



AMA

2016

AMA REPORT CARD ON INDIGENOUS HEALTH

A CALL TO ACTION TO PREVENT NEW CASES OF RHEUMATIC HEART DISEASE IN INDIGENOUS AUSTRALIA BY 2031



FOREWORD

RHD - getting to the heart of the problem

Since 2002, the AMA Report Cards on Indigenous Health have covered important Aboriginal and Torres Strait Islander health issues, including low birth weight babies, institutionalised inequity, the inadequacy of government funding, best practice in primary care, Indigenous medical workforce, and incarceration.

These Report Cards have contributed to the broader debate around progress, or lack of it, in Indigenous health, and have been catalysts for informed further discussion.

The 2016 Report Card on Indigenous Health focuses on the enormous impact that Rheumatic Heart Disease (RHD) is having on Indigenous people in Australia.

RHD is a disease of poverty, and it is preventable. Yet it is devastating lives and killing many people here in Australia – one of the world's wealthiest countries.

In fact, Australia has one of the highest rates of RHD in the world, almost exclusively localised to Indigenous communities.

Indigenous Australians are 20 times more likely to die from RHD than their non-Indigenous peers – and, in some areas, such as in the Northern Territory, this rate rises to 55 times higher.

These high rates speak volumes about the fundamental underlying causes of RHD, particularly in remote areas - poverty, housing, education, and inadequate primary health care.

The necessary knowledge to address RHD has been around for many decades, but action to date has been totally inadequate.

The lack of action on an appropriate scale is symptomatic of a national failure.

We have seen some progress through Closing the Gap measures in housing, education, and health funding, but a committed and coordinated effort is desperately needed.

RHD must be eradicated – it must no longer occur in Australia.

With this Report Card, the AMA calls on all Australian governments to stop new cases of RHD from occurring.

We urge our political leaders at all levels of government to take note of this Report Card and be motivated to act to implement solutions.



Dr Michael Gannon

President, Australian Medical Association
November 2016

INTRODUCTION

Every year, Rheumatic Heart Disease (RHD) kills people and devastates lives – particularly the lives of young Australians. It causes strokes in teenagers, and requires children to undergo open heart surgery. Yet it starts with symptoms as innocuous as a sore throat, or a skin infection commonly known as ‘school sores’.¹

RHD is an entirely preventable public health problem. The conditions in which RHD thrives, how the disease develops, and the points at which interventions can be made are understood sufficiently to act now. RHD is not an ‘intractable issue’. Its devastating impact can be halted within existing medical knowledge, applied in a strategic and cost-effective manner.

RHD is a disease of poverty. Worldwide, it is a disease of poorer, developing countries. Most cases are in the Sub-Saharan African, Indian Sub-continent, and Pacific Island regions.²

For most Australians, RHD is consigned to historical memory – along with the overcrowded inner-city slums, and the pre-penicillin era in which the disease once thrived in this country. Yet RHD remains in some Australian communities, and at rates among the highest in the world.³ These are Australia’s Indigenous communities. In fact, in Australia, RHD is almost exclusively a disease of Indigenous communities. Here, as in developing nations, poverty, poor quality and overcrowded housing, and limited access to health services are the norm. These are the conditions that give RHD its last remaining Australian foothold.

RHD is emblematic of the well-known life expectancy gap between Indigenous and non-Indigenous people. But when considering RHD, the gap becomes a yawning chasm. Indigenous Australians are more than 20 times more likely to die from RHD than other Australians. In the Northern Territory (NT), that rate rises to 55 times.⁴ In terms of prevalence, RHD among Indigenous Northern Territorians is reported at 39 times the rate of their non-Indigenous peers in the NT. In Queensland, the differential rate is 206 times higher. While RHD is not as prevalent as diabetes or kidney disease in the Indigenous population overall, the gaps associated with these conditions are actually narrower than that of RHD in the Indigenous communities where it is prevalent.^{5,6}

So, what medicine is required to prevent new cases of RHD? Awareness and political will. For the former, there is growing public awareness about the terrible impact of RHD in Indigenous communities. In particular, the international *Take Heart* campaign released a feature film about RHD in Indigenous communities, which was broadcast on Australian television.⁷ This Report Card adds to this groundswell.

In relation to political will, the AMA makes a *Call to Action* to prevent new cases of RHD in Indigenous Australia by 2031. This is also the target year of the Council of Australian Governments (COAG) Closing the Gap Framework objective to improve the life expectancy of Indigenous Australians.⁸ Preventing new cases of RHD in Indigenous Australia by 2031 will make an important and necessary contribution to the achievement of this overarching life expectancy target.

Perhaps more significantly, Australia is at a unique juncture that gives it the levers to close the RHD gap within 15 years. The End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE), which is funded by the National Health and Medical Research Council, and engages Australia’s leading RHD experts, is currently working to identify a set of costed, step-wise interventions, which are most likely to reduce the prevalence of RHD for Indigenous Australians to the same level as non-Indigenous Australians. It is due to report in 2020 with the basis for a comprehensive strategy to end RHD as a public health problem in Australia.⁹ Setting a 2031 target to prevent new cases of RHD in Indigenous Australia not only allows for the development of such a strategy by 2021, but also for a decade of its implementation. This Report Card calls for an interim, evidence-based, strategic and cost-effective strategy, to provide the best possible foundation, to eradicate RHD to be conducted in the years, 2016-2021.

Further, the AMA calls for a target that no child in Australia dies as a result of Acute Rheumatic Fever (ARF) and its complications by 2025. ARF is the precursor condition and cause of RHD (discussed further in Part 2). Not only is this a worthy goal in its own right, it will also act as a national ‘performance indicator’ for the achievement of the 2031 target. It also aligns the vision of Rheumatic Heart Disease Australia (RHDA), the national coordination body working to control RHD in this country (discussed in Part 2),¹⁰ with a target year aligned with the World Heart Federation’s target to achieve, worldwide, a 25 per cent reduction in ARF and RHD deaths among individuals under 25 years of age by 2025.¹¹

The AMA *Call to Action* is framed as two recommendations:

A Call to Action to Prevent New Cases of RHD in Indigenous Australia by 2031

Recommendation 1: For Australian governments to commit to a target to prevent new cases of RHD reported among Indigenous people by 2031. As a milestone to achieving this target, Australian governments should also commit to a sub-target that no child in Australia dies of ARF and its complications by 2025.

Recommendation 2: To achieve the targets in Recommendation 1, Australian governments to work in partnership with Indigenous health bodies, experts, and key stakeholders to develop, fully fund, and implement a strategy to end RHD as a public health problem in Australia by 2031, comprising:

- an interim strategy (operational from 2016-2017 until 2021); and
- upon the 2020 receipt of the final report of the END RHD CRE, a comprehensive 10-year strategy (operational from 2021-2031).

The strategy should provide a firm foundation for an evidence-based, focussed, and cost-effective intergovernmental, multi-sectoral, and multidisciplinary national effort to prevent new cases of RHD reported among Indigenous people by 2031.

In 2015, there were just under 6,000 Australians (the vast majority Indigenous) who were known to have experienced ARF or have RHD (and there will be many unknown cases).⁴ Over 2010–2013, there were 743 new or recurrent cases of RHD nationwide, with 94 per cent of these cases affecting Indigenous Australians. Fifty two per cent of these cases were among Indigenous children aged 5–14 years, and 27 per cent were among those aged 15–24 years.⁵

When it comes to stopping new cases of RHD, there are a relatively small number of potential cases – involving about *one three hundredth of one percent* of the approximate 24 million people in Australia.¹² This is assuming that the 2012-2013 rate of about 750 new cases per year continues.

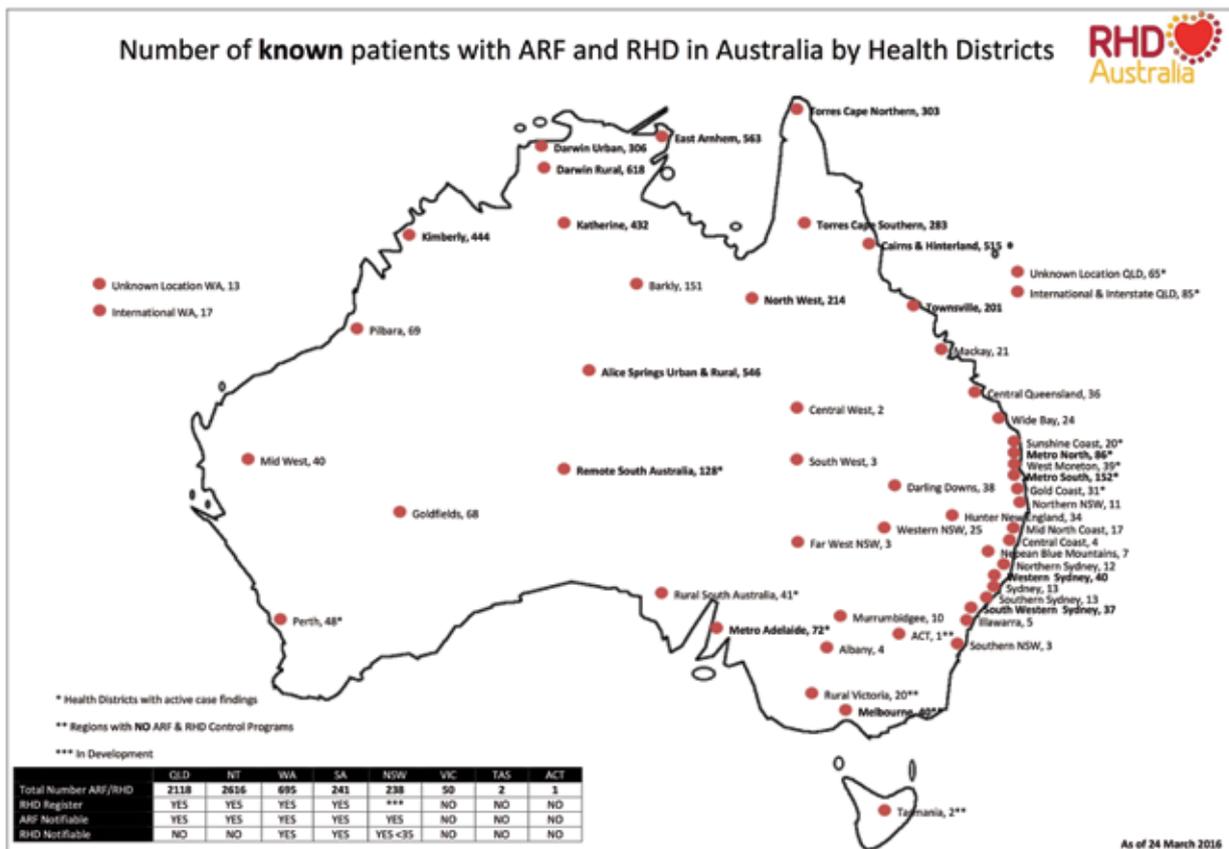
Further, at least in the jurisdictions where medical practitioners are required to report ARF and RHD (NT, Western Australia (WA), Queensland, New South Wales (NSW) and South Australia (SA)) the regions and communities most at risk are known. Diagram 1 on page 4 (a map developed by RHDA)¹³ highlights the main health districts of concern. It also identifies cases in Victoria and Tasmania that have been informally recorded.

From this it can be identified that significant concentrations of cases are found in the Indigenous communities of the following areas:

- in WA, the Kimberley (444 reports of ARF or RHD);
- in the NT, Katherine (432), Darwin Urban (306), Darwin Rural (618), East Arnhem Land (563), Barkly (151), and Alice Springs Urban and Rural (524); and
- in Queensland, Torres Cape Northern (303), Torres Cape Southern (283), Cairns and Hinterland (515), Townsville (201), and Queensland North-West (214).

It is also noteworthy that significant concentrations are found in Remote South Australia (128), and in a Brisbane-to-Sydney band of health districts that have reported a relatively small number of cases each, which overall amount to about 500 cases (this includes Brisbane South Metro, with 152 cases alone).

Diagram 1: Number of known patients with ARF and RHD in Australia by Health Districts



This evidence suggests the opportunity for significant returns on, and the cost-effectiveness of, an evidence-based, geographically-focussed, national effort to prevent new cases of RHD reported among Indigenous people by 2031. This is the AMA's *Call to Action*.

A dry description of the development of RHD does not convey its impact on the lives of Indigenous children, teenagers, and adults. The AMA is grateful to Mr Eddie Masina, a North Queensland Aboriginal man who has lived with RHD since he was five years old, for sharing his story.

'Why hasn't anything been done about it!?'

- Eddie Masina's Story

Not feeling anything in his legs is the first thing Eddie remembers about RHD. He was a sports mad five year old sitting at the breakfast table and suddenly he couldn't move. He and his 'freaked out' Mum were soon on the long journey from his Innisfail home to Cairns Hospital. After a month of what 'felt forever', he finally returned home. But his old active life never did.

While Eddie didn't understand what RHD or a heart murmur was, he knew that something serious had happened: mostly because he was no longer allowed to play his much-loved rugby. Eddie was supposed to take oral penicillin daily, and he recalls the fibs and tricks he used to avoid taking the medicine. He also recalls how much he worried his Mum and Dad.

Eddie estimates that he has spent about two-and-a-half years in a hospital bed over his 35 or so years: almost seven per cent of his life. All that started with the first attack of ARF. The sore joints, the breathlessness, and the flu-like symptoms – and with them the hospital stays – kept coming. Sometimes he felt so bad he would ask to be admitted to hospital.

In year seven of school, Eddie had the first of his open heart surgeries: something most 12-year-old boys would not even begin to contemplate. He had been really sick. His ankles were swollen, and he was finding it hard to breathe. An X-ray revealed an enlarged heart and a damaged valve. His parents were worried sick by the stress of it all. His Mum had a sister who had died from RHD at 16 years of age.

Eddie still carries the metal ring in his body from his first valve surgery. Then other valves started to leak. Eddie underwent more open heart surgeries which marked his 16th, 21st, and 26th years. Every time it happens he goes back into hospital with all the worry, the lost time, and time away from family. The most recent time – his fifth – was in 2014. At times, he and his family thought he would die in a hospital bed.

Eddie also had two strokes: at ages 18 and 20. After open heart surgery, he was required to take blood thinning medication - but being a teenager, he often forgot. He just wanted to be 'normal' - and dealing with a heart condition is not something 'normal' teenagers do. But the consequences were awful.

Eddie still takes oral penicillin, and has done daily for 30 years (he only found out about the possibility of Benzathine Penicillin G (BPG) shots in 2006, and, by then, it was too late to change). Eddie mentors other Indigenous men with RHD who have the BPG shots - every 28 days, and for years. They don't like the pain and the needle. But Eddie counsels them: 'You may live to be 80 or 90. You'll only have to do this for a few years. Then you can get on with your life.'

It was only in 2016 that Eddie was shocked to be told that RHD is entirely preventable. This was about the same time he got the devastating news that his young niece may have RHD. When asked what his message to the readers of this Report Card would be, he said: **'RHD is 100 per cent preventable: Why hasn't anything been done about it?'**

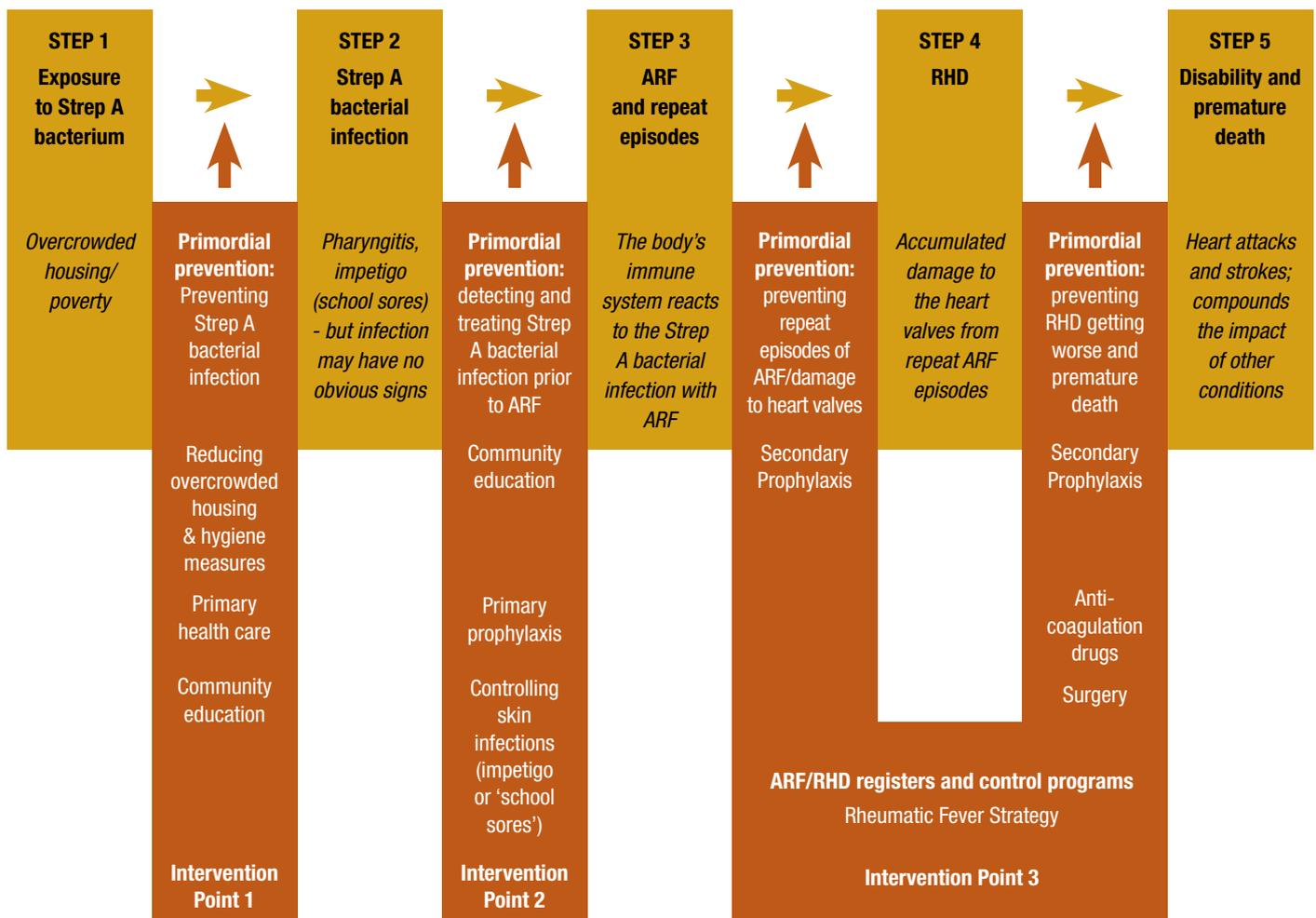
PART 1

HOW TO PREVENT NEW CASES OF RHD IN INDIGENOUS AUSTRALIA BY 2031

The development of RHD is illustrated in Diagram 2. The elements of this diagram are significantly expanded on in the Appendix to this Report Card, which discusses in greater detail how RHD develops, the interventions that can be made, some of the challenges to making interventions, and how these challenges can be overcome.

RHD starts with a Group A Streptococcal (Strep A) bacterial infection that, symptomatically, can be as innocuous as a sore throat or a skin infection - impetigo or 'school sores' (Steps 1-2). Next, the person's immune system reacts with joint pain, fever, and other symptoms: ARF (Step 3). While ARF is serious, it usually clears up. But it can cause damage to heart valves - particularly over multiple ARF episodes. Damage to the heart valves is RHD (Step 4). There are varying degrees of RHD, from mild to severe. Without medical and surgical management, death and disability can result (Step 5).¹

Diagram 2: The Development of RHD and Three Intervention Points to Stop RHD¹



This Report Card is specifically concerned with preventing new cases of RHD in individuals, with the long-term goal of eradicating this particular disease by 2031. Managing RHD is not its focus, although this and tertiary prevention to stop RHD progressing from mild to severe forms is discussed in the Appendix. For those already living with RHD, continuing high quality care is required, alongside the national effort to prevent new RHD cases called for here.

When considering how to prevent new cases of RHD, three activities are critical:

- Preventing Strep A bacterial infection. If transmission and infection can be stopped, then ARF will simply not happen. (Intervention Point 1 in Diagram 2).
- Detecting and rapidly treating Strep A bacterial infection when it does occur. An infection can be treated prior to triggering the ARF response by administering intramuscular BPG shots as discussed below. (Intervention Point 2).
- Stopping Strep A bacterial re-infection once ARF has occurred, again by using BPG shots as a preventive measure. This is important because it often takes multiple episodes of ARF to cause RHD. (Intervention Point 3).

So, what is required?

- **First, improving the overcrowded and unhygienic conditions in which Strep A bacterium can thrive and spread**

The Strep A bacterium thrives and spreads in overcrowded conditions. This is why RHD is described as a disease of poverty. A recent Australian survey screened almost 4,000 Indigenous five- to 15-year-olds from four regions of northern and central Australia for RHD. The poorest of the four regions, with the highest rates of overcrowding, had the highest RHD rates.¹⁴

Conversely, dramatic falls in the rates of ARF/RHD have been observed as social and environmental conditions improve.¹ Improving overcrowded and unhygienic conditions is key to stopping new cases of RHD. The *National Aboriginal and Torres Strait Islander Health Plan 2013-23* notes the association of RHD with 'extremes of poverty and marginalisation.' RHD 'will remain a risk while socioeconomic disadvantage and barriers to accessing health care persist.'¹⁵ It should also be noted that these are the same conditions associated with a number of diseases that are largely or almost exclusively diseases of Indigenous Australia: trachoma,⁶ tuberculosis,¹⁶ scabies,¹⁷ paediatric chronic suppurative lung disease,¹⁸ otitis media,⁶ and acute post-streptococcal glomerulonephritis.¹⁹

- **Second, educating Indigenous community members about Strep A bacterial infection, ARF, and RHD**

This includes how to stop the spread of strep A bacterium, and how to identify the symptoms of Strep A infections, ARF, and RHD, and the need to seek help – and quickly – if they are identified. It has also been reported that, for some Indigenous communities, Strep A infections (particularly skin infections) have become ‘normalised’. Education campaigns that challenge such ‘norms’ are critical. In an Indigenous community context, this means meeting people where they are: working with communities, and within distinct cultural settings that will vary from community to community. It means proactively reaching out with education packages in Indigenous languages that are age- and culturally-appropriate. It means not assuming English fluency or literacy. And, given the high rates of otitis media in Indigenous communities, hearing impairment must also be accounted for.⁵

- **Third, educating medical practitioners about Strep A bacterial infection, ARF, and RHD**

Practitioners must be able to detect Strep A bacterial infection, ARF, and RHD rapidly and accurately. An important contribution to that end has been RHDA’s development of *The Australian Guidelines for Prevention, Diagnosis, and Management of Acute Rheumatic Fever and Rheumatic Heart Disease*¹ (Australian Guidelines), with a third edition planned for 2017. The AMA supports the call of the report of the Better Cardiac Care for Aboriginal and Torres Strait Islander People Project to increase clinicians’ awareness and capacity to diagnose and manage ARF and RHD, in line with the current Australian Guidelines for the prevention, diagnosis, and management of ARF and RHD, particularly in high-risk or endemic communities.²⁰

- **Fourth, establishing and supporting functional primary health care clinics that are culturally safe, employ culturally competent RHD-informed practitioners and Aboriginal health workers, and have models of care that are patient- and family-focussed**

It is noteworthy that dramatic ARF rate reductions are observed where primary health care is introduced in areas with high rates of ARF/RHD.¹ This is even when primary health care is not intended as a specific response to ARF/RHD.¹ Primary health care in the communities affected by ARF/RHD is an essential part of the *Call to Action*. Not only is it the essential ‘other half’ to health-seeking behaviour, it can also support detection efforts, secondary prophylaxis adherence, and, by improving the health of all community/household members simultaneously, it can help stop the transmission, infection, and cycles of re-infection by the Strep A bacterium.

Where possible, this should be provided by or through Aboriginal Community Controlled Health Services (ACCHSs). These health services are initiated, operated, and controlled by the communities they are established to serve. They deliver holistic, comprehensive, and culturally appropriate health care. Studies have found that, for Indigenous people, ‘where ACCHSs exist, the community prefers to, and does, use them.’²¹ With appropriate resources, an ACCHS is able to implement a culturally competent and comprehensive primary health care model that can include a model of care to rapidly detect and treat Strep A bacterial infection and ARF.

- **Fifth, improving access to intramuscular BPG shots**

Used as a **primary prophylaxis**, a BPG shot can protect against (or treat) Strep A bacterial infection and is effective for about four weeks. Repeat doses are required for as long as protection is needed. More importantly, BPG shots are the mainstay of **secondary prophylaxis** to prevent re-infection of a person who has had ARF (or, indeed, for people with RHD). This comprises a regime of 13 shots annually – usually for a decade or until the age of 21 or, in the case of more severe RHD, until the age of 40 or longer.¹

Secondary prophylaxis is an onerous, painful, and intrusive measure, and adherence is challenging. In 2013, in the NT, 24 per cent of Indigenous Australians on the ARF/RHD control program (discussed below) received less than 50 per cent of required doses in the previous 12 months; 42 per cent received 50 to 80 per cent; and only a third received greater than 80 per cent.²² But, when adhered to, secondary prophylaxis is extremely effective. Between 2002 and 2009, no patients in the NT who received 100 per cent of their four-weekly injections had a recurrent episode of ARF.¹

Hospitalisation upon ARF diagnosis provides the best start to secondary prophylaxis by providing an opportunity to establish trust between health services and patients that can be built upon in primary health care settings. Here, too, education about adherence – including of children’s parents and carers – is critical.¹ Culturally appropriate tools to support adherence – such as injection calendars and Apps – have been developed.²³ In primary health care and other clinical settings, dedicated staff to deliver the BPG shots can ensure better monitoring and coordination of other care services that might be needed. Conversely, a high staff turnover is associated with lower adherence rates.¹

Proactive follow-up by services to remind and otherwise ensure patients get their shots is also important.¹ When working with mobile Indigenous patients, such follow-up is even more effective if it extends beyond the boundaries of the community. Use of jurisdictional and local ARF/RHD registers to record adherence,¹ and regional centralised coordinators, are also important for monitoring patients who might be moving between communities.¹ Networking between clinics is also important when working with mobile patients.¹

In relation to adherence, community-based primary health care provides the best context. A study in the NT found that trust between a patient and health service staff, and a patient’s sense of ‘belonging’ to the clinic, improved adherence.¹ Aboriginal Health Workers assisted with improving adherence,¹ suggesting that they play a key role in stopping new cases of RHD.

- **Sixth, establishing ARF/RHD patient registers and population ARF/RHD control programs**

The 2009 *Rheumatic Fever Strategy* (RFS) – a national agreement and program²⁴ – funds ARF/RHD control programs and ARF/RHD registers in the NT, Queensland, WA, and SA. In addition, NSW operates an ARF/RHD register and control program, but this is independent of the RFS.

These registers have had a positive impact. In 1997, the NT was the first Australian jurisdiction to make ARF/RHD a notifiable disease and initiate a control program. In the years between 2006 and 2013, there was a 41 per cent decline in new RHD registrations of Indigenous Australians in the NT.⁵ The NT model has been adapted in the four other jurisdictions, although each of the five programs

and registers has some different features. However, in common, they identify people with or at risk of ARF and RHD, and include their details on a disease register, with the aim of improving delivery of long-term secondary prophylaxis.²⁵

The RFS also established the national coordination unit, RHDA, to support the four RFS-funded control programs and registers. It is based at the Menzies School of Health Research in Darwin. RHDA aims to: support ARF/RHD control programs; establish a national data collection and reporting system (currently a work in progress); disseminate best practice in ARF/RHD; and increase community awareness of ARF and RHD and its prevention.²⁶

- **Finally, ensuring that echocardiographic (echo) screening has a role to play in RHD control**

Echocardiographic screening creates a picture of how a person's heart and valves are functioning. It is a vital tool in detecting cases of RHD that may have resulted from unrecognised episodes of ARF. Early case detection means that those identified can be commenced on secondary prophylaxis, which, if successfully delivered, will prevent the ARF recurrences that result in worsening of RHD. The development of portable echocardiographic machines means that echo screening can be delivered in community settings.

A 2008-2010 Australian study, which involved screening approximately 5,000 children (4,000 of whom were Indigenous), confirmed that echo screening is feasible in remote settings, and that extra cases were detected. However, a recent workshop at the Cardiac Society of Australia and New Zealand Annual Scientific Meeting, involving Australian experts in the field, concluded that echo screening should not be used as a stand-alone intervention. Rather, it must be coupled with increased resources to improve secondary prophylaxis adherence among the extra RHD patients who will potentially be detected by screening. This includes ensuring that primary and specialist health services are appropriately resourced to manage the additional patients.¹⁵ One way to understand and address these concerns, and the resource implications of echo screening, would be to trial it in selected communities over a period of time with clear evaluation endpoints.²⁶

In concluding Part 1, the overarching point must be highlighted again: that, at every step prior to the development of RHD, it is possible to intervene, and to prevent the progression of the disease. It is for this reason that RHD is an entirely preventable public health issue. It is why the AMA says awareness and political will are required for a nation-wide 'cure'. It is why the AMA is making the *Call to Action* for a nationwide effort to prevent new cases of RHD in Indigenous Australia by 2031.

PART 2

A call to prevent new cases of RHD in Indigenous Australia by 2031

Recommendation 1: For Australian governments to commit to a target to prevent new cases of RHD reported among Indigenous people by 2031. As a milestone to achieving this target, Australian governments should also commit to a sub-target that no child in Australia dies of ARF and its complications by 2025.

Targeted ARF/RHD campaigns have a good track record. Setting a target can have a galvanising effect on governments, stimulating investment and attention. And there is no need to look too far for an example. In 2012, the New Zealand (NZ) Government set a target for a two-thirds reduction in ARF cases by June 2017,²⁷ largely to reduce the high incidence of ARF/RHD among disadvantaged Maori populations in the North Island.²⁸

That target led to an investment of more than NZ \$65 million to identify and trial initiatives to reduce ARF and achieve the target. It is a geographically focussed response – largely in the 11 district health board areas in NZ with the highest incidence of ARF hospital admissions.²⁷ The results are promising. In March 2016, the NZ Health Minister announced a 45 per cent reduction in ARF cases, with the majority of the reduction in children younger than 14 years old.²⁷

Australia should adopt a targeted approach to prevent new cases of RHD by 2031. The sub-target that no child in Australia dies of ARF and its complications by 2025 is an important milestone to the 2031 target, and would act, in a sense, as a ‘performance indicator’ of the wider national effort to achieve the 2031 target. It would also ensure that the youngest Australians are prioritised within the national effort.

Recommendation 2: To achieve the targets in Recommendation 1, Australian governments to work in partnership with Indigenous health bodies, experts, and key stakeholders to develop, fully fund and implement a strategy to end RHD as a public health problem in Australia by 2031, comprising:

- an interim strategy (operational from 2016–2017 until 2021); and
- upon the 2020 receipt of the final report of the END RHD CRE, a comprehensive 10–year strategy (operational from 2021–2031).

The strategy should provide a firm foundation for an evidence-based, focussed, and cost-effective intergovernmental, multi-sectoral, and multidisciplinary national effort to prevent new cases of RHD reported among Indigenous people by 2031.

Key elements of the above include:

- **Building on the success of the 2009 RFS to develop, fully fund, and implement a strategy to end RHD as a public health problem in Australia by 2031**

An important part of this Report Card's *Call to Action* is building on the success of the RFS as the starting point of a new strategy to end RHD as a public health problem in Australia by 2031, and achieve associated targets.

As this Report Card shows, enough is known about stopping RHD to take the current RFS-based effort to the next, more ambitious stage. The work of RHDA in developing a framework to enable a coordinated approach to ARF and RHD in Australia,²⁶ and the ambitious 2015 *Developing an Endgame for Rheumatic Heart Disease in Australia* prospectus of the END RHD CRE,²⁹ provide a sound foundation – and both have informed this Report Card.

In particular, the END RHD CRE has brought together 20 leading ARF/RHD investigators from 16 institutions to develop a strategy for how Australia can eliminate RHD as a public health problem. By 2020, it will provide a step-wise roadmap to ending RHD in Australia.³⁰ This is an excellent starting point for the development of an evidence-based strategy to end RHD as a public health problem in Australia by 2031, in both its interim and final forms.

Further, the Better Cardiac Care for Aboriginal and Torres Strait Islander People Project report identifies 21 Better Cardiac Care measures;²¹ and the *Essential Service Standards for Equitable National Cardiovascular Care for Aboriginal and Torres Strait Islander People (ESSENCE)* project could also provide quality indicators to inform strategy development.³¹

- **Make ARF/RHD notifiable across Australia and establish a national register**

Related to the above point, it is time to bring to completion efforts already underway by RHDA to make ARF/RHD a notifiable disease in all States and Territories, and have a nationwide control program. Further, it is also time to establish a central ARF/RHD register.²⁶ It is essential that the implementers of a national strategy have a nation-wide perspective on the disease, and that they are able to both identify and respond to ARF outbreaks rapidly. Monitoring the impact of the national effort and campaign right down to the community level, and in 'real time', requires an efficient data gathering system as a part of a national register.

The AMA's call for the above reinforces recommendations 5.1 and 5.2 for priority areas for reform that emerged from the Better Cardiac Care for Aboriginal and Torres Strait Islander People Forum, a joint initiative of Federal, State, and Territory governments that was held in March 2014, and involved representatives from the Commonwealth Department of Health and State and Territory health departments.²¹ It is also noteworthy that the Australian Institute of Health and Welfare has already begun reporting on ARF/RHD, in effect, nationally (although, in practice, limited to data from those States and Territories with ARF and RHD registers).³²

- **People living with ARF and RHD and their communities must be at the heart of the national effort and campaign**

In particular, when operating in Indigenous communities, efforts should operate on the basis of community partnerships with effective community engagement. This is not only by virtue of any responses needing to address cultural implications and ‘lived experience’ elements of ARF/RHD, but also because of Indigenous communities’ right to be involved in health service program design and delivery. Their right as Indigenous communities to self-determination (or self-governance) in matters that impact upon their community life, including matters related to ARF/RHD, must also be respected.³³

Ensuring Indigenous communities drive the community-level changes is among the most important considerations if local level campaigns to stop new cases of RHD are to be ‘owned’ by communities, and sustainable outcomes are to be achieved. Governments and service providers must be able to respond to a community’s priorities as much as possible. Further, community-level interventions cannot be ‘standardised’ across communities, but must reflect local needs and conditions.

- **A holistic, multisectoral, and multidisciplinary approach**

Complex challenges such as addressing the causes of, and effectively treating, Strep A bacterial infection and ARF are not likely to be resolved by a single organisation, discipline, or sector. Rather, a program with multiple, simultaneous, evidence-based actions is required to prevent new cases of RHD by 2031: addressing housing and hygiene in communities or households, building primary health care capacity to detect and respond to Strep A infections and ARF; focussing on secondary prophylaxis adherence; and undertaking education campaigns, for example. And, of course, at the centre of these approaches must be the Indigenous communities affected.

- **A targeted, cost-effective focus on primordial prevention**

Current programs to address overcrowded and substandard Indigenous housing should be continued – in particular, the COAG *National Partnership Agreement on Remote Indigenous Housing* should continue beyond 2018. This is the primary national response to overcrowded and poor quality Indigenous housing stock. But responding to RHD with a proposal for a nationwide multi-billion-dollar housing program is likely to be counterproductive. Thankfully, it is also unnecessary. As has been discussed in Part 1, ARF/RHD occurs among relatively small numbers of people and in identified communities and regions.

To maximise the impact of resources, ARF/RHD affected communities, clusters of households in communities, and even specific households could be sensitively identified and, working in partnership with their members, their housing made the focus of environmental health measures.²⁵ Given the strong possibility of skin infections contributing to ARF rates, a focus on relatively inexpensive measures to improve household hygiene to stop the spread of Strep A bacterium may also provide cost-effective ways of primordial prevention.³⁴

- **Continue funding Strep A bacteria vaccine/reformulation of penicillin delivery method development**

A vaccine against Strep A bacterial infection has been described as the 'Holy Grail'³⁵ of RHD prevention, and offers promise for the almost total control of ARF, RHD, and other diseases caused by the Strep A bacteria. Attempts to develop a vaccine have been underway since the early 1920s.³⁸ Progress towards a safe and affordable vaccine has accelerated in recent years. In particular, the Coalition to Advance New Vaccines Against Group A Streptococcus (CANVAS) initiative began in 2013. It is a collaborative venture between the Australian and New Zealand Governments,³⁸ and involves the Telethon Kids Institute (WA), the University of Auckland (NZ), and the Murdoch Children's Research Institute (Victoria).³⁶ A number of vaccine candidates are reported to be in early human trials. CANVAS program funding is due to expire in 2016, and the AMA supports the re-funding and extension of the program until a vaccine is developed.

Also of great potential is research towards developing a new formulation of long-acting penicillin that would be more acceptable, and potentially reduce the need for people to receive regular painful injections. The Telethon Kids Institute is currently working towards the development of either an under-the-skin penicillin implant or a longer acting injectable form of penicillin over the next few years. Such measures should continue to be funded as a potential 'game changer' for ARF/RHD control – not only in Australia, but around the world.³⁷

However, the development of a vaccine or reformulated penicillin delivery method should not be seen as 'quick-fixes' that eclipse the critical importance of reducing overcrowded and unhygienic housing as part of an overall response. Nor can the development of a vaccine or a reformulated penicillin delivery method necessarily be relied on to boost the strategy to end RHD as a public health problem in Australia by 2031, or the achievement of the target to prevent new cases of RHD in Indigenous Australia by 2031.

- **Additional funding**

The RFS, while bringing great benefits, should not be mistaken for the scale of response required if the RHD gap is to close. In addition to the elements discussed above, significant additional funding is required. The RFS received initial investment of just over \$11 million over five years to June 2012, with just under \$13 million over four years to June 2016, bringing the total commitment to date to about \$24 million over nine years.³⁸ A further \$3.1 million has been committed to the RFS over 2016-2017.³⁹ Beyond that, the long-term funding of the RFS is uncertain.

Compared to the NZ investment of NZ \$65 million to address RHD (discussed above), the Australian Government's commitment to the RFS to date, while welcome, is 'bare-bones' funding: maintaining the registers in four jurisdictions and the important work of RHDA, but insufficient for the more ambitious response required and called for in this Report Card. For example, it excludes any funding that might be required to address the significant numbers of cases being detected in NSW and Victoria (see Diagram 1). In the development of this Report Card, key stakeholders have reported to the AMA that there is insufficient funding to enable the existing control programs to be effective. This includes the vitally important education of health service staff or families (see the second and third bullet points of Part 1), and the employment of Aboriginal health workers and community workers in service-level responses to support adherence to secondary prophylaxis, and otherwise better support for people with ARF/RHD.

Additional funding could be made to go further by targeting resources efficiently, as this Report Card has demonstrated can be done. As noted, potentially expensive elements, such as tackling housing problems, could be sensitively and geographically targeted to specific regions, communities, and even to households. Further, the AMA believes significant medium- and long-term savings could be expected as a result of the strategy proposed here, particularly in relation to the costs of open heart surgery often required for people with RHD. Indeed, the identification of such savings could provide justification for the increased allocations required in the short term. Because of this, a cost-benefit analysis of preventing new cases of RHD by 2031 as a way forward to securing long-term, appropriate funding for a strategy to end RHD as a public health problem in Australia by 2031 should be undertaken as the basis for the funding of the response recommended in this Report Card.

Ending RHD as a public health problem in Australia by 2031 requires the nation to think big – and beyond the RFS. In doing so, it must be recognised that RHD is a disease that primarily affects Indigenous people. As such, it is only appropriate that Australia also aims to prevent new cases of RHD in Indigenous and non-Indigenous Australia by 2031, including as a major contributor to closing the Indigenous life expectancy gap that same year.

By 2020, with the reporting of the END RHD CRE, Australia will have the potential to develop an evidence-based, targeted, and cost-effective strategy to achieve these goals and targets. With the proper resources to implement this strategy, Australia could see an end to see the scourge of ARF/ RHD in our communities, and in our Indigenous communities in particular.

APPENDIX

The appendix sets out the progress of RHD and the possible interventions, the barriers to making the interventions, and how they could be overcome.

What happens and why?

With reference to Diagram 1 in the Report Card

Steps 1-2: Stopping Strep A infection

Strep A bacterium must infect tissue to cause the ARF immune system response.¹ In particular, pharyngitis (infections of the throat and tonsils) is associated with ARF. But skin infections (impetigo or 'school sores') are also implicated. Certainly, they help explain some of the patterns of the disease observed in Indigenous communities.¹ While the exact nature of the causal pathways is unclear, what is clear and undisputed is that higher rates of ARF and RHD are found in the overcrowded conditions associated with poverty, where the bacteria can spread.¹

What interventions will work?

Reducing overcrowded/unhygienic conditions is a primary defence. Dramatic falls in the rates of ARF/RHD are observed in populations as their social and environmental conditions improve.¹

Dramatic ARF rate reductions are observed when primary health care is introduced,¹ even when it was not intended as a specific response to ARF/RHD.¹ Primary health care can improve the health of all community/household members simultaneously helping stop infections and re-infections.

Pre-emptive primary prophylaxis.

What are the barriers?

The cost of replacing Indigenous housing stock is high. Responding to RHD with a proposal for a nationwide multi-billion-dollar housing program is likely to be counterproductive.

Providing primary health care in remote areas can be challenging and it must be delivered in a culturally appropriate way.

The Australian Guidelines do not recommend the use of BPG shots in a pre-emptive way. BPG shots are costly and there is also risk of side effects. There are also concerns about the development of BPG-resistant Strep A bacteria strains. As such, BPG shots are only recommended as a pre-emptive primary prophylaxis in extreme circumstances.¹

How can the barriers be overcome?

- RHF/RHD occurs in clusters and among relatively small numbers of people. To maximise the impact of resources, specific communities and/or households are identified and made the focus of primordial activity.²⁶
- Given the strong possibility of skin infections as a cause, washing machines and health hardware is important and relatively low cost.
- Health education has a role to play at this stage.
- Expansion of the RFS-based control program to include a focus on primordial and primary prevention.

Promoting ACCHSs located in communities, staffed by trained community members with support as required.

Develop protocols for when it is appropriate to use BPG shots as a pre-emptive measure.

What happens and why?
With reference to Diagram 1 in the Report Card
Step 2-3: Stopping the ARF response

A Strep A infection is needed to trigger the ARF immune system response, but it does not occur immediately. Stopping the ARF response within that limited window of opportunity is the challenge.

The way to stop it is to commence BPG shots within nine days of a person becoming symptomatic (see secondary prophylaxis below for the barriers and ways to overcome).¹

What interventions will work?

Rapid diagnosis of strep A infection using throat swabs is 'gold standard' for detecting Strep A infection.¹

Practitioner education.

Community/family health literacy about the symptoms of ARF (and RHD) and what to do if it is suspected (help-seeking).

What are the barriers?

Lab testing of throat swabs might not be feasible in remote areas and testing can add up to three days to diagnosis time.¹ Rapid Strep Tests in their current forms are deemed of limited use by the Australian Guidelines.¹

There are many pitfalls to diagnosis, particularly in remote areas.¹ And ARF/RHD is not within the clinical experience of most Australian medical practitioners.¹

Materials must be age, language and culturally appropriate. Further, literacy should not be assumed, and the high incidence of hearing impairment among Indigenous people in remote areas considered.

How can the barriers be overcome?

- Progress a range of rapid detection options:
 - Support more efficient lab testing of throat swabs.
 - Improve Rapid Strep Testing.
 - Clinical scoring methods.¹
 - Promote the Australian Guidelines as a critically important resource for practitioner education.
 - Promote RHDA national education and training resources based on the Australian Guidelines, including for smartphones and tablets (with a diagnosis calculator),⁴⁰ and in poster form.⁴¹
 - Options for training and ongoing professional development through completion of the RHDA online learning modules. Some remote area health facilities and medical/nursing recruitment/placement agencies have made these mandatory.
 - Promote the use of the Communicable Diseases Network Australia's ARF/RHD Series of National Guidelines when they are finalised.⁴²
- Age and culturally appropriate educational materials have been developed by RHDA,⁴³ the RHDA Queensland,⁴⁴ and the NT Department of Health and Families and others. These provide a basis for further development.

What happens and why?
With reference to Diagram 1 in the Report Card

	What interventions will work?	What are the barriers?	How can the barriers be overcome?
	<p>Primary health care brings increased opportunities for earlier detection and is a platform for ARF/RHD health literacy and enabling help-seeking behavior to be supported.</p>	<p>Providing primary health care in remote areas can be challenging and must be delivered in a culturally appropriate way.</p>	<p>Promoting ACCHSs located in communities, staffed by trained community members, with support as required.</p>
<p>Step 3-4: Stopping repeat ARF episodes</p> <p>Over 2010–2013, there were 743 new or recurrent cases nationwide: 94 per cent were in Indigenous Australians, with 52 per cent of these being in Indigenous children aged 5–14 years, and 27 per cent in the 15–24 years age group.⁵ Immediate hospitalisation is recommended at this stage. ARF symptoms can require pain management.¹ Hospitalisation at this stage is to get adherence to secondary prophylaxis off to the best start.</p>	<p>Diagnose ARF as accurately as possible as the basis of secondary prophylaxis.</p> <hr/> <p>Secondary prophylaxis. A structured care plan should be developed and recorded in the primary healthcare record.¹</p> <hr/> <p>Ongoing primary health care to support the above. Annual general health and dental checkups. Echocardiography recommended every two years for children, and every three years for adults.¹</p> <p>Notify the jurisdictional ARF/RHD register to further support adherence and ARF/RHD control.</p>	<p>ARF symptoms include fever, painful arthritic joints, rashes, and uncontrolled jerky movements of the arms, legs, tongue, and face.¹ There are also a range of minor symptoms.¹ But there is no simple 'ARF test.' Diagnosis requires clinical judgment.¹</p> <hr/> <p>Adherence.</p> <hr/> <p>The capacity, availability, and acceptability of health services. Working with cultural and language differences/distrust of health services.</p>	<p>Supported diagnosis by the use of echocardiography¹ and blood tests¹ as standard procedure.</p> <hr/> <p>Utilise a range of identified success factors in ensuring adherence, as discussed in Part 1 of the Report Card and in the Australian Guidelines.</p> <p>Support for the jurisdictional control programs in the administration of BPG shots in clinical settings.</p> <hr/> <p>A study in the NT found that a sense of personalised care based on relationships of trust with health services' staff and a sense of 'belonging' to the clinic improved adherence.¹ Aboriginal Health Workers play a key role in this¹.</p>

What happens and why?
**With reference to
Diagram 1 in the Report
Card**
**Steps 4-5: Managing RHD
and stopping premature
death:**

Secondary prophylaxis (as above) is also standard treatment for people with RHD.

What interventions will work?
What are the barriers?
**How can the barriers be
overcome?**

Early case detection: echocardiographic screening for RHD in high-risk populations.

Operating in remote communities: difficulties travelling, finding and obtaining consent from the children to be screened, clinical follow-up and communication with families and health care, capacity of health services to deal with potentially significant increases case numbers.

Use, but not as a stand-alone intervention. It must be coupled with increased resources to improve secondary prophylaxis, and ensure health systems can deal with the extra cases that will be detected by screening.

Regular check-ups with cardiograms.

Portable, attaché case-sized and smaller echocardiograms have improved access. But the machine must be used and the results interpreted by highly skilled sonographers and cardiologists.¹

Responses to these disparities include the Better Cardiac Care for Aboriginal and Torres Strait Islander People Project, an initiative of Australian governments;⁵ and the ESSENCE project.

A recent audit of RHD control programs in far north Queensland and the Kimberley, WA, found that only 61 per cent had a timely echocardiogram.⁵

Assessment for potential surgical interventions including valve repairs or the replacement of damaged valves with prosthetic versions.

Indigenous Australians are less likely than other Australians to have had at least one heart valve procedure performed (28 per cent compared with 49 per cent).³² In general, lower access to cardiac procedures: in the two years until June 2013, Indigenous people hospitalised with coronary heart disease were nearly half as likely to receive coronary procedures as other Australians.⁵

See above.

Monitor morbidity and mortality outcomes post-valve replacement.

Anti-blood coagulation drugs.¹

Adherence.

In women - closely monitoring pregnancy, which can place an additional burden on the heart.

Barriers to effective care identified include: poor transport services, poor communication, lack of child care, patient's reception at health services, poor health literacy, high rates of transfer when women give birth, and information systems that do not support sharing of records and patient information.⁴⁵

Apply the outcomes of the Australasian Maternity Outcomes Surveillance System RHD in Pregnancy Population Study.⁴⁶

Educate health workers about the impact of RHD on pregnancy.²⁵

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