




# BMJ Open Trends in incident acute rheumatic fever or rheumatic heart disease in Indigenous youth in Western Australia: a retrospective cohort study

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## ABSTRACT

**Objective** To determine age-specific and age-standardised incidence trends of acute rheumatic fever (ARF) or rheumatic heart disease (RHD) among Indigenous Western Australians aged less than 35 years of age.

**Design** A population-based retrospective cohort study with linked data analysis.

**Setting** Western Australian hospital admissions (1996–2022) and RHD notifications to the state-based register (2011–2015).

**Participants** Patients, both Indigenous and non-Indigenous aged <35 years at diagnosis with incident ARF or RHD.

**Results** Of 1746 incident ARF/RHD cases, 1526 (87%) were Indigenous peoples, with the highest rates observed in patients aged 5–14 years, with an annual estimated increase of 4.3% (95% CI 3.2% to 5.2%). The 0–4 years age group experienced an annual increase in incidence rates of 4.8% (95% CI 1.4% to 8.2%). Overall, Indigenous patients experienced an annual increase of 1.9% (95% CI 1.3% to 2.6%) from 1996 to 2022. However, most cases (n=894) were identified after multiple significant policy developments (2011–2022) with an annual increase of 5.7% (95% CI 3.7% to 7.5%) for this period.

**Conclusion** Increasing trends of incident ARF/RHD were observed in Indigenous patients aged under 15 years, with the greatest annual increments observed after policy implementation for disease reporting and awareness in the period from 2011 to 2022. Improvement in case ascertainment of ARF/RHD may be contributing towards increasing trends with improved reporting and monitoring of incident cases in very young Indigenous Australians more recently.

## INTRODUCTION

Rheumatic heart disease (RHD), a consequence of acute rheumatic fever (ARF), is a chronic acquired heart disease associated with significant morbidity and mortality.<sup>1</sup> ARF occurs secondary to a Group A streptococcus (GAS) infection of the skin or throat.<sup>1 2</sup> Aboriginal and/or Torres Strait Islander people (hereafter, respectfully

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Data linkage has enabled the reporting of incident acute rheumatic fever (ARF) and/or rheumatic heart disease (RHD) over almost three decades.
- ⇒ Our analysis of linked data has allowed for accurate reporting of the annual incidence of first-ever ARF or RHD among Indigenous and non-Indigenous West Australians aged <35 years.
- ⇒ The use of incidence trends allows us to show increases in ARF in Indigenous Australians, especially those aged less than 15 years old.
- ⇒ Under-recording of Indigenous status in hospital data is well-documented, particularly in older data, and may still influence incidence rates.
- ⇒ Hospital-only data have limitations, with some cases potentially being missed, as ARF cases are sometimes managed in the community and milder cases may present less frequently.

referred to as Indigenous Australians) experience higher rates of both ARF and RHD than non-Indigenous Australians due to a range of factors, including socioeconomic determinants of health.<sup>3–5</sup> Incidence rates of ARF peak between 5 and 14 years of age,<sup>1</sup> with Australia reporting some of the highest rates in the world.<sup>6 7</sup> Population-based studies data ies have suggested we are missing opportunities to diagnose ARF and RHD.<sup>8</sup> There remains undiscovered ARF/RHD, as noted in recent echocardiogram screening programmes, that could indicate an underestimation of current disease burden.<sup>9 10</sup>

Public health measures, improved monitoring of patients, echocardiographic screening and prophylactic treatment with antibiotics are all designed to reduce ARF and RHD.<sup>1 7</sup> The Australian Rheumatic Fever Strategy was funded in 2009 across multiple jurisdictions with introductions of mandatory reporting of ARF and, at a later point, RHD.<sup>11</sup>



In Western Australia (WA), policy changes occurred from 2009 with the introduction of mandatory reporting for ARF, with further requirements under public health legislation in 2015 where it became mandatory for health practitioners to notify RHD cases to improve reporting of disease.<sup>7 12</sup> In addition, advisory committees' development, RHD strategic plans and the establishment of formal control programmes occurred across this period.<sup>9 13</sup> Projects like the END Rheumatic Heart Disease in Australia: Study of Epidemiology (ERASE) have used linked hospital and registry data to contribute towards disease surveillance within the changing landscape of ARF and RHD public health policy.<sup>14</sup>

Monitoring trends in the incidence of ARF and RHD is critical for reviewing progress in public health measures to control disease burden and addressing barriers to the disease control strategy.<sup>15</sup> We aimed to determine trends in incident cases, whether ARF or RHD, among Indigenous Western Australians aged under 35 years from 1996 to 2022. Our primary objective was to determine annual age-standardised incidence rates to assess year-to-year trends for Indigenous Australians aged <35 years. Specific objectives included: (1) calculating incidence trends of hospitalised ARF/RHD cases and assessing the effect of policy changes on rates (1996–2010 vs 2011–2022), (2) measuring age- and sex-specific trends in incidence and (3) assessing the value of adding registry to hospital data by assessing trends derived from combined data sources (2011–2015).

## METHODS

### Data sources

This single jurisdictional study investigating trends (1996–2022) of incident ARF or RHD used retrospective, linked longitudinal administrative data. The datasets used were generated from the ERASE project<sup>14</sup> and datasets supplied by the Western Australian Department of Health (DoH) Epidemiology Directorate. Data were accessed between 23 June 2023 and 6 February 2024.

ERASE is a multi-jurisdictional linked administrative data project using ARF/RHD data from registers, inpatient admissions, emergency department presentations, death records and the National Cardiac Surgery Database of the Australian and New Zealand Society of Cardiac & Thoracic Surgeons covering five Australian jurisdictions.<sup>16</sup> For WA, the ERASE database includes all ARF and RHD cases in hospital data (1980–2016) and RHD register data (2011–2015). Additionally, the DoH Epidemiology Branch provided aggregated hospital numerators per year from 2015 to enable calculation of more recent incidence trends, extracted using the same methodology as ERASE data (see definitions).

### Incident case definition in hospital data

Hospitalised incident ARF and/or RHD cases were identified using the International Classification of Diseases, Tenth Revision, Australian Modification (ICD) codes.<sup>17</sup>

A combination of first-ever ARF or RHD was selected to reflect the total number of incident cases.<sup>13</sup> ARF cases were selected with principal diagnosis field I00–I02, given their high validated positive predictive value.<sup>18</sup> Previously identified biases in the predictive accuracy of the ICD codes for RHD (I05–I09) were addressed in the ERASE project through an algorithm for better case identification.<sup>19</sup> We used this algorithm in hospital data to account for false positive cases, including non-rheumatic valvular heart disease coded as RHD.<sup>19</sup> The application of a person-level 15-year look-back period within hospital data reduced the effect of a prevalent pool artefact.

### Cohort definitions

We created two distinct cohorts of incident ARF or RHD cases aged <35 years at diagnosis, with this age cut-off of 35 years selected to capture emerging disease in the context of known disease epidemiology.<sup>14</sup> Our main cohort, entitled the *hospital-only* cohort, was comprised of cases identified from hospital data only and included ERASE hospital data (1996–2014) and DoH hospital data (2015 onwards) with aggregated numbers of incident cases by Indigenous status, age group, sex and calendar year. We divided the cohort further into an early (1996–2010) and late (2011–2022) period to reflect funding of the Australian Rheumatic Fever Strategy (late 2009), with appreciation that policy changes would not be seen immediately.<sup>11</sup>

A second cohort of WA *hospital/registry* data comprised incident ARF or RHD identified on the first identifiable source, registry *or* hospital data, from the parent ERASE project from 2011 to 2015, to incorporate primary care-notified cases that were not hospitalised with expected discrepancies in cases between RHD registry and hospital data.<sup>12</sup>

We used an enhanced identifier in the ERASE data to allow more accurate Indigenous identification,<sup>20</sup> given the known under-identification of Indigenous patients in administrative data. WA population counts by year, age, sex and Indigenous status were obtained from the Australian Bureau of Statistics as denominators for the calculation of incidence rates.<sup>21</sup> The term 'youth' has been used to describe patients under 35 years of age for the purpose of this study.

### Statistical analysis

Annual ARF/RHD incidence rates were calculated by dividing numerators (per age group, sex and ethnicity) by the corresponding population counts as denominators and presented per 100 000 person-years.<sup>21</sup> As this is a population-based study using administrative datasets, all eligible individuals in WA were included in the analysis and no sample size calculation was required.

Analysis included a description of case numbers, proportions and annual age-specific incidence rates (stratified into 0–4, 5–14, 15–24 and 25–34 year age groups). Annual age-standardised incidence rates for <35-year-olds for each year were generated using the direct method

**Table 1** Baseline demographics of patients aged 0–34 years at diagnosis of acute rheumatic fever (ARF) or rheumatic heart disease (RHD) selected from person-level linked hospital-only or combined hospital-registry data, by Indigenous status

	Indigenous		Non-Indigenous	
	Hospital only	Hospital-registry	Hospital only	Hospital-registry
	n (%)	n (%)	n (%)	n (%)
Total patients	1526	297	220	99
Incident disease				
ARF	1201 (79)	116 (39)	136 (61)	16 (16)
RHD	325 (21)	181 (61)	84 (38)	83 (84)
Age group (years)				
0–4	64 (4)	10 (3)	13 (16)	5 (5)
5–14	700 (46)	166 (56)	53 (24)	14 (14)
15–24	352 (23)	66 (22)	59 (27)	28 (28)
25–34	410 (27)	55 (19)	95 (43)	52 (53)
Sex				
Male	656 (43)	117 (39)	91 (41)	37 (37)
Female	870 (57)	180 (61)	129 (59)	62 (63)
Period				
1996–2010	632 (41)	N/A	118 (54)	N/A
2011–2022	894 (59)	N/A	102 (46)	N/A

with the 2001 WHO population as the standard to allow comparability of rates. Additionally, we calculated trends in the early and late periods, with a crude trend analysis undertaken using Poisson log-linear regression with calendar year as a continuous variable. Calculation of an average annual percentage change in incidence rates over time, with 95% CIs, was derived from the exponential of the  $\beta$ -coefficient for calendar year. For improved visualisation of trends, we included a 3-year rolling average of case numbers alongside annual incidence rates. Software used included SAS V.9.4 (SAS Institute, Cary, North Carolina, USA) and R (R Studio V.3.6.1 R Foundation for Statistical Computing, Vienna, Austria).<sup>22</sup>

## RESULTS

### Hospital-only cohort

The *hospital-only* cohort (1996–2022) consisted of 1746 incident cases of ARF or RHD, of which 1526 (87%) were Indigenous cases. Most cases were female (n=870; 57%) and between the ages of 5 and 14 years (n=700; 46%). Most recorded incident events occurred between 2011 and 2022 (894; 59%) (table 1).

Age-specific incidence rates of ARF or RHD were high in Indigenous persons aged 5–14 years (figure 1) with an estimated annual increase of 4.3% (95% CI 3.2% to 5.2%, table 2). Among Indigenous children aged 0–4 years, the annual increase of 4.8% (95% CI 1.4% to 8.2%) was due to a significant increase in female cases (1.9%/year (95% CI 1.0% to 2.8%). By comparison, non-Indigenous patients showed significantly increasing incidence rates in the 5–14 year group only, with an increase of 3.8%/

year (95% CI 2.4% to 7.4%). Trends in all age groups are detailed in figure 1 and table 2.

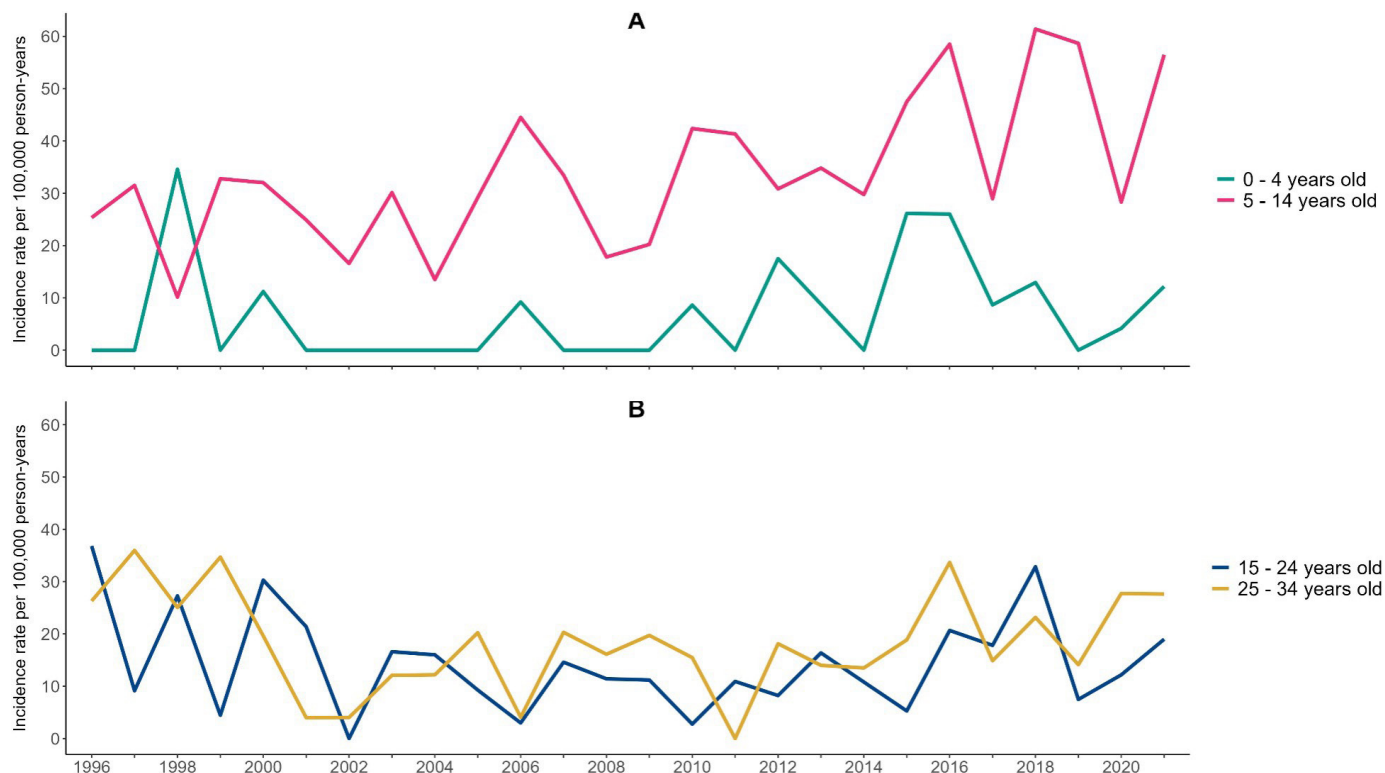
The age-standardised incidence rates of ARF or RHD among Indigenous Australians aged 0–34 years increased by 2% per year (95% CI 1.3% to 2.6%) from 25.0 to 31.4 per 100 000 person-years between 1996 and 2022 (table 2). The age-standardised incidence rates increased significantly for Indigenous males (2.08%/year, 95% CI 1.0% to 3.1%) and females (+1.9%/year, 95% CI 1.0% to 2.8%). Rates tended to be higher in later parts of the study period (online supplemental table 1).

### Early and late period

In the period before WA introduced RHD policy changes (1996–2010), Indigenous people comprised 41% (n=632) of all ARF or RHD cases, with rates decreasing significantly by 2.7%/year (95% CI –4.5% to –0.9%) as shown in figure 2 (and online supplemental table 2). From 2011 to 2022, Indigenous cases comprised 88% (n=894) of cases, with an increasing trend of 5.7%/year (95% CI 3.7% to 7.5%). Most non-Indigenous cases (n=118/220; 54%) occurred in the period from 2011 to 2022 with no significant changes in age-specific or age-standardised rates over time (online supplemental tables 1 and 2).

### Hospital/registry data

Indigenous cases comprised 297 (75%) of 396 cases in combined hospital and registry data (2011–2015), with no significant change in incidence rates noted among both Indigenous and non-Indigenous populations (online supplemental table 3).



**Figure 1** Age-specific incidence rates of acute rheumatic fever/rheumatic heart disease in Indigenous patients from 1996 to 2022 in Western Australia in younger (A) and older (B) age groups.

## DISCUSSION

This study reports the annual incidence of first-ever ARF or RHD among Indigenous and non-Indigenous West Australians aged <35 years using hospital data for the 28-year period 1996–2022. Overall trends in Indigenous Australians reflected increasing age-specific incidence

rates in children aged 5–14 and those <5 years. Overall trends were also influenced by increasing annual hospitalised incidence rates occurring from 2011. Our findings are important for ARF/RHD monitoring in WA and suggest that upwards trends in the incidence rates in younger Indigenous Australians have changed with

**Table 2** Trends in age-specific and age-standardised incidence rates of acute rheumatic fever/rheumatic heart disease, by Indigenous status and sex (hospital-only cohort 1996–2022)

Age groups	All		Female		Male	
	Incident events (n)	Annual % change (95% CI)	Incident events (n)	Annual % change (95% CI)	Incident events (n)	Annual % change (95% CI)
<b>Indigenous</b>						
0–4 years	64	+4.8 (1.4 to 8.2)*	25	+5.7 (0.2 to 11.3)*	39	+1.0 (–0.3 to 8.6)
5–14 years	700	+4.3 (3.2 to 5.2)*	337	+5.3 (3.7 to 6.7)*	363	+3.3 (1.9 to 4.7)*
15–24 years	352	–1.1 (–2.4 to 0.3)	229	–1.5 (–3.2 to 0.2)	123	–0.3 (–2.7 to 2.0)
25–34 years	410	+2.7 (–0.9 to 1.5)	279	+0.3 (–1.2 to 1.9)	131	+0.4 (–1.8 to 2.7)
0–34 years	1526	+1.9 (1.3 to 2.6)*	870	+1.9 (1.0 to 2.8)*	656	+2.1 (1.0 to 3.1)*
<b>Non-Indigenous</b>						
0–4 years	13	–5.3 (–12.9 to 1.5)	6	–4.6 (–15.8 to 5.7)	7	–5.9 (–16.7 to 3.4)
5–14 years	53	+3.8 (2.4 to 7.4)*	19	+2.3 (–3.5 to 8.3)	34	+4.74 (0.2 to 9.3)*
15–24 years	59	+3.3 (–0.1 to 6.8)	34	+6.0 (–2.8 to 6.1)	25	+5.86 (0.4 to 11.5)*
25–34 years	95	–2.4 (–4.9 to 0.2)	70	–2.2 (–5.3 to 0.7)	25	–2.75 (–7.9 to 2.3)
Age standardised total	220	+0.4 (–1.3 to 2.1)	129	–0.6 (–2.8 to 1.6)	91	+1.90 (–0.8 to 4.6)

\*Trend that is significant (trends represent the average annual change over the study period calculated from log-linear Poisson regression models).



**Figure 2** Annual age-standardised hospitalised incidence rates for acute rheumatic fever or rheumatic heart disease for Indigenous people, with 3-year moving average (red line), early (1996–2010; blue line) and late (2011–2022; green line) policy periods in Western Australia.

multiple, more recent, improvements in case ascertainment within hospital data.

Trends in age-standardised incidence rates in Indigenous Western Australians are due to upward trends among patients aged 5–14 years (4.3% per year). Factors contributing to this trend include better case ascertainment, but cannot discriminate between this and worsening disease trends. High incidence rates have previously been demonstrated in this age group among Indigenous Australians,<sup>23 24</sup> with this being the first study to document upward trends within incident ARF/RHD in WA. Our paper builds on prior ERASE research showing that ARF first-ever rates were 0.60 per 100 000 person-years and 61.4 times higher in Indigenous Australians.<sup>13</sup> We add to this using a longer timeframe, using ARF or RHD as first-ever cases and by reporting on trends<sup>13</sup> and changing the focus to specific high-risk groups for ARF/RHD for targeting future interventions.<sup>23 25</sup> In New Zealand, the demonstration of increasing ARF incidence rates over time in at-risk populations has informed targeted interventions.<sup>25</sup> Comparison to many countries remains limited due to the influence of variable recording measures<sup>26</sup> and other challenges, such as considerations of whether to count ‘borderline’ RHD in estimates.<sup>27 28</sup> Changes in GAS strains, previously tied to resurgences of ARF, may be another factor that warrants consideration in the context of increasing trends.<sup>29 30</sup> Within WA, there are increasing rates of invasive GAS, but no particular subtype of GAS has become apparent.<sup>31 32</sup> Either way, an upward

incidence trend in Indigenous children aged 5–14 years should form a basis for targeted policy to improve monitoring and prevent cases in high-risk groups.

An emerging upward ARF/RHD incidence trend in Indigenous females <5 years of age is evident, an age group in which the disease has previously been under-recognised.<sup>23 24</sup> Australian epidemiological studies in other jurisdictions report only a few cases in this age group compared with other age groups, making it difficult to produce accurate trends over time.<sup>7 18</sup> Clinically, the diagnosis of ARF or RHD <5 years of age remains challenging due to the overlap of symptoms with common infectious and clinical cardiac findings during childhood.<sup>1 8</sup> In our study, those under 5 years of age met criteria for ARF or RHD on the most recent Australian RHD guidelines. We believe that recognition of ARF and RHD in this age group will improve over time, driven by clinical awareness and the development of echocardiographic screening programmes.<sup>8 33</sup> A specific focus of future public health initiatives should prioritise identifying disease in younger children.

Our study has demonstrated that until 2010, age-specific incidence rates of incident hospitalised ARF and/or RHD in WA were declining. The change to an upward trend from 2011 somewhat reflects increased clinician awareness and improved recognition of ARF/RHD, which limits our ability to comment on true trends in underlying disease. This may suggest a delay in increasing case recognition after the start of changes in



policy. Around this time, there were national policy shifts with RHD guideline introduction (2006),<sup>7</sup> adoption of the modified Jones criteria (2006 with updates in 2015),<sup>7</sup> Close the Gap initiatives (2007),<sup>34</sup> Australian Institute of Health and Welfare monitoring reports (2016),<sup>24</sup> RHD programme transition to funding of the National Aboriginal Community Controlled Health Organisation (2020)<sup>35</sup> and the END RHD strategy (2020).<sup>36</sup> Locally, the inception of the WA RHD Register (2010) and the mandatory reporting for WA health practitioners for ARF (2008) and RHD (2015) have contributed towards increased notifications.<sup>14 33 36</sup> A jump in case ascertainment and incidence rate from 2015 (figure 2 and online supplemental table 2) is also notable within our data and may be an influence of mandatory reporting changes for RHD.<sup>7</sup> The introduction of secondary ARF prophylaxis programmes, screening echocardiogram research<sup>37</sup> and consecutive changes to World Heart Federation criteria for diagnosis must also be considered when interpreting data.<sup>27 38</sup> Shorter time periods for the estimation of trends, such as in our hospital and registry cohort, may not be informative where changes are slow or limited. There were no observable declines associated with the COVID pandemic and border closures, as were seen in some other jurisdictions with a high burden of ARF/RHD, as was experienced in New Zealand.<sup>39</sup> The complex changes in ARF/RHD policy and guidelines influence the interpretation of trends and emphasise the importance of ongoing trend monitoring using multiple linked data sources.

### Study limitations

Data linkage has enabled the reporting of incident ARF and/or RHD over almost three decades. Using routine administrative hospital data has limitations, as it relies on factors such as coding practices. Recently updated echocardiogram diagnosis guidelines have clarified RHD severity into stages, better aligning with progression risk and these may impact monitoring.<sup>38</sup> Under-recording of Indigenous status in hospital data is well-documented, particularly in older data and may still influence rates, even despite recent improvements via the 'Getting our Stories Right' project.<sup>21 24</sup> To overcome this, we used a WA-specific Indigenous flag to provide a rigorous assessment of Indigenous status.<sup>20</sup> Hospital-only data have limitations as ARF cases are sometimes managed in the community and undetected mild RHD cases present less frequently.<sup>7</sup> As such, there remain many ongoing considerations for future studies using linked data for studying ARF and RHD epidemiology.

### CONCLUSION

Our study concluded that the incidence of ARF and RHD in young Indigenous Western Australians is increasing, particularly since 2011. Increasing case ascertainment in those <14 years with recognition of disease occurring in those <5 years of age influenced the overall trends

observed. The timing of this increase relative to the introduction and changes of ARF/RHD policy suggests that improved recognition and reporting influence incidence rates. Action on RHD control is required, with a focus on groups for which an upward trend in ARF and RHD has been shown. This should include investments in improving environmental health in remote communities for primordial prevention and ongoing training in identification of impetigo and sore throat<sup>40</sup> for early treatment of GAS infections.<sup>7</sup> In addition, systems to improve the capture and analysis of data as modern technologies emerge could be considered. Further analysis on incidence trends should continue to monitor progress, particularly as new guidelines from the World Heart Federation<sup>38</sup> and RHD Australia (February 2025) are introduced.

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