatly from year to year. For 2008–09, the areas of health expenditure that could not be allocated by disease were:

- hospital non-admitted patient services
- over-the counter medications
- other health practitioner services (apart from optometry)
- community health programs (apart from community mental health)
- public health (apart from cancer screening programs)
- health administration
- patient transport services
- health aids and appliances
- health research
- capital expenditure.

How much is spent on ARF and RHD?

In 2008-09, about $74 million (0.1%) of the $74.2 billion health expenditure that could be allocated by disease was spent on ARF and RHD, equating to just 1% of all CVD health expenditure. Expenditure per person for ARF and RHD was highest among people aged 75–

84 years ($20.10 per person in the Australian population). Among 5–34 year olds, expenditure for ARF and RHD was $0.73 per person, while for those aged 35–74 it ranged from $1.33 to $12.72 per person. The per person expenditure was higher for females than males between 15 to 74 but the opposite was true for the 75 to 84 year age group where males had higher expenditures than females ($20.60 compared with $19.71 per person) (Figure 6.1).



Source: AIHW Disease Expenditure Database.

Figure 6.1: Health care expenditure ($) for ARF and RHD per person, by age and sex, 2008–09

In 2008-09, estimated expenditure on admitted patients ($73.5 million) accounted for 98.8% of the total expenditure that could be allocated to ARF and RHD. Of the remaining expenditure on ARF and RHD in 2008–09, $553,600 (0.7%) was spent on out-of-hospital medical services, and $365,300 (0.5%) on prescription pharmaceuticals.

Aboriginal and Torres Strait Islander people

In 2008–09, expenditure on hospitalisations for Aboriginal and Torres Strait Islander people with ARF or RHD was $5.9 million, which accounted for 0.4% of all admitted patient expenditure for Aboriginal and Torres Strait Islander people ($1,470.5 million) (AIHW 2011b). Hospital expenditure per person for ARF and RHD for Aboriginal and Torres Strait Islander people was 4.3 times as high as that for non-Indigenous Australians ($10.9 compared with $2.5). However, this only reflects the cost of in-hospital care, while a great part of the care including prophylaxis is supplied by community health-care centres. However, it should be noted that these estimates were modelled using Indigenous under-identification factors. As some of the expenditure patterns may be influenced by variations in the completeness of Indigenous identification, it is possible that health expenditure estimates for Indigenous Australians may slightly overestimate or underestimate the actual level of health expenditure. As a result, these estimates should be interpreted with caution.

7 International comparisons

7.1 Incidence of ARF

International comparisons of ARF incidence are difficult to make and for many regions (including China and sub-Saharan Africa) no studies are available. Based on studies from countries for which data were available, it has been estimated that at least 471,000 new cases of ARF occur each year, with 95% of those coming from low- to middle-income countries (Carapetis et al. 2005b; World Health Organization 2005).

Based on studies conducted between the late 1970s and 2002, the highest ARF incidence rates among children and adolescents were in the Pacific Island and Indigenous Australian and New Zealand populations. Incidence rates in this group ranged from 40 to 815 per 100,000 population, with a median incidence of 374 cases per 100,000 (WHO 2005). By comparison, the lowest incidence rates—about 10 cases per 100,000 population—were observed in studies conducted in New Zealanders of European descent and in Hawaii (WHO).

Authors of a more recent international review confirm the high incidence of ARF in the Western Pacific region, which includes Australia (Seckeler & Hoke 2011). These authors compared the reported incidence of ARF in WHO regions worldwide and found that it was decreasing in all regions except the Americas and the Western Pacific. Improved living conditions and antibiotic treatment for GAS infection are believed to have contributed to the decreasing trend in ARF incidence in most regions of the world. The increase in ARF incidence in the Western Pacific is thought to be due to improved recognition and reporting of ARF in this region since the early 1990s.

How does the incidence of ARF in the Northern Territory compare?

Data from the Northern Territory RHD register presented in this report, and elsewhere, show that the incidence of ARF in the Northern Territory, particularly among Aboriginal and Torres Strait Islander children, is much higher than that reported for other developed countries. Between 2005 and 2010, the incidence rate in the Northern Territory was about 110 per 100,000 population for girls aged 5–14 and 70 per 100,000 for boys of the same age (Figure 2.3). For Aboriginal and Torres Strait Islander children aged 5–14 in the Northern Territory, Parnaby & Carapetis (2010) estimated that the incidence of ARF between 2002 and 2008 ranged from 150 to 380 per 100,000 population.

7.2 Prevalence of RHD

In their review of the global burden of group A streptococcal diseases, Carapetis et al. (2005b) estimated that globally there were at least 15.6 million people with RHD and that 60% of all cases of ARF would develop RHD each year.

The review of published evidence by Seckeler and Hoke (2011) found that the prevalence of RHD had been increasing in the major regions (Africa, South East Asia, Americas, Eastern Mediterranean and Western Pacific) of the world except Europe, despite a continuous decrease in the incidence of ARF between 1970 and 2009 in most of these regions. Improved diagnosis and an increase in survival of people with RHD are believed to contribute to this worldwide trend.

Internationally among children aged 5–14, Carapetis et al. (2005b) found that the prevalence of RHD between 1985 and the early 2000s was highest in sub-Saharan Africa (570 cases per 100,000 population), followed by the Pacific and the Indigenous populations of Australia and New Zealand (350 cases per 100,000 population) and south Central Asia (220 cases per 100,000 population). In contrast, the estimated prevalence of RHD among children living in regions defined as established market economies (non-Indigenous Australian and New Zealand populations, Japan, Northern Europe, Southern Europe, Western Europe, and Northern America) was 30 per 100,000 population.

Disparities in RHD prevalence across regions of the world and between specific population groups within these regions are believed to reflect disparities in socioeconomic and environmental conditions (RHD Australia 2012). In the case of Australia and New Zealand, disparities found in the prevalence of RHD among young children from Indigenous compared with non-Indigenous populations reveal a major health gap.

How does the prevalence of RHD in the Northern Territory compare?

In the light of these comparisons, findings from the Northern Territory reveal even greater disparity. In 2010, the overall prevalence of RHD in Aboriginal and Torres Strait Islander people in the Northern Territory was 26 times as high as that of their non-Indigenous counterparts (2,474 compared with 94 cases per 100,000 population). Further, between 2004 and 2010 the age-adjusted prevalence of RHD in the Northern Territory increased from 555 to 647 per 100,000 population (Table A2.1).

7.3 Hospitalisations and deaths

There is limited recent information on ARF and RHD hospitalisations in other countries. New Zealand data for 0–24 year olds for 2002–2006 show differences between some ethnic groups in hospitalisation rates for ARF and RHD (Craig et al. 2007). For example, ARF admission rates among people aged 0–24 over the 5 years were highest among those of Pacific and Maori ethnicity (62 and 29 per 100,000 population respectively), while those of European and Asian or Indian ethnicity had ARF admission rates of 1.3 per 100,000 population.

Based on studies from countries for which data were available, Carapetis et al. (2005b) estimated that worldwide there were at least 233,000 deaths due to RHD each year. However, it should be noted that it is difficult to obtain data on deaths from ARF and RHD in low- to middle-income countries, where these diseases are most common, because there are often no cause of death data collected or the data are not reliable (WHO 2005).

Appendix A Detailed statistical tables

A.1 Acute rheumatic fever

Table A1.1: Acute rheumatic fever incidence in the Northern Territory, by age and sex, 2005–2010

	Males		Females		Persons	
Age group (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
0–4	3	2.4	3	1.5	6	1.9
5–14	77	62.6	106	54.6	183	57.7
15–24	30	24.4	46	23.7	76	24.0
25–34	8	6.5	21	10.8	29	9.1
35+	5	4.1	18	9.3	23	7.3
Total	**123**	**100.0**	**194**	**100.0**	**317**	**100.0**

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Program data.

A.2 Rheumatic heart disease

Table A2.1: Prevalence of rheumatic heart disease in the Northern Territory, by age, 2004 to 2010

Age group (years) as at 31 December	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
				Number of cases per 100,000 population[(a)]			
0–14	207.0	208.1	201.8	216.1	236.7	247.2	228.5
15–24	854.4	861.0	905.1	930.7	923.5	907.1	863.7
25–34	756.6	810.1	848.8	824.3	804.0	794.8	823.3
35–44	682.3	728.1	733.0	795.8	832.8	832.3	847.5
45–54	537.9	552.3	612.5	649.9	654.3	695.0	717.4
55–64	538.6	538.2	580.9	604.4	545.1	540.4	537.1
65+	432.6	554.1	544.2	553.1	585.2	616.9	649.9
Total	**560.2**	**586.3**	**611.0**	**633.1**	**637.6**	**643.7**	**645.1**
***ASR*[(b)]**	***554.6***	***587.8***	***610.0***	***630.9***	***635.9***	***643.4***	***647.1***

(a) Age-specific rates calculated using the estimated resident population for the Northern Territory for each year.

(b) Age-standardised to the 2001 Australian population.

Source: AIHW analysis of Northern Territory Rheumatic Heart Disease Program data.

Table A2.2: Deaths from rheumatic heart disease, by age and sex, 2007–2009[a]

	Number of deaths			Deaths per 100,000 population		
Age group (years)	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
<35	14	17	31	0.1	0.1	0.1
35–54	14	33	47	0.2	0.4	0.3
55–64	35	40	75	1.0	1.1	1.0
65–74	41	86	127	1.9	3.7	2.8
75–84	110	221	331	8.5	13.6	11.3
85+	77	209	286	21.4	29.2	26.6
Total	291	606	897	0.9	1.9	1.4
ASR[b]				*1.0*	*1.5*	*1.3*
Rate ratio per 100,000 (Female rate÷Male rate)[c]						*1.6*
Rate difference per 100,000 (Female rate-Male rate)[d]						*0.5*

(a) Cause of death data for 2009 are preliminary and subject to further revision.

(b) Age-standardised to the 2001 Australian population.

(c) The rate ratio was calculated by dividing the ASR for females by the ASR for males. The rate ratio was calculated before rounding ASRs to one decimal place.

(d) The rate difference was calculated by subtracting the ASR for males from the ASR for females. The rate difference was calculated before rounding ASRs to one decimal place.

Source: Analysis of the AIHW National Mortality Database.

Table A2.3: Deaths from rheumatic heart disease, by age and Indigenous status, 2004–2007

	Deaths		Deaths per 100,000 population	
Age group (years)	**Indigenous Australians**	**Non-Indigenous Australians**	**Indigenous Australians**	**Non-Indigenous Australians**
0-44	38	17	2.9	0.1
45-64	18	57	8.9	0.5
65+	7	516	15.1	7.9
Total	**63**	**590**	**4.1**	**1.2**
ASR[(a)]			*5.8*	*1.1*
Rate ratio per 100,000 (Indigenous÷non-Indigenous rate)[(b)]				5.2
Rate difference per 100,000 (Indigenous-non-Indigenous rate)[(c)]				4.7

(a) Age-standardised to the 2001 Australian population.

(b) The rate ratio was calculated by dividing the ASR for Indigenous Australians by the ASR for other Australians. The rate ratio was calculated before rounding ASRs to one decimal place.

(c) The rate difference was calculated by subtracting the ASR for other Australians from the ASR for Indigenous Australians. The rate difference was calculated before rounding ASRs to one decimal place.

Notes

1. Based on data for deaths in persons usually resident in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory.
2. There were 8 records (1% of deaths) where Indigenous status was not stated and these cases were excluded from the analysis.

Source: Analysis of the AIHW National Mortality Database.

Table A2.4: Deaths from rheumatic heart disease, by state and territory of residence, 2005–2007

		Deaths per 100,000 population	
State and territory of residence	**Number of deaths**	**Crude rate**	**Age-standardised rate[(a)]**
NSW and ACT	252	1.2	1.1
Vic	200	1.3	1.2
Qld	151	1.2	1.2
WA	91	1.5	1.5
SA	67	1.4	1.2
Tas	31	2.1	1.8
NT	26	4.1	5.8
Australia	**818**	**1.3**	**1.2**

(a) Age-standardised to the 2001 Australian population.

Source: Analysis of the AIHW National Mortality Database.

Table A2.5: Deaths from rheumatic heart disease, by sex, 1979 to 2009

	Number of deaths			Deaths per 100,000 population[(a)]		
Year	Males	Females	Persons	Males	Females	Persons
1979	149	282	431	2.0	3.1	2.6
1980	156	281	437	2.1	3.1	2.7
1981	153	227	380	2.1	2.4	2.3
1982	153	254	407	1.9	2.6	2.3
1983	135	246	381	1.7	2.4	2.1
1984	127	287	414	1.5	2.8	2.3
1985	149	280	429	2.0	2.7	2.3
1986	130	264	394	1.5	2.5	2.1
1987	139	253	392	1.7	2.3	2.0
1988	147	258	405	1.6	2.3	2.0
1989	146	279	425	1.6	2.4	2.1
1990	131	229	360	1.5	1.9	1.7
1991	132	255	387	1.4	2.1	1.8
1992	116	240	356	1.2	1.9	1.6
1993	114	248	362	1.2	1.9	1.6
1994	110	229	339	1.1	1.8	1.5
1995	92	175	267	0.9	1.3	1.1
1996	97	159	256	0.9	1.1	1.1
1997	108	213	321	1.5	2.2	1.9
1998	67	144	211	0.9	1.4	1.2
1999	84	175	259	1.1	1.7	1.4
2000	99	162	261	1.3	1.5	1.4
2001	79	157	236	1.0	1.4	1.2
2002	81	188	269	0.9	1.7	1.3
2003	97	189	286	1.1	1.6	1.4
2004	80	169	249	0.9	1.4	1.2
2005	100	183	283	1.1	1.5	1.3
2006	87	194	281	0.9	1.5	1.3
2007	85	169	254	0.9	1.3	1.1
2008	109	222	331	1.1	1.6	1.4
2009	97	215	312	0.9	1.6	1.3

(a) Age-standardised to the 2001 Australian population.

Notes

1. Death rates for 1979–1996 have been adjusted to ICD-10 standards using a comparability factor of 0.69.
2. Cause of death data for 2009 are preliminary and subject to revision by the Australian Bureau of Statistics (ABS).

Sources: Analysis of the AIHW National Mortality Database.

A.3 Hospitalisations for acute rheumatic fever and rheumatic heart disease

Table A3.1: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease by age and sex, 2009–10

	Hospitalisations			Hospitalisations per 100,000 population		
Age group (years)	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
0–4	10	10	20	1.4	1.4	1.4
5–9	31	42	73	4.5	6.4	5.4
10–14	52	72	124	7.3	10.6	8.9
15–19	42	28	70	5.6	3.9	4.8
20–24	16	40	56	1.9	5.1	3.5
25–34	34	80	114	2.2	5.2	3.7
35–44	66	120	186	4.2	7.6	5.9
45–54	81	139	220	5.4	9.1	7.3
55–64	176	231	407	14.2	18.4	16.3
65–74	272	363	635	35.2	45.2	40.3
75–84	257	344	601	58.6	62.9	61.0
85+	43	117	160	33.8	46.9	42.4
All ages	**1,080**	**1,586**	**2,666**	**9.9**	**14.4**	**12.2**
ASR[(a)]				*9.9*	*13.3*	*11.7*
Rate ratio per 100,000 (Female rate÷Male rate)[(b)]						*1.3*
Rate difference per 100,000 (Female rate-Male rate)[(c)]						*3.4*

(a) Age-standardised to the 2001 Australian population.

(b) The rate ratio was calculated by dividing the ASR for females by the ASR for males. The rate ratio was calculated before rounding ASRs to one decimal place.

(c) The rate difference was calculated by subtracting the ASR for males from the ASR for females. The rate difference was calculated before rounding ASRs to one decimal place.

Note: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.

Source: AIHW National Hospital Morbidity Database.

Table A3.2: Hospitalisations[a] with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by age and Indigenous status, between 2007–08 and 2009–10

	Number of hospitalisations		Hospitalisations per 100,0000 population	
Age group (years)	Indigenous Australians	Other Australians[b]	Indigenous Australians	Other Australians[b]
0–4	19	31	9.9	0.8
5–9	142	57	76.1	1.5
10–14	229	83	123.4	2.2
15–19	118	91	67.1	2.3
20–24	99	41	71.2	0.9
25–34	148	127	68.0	1.5
35–44	149	283	76.3	3.2
45–54	90	625	63.8	7.4
55–64	40	1,160	50.0	16.8
65+	31	4,021	61.5	49.0
Total	**1,065**	**6,519**	**68.1**	**10.8**
ASR[c]			*66.9*	*10.0*
Rate ratio per 100,000 (Indigenous÷Other)[d]				*6.7*
Rate difference per 100,000 (Indigenous-Other)[e]				*56.9*

(a) Based on patients usually resident in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory; excludes private hospitals in the NT.

(b) Other Australians includes people whose Indigenous status was 'Not stated'.

(c) Age-standardised to the 2001 Australian population.

(d) The rate ratio was calculated by dividing the ASR for Indigenous Australians by the ASR for other Australians. The rate ratio was calculated before rounding ASRs to one decimal place.

(e) The rate difference was calculated by subtracting the ASR for other Australians from the ASR for Indigenous Australians. The rate difference was calculated before rounding ASRs to one decimal place.

Note: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.

Source: AIHW National Hospital Morbidity Database.

Table A3.3: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by state and territory of residence, 2009–10

State and territory of residence	Number of hospitalisations	Hospitalisations per 100,000 population[(a)]	Crude rate per 100,000 population
NSW	643	8.4	9.0
Vic	567	9.7	10.4
Qld	649	14.6	14.8
WA	270	11.9	11.9
SA	209	10.8	12.9
Tas	31	5.1	6.1
ACT	20	6.3	5.6
NT	206	86.4	90.2
Australia[(b)]	**2,666**	**11.7**	**12.2**

(a) Age-standardised to the 2001 Australian population.

(b) Total does not equal subcategories due to incomplete reporting for the state of usual residence variable.

Note: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.

Source: AIHW National Hospital Morbidity Database.

Table A3.4: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease, by sex, 1999–00 to 2009–10

	Number of hospitalisations			Hospitalisations per 100,000 population[(a)]		
Year	Males	Females	Persons	Males	Females	Persons
1999–00	827	1,364	2,191	9.3	14.0	11.7
2000–01	819	1,248	2,067	9.1	12.5	10.8
2001–02	893	1,363	2,256	9.6	13.4	11.5
2002–03	916	1,380	2,296	9.7	13.3	11.5
2003–04	915	1,377	2,292	9.5	13.0	11.3
2004–05	1,005	1,443	2,448	10.2	13.3	11.8
2005–06	977	1,533	2,510	9.8	14.0	11.9
2006–07	1,054	1,507	2,561	10.3	13.4	11.9
2007–08	1,187	1,514	2,701	11.3	13.2	12.3
2008–09	1,073	1,541	2,614	10.1	13.2	11.7
2009–10	1,080	1,586	2,666	9.9	13.3	11.7

(a) Age-standardised to the 2001 Australian population.

Note: Hospitalisations with a principal diagnosis of acute rheumatic fever or rheumatic heart disease; excludes hospitalisations for unqualified neonates, boarders and organ procurement.

Source: AIHW National Hospital Morbidity Database.

Appendix B National data sources

AIHW National Hospital Morbidity Database

The AIHW's National Hospital Morbidity Database (NHMD) is compiled from data supplied by the state and territory health authorities. It is a collection of electronic confidentialised summary records for separations (that is, episodes of admitted patient care) in almost all hospitals in Australia, including public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free-standing day hospital facilities. Public sector hospitals that are not included are those not within the jurisdiction of a state or territory health authority (hospitals operated by the Department of Defence or correctional authorities, for example, and hospitals located in offshore territories).

The data supplied to the NHMD are based on the National Minimum Data Set for Admitted Patient Care and include demographic, administrative and length of stay data, and data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.

The data are episode-based, and do not contain identifiers for individual people. As a result, it is not possible to count patients individually. A 'hospitalisation' or 'separation' refers to an episode of care for an admitted patient, which can be a total hospital stay (from admission to discharge, transfer or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation).

Since 1998–99, diagnoses in the NHMD have been coded to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) by clinical coders in each hospital, based on the diagnosis reported by a medical practitioner on discharge of the patient. The diagnosis is recorded for each hospital episode and is specific to that episode. The diagnosis-related hospital morbidity data presented in this report mainly cover 1 July 2007 to 30 June 2010 but trends are reported for 1 July 1999 to 30 June 2010. In 2007–08, diagnoses and external causes of injury were recorded using the fifth edition of the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) (NCCH 2006), while in 2008–09 and 2009–10, diagnoses and external causes of injury were recorded using the sixth edition of the ICD-10-AM (NCCH 2008).

Most of the hospitalisations data presented in this report relate to separations with a principal diagnosis of ARF (ICD-10-AM I00–I02) or RHD (ICD-10-AM I05–I09). The principal diagnosis is the diagnosis established after study to be chiefly responsible for the episode of admitted patient care.

Separations for which the care type was reported as Newborn without qualified days, and records for Hospital boarders and Posthumous organ procurement have been excluded from statistics on hospital separations reported here.

Procedures for 2007–08 were classified, coded and reported to the National Hospital Morbidity Database by all states and territories, using the fifth edition of the Australian Classification of Health Interventions (ACHI) (NCCH 2006), while procedures for 2008–09 and 2009–10 were classified, coded and reported using the sixth edition of the ACHI (NCCH 2008).

The ACHI heart valve surgery procedure codes used in conjunction with a principal diagnosis of ARF or RHD this report were:

- **Aortic Valve** (Blocks 621, 622, 623, 624): 38456-10, 38483-00, 38270-01, 38480-00, 38481-00, 38488-00, 38488-01, 38489-00, 38489-01, 38456-15, 38653-04, 38475-02, 38477-02.
- **Mitral valve** (Blocks 625, 626, 627, 628, 629, 630): 38487-00, 38485-01, 38270-02, 38480-01, 38481-01, 38475-00, 38477-00, 38488-02, 38488-03, 38489-02, 38485-00, 38456-16, 38653-05.
- **Tricuspid valve** (Blocks 631, 632, 633, 634, 635): 38456-11, 38480-02, 38481-02, 38475-01, 38477-01, 38488-04, 38488-05, 38489-03, 38456-17, 38653-06.
- **Pulmonary valve** (Blocks 636, 637, 638): 38456-01, 38270-03, 38488-06, 38488-07, 38489-04, 38489-05, 38456-18, 38653-07.

One or more procedures can be reported for each separation, but procedures are not undertaken for all hospital admissions, so only some of the separation records include procedure data.

The data quality statement for the AIHW National Hospital Morbidity Database can be found at on the AIHW's Metadata Online Registry (METeOR)—<http://meteor.aihw.gov.au/content/index.phtml/itemId/511338>.

AIHW National Mortality Database

The mortality data used in this report were provided by the Registries of Births, Deaths and Marriages, the Australian Bureau of Statistics and the National Coronial Information System. These data are maintained at the Australian Institute of Health and Welfare in the National Mortality Database.

The National Mortality Database contains coded causes of death from the information documented by the medical practitioner certifying the death or by a coroner. Registration of deaths is the responsibility of the state and territory Registrars of Births, Deaths and Marriages. These data are then collated and coded by the Australian Bureau of Statistics (ABS) to the International Statistical Classification of Diseases and Related Health. Since 1997, deaths in Australia have been coded to the 10th Revision of the International Classification of Diseases (ICD-10).

Data on deaths from ARF (ICD-10 I00–I02) and RHD (ICD-10 I05–I09) in this report have been identified based on the 'underlying cause'—the disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury. In Australia, the underlying cause is derived from information on the death certificate, using an automated process.

In addition, the death data presented in this report have been collated according to the *year of registration of the death* and cover the period 1 January 1979 to 31 December 2009.

The data quality statements underpinning the AIHW National Mortality Database are in the following ABS publications: ABS Quality declaration summary for *Causes of death 2010* (ABS cat. no. 3303.0) <http://www.abs.gov.au/Ausstats/abs@.nsf/0/D4A300EE1E04AA43CA2576E800156A24?OpenDocument> and ABS Quality declaration summary for *Deaths, Australia 2010* (ABS cat. no. 3302.0) <http://www.abs.gov.au/Ausstats/abs@.nsf/0/9FD0E6AAA0BB3388CA25750B000E3CF5?OpenDocument>.

AIHW Disease Expenditure Database

A comprehensive database that allocates health expenditure estimates by disease category, area of expenditure, and by age and sex.

This report provides direct health expenditure on ARF and RHD under three categories:

- Admitted patient hospital services covering the expenditure on services provided to an admitted patient, including expenditure on medical services delivered to private admitted patients in hospitals.
- Prescription pharmaceuticals including prescriptions subsidised under government schemes (for example, the Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme), private prescriptions and under co-payment prescriptions. Pharmaceuticals dispensed in hospitals were included in the estimates of hospital costs.
- Out-of hospital medical services comprising medical services primarily funded under the Medical Benefits Schedule, such as primary health visits, pathology and specialist services. Practice Incentive Payments are also included. In addition, medical services funded by Department of Veteran's Affairs, compulsory motor vehicle third party insurance, workers compensation insurance, private health insurance funds, the Australian Government premium rebates allocated to medical services as well as Medicare co-payments and other out-of-pocket payments are all included. In hospital medical expenditure for private patients was not included here but as part of admitted patient hospital services.

The data quality statement for the AIHW Disease Expenditure Database 2008–09 can be found at on the AIHW's Metadata Online Registry (METeOR)—<http://meteor.aihw.gov.au/content/index.phtml/itemId/512599 >.

Appendix C Data and statistical methods

Reporting Indigenous deaths data

The ABS has assessed the quality of Indigenous identification in death registration data by state and territory in the Census Data Enhancement Indigenous Mortality Quality Study. This study involved linking Census records with death registration records to examine differences in reporting of Indigenous status across two data sets. This assessment indicates that the Indigenous identification rate is 87% or higher in New South Wales, Queensland, Western Australia and the Northern Territory, and about 65% for the remaining jurisdictions. Historically, Indigenous identification in South Australia, Western Australia and the Northern Territory has been of sufficient quality to include in analyses from 1991 onwards. Queensland was included in analysis from 1998 onwards and, in 2010, a decision was made to include data from New South Wales from 2001 onwards. Therefore, analysis of deaths data by Indigenous status between 2004 and 2007 in this report are based on data where the deceased's state of residence was New South Wales, Queensland, Western Australia, South Australia or the Northern Territory.

Reporting Indigenous hospitalisations data

In February 2010, the AIHW released a report on the quality of Indigenous identification in hospital separations data (AIHW 2010). The report recommended that, from 2004–05, the level of Indigenous identification in hospitalisations data was acceptable for analysis purposes (that is, the level of Indigenous identification was 80% or greater) for data from New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory (public hospitals only). Data are reported based on the state or territory of the patient's usual residence for these six jurisdictions. As at June 2010, the proportion of the Indigenous population covered by these six jurisdictions was 96% (ABS 2009).

Populations used in this report

Population data are used in this report to calculate rates. The population data used are estimated resident populations (ERPs) derived from the ABS Census of Population and Housing. ERPs adjust Census data to add people missed by the Census and people overseas on Census night, and to remove overseas visitors. In between Census years, the ERPs are updated using indicators of population change such as deaths, births and net migration. The ERPs used in this report are based on the 2006 Census.

For death data, a rate was calculated for a calendar year and the population used was the ERP as reported at 30 June of that year. For hospital data, a rate was calculated for a financial year and the population used was the ERP for 31 December of the year in the middle span. For example, to calculate the hospitalisation rate of the 2009–10 financial year, the population for 31 December 2009 was used.

Throughout the report, rates of deaths and hospitalisations are age-standardised. In these cases, the standard population used to calculate the age-standardised rate was the Australian ERP as at 30 June 2001.

Indigenous population

Australia's Indigenous population is calculated from the Census, and uses ERPs as described above. Four years of data (2004 to 2007) were combined for the analyses of ARF and RHD deaths by Indigenous status to overcome the small numbers and year-to-year variability in deaths. For these analyses, the Indigenous population reference years were combined from 30 June 2004 to 30 June 2007.

For hospitalisations, 3 years of data from 2007–08 to 2009–10 were combined due to small numbers. The Indigenous ERP for each financial year was calculated by taking the average of the 30 June Indigenous ERPs. For example, to derive the Indigenous ERP as at 31 of December 2009, the Indigenous ERPs (for the relevant states and territories) at 30 June 2009 and at 30 June 2010 were summed and averaged. To get the equivalent ERP for Other Australians, the derived Indigenous ERP was subtracted from the Australia-wide ERP (selecting only the relevant states and territories) at 31 December for a given year.

Crude and age-specific rates

Crude rates and age-specific rates are calculated by dividing the number of events in a specified time period by the total number of individuals in the population (in the same age group). Age-specific rates are not age-standardised.

Age-standardised rates

Age-standardisation is a technique used to take account of the effect of differences in population age structures when comparing rates across different population groups (such as men and women) or across time. The direct method of standardisation was used to calculate age-standardised rates (ASRs) in this report, including ASRs for length of stay.

Direct age-standardisation

Age-standardised proportions have been calculated using the following formula:

$$\text{Age-standardised proportion (ASR)} = \Sigma(r_i P_i)/\Sigma P_i$$

where:

r_i is the sex- and age group-specific rate for sex and age group i in the population being studied

P_i is the population of age group i in the standard population.

The standard population used was the Australian estimated resident population as at 30 June 2001.

Appendix D Diagnosis guidelines

Table D1: The 2012 updated Australian guidelines for the diagnosis of ARF

	High-risk groups[a]	All other groups
Definite initial episode of ARF	2 major or 1 major and 2 minor manifestations plus evidence of a preceding GAS infection[b]	
Definite recurrent episode of ARF in a patient with known past ARF or RHD	2 major or 1 major and 1 minor or 3 minor manifestations plus evidence of a preceding GAS 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 cases should be further categorised according to the level of confidence with which the diagnosis is made: Highly suspected ARF Uncertain ARF	
Major manifestations	Carditis (including subclinical evidence of rheumatic valvulitis on echocardiogram) Polyarthritis[c] or aseptic mono-arthritis or polyarthralgia Chorea[d] Erythema marginatum[e] Subcutaneous nodules	Carditis (including subclinical evidence of rheumatic valvulitis on echocardiogram) Polyarthritis[c] Chorea[d] Erythema marginatum[e] Subcutaneous nodules
Minor manifestations	Monoarthralgia Fever[f] ESR[h] ≥30 mm/hor CRP[h] ≥30 mg/L Prolonged P-R interval on ECG[g]	Fever[f] Polyarthralgia or aseptic mono-arthritis ESR[h] ≥30 mm/h or CRP[h] ≥ 30 mg/L Prolonged P-R interval on ECG[g][h]

(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). Aboriginal people and Torres Strait Islanders living in rural or remote settings are known to be at high risk. Data are not available for other populations, but Aboriginal and Torres Strait Islander 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 antisreptolysin O or other streptococcal antibody, or a positive throat culture or rapid antigen test for GAS.

(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 GAS 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 ≥38°C 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

(h) CRP, C-reactive protein; ECG, electrocardiogram; ESR, erythrocyte sedimentation rate.

Source: RHD Australia 2012.

Table D2: The World Heart Federation criteria for echocardiographic diagnosis of RHD

1. Echocardiographic criteria for individuals ≤20 years of age
Definite RHD (either A, B, C or D):
(A) Pathological MR[(a)] and at least two morphological features of RHD of the mitral valve
(B) Mitral stenosis (MS)[(b)] mean gradient ≥4 mmHg (note: congenital mitral valve anomalies must be excluded)
(C) Pathological AR[(c)] and at least two morphological features of RHD of the aortic valve (note: bicuspid aortic valve and dilated aortic root must be excluded)
(D) Borderline disease of both the aortic and mitral valve[(d)]
Borderline RHD (either A, B or C):
(A) At least two morphological features of RHD of the mitral valve without pathological MR or MS
(B) Pathological MR
(C) Pathological AR
Normal echocardiographic findings (all of A, B, C and D):
(A) Mitral regurgitation (MR) that does not meet all four Doppler criteria (physiological MR)
(B) Aortic regurgitation (AR) that does not meet all four Doppler criteria (physiological AR)
(C) An isolated morphological feature of RHD of the mitral valve (e.g. valvular thickening), without any associated pathological stenosis or regurgitation
(D) Morphological feature of RHD of the aortic valve (e.g. valvular thickening), without any associated pathological stenosis or regurgitation
2. Echocardiographic criteria for individuals >20 years of age
Definite RHD (either A, B, C or D):
(A) Pathological MR and at least two morphological features of RHD of the mitral valve
(B) MS mean gradient ≥4 mmHg (note: congenital mitral valve anomalies must be excluded)
(C) Pathological AR and at least two morphological features of RHD of the aortic valve in individuals <35 years of age only (note: hypertension, bicuspid aortic valve and dilated aortic root must be excluded)
(D) Pathological AR and at least two morphological features of RHD of the mitral valve

(a) Mitral regurgitation

(b) Mitral stenosis

(c) Aortic regurgitation

(d) Combined AR and MR in high-prevalence regions and in the absence of congenital heart disease is regarded as rheumatic.

Source: RHD Australia 2012.

Glossary

Aboriginal or Torres Strait Islander: A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander and is accepted as such by the community in which he or she lives.

age-specific rate: A rate for a specific age group. The numerator and denominator relate to the same age group.

age-standardisation: A method of removing the influence of age when comparing populations with different age structures. This is usually necessary because the rates of many diseases vary strongly (usually increasing) with age. The age structures of the different populations are converted to the same 'standard' structure, the disease rates that would have occurred with that structure are then calculated and compared.

associated causes of death: Causes, other than the underlying cause, that were instrumental in causing death. They encompass conditions that intervened or significantly contributed to the death. Associated causes include:

- the immediate (or direct) cause; that is, the condition that occurred immediately before death or closest to the time of death
- all intermediate (or intervening) causes; that is, the conditions that occurred between the underlying and immediate causes
- all significant contributing causes; that is, all significant conditions contributing to the death but which did not bring about the underlying cause, including significant pre-existing conditions.

cardiovascular disease (CVD): Any disease of the *circulatory system*, namely the heart (cardio) or blood vessels (vascular). Includes *heart attack, angina, stroke* and *peripheral vascular disease*. CVD is also known as *circulatory disease.*

cause of death: Causes of death are defined (in 1967, by the World Health Assembly) as 'all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstances of the accident or violence which produced any such injuries' (WHO 2009). This definition aims to capture all the relevant information on the death certificate thereby reducing bias that might arise if, for example, the certifier selected some conditions for entry and rejected others. The causes of death, as documented on the death certificate, should not include symptoms or the mode of dying. See also **underlying cause of death**.

communicable diseases (infectious diseases): Diseases or illnesses due to infectious organisms or their toxic products. Communication may occur directly or indirectly through contact with other humans, animals or other environments that harbour the organism.

crude death rate: The number of deaths in a given period divided by the size of the corresponding population indexed to 100,000.

disease: A physical or mental disturbance involving *symptoms* (such as pain or feeling unwell), dysfunction or tissue damage, especially if these *symptoms* and *signs* form a recognisable clinical pattern.

hospitalisation: See **separation**.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period. Compare with **prevalence**.

International Classification of Diseases: The World Health Organization's internationally accepted classification of death and disease. The 10th Revision (ICD-10) is currently in use (WHO 2009). In this report, causes of death classified before 1979 under previous revisions have been reclassified to ICD-10 by the AIHW. ICD-10-AM is the Australian modification of ICD-10, used for diagnoses and procedures recorded for patients admitted to hospitals.

morbidity: Refers to ill health in an individual and to levels of ill health in a population or group.

Other Australians People who are not of Aboriginal or Torres Strait Islander descent, or whose status is not known.

prevalence: The number or proportion (of cases, instances, and so forth) present in a population at a given time. Compare with **incidence**.

principal diagnosis: The diagnosis listed in hospital records to describe the problem that was chiefly responsible for the patient's episode of care in hospital.

private hospital: A privately owned and operated institution, catering for patients who are treated by a doctor of their own choice. Patients are charged fees for accommodation and other services provided by the hospital and relevant medical and allied health practitioners.

public hospital: A hospital controlled by a state or territory health authority. In Australia public hospitals offer free diagnostic services, treatment, care and accommodation to all Australians who need them.

rheumatic fever: 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. Is brought on by a reaction to a throat infection by a particular bacterium. Now very rare in the non-Indigenous population, it is still at unacceptably high levels among Indigenous Australians living in remote areas. See **rheumatic heart disease**.

rheumatic heart disease (RHD): Chronic disease from damaged heart valves caused by earlier attack(s) of **rheumatic fever**.

risk factor: Any factor that represents a greater risk of a health disorder or other unwanted condition or event. Some risk factors are regarded as causes of disease, others are not necessarily so. Along with their opposites, protective factors, risk factors are known as *determinants*.

separation: An episode of care for an admitted patient, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation). Separation also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital or changing type of care.

underlying cause of death: The disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury. Compare with **associated causes of death**.

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