









ORIGINAL ARTICLE

Acute rheumatic fever and rheumatic heart disease in children and adolescents in Victoria, Australia

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Aim: To describe the epidemiology and clinical profile of children and adolescents with acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in Victoria, Australia.

Methods: A retrospective audit was undertaken of children and adolescents with ARF and RHD attending the Royal Children's and Monash Children's Hospitals in Victoria, Australia between 2010 and 2019. Potential cases were identified by searching multiple sources for relevant ICD-10-AM codes and keywords, then reviewed manually. For confirmed cases, we collected data on patient demographics, clinical features, comorbidities and management.

Results: Of 179 participants included, there were 108 Victorian residents and 71 non-Victorian residents. 126 had at least one episode of ARF during the study period and 128 were diagnosed with RHD. In the Victorian resident group, the overall incidence of ARF was 0.8 per 100 000 5–14 year olds. This incidence was higher in Victorian Aboriginal and/or Torres Strait Islander (3.8 per 100 000) and Pacific Islander (32.1 per 100 000) sub-populations. Of 83 Victorian residents who had an ARF episode, 11 (13%) had a recurrence. Most Victorian residents with RHD had mixed aortic and mitral valve pathology (69.4%) and moderate to severe disease (61.9%). Most non-Victorian residents were Aboriginal and/or Torres Strait Islander people (80.3%) and were commonly transferred for tertiary or surgical management of RHD (83.1%).

Conclusions: ARF and RHD continue to affect the health of significant numbers of children and adolescents living in Victoria, including severe and recurrent disease. Specialised services and a register-based control program may help to prevent complications and premature death.

Key words: acute rheumatic fever; epidemiology; Indigenous health; Pacific Islander; paediatric; rheumatic heart disease.

What is already known on this topic

- 1 The epidemiology and clinical profile of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are well documented in endemic regions of Australia.
- 2 Paediatric admissions for ARF and RHD in Victoria have decreased substantially since the 1940s.
- 3 Patient registers and RHD control programs have been implemented in most jurisdictions of Australia.

What this paper adds

- 1 The epidemiology and clinical profile of ARF and RHD in Victorian children and adolescents are described for the first time.
- 2 ARF and RHD persist in Victorian children and adolescents, including recurrent ARF and severe RHD.
- 3 Children from Pacific Islander, Aboriginal and/or Torres Strait Islander ethnic backgrounds appear to be at a substantially higher risk of ARF and RHD.

Acute rheumatic fever (ARF) is an immune-mediated condition triggered by infection with *Streptococcus pyogenes* (Group A Streptococcus), most commonly presenting between 5 and 14 years of age.¹ ARF is a

clinical syndrome with diagnosis informed by the revised Jones Criteria (2015),² although the RHD Australia Guidelines are used in the Australian setting.³ Around 60% of patients who experience an episode of ARF develop the chronic complications of rheumatic heart disease (RHD). Risk factors for developing ARF and RHD relate largely to social determinants of health, including socio-economic disadvantage⁴ and overcrowding.⁵ The RHD Endgame Strategy offers a blueprint to eliminate RHD in Australia by 2031.⁶

A very high burden of ARF and RHD has been documented in northern Australia, particularly amongst Aboriginal and Torres

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Strait Islander Peoples.⁷ However, there is a paucity of data regarding the burden of ARF and RHD in the southern states of Australia where the risk is assumed to be lower.⁸ Recent studies from the state of Victoria reveal that although paediatric ARF/RHD admissions have decreased substantially since the 1940s,⁹ a significant number of people under 40 years of age continue to be admitted to Victorian hospitals for ARF and RHD.¹⁰ The epidemiology and medical comorbidities of children and adolescents with ARF and RHD seeking care in Victorian hospitals have not been described. These data are needed to inform clinical management and public health prevention strategies at a jurisdictional and national level. Therefore, we aimed to comprehensively describe the clinical epidemiology of children and adolescents with ARF and RHD at two main tertiary paediatric hospitals in Victoria.

Methods

Study design and setting

We undertook a retrospective evaluation of the epidemiology of paediatric ARF and RHD patients attending two tertiary paediatric hospitals in Victoria, Australia, between 1 January 2010, and 31 December 2019. Victoria has a population of 5.9 million, including 1.4 million children and adolescents, of whom 4.5 million live in the capital of Melbourne. Aboriginal and/or Torres Strait Islander peoples comprise 0.8% of the Victorian population, compared to 2.8% of the total Australian population.¹¹ People from a Pacific Island ethnic background are estimated to make up 0.6% of the Victorian population.¹²

The Royal Children's Hospital (RCH) and Monash Children's Hospital (MCH) are tertiary referral centres for Victorian children and adolescents (up to 21 years of age) with suspected or confirmed ARF and/or RHD. They also provide care for patients transferred from interstate and overseas, predominantly for surgical management of RHD.¹³ During the study period, there were no other hospital services for paediatric cardiology or infectious diseases in Victoria and all outreach services to regional areas were linked to RCH or MCH clinical records.

Case-finding

We used several methods to identify records of children and adolescents who had been diagnosed with ARF or RHD who attended RCH or MCH during the study period. We searched Health Information Services records for all admissions with an International Classification of Disease (10th Edition, Australian Modification, ICD-10-AM) code potentially related to ARF or RHD (I00.0-I09.9, inclusive).¹⁴ At RCH, we also searched the electronic medical record (Epic Systems, WI, USA) to identify all patients with ICD-10-AM codes I00.0-I09.9; with a documented diagnosis or 'reason for attendance' of ARF or RHD; and those who were prescribed benzathine benzylpenicillin injection. We also manually searched clinic lists from the RCH Rheumatic Fever clinic. At MCH, we also searched echocardiogram reports in the electronic cardiology database (HealthTrack Medical Systems, Milton, QLD, Australia) for the word 'rheumatic'. Duplicate records and individuals aged over 21 at first encounter were excluded.

Participants and data collection

We manually reviewed the electronic health record of all potential cases to determine eligibility. All children and adolescents considered to have ARF or RHD during the study period and who were aged 21 years and younger at the time of initial diagnosis were eligible for inclusion. Cases were included even if their initial presentation with ARF or RHD occurred at another health service. Cases were excluded if a definitive alternative diagnosis was made, such as individuals who were initially diagnosed with ARF or RHD but later reclassified.

For cases that met the eligibility criteria, we manually searched the electronic and scanned medical records, and collected de-identified data on demographics, clinical features of ARF/RHD, management plans, comorbidities and health-care encounters. Where individuals had attended both RCH and MCH, data were combined into a single record. We recorded the presence or absence of ARF clinical features from the first episode within the study period. RHD features were taken from echocardiogram reports and clinical notes. Non-pathological or 'trivial' regurgitation of the mitral or aortic valves were considered normal findings.¹⁵ Data were entered into a Research Electronic Data Capture (REDCap) database hosted at the Murdoch Children's Research Institute.¹⁶

Statistical analysis

As many non-Victorian residents are transferred to the RCH or MCH for surgical management of severe RHD, cases were categorised into Victorian and non-Victorian resident sub-populations by postcode. Descriptive analyses were performed for each cohort. Classification of ARF and RHD severity was determined according to the 2020 Australian guidelines.³ Socio-economic status was estimated by postcode using the Index of Relevant Socio-Economic Disadvantage¹⁷ and rurality was described using the Remoteness Areas Structure.¹⁸

Crude annual ARF incidence rates were calculated using the total number of episodes that occurred in Victoria for 5–14 years old Victorian residents by the population of Victorian residents in this age range,¹² averaged over the study period. Incidence rates for Aboriginal and/or Torres Strait Islander, and Pacific Islander ethnicities were also estimated using denominator data obtained from the Australian Bureau of Statistics.¹² Incidence rate ratios (IRRs) were calculated with 95% confidence intervals (CIs).

Definitions for fever and cutoff values for anti-streptolysin O titre (ASOT), anti-DNAse B, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP) and electrocardiogram PR interval were based on Australian guidelines.³ Overweight and obesity were defined using World Health Organization Body Mass Index-for-age sex-specific charts.¹⁹ All analyses were undertaken using STATA version 14.0 (StataCorp, College Station, TX, USA).

Ethical approval

The study protocol was approved by RCH (HREC 2019.211.1) and Monash Health Human Research Ethics Committees (HREC/59426/RCHM-2019).

Results

About 811 potential cases were identified, from which 179 eligible patients met the inclusion criteria. There were 147 (82.1%) RCH patients, 24 (13.4%) MCH patients, and 8 (4.5%) who had attended both hospitals. There were 51 participants with ARF alone, 75 with ARF and RHD, and 53 with RHD but no recorded ARF episodes within the study period.

Epidemiology

The median age at diagnosis was 10.2 years (interquartile range (IQR): 7.9–12.6 years). Five children (2.8%) were diagnosed under 5 years of age (Table 1). Females comprised 46.3% of the

Victorian cohort, and 63.4% of the non-Victorian cohort. Of 108 Victorian residents, 86 (79.6%) had ethnicity data available. Of those with ethnicity recorded, 12.8% were of Aboriginal and/or Torres Strait Islander background and 57.0% were of Pacific Islander background. Most Victorian residents with ARF or RHD were from major cities ($n = 87$, 80.6%). Based on post-code data, 69.4% of cases came from the lower three socioeconomic quintiles.

Of 71 non-Victorian residents, 53 (74.6%) resided in the Northern Territory and 7 (9.9%) in neighbouring countries. Most identified as Aboriginal and/or Torres Strait Islander people ($n = 57$, 80.3%) and lived in remote areas ($n = 49$, 69.0%) from postcodes representing the most disadvantaged geographic socioeconomic quintile ($n = 45$, 70.3%).

Table 1 Characteristics of children and adolescents with acute rheumatic fever or rheumatic heart disease in Victoria, Australia, 2010–2019

	Victorian <i>n</i> (%)	Non-Victorian† <i>n</i> (%)	Total <i>n</i> (%)
Age at initial diagnosis, years			
0–4	1 (0.9%)‡	4 (5.6%)§	5 (2.8%)
5–9	46 (42.6%)	36 (50.7%)	82 (45.8%)
10–14	47 (43.5%)	26 (36.6%)	73 (40.8%)
≥15	14 (13.0%)	5 (7.0%)	19 (10.6%)
Sex			
Female	50 (46.3%)	45 (63.4%)	95 (53.1%)
Ethnic background			
Aboriginal and/or Torres Strait Islander	11 (10.2%)	57 (80.3%)	68 (38.0%)
Pacific	49 (45.4%)	2 (2.8%)	51 (28.5%)
<i>Samoan</i>	36 (33.3%)	1 (1.4%)	37 (20.7%)
Southeast Asian	6 (5.6%)	6 (8.5%)	12 (6.7%)
African	5 (4.6%)	1 (1.4%)	6 (3.4%)
Māori	5 (4.6%)	0 (0.0%)	5 (2.8%)
Caucasian	4 (3.7%)	1 (1.4%)	5 (2.8%)
South Asian	3 (2.8%)	1 (1.4%)	4 (2.2%)
Middle Eastern	3 (2.8%)	0 (0.0%)	3 (1.7%)
Not recorded	22 (20.4%)	3 (4.2%)	25 (14.0%)
Refugee background	10 (9.3%)	2 (2.8%)	12 (6.7%)
Interpreter required	7 (6.5%)	13 (18.3%)	20 (11.2%)
Socioeconomic status			
First quintile	28 (25.9%)	45 (70.3%)¶	73 (42.4%)
Second quintile	21 (19.4%)	4 (6.3%)¶	25 (14.5%)
Third quintile	26 (24.1%)	4 (6.3%)¶	30 (17.4%)
Fourth quintile	17 (15.7%)	8 (12.5%)¶	25 (14.5%)
Fifth quintile	16 (14.8%)	3 (4.7%)¶	19 (11.0%)
Rurality			
Major cities	87 (80.6%)	4 (5.6%)	91 (50.8%)
Inner regional	12 (11.1%)	4 (5.6%)	16 (8.9%)
Outer regional	9 (8.3%)	7 (9.9%)	16 (8.9%)
Remote	0 (0.0%)	9 (12.7%)	9 (5.0%)
Very remote	0 (0.0%)	40 (56.3%)	40 (22.3%)
N/A (International)	–	7 (9.8%)	7 (3.9%)
Total	108 (60.3%)	71 (39.7%)	179

† Includes participants from Northern Territory ($n = 53$), Queensland ($n = 1$), Western Australia ($n = 3$), South Australia ($n = 3$), New South Wales ($n = 2$), Tasmania ($n = 2$) and overseas ($n = 7$). ‡ Age: 4 years 5 months. § Ages: 2 years 10 months, 4 years 1 month, 4 years 2 months and 4 years 4 months. ¶ Interstate residents only. Not calculated for overseas residents.

Table 2 Disease classification of children and adolescents with acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in Victoria, Australia, 2010–2019

	Victorian (N = 108)	Non-Victorian (N = 71)	Total (N = 179)
ARF	45 (41.7%)	6 (8.5%)	51 (28.5%)
Possible ARF	7 (6.5%)	1 (1.4%)	8 (4.5%)
Probable ARF	6 (5.6%)	1 (1.4%)	7 (3.9%)
Definite ARF without cardiac involvement	16 (14.8%)	2 (2.8%)	18 (10.1%)
Definite ARF with cardiac involvement	16 (14.8%)	2 (2.8%)	18 (10.1%)
RHD	63 (58.3%)	65 (91.5%)	128 (71.5%)
Borderline RHD	1 (0.9%)	0 (0.0%)	1 (0.6%)
Mild RHD	23 (21.3%)	2 (2.8%)	25 (14.0%)
Moderate RHD	9 (8.3%)	2 (2.8%)	11 (6.1%)
Severe RHD	30 (27.8%)	61 (85.9%)	91 (50.8%)

Table 3 Comorbidities of children with acute rheumatic fever and rheumatic heart disease in Victoria, 2010–2019

	Victorian residents (N = 108)	Non-Victorian residents (N = 71)	Total (N = 179)
Overweight and obesity	72 (69.9%)†	13 (22.0%)†	85 (52.5%)†
Overweight	14 (13.6%)†	4 (6.8%)†	18 (11.1%)†
Obese	58 (56.3%)†	9 (15.3%)†	67 (41.4%)†
Dermatological	20 (18.5%)	29 (40.8%)	49 (27.4%)
Scabies	4 (3.7%)	15 (21.1%)	19 (10.6%)
Eczema	10 (9.3%)	2 (2.8%)	12 (6.7%)
Other	6 (5.6%)	12 (16.9%)	18 (10.1%)
Nutrient deficiency	20 (18.5%)	25 (35.2%)	45 (25.1%)
Iron deficiency ± anaemia	8 (7.4%)	14 (19.7%)	22 (12.3%)
Vitamin D deficiency	8 (7.4%)	3 (4.2%)	11 (6.1%)
Malnutrition	2 (1.9%)	6 (8.5%)	8 (4.5%)
Other	2 (1.9%)	2 (2.8%)	4 (2.2%)
Dental	14 (13.0%)	19 (26.8%)	33 (18.4%)
Caries	13 (12.0%)	18 (25.4%)	31 (17.3%)
Other	1 (0.9%)	1 (1.4%)	2 (1.1%)
Respiratory	14 (13.0%)	9 (12.7%)	23 (12.8%)
Asthma	12 (11.1%)	4 (5.6%)	16 (8.9%)
Other	2 (1.9%)	5 (7.0%)	7 (3.9%)
Cardiac	10 (9.3%)	8 (11.3%)	18 (10.1%)
Infectious	6 (5.6%)	11 (15.5%)	17 (9.5%)
Allergies	10 (9.3%)	3 (4.2%)	13 (7.3%)
Food	5 (4.6%)	1 (1.4%)	6 (3.4%)
Other	5 (4.6%)	2 (2.8%)	7 (3.9%)
Mental health	8 (7.4%)	3 (4.2%)	11 (6.1%)
Gastrointestinal	4 (3.7%)	2 (2.8%)	6 (3.4%)
Developmental/behavioural	2 (1.9%)	4 (5.6%)	6 (3.4%)
Neurological	4 (3.7%)	1 (1.4%)	5 (2.8%)
Orthopaedic	2 (1.9%)	2 (2.8%)	4 (2.2%)
Metabolic	1 (0.9%)	2 (2.8%)	3 (1.7%)
Ear, nose and throat	1 (0.9%)	2 (2.8%)	3 (1.7%)
Renal	1 (0.9%)	2 (2.8%)	3 (1.7%)
Other, not above	2 (1.9%)	5 (7.0%)	7 (3.9%)
Child protection involvement	7 (6.5%)	4 (5.6%)	11 (6.1%)

† Adjusted denominator, data unavailable for 5 Victorians and 12 non-Victorians.

Table 4 Clinical features of the first episode of acute rheumatic fever in Victorian children and adolescents, 2010–2019

Clinical feature (n = 83)	n/N† (%) or specified
Median age at initial diagnosis, years (IQR)	10.5 (8.3–13.2)
Setting of first episode	
Victoria	56 (67.5%)
Other Australian‡	5 (6.0%)
International§	22 (26.5%)
Episodes during study period	–
One episode	72/83 (86.7%)
Recurrence during study	11/83 (13.3%)
Evidence of recent <i>S. pyogenes</i> infection	–
Recent history of pharyngitis	28/51 (54.9%)
Recent history of skin infection	12/30 (40.0%)
Elevated anti-streptolysin O titre	52/57 (91.2%)
Elevated anti-DNAse B titre	21/36 (58.3%)
GAS throat culture positive	5/30 (16.7%)
Carditis¶	47/83 (56.6%)
Clinical carditis	35/83 (42.2%)
Sub-clinical carditis	12/83 (14.5%)
Unknown	2/83 (2.4%)
Joint involvement	53/83 (63.9%)
Polyarthritis¶	14/83 (16.9%)
Polyarthralgia††	27/83 (32.5%)
Aseptic monoarthritis††	8/83 (9.6%)
Monoarthralgia	3/83 (3.6%)
Unknown	14/83 (1.6%)
Chorea¶	16/83 (19.3%)
Erythema marginatum¶	1/83 (1.2%)
Subcutaneous nodules¶	2/83 (2.4%)
Fever††	39/58 (67.2%)
Prolonged PR interval on ECG††	31/83 (37.3%)
ESR raised††	36/83 (63.2%)
CRP raised††	46/83 (85.2%)

CRP, C-reactive protein; ECG, electrocardiogram; ESR, erythrocyte sedimentation rate; GAS, group A Streptococcus; IQR, interquartile range. † N = Number for which adequate documentation were available. ‡ Northern Territory (n = 4) and Western Australia (n = 1). § New Zealand (n = 12), Egypt (n = 3), Samoa (n = 2), Papua New Guinea (n = 1), Pakistan (n = 1), Mozambique (n = 1), Greece (n = 1) and Thailand (n = 1). ¶ Major criterion in all risk groups. †† Minor criterion in low-risk population.

Classification of disease and comorbidities

Victorian cases included 45 (41.7%) with ARF only (including possible and probable cases), and 63 (58.3%) with RHD (Table 2). Of those with RHD, most had moderate to severe disease (n = 39, 61.9%). The vast majority of non-Victorian cases (n = 65, 91.5%) had moderate or severe RHD (n = 63, 96.9%).

A majority of Victorian children and adolescents were overweight or obese (n = 72, 69.9% of those with available data, Table 3). This was less common in non-Victorian participants (n = 13, 22.0%). Other common comorbidities included dental caries and scabies.

Acute rheumatic fever

There were 83 (67.5%) Victorian participants who experienced at least one episode of ARF between 2010 and 2019. Of the first episodes recorded, 56 (67.5%) occurred in Victoria, 5 (6.0%) occurred elsewhere in Australia and 22 (26.5%) occurred overseas, including 12 in New Zealand (Table 4). The median age at diagnosis was 10.5 years (IQR 8.3–13.2, range 5.3–17.8 years). There were 15 documented episodes of recurrent ARF affecting 11 of the 83 individuals (13.3%) with ARF during the study period. Eleven (73.3%) of these recurrences occurred in Victoria. The average annual incidence of ARF in Victorian 5–14 years old from 2010 to 2019 was 0.77 per 100 000 (Table 5). The incidence was higher in the Aboriginal and/or Torres Strait Islander sub-group (3.8 per 100 000, IRR: 9.8 (95% CI 2.5–28.3)) and the Pacific Islander sub-group (32.1 per 100 000; IRR: 82.1 (95% CI 45.4–147.9)) compared to all other ethnicities.

Joint involvement (n = 53, 63.9%) and carditis (n = 47, 56.6%) were the most common major manifestations. Chorea was documented in 16 cases (19.3%), while subcutaneous nodules and erythema marginatum were rare. Minor manifestations included fever (67.2% of patients for whom data were available), elevated CRP (85.2%) and elevated ESR (63.2%). Antecedent streptococcal infection was typically demonstrated by a raised anti-streptolysin-O titre (n = 52, 91.2% of those with adequate documentation) (Table 4).

Rheumatic heart disease

There were 63 Victorian residents with RHD. The median age at diagnosis was 10.8 years (IQR 8.2–13.7 years, range 4.4–21.7 years). Most had mixed mitral and aortic valve pathology (n = 43, 69.4%). A high proportion of individuals had severe

Table 5 Estimated incidence of acute rheumatic fever in 5–14 years old in Victoria by ethnic background, 2010–2019

	Cases	Population†	Annual incidence (per 100,000)	Incidence rate ratio (95% CI)
Aboriginal and/or Torres Strait Islander	4	10 410	3.8	9.8 (2.5–28.3)
Pacific Islander	24	7486	32.1	82.1 (45.4–147.9)
All other ethnicities	27	691 802	0.39	Ref
Total	55	709 698	0.77	–

CI, Confidence interval. † Calculated using Australian Bureau of Statistics 'Table Builder'.¹²

mitral ($n = 19$, 30.2%) or aortic ($n = 13$, 20.6%) regurgitation, and 13 (20.6%) had mitral stenosis (Table 6).

Hospital encounters

There were 37 Victorian residents who had 46 total admissions for investigation or management of ARF, and 19 (15.4%) who accounted for 33 total admissions for care related to RHD (Table 7). Almost all admissions for non-Victorian residents were for RHD surgical assessment and management. Sixty-eight (63.0%) Victorian residents missed one or more outpatient appointments.

Secondary antibiotic prophylaxis

Of 108 Victorian children and adolescents with ARF or RHD, 104 (96.3%) had a documented prescription for secondary antibiotic prophylaxis. Intramuscular benzathine penicillin G injections were prescribed for 86 individuals, of whom 58 (67.4%) were

prescribed 4-weekly, 25 (29.1%) monthly, and 2 (2.3%) 3-weekly. Injections were mostly administered in private general practice clinics ($n = 77$, 89.5%). Oral phenoxymethylpenicillin was prescribed for 18 patients (17.1%).

Discussion

We report a significant burden of paediatric ARF and RHD in Victoria. The cohort comprises two distinct groups: young people living in Victoria and those transferred from other jurisdictions, predominantly for surgical management. The epidemiology of ARF and RHD in Victoria is different to high-risk areas of northern Australia, with overrepresentation of people from Pacific Islander ethnic backgrounds, similar to Sydney⁸ and New Zealand.⁴ Aboriginal and/or Torres Strait Islander young people were also over-represented.

The overall annual incidence of ARF of 0.8 per 100 000 5–14 years old is consistent with the definition of a low-risk setting.² Although direct comparison of results with studies from other settings is limited by heterogeneous methods, our study detected a higher overall incidence than for children in the United States,^{4,20} lower than in New Zealand (2.9 per 100 000 people),²¹ and much lower than among Aboriginal and/or Torres Strait Islander children in the Northern Territory (194 per 100 000 people aged 5–14 years). However, the estimated incidence was much higher in children from Aboriginal and/or Torres Strait Islander and Pacific Islander backgrounds (3.8 and 32.1 per 100 000, respectively). These very high incident rate ratios (82 times higher for children from Pacific Islander background) suggests the risk for children in different circumstances across the state may vary considerably. Similar inequalities have been documented in New Zealand.²² Of further note, the proportion of Victorian cases with a documented ARF recurrence was very high (13.4% over 10 years), similar to a Northern Territory cohort (12.5% over 14 years).⁷

Of Victorian participants with RHD, a very high proportion (62%) had moderate or severe disease. The severity of diagnosed RHD and high rate of recurrent ARF suggest a pressing need for improvements in clinical management and public health strategies to prevent RHD-related morbidity and mortality in Victoria. Based on the known epidemiology of RHD in other settings, these results raise the possibility of a larger group with asymptomatic or mild RHD that are not being detected.²³

Table 6 Echocardiographic features of valve abnormalities in Victorian children and adolescents with mild, moderate or severe rheumatic heart disease, 2010–2019 ($N = 62$ †)

Echocardiographic abnormality	n (%)
Isolated mitral valve pathology	15 (24.2%)
Isolated aortic valve pathology	4 (6.5%)
Mitral and aortic valve pathology	43 (69.4%)
Mitral regurgitation	51 (81.0%)
Mild	19 (30.2%)
Moderate	13 (20.6%)
Severe	19 (30.2%)
Mitral stenosis	13 (20.6%)
Mild	10 (15.9%)
Moderate	1 (1.6%)
Severe	2 (3.2%)
Aortic regurgitation	38 (60.3%)
Mild	19 (30.2%)
Moderate	6 (9.5%)
Severe	13 (20.6%)

† Valve abnormalities unknown for one participant.

Table 7 Hospital admissions for management of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) at Royal Children's and Monash Children's Hospital in Victoria, 2010–2019 ($N = 179$)

	Participants with ≥ 1 admission, n (%)	Total Admissions	Length of stay, days median (IQR)	Length of stay, range
ARF admissions				
Total participants ($N = 179$)	39 (21.8%)	49	4 (2–6)	0–25
Victorian ($N = 108$)	37 (34.3%)	46	4 (2–6)	0–21.0
Non-Victorian ($N = 71$)	2 (2.8%)	3	–	2–25
RHD admissions				
Total participants ($N = 179$)	78 (43.6%)	108	6 (5–13)	1–81
Victorian ($N = 108$)	19 (17.6%)	33	6 (3–11)	1–81
Non-Victorian ($N = 71$)	59 (83.1%)	75	7 (5–13.5)	1–72

The clinical presentation of ARF was similar to other Australian studies^{7,8} with regards to joint involvement, chorea and fever. Skin manifestations were rare. More Victorian participants had clinically evident carditis than in the Northern Territory cohort (52% versus 27.5%), most likely explained by differences in the diagnostic criteria for the high-risk setting in the Northern Territory.⁷ The proportion of patients with carditis in our study is similar to reports from the United States.²⁴ Consistent with other studies, RHD lesions most commonly affected the mitral and aortic valves¹⁵ and a high proportion (70%) of Victorian participants had mixed mitral and aortic valvular disease.

Approximately half of the 157 ARF or RHD admissions during the study period were for non-Victorian residents transferred for specialist care. We also noted a high number of missed clinic appointments for Victorian residents. There was some variation in documented plans for secondary antibiotic prophylaxis, and there may be clinical benefit in 4-weekly, rather than monthly injections.³ A substantial proportion (17%) were prescribed oral penicillin, a second-line approach, although this was lower than in the United States (42%).²⁴ Coordination of secondary prevention is recommended through a dedicated public-health control program and disease register, which occurs in most Australian jurisdictions, but not in Victoria.³ Although ARF and RHD are not common conditions in Victorian children, the severity, complexity and challenges with follow-up suggest that such a program is justified, and necessary to End RHD in Australia by 2031.⁶ Engagement and partnerships with Aboriginal and Pacific Islander communities are needed to plan culturally sensitive clinical and public health services.

We did not find a clear relationship between socio-economic status and ARF or RHD diagnoses, possibly related to the limitation of using the proxy of resident postcode. It is likely that unreported social determinants of health, such as household overcrowding and reduced access to care are more predictive of ARF and RHD in Victoria.⁵ High rates of comorbid overweight or obesity and dental caries in the Victorian population with ARF and RHD may also reflect socio-economic disadvantage, and add considerable cardiovascular risk.

There are several limitations. While we used robust case-finding strategies across the two tertiary paediatric hospitals in Victoria, a small number of milder cases managed at other centres may not have been captured. The accuracy of incident rate ratios was dependent on available ethnicity data derived from the Census. This retrospective study was also limited by the completeness of information in clinical records, particularly where patients were referred from other health services. Of note, ethnic background was not documented for 20% of Victorian residents which may have affected the ARF incidence estimates. Some important epidemiological information, such as socio-economic status and household crowding, were not available.

Conclusion

There is a persistent burden of ARF and RHD among children and adolescents in Victoria, including severe and recurrent disease. Certain groups are over-represented, suggesting subpopulations of increased risk. Further research is required to understand the impact of medical and psychosocial comorbidities, quantify

adherence to secondary antibiotic prophylaxis and identify opportunities to improve recognition, diagnosis and culturally sensitive, family centred care. In addition, a dedicated disease register and control program deserve strong consideration to prevent the morbidity and mortality of ARF and RHD in Victoria.

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