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Is the Australian primary healthcare system ready for the Rheumatic Heart Disease Endgame strategy? Data synthesis and recommendations

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Rheumatic Heart Disease (RHD) involves damage of heart valves following acute rheumatic fever (ARF), itself an autoimmune reaction to untreated/recurrent Strep A throat and/or skin infections often resulting in premature death. The incidence of ARF and prevalence of RHD among Aboriginal and Torres Strait Islander (hereafter respectfully Indigenous) peoples are 120 and 61 times higher than non-Indigenous Australians, respectively.¹ This high disparity is driven by indirect causes of the disease, including the ongoing effects of colonisation, socio-economic inequities, inadequate housing, overcrowded living conditions, and sub-optimal access to timely, effective, and culturally-responsive health care.

Those living with RHD have a lifetime of disease management and medical/surgical appointments across numerous specialties and levels of the health system.² This requires integrated care that relies on strong primary health care (PHC) service co-ordination² and inter-sectoral efforts to address socioeconomic and environmental disadvantage. Two key recent documents strongly advocate for the provision of care within a culturally safe framework. The 2020 Australian ARF/RHD guidelines² (the *Guidelines*) had holistic Indigenous review, ensuring that models of clinical care were consistent with best cultural practice.^{5,7} The RHD Endgame Strategy³ (the *Endgame*) was published as a synthesising document to outline strategies for elimination of RHD as a public health problem in Australia, including recommendations that were considered feasible, equitable for all people, acceptable

to Indigenous communities, and likely to have an impact.

The End RHD in Australia: Study of Epidemiology (ERASE) was conducted to support recommendations made in the *Endgame*.¹ Besides epidemiological research, a health systems component of ERASE aimed to identify barriers and enablers within Australia's primary healthcare (PHC) system for suitably managing ARF/RHD. The study focused specifically on the influences, enablers and barriers that permit or preclude achievement of health service goals, including prevention and clinical management. These were considered in two separate sub-studies from the perspectives of PHC service providers and senior Indigenous health stakeholders. The World Health Organization (WHO) framework for analysing and strengthening health systems was used,⁴ including their six building blocks, adapted to the Australian context. Data from New South Wales, Northern Territory, Queensland, South Australia and Western Australia were collected using a mixed-methods approach, including survey and yarning interview methodologies in the two separate sub-studies. A detailed outline of the methods and results are available elsewhere in a web-based report⁵ and journal paper.⁶ The results provide direction on strengthening the PHC system to support the control of ARF/RHD.

In this commentary, we synthesise the findings and recommendations emanating from these two research projects. We examine findings in the context of enabling the implementation of the *Guidelines* and

Endgame. We use the six WHO Health System pillars to map four sources of information: 1) primary health care recommendations drawn from the *Endgame*; 2) principles for service delivery drawn from the *Guidelines*; 3) survey responses from participants reflecting on the health services they currently work in; and 4) interviews with prominent RHD stakeholders taking a broad health systems view.⁵ Finally our RHD-specific recommendations are incorporated using the WHO Innovative Care for Chronic Conditions framework.⁷

Key findings from primary health care and Indigenous health stakeholders

Leadership and governance

Both the *Endgame* and *Guidelines* stress the importance of Indigenous leadership to effectively implement all recommended strategies. The *Endgame* focuses more broadly by recommending an Indigenous-led national Implementation Unit. The *Guidelines* focus on clinical service delivery and emphasise the role of Aboriginal community-controlled health services (ACCHSs) and Indigenous health workforce in providing a balanced approach between clinical and cultural competence. The responses from Indigenous interviewees reflect the sentiments of the *Endgame* and *Guidelines* but go further by recommending that Indigenous leadership and decision-making authority needs to come from senior Indigenous health leaders working with senior community leaders without non-Indigenous intermediaries.⁶ Furthermore, rather than simply consulting Indigenous people, Indigenous leadership will increasingly make decisions for planning and allocating funding (governance).

Survey responses suggests that mechanisms are currently in place in the PHC context to include Indigenous leadership in health service governance, however, it is not possible to ascertain the extent to which these protocols and policies are put into practice. Indigenous interviewees identified challenges related to transition to Indigenous leadership and suggested that support was needed to mitigate negative responses from some non-Indigenous health professionals/clinicians/managers.

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Health workforce

General workforce

Both the *Endgame* and *Guidelines* highlight the need for an equipped, culturally secure and responsive health system with a stable, supported, adequately resourced workforce. Survey responses indicated that in the current PHC context there is generally good access to the required health workforce. However, the workforce is unstable; specifically, difficulties exist in recruitment of staff, together with high turnover and burnout. Further, there need to be strategies in place to address the ageing workforce, particularly in the rural/remote Indigenous context. Recommendations from the interviews include: providing incentives (housing, salary) for clinical staff; supporting general and specialist clinicians to provide enhanced culturally secure care that improves patients' experiences and in turn improves clinician retention (clinician satisfaction at providing good care mitigates against burnout⁸); and ensuring health workers are skilled in diagnosing/treating Strep A infections. The latter requires more training at all levels to increase awareness of ARF/RHD. This will ensure cases are not missed and receive prompt treatment to prevent recurrence and/or progression.

Indigenous workforce

Both the *Endgame* and *Guidelines* highlight the importance of an increased and adequately trained and supported Indigenous workforce, particularly emphasising skills in appropriate care of children and families with ARF/RHD, across all professions and specialities such as Indigenous nurses, doctors and Allied Health workers. Significantly, in the current PHC context, while most PHC services had an Aboriginal Health Worker (AHW) and/or Aboriginal Health Practitioner (AHP) workforce, there was wide variation in types of tasks/roles, with many not having skills fully utilised.⁹ For example, in rural/regional areas AHW/AHP provided health education and administrative tasks, while in remote areas these positions had broader responsibilities, including clinical roles.

While no survey responses directly referenced retention of the AHW/AHP workforce, the interviews and commentaries all recommended increasing and better supporting the AHW/AHP workforce. Good relationships between health services and patients and continuity of care are important for the health and wellbeing of people with

ARF and RHD². Suggestions for valuing and supporting Indigenous staff included providing culturally secure and safe work environments. Relationship-building in the community and with patients was seen as key to improved care. Therefore time (and personal costs) need to be valued by employing organisations. Specific to the RHD context, training was recommended to ensure all health workers are skilled in diagnosing/treating Strep A infections.

Service delivery

In the service delivery context, the *Endgame* has a broad focus on improved PHC services with particular attention to environmental health and healthy living practices and recommendations for outreach. Conversely, the *Guidelines* are more focused on clinical service delivery, for example recommending interpreters, and accessible and culturally safe services, especially for adolescents.

Survey questionnaire responses suggest that in the current PHC context there is a good availability of free and flexible services, including: outreach and medicines; regular access to and use of guidelines; use of systems for treatment reminders and high provision of self-management support and family involvement in care. This contradicts the many barriers to effective service delivery that the same survey respondents highlighted in free text responses. Some services continue to lack cultural safety, with institutional racism and judgemental attitudes still prevailing. Health care is often compromised by medical-centred vs community-centred models of care, further exacerbated by inconsistent/unsatisfactory access to translation services and limited incorporation of traditional healers into the system. Physical access to care is challenging including travel, distance and waiting times (funding managed centrally, not by PHC). Deterioration in PHC-hospital collaboration over the last two years was reported by 29% of rural respondents, with deterioration in access to dental services reported by 33% of remote respondents. Besides the challenges of workforce shortages, staff safety is sometimes compromised when providing outreach services.

Discussing future directions in this domain, interviewees focused on the need for improvements in service delivery to be based in community-centred models of care and community leadership related to service provision. They also emphasised the

need for partnerships and collaboration between community development, social, environmental, housing, and clinical services, bringing together core health messages applicable to multiple conditions (in effect a multi-sectorial primordial prevention focus).

Health information

The *Endgame* and *Guidelines* are both aligned in advocating for the importance of Indigenous data sovereignty. In particular, accessible, accountable data structures respecting individual and collective interests should be used for planning and monitoring. The *Guidelines* suggest local communities could be more active in determining which data should be collected, and how and who data should be shared with.

Reflecting the current PHC, surveys responses suggest that there is a range of technological and communication barriers to effective use of health data by Indigenous leaders, including relatively poor access to, and feedback from, RHD registers that were established as a central source of data on RHD patients and services. The need for better access to all data was a strong focus from Indigenous interviewees; they highlighted the potential of data collection systems/registers and subsequent continuous quality improvement to empower local communities and improve services through co-design and community leadership. This will also require training/support/capacity building for communities, including research and evaluation using participatory methods to facilitate data literacy and co-design. The different data sources suggest that there are two areas of work: to fix technological and communication problems and to enable data sovereignty.

Medical products & technology

Both the *Endgame* and *Guidelines* are aligned in recommending that technology can support better prevention and care of ARF and RHD as part of an enhanced primary care approach. The *Guidelines* have a chapter on emerging technologies such as streptococcal vaccines, community-access to point-of-care diagnostic technology and alternatives to monthly injections.

Surveys responses suggest that in the current PHC context there is good support for the *Endgame* strategies, such as telehealth and point-of-care diagnostics. Similarly, survey responses report that there is good access to health education and promotion resources designed for Indigenous people. However,

this finding was not supported by the interview data.

Both the survey and interview participants suggested that there is a need for adoption and further development of technologies to reduce pain of long-term monthly BPG injections for secondary prevention of RHD. Notably, the findings from the interviews indicated less alignment with *Endgame* and *Guidelines*, highlighting some disquiet that a focus on Strep A vaccines reduces the focus on community development and socio-environmental change.

Financing

Both the *Endgame* and *Guidelines* provide strong economic arguments for increased and sustained PHC resourcing to improve recognition, prevention and treatment of ARFF, including travel, appropriate education resources, interpreter services and monitoring. The survey did not reflect resource needs specific to RHD. However, participants' open-text responses suggest that the resources available for comprehensive ARF/RHD management are not sufficient. Also reflecting the need for better resourcing, interviewees provided innovative multi-sectoral ideas not cited in in the *Endgame* and *Guidelines*, including the need for funding beyond health services e.g. housing; realignment of funding to reflect community priorities; longer funding cycles for service-related programs and better coordination of funding/more effective partnerships.

Recommendations

Indigenous leadership is central to eliminating RHD in Australia, whether in a national implementation unit for RHD strategy, through ACCHS and/or Indigenous local community leadership. Integral to this is identifying, facilitating and promoting Indigenous leadership. This may include informal training or mentoring, or formal training embedded in governance structures that mandate Indigenous decision-making authority. Institutions must create the space and provide support for leaders to emerge, lead and develop in their field.

Service delivery systems need to support comprehensive and integrated care for RHD. The single most important area for attention in this context is training, supporting, and retaining a motivated and skilled workforce. This includes initiatives such as RHD-specific training to increase awareness of disease and best practice for diagnosis and management. Health service management training (for example strategic planning, human resources and partnership development) for Indigenous and non-Indigenous health leaders will facilitate improved service level systems and practices. Appointment, training and support for AHW/AHP staff and Community based workers is crucial.

Indigenous leadership and improved service delivery will require cultural safety to be integrated into all levels of the health system, including policy and clinical practice, and in funding and programming, as the primary

pathway for improvement. Cultural safety extends cultural awareness/competency training, to include an ongoing process of self-reflection to improve intercultural relationships and equitable care (2,5,6,10 for detailed discussion).

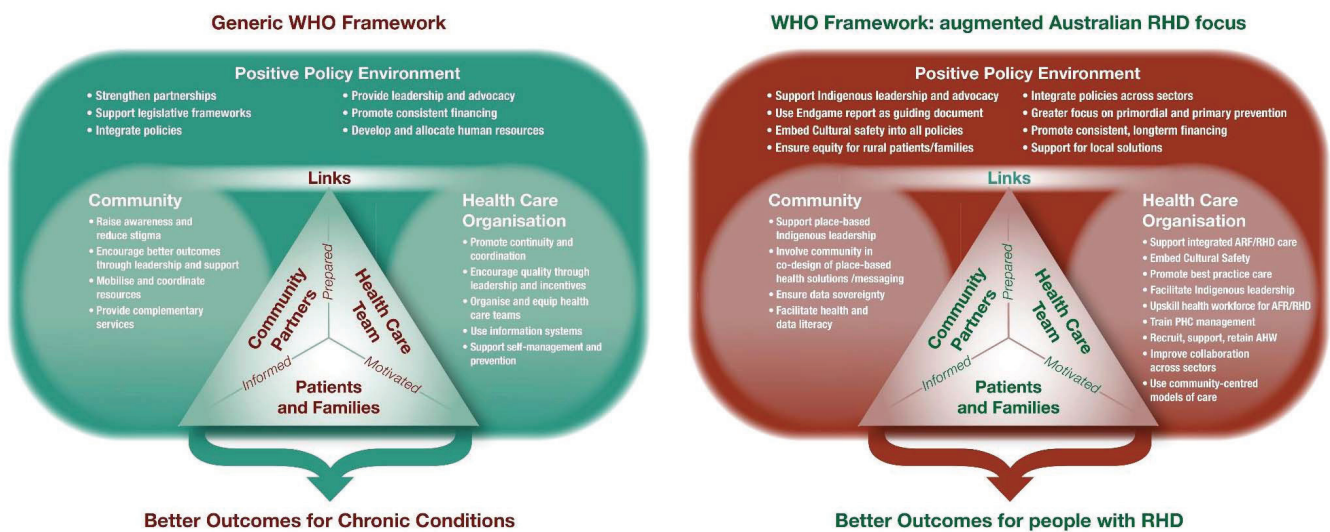
Emphasis should be on development of local place-based solutions and messaging, that are identified and led by community.¹¹ Recognising the strength of local Indigenous people and leadership will facilitate opportunities for co-designing interventions and solving challenges including with people affected by RHD. Data sovereignty, including capacity building for generating and using local data, will facilitate community decision-making and governance.

At the broad policy level, investment for prevention strategies should be on par with vaccine development, recognising that such strategies can address many diseases. This should promote cross-sector collaborations based on sustained and meaningful partnerships.

Conclusion

This health systems project identified barriers and enablers within Australia's primary healthcare system for managing ARF/RHD in Australia. Our analysis demonstrates the need for ongoing resourcing of the PHC sector, concurrently with multi-sector and multi-level concurrent actions to address this important public health problem which, without concerted action, will effect >10,000

Figure 1: The WHO innovative care for chronic conditions framework – in general and specific to rheumatic heart disease in Australia.



Notes:

PHC: primary health care; ARF: acute rheumatic fever; RHD: rheumatic heart disease

Source: Adapted from World Health Organization. *Everybody business: strengthening health systems to improve health outcomes: WHO's framework for action*. 2007.

new cases by 2031 at a potentially avoidable cost of \$300M.¹² The specific RHD-related strategies that arose from this research have been organised into the WHO Innovative Care for Chronic Conditions framework⁷ (Figure 1). This framework articulates the detailed actions required to implement the recommendations made in RHD Endgame Strategy and the 2020 Australian ARF/RHD guidelines. While our study has focused on primary healthcare services, the framework emphasises the requirement for a strong positive policy environment and community engagement to better support patients and families.

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