

The rationale for action to end new cases of rheumatic heart disease in Australia

Closing the gap in cardiovascular health

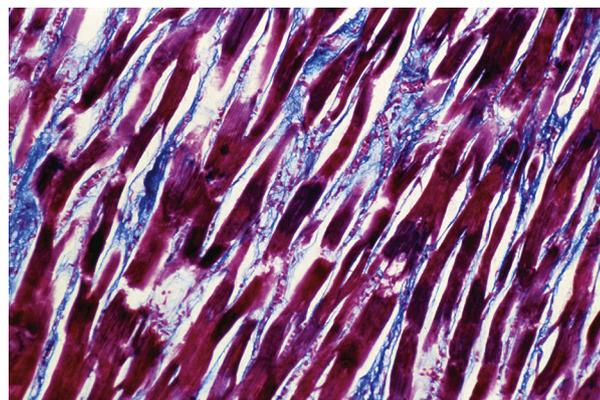
On 25 November 2016, the Australian Medical Association (AMA) launched their annual Report Card on Indigenous Health entitled *A call to action to prevent new cases of rheumatic heart disease in Indigenous Australia by 2031*.¹ In 14 years of AMA report cards, this is the first to focus on a single pathology. The choice of rheumatic heart disease (RHD) is telling: the disease is a striking marker of inequality, a novel lens for considering health systems and a feasible target for definitive disease control.

Stemming from childhood group A streptococcal (GAS) infections of the throat, and likely of the skin, RHD is a consequence of repeated episodes of acute rheumatic fever (ARF). In some young people, abnormal immune responses to GAS infection cause pathologic molecular mimicry — resulting in fevers, malaise and symptoms of the skin, synovium, brain and heart.² The symptoms of ARF resolve, but damage to the heart valves persists and may be amplified with each subsequent GAS infection and ARF recurrence. RHD is characterised by established valve disease, which in turn causes heart failure, arrhythmia, stroke and infective endocarditis and increases cardiovascular risk in the peripartum period.²

In September 2016, the Australian Institute of Health and Welfare (AIHW) published the 3rd Australian Burden of Disease Study focusing on the health of Aboriginal and Torres Strait Islander Australians in 2011.³ The study measures burden in disability adjusted life years (DALYs) to quantify the combined fatal and non-fatal impact of individual diseases. Hidden in this report, covering some 200 specific diseases, are the data which demand action on RHD.

At a superficial level, in the Australian Burden of Disease Study, the contribution of RHD to total disease burden appears relatively small (5.1% of cardiovascular diseases and 0.6% of total DALYs).³ Yet the RHD–DALY rate in Indigenous Australians was 6.6 times higher than in non-Indigenous people. This was the single highest differential among all other cardiovascular diseases and the 5th highest differential of all specific diseases studied (after pneumococcal disease, relative risk [RR] = 10.3; endometriosis, RR = 8.0; pancreatitis, RR = 7.6; chronic kidney disease, RR = 7.3). In addition, RHD burden was dominated by mortality burden (83.6% of total RHD burden).

The relative youth of Australia's Indigenous community amplifies this inequality.⁴ Forty-seven per cent of Indigenous Australians are aged less than 20 years, when the risk of ARF is highest; whereas only 25% of non-Indigenous population fall in this age category.⁵ RHD was the highest contributor to the Indigenous cardiovascular disease burden under the age of 20 years, and women with RHD account for 61% of the total Indigenous RHD



burden.³ This compounds the effects of RHD on young Indigenous women, who incur substantial risks from valvular heart diseases during pregnancy and labour. Indeed, RHD is one of the top 20 causes of fatal DALY burden for Indigenous women.³

Once common throughout Australia, it is clear that ARF and RHD now almost exclusively affect Indigenous people, which is confirmed by notifications and hospitalisation data in the Northern Territory, Western Australia and Queensland, where 94% of cases of RHD occur in Indigenous Australians.⁶ This predilection is driven by the social determinants of health — inequality, overcrowding, inadequate health hygiene infrastructure and poor access to health services.⁷

Given that RHD–DALY estimates from the AIHW rely entirely on hospital and mortality records, the burden is likely to have been underestimated due to the pool of undiagnosed cases in Indigenous communities, particularly in remote areas. In northern Australia, 53% of the cases identified in a screening study had not been previously diagnosed.⁸ The importance of timely and trackable data is increasingly clear. For example, the AIHW report shows an 18% reduction in Indigenous RHD age-standardised DALY rates between 2003 and 2011. Yet without information on ARF incidence, disease progression rates or service delivery indicators celebration would be premature. The AMA has called for targets to prevent new cases of RHD and deaths from ARF by 2031 — in line with Commonwealth targets to close the gap in life expectancy by 2031. Only with a living dataset is it possible to track progress towards these targets and the key performance indicators that will underpin them. A national mechanism for quantifying the burden of RHD and monitoring progress towards established goals should be one of the first priorities.

It is the relative inequality of RHD, rather than the absolute magnitude, which should compel Australia to action. In doing so, we have the opportunity to address

Rosemary Wyber¹

Judith M Katzenellenbogen^{1,2}

Glenn Pearson¹

Michael Gannon³

¹ Telethon Kids Institute, University of Western Australia, Perth, WA.

² Western Australian Centre for Rural Health, University of Western Australia, Perth, WA.

³ Australian Medical Association, Canberra, ACT.

rosemary.wyber@telethonkids.org.au

doi:10.5694/mja1700246

a broad array of health and service delivery challenges. The frontlines of this disease are in primary care, where skin sores and sore throats are treated, ARF diagnosed, secondary prophylaxis delivered, anticoagulation monitored and health education provided.⁹ These diverse and complex tasks exemplify the breadth of tasks of general practice, and are further amplified in Indigenous settings. Only a stable and well supported primary care workforce can achieve these goals — for RHD and beyond. Integration with secondary and allied services — to access echocardiography, dental services, focused antenatal care and specialist review — is critical to follow-up and timely interventions. Register-based programs to support the delivery of secondary prophylaxis remain essential to changing outcomes in people with a history of ARF and RHD.¹⁰ In advanced disease, transfer to tertiary and quaternary hospitals for specialist surgery prolongs life. Navigating each of these steps requires robust health information systems, appropriate and well resourced processes, excellence in cultural competence and patient engagement — offering lessons and innovations applicable far beyond RHD. Few other diseases span infectious aetiology and non-communicable service models as comprehensively as sore throats in remote primary care and cardiothoracic units in capital cities. The breadth of GAS, ARF and RHD pose tremendous challenges but offer substantial and generalisable rewards if components can each be optimised. Substantial financial and human resources will be needed to achieve measurable outcomes in the decade ahead, although the costs of inaction may well be higher.¹¹

Apart from strengthening clinical service delivery, RHD is a powerful vehicle to address the social determinants of this disease and others. Rectifying the primordial causes of RHD demands collaboration between stakeholders from community, health, housing and education sectors. These same partnerships are a prerequisite for managing other diseases of overcrowding and deprivation, including respiratory infections, soft tissue infection, infectious gastroenteritis, otitis media and trachoma.¹² Collective action to deal with poverty, inequality, overcrowding, inadequate housing infrastructure, insufficient hygiene infrastructure and paucity of appropriate health services would improve lives and a multitude of endpoint metrics. RHD provides a tangible, urgent driver for tackling these challenges. Few outcomes are as confronting as the sternotomy scars of Indigenous children who, for want of acceptable housing, have had major surgery and face a lifetime of medical intervention.

The AMA has made a powerful statement about the importance of this disease and the opportunities for RHD control. The National Health and Medical Research Council-funded END RHD Centre for Research Excellence (END RHD CRE) has already been charged

with delivering an Endgame Strategy by 2020: a set of costed, stepwise interventions to end RHD in Australia. The medical knowledge and technology to end RHD largely already exists; the challenges now are implementation, resourcing, engaging people and communities living with RHD, and political will. The priority is for a living dataset to track progress, investment in proven medical interventions and health systems that change outcomes, a sustained effort to improve the social determinants driving this disease, a partnership approach with Indigenous people across all these areas and a national conversation about how and why ending RHD is a rightful national priority. To that end, six peak bodies have announced the formation of the END RHD Coalition. The AMA, the National Heart Foundation of Australia, the National Aboriginal Community Controlled Health Organisation, RHD Australia, Aboriginal Medical Services Alliance Northern Territory and the END RHD CRE have committed to amplifying acceptable and appropriate interventions for disease control.

The end of RHD in Australia is a feasible target. Control of this disease has been achieved in Cuba and in the French Caribbean and is showing increasingly promising results from New Zealand.¹³ The New Zealand model has seen government investment, widespread focus on primary prevention measurable targets and community engagement, which have contributed to a decline in first episode hospital admissions for ARF by 23% over 5 years.¹⁴ Individually, no international example mirrors the exact geographic, social or economic settings where RHD flourishes in Australia. Collectively, however, they show that ambitious goals for ending RHD can be achieved with a comprehensive approach. Common elements include a focus on community education, engagement, tackling the social determinants of health and governmental leadership. The Australian endgame will necessarily draw on these global lessons, alongside novel interventions for this unique setting. In turn, we may be able to provide new leadership to low- and middle-income countries with an ongoing scourge of RHD. It is clear that Australia can dramatically reduce the prevalence of this disease and has a moral obligation to do so. The differential in morbidity and mortality from RHD in Australia is striking and shameful. With collective action it is possible to end RHD and to develop approaches relevant to other diseases of disparity.

Acknowledgements: The founding members of the END RHD Coalition are the END RHD CRE, the AMA (President Michael Gannon), the National Aboriginal Community Controlled Health Organisation (Chief Executive Officer [CEO] Patricia Turner), RHD Australia (Director Bart Currie), Aboriginal Medical Services Alliance Northern Territory (CEO John Paterson) and the National Heart Foundation of Australia (CEO John Kelly).

Competing interests: No relevant disclosures.

Provenance: Not commissioned; externally peer reviewed. ■

© 2017 AMPCo Pty Ltd. Produced with Elsevier B.V. All rights reserved.

References are available online at www.mja.com.au.

- 1 Australian Medical Association. AMA Report Card on Indigenous Health: a call to action to prevent new cases of rheumatic heart disease in Indigenous Australia by 2031. Canberra: AMA; 2016. <https://ama.com.au/system/tdf/documents/2016-AMA-Report-Card-on-Indigenous-Health.pdf?file=1&type=node&id=45394> (accessed Aug 2017).
- 2 Carapetis J, Beaton A, Cunningham MW, et al. Acute rheumatic fever and rheumatic heart disease. *Nat Rev Dis Primers* 2016; 2: 15084.
- 3 Australian Institute of Health and Welfare. Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people, 2011. Canberra: AIHW; 2011. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129557109> (accessed Aug 2017).
- 4 Roberts KV, Maguire GP, Brown A, et al. Rheumatic heart disease in Indigenous children in northern Australia: differences in prevalence and the challenges of screening. *Med J Aust* 2015; 203: 221. <https://www.mja.com.au/journal/2015/203/5/rheumatic-heart-disease-indigenous-children-northern-australia-differences>
- 5 Australian Bureau of Statistics. 2075.0 – Census of population and housing, 2011 census counts: Aboriginal and Torres Strait Islanders peoples. Canberra: ABS; 2012. <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2075.0main+features32011> (accessed Aug 2017).
- 6 Australian Health Ministers' Advisory Council. Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report. Canberra: Commonwealth of Australia; 2015. https://www.pmc.gov.au/sites/default/files/publications/Aboriginal_and_Torres_Strait_Islander_HPF_2014%20-%20edited%2016%20June2015.pdf (accessed Aug 2017).
- 7 Australian Institute of Health and Welfare. Rheumatic heart disease and acute rheumatic fever in Australia: 1996–2012 (Cardiovascular Disease Series No.36). Canberra: AIHW; 2013. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129542747> (accessed Aug 2017).
- 8 Roberts K, Maguire G, Brown A, et al. Echocardiographic screening for rheumatic heart disease in high low risk Australian children. *Circulation* 2014; 129: 1953-1961.
- 9 Smith MT, Zurynski Y, Lester-Smith D, et al. Rheumatic fever. identification, management and secondary prevention. *Aust Fam Physician* 2012; 41: 31-35.
- 10 McDonald M, Brown A, Noonan S, Carapetis JR. Preventing recurrent rheumatic fever: the role of register based programmes. *Heart* 2005; 91: 1131-1133.
- 11 Watkins DA, Mvundura M, Nordet P, Mayosi BM. A cost-effectiveness analysis of a program to control rheumatic fever and rheumatic heart disease in Pinar del Rio, Cuba. *PLoS One* 2015; 10: e0121363.
- 12 Baker MG, McDonald A, Zang J, Howden-Chapman P. Infectious diseases attributable to household crowding in New Zealand: a systematic review and burden of disease estimate. Wellington, New Zealand: He Kainga Oranga/Housing and Health Research Programme, University of Otago; 2013. <http://www.healthyhousing.org.nz/wp-content/uploads/2010/01/HH-Crowding-ID-Burden-25-May-2013.pdf> (accessed Aug 2017).
- 13 Zühlke LJ, Karthikeyan G. Primary prevention for rheumatic fever: progress, obstacles, and opportunities. *Glob Heart* 2013; 8: 221-226.
- 14 Ministry of Health New Zealand. Progress on the Better Public Services rheumatic fever target: Ministry of Health New Zealand, 2017. <http://www.health.govt.nz/about-ministry/what-we-do/strategic-direction/better-public-services/previous-mps-target-reduce-rheumatic-fever> (accessed Apr 2017). ■