

# Improving primary care for Aboriginal and Torres Strait Islander people with rheumatic heart disease

## *What can I do?*

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### Background

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) disproportionately affect Aboriginal and Torres Strait Islander people in Australia, with devastating impacts on morbidity, mortality and community wellbeing. Research suggests that general practitioners and primary care staff perceive insurmountable barriers to improving clinical outcomes, including the need for systemic change outside their scope of practice.

### Objective

The aim of this article is to identify constructive, micro-level strategies that primary healthcare clinicians can consider, adopt and sustainably use to improve care for people with ARF and RHD in their routine clinical practice.

### Discussion

Through skilled clinical care, reflection and culturally safe practices, individual primary healthcare clinicians have substantial capacity to improve care experiences and outcomes for Aboriginal and Torres Strait Islander people and communities affected by ARF and RHD.

**THE FOUR CORNERS** television program of 8 March 2022 told the stories of three Aboriginal women from Northern Queensland who died of rheumatic heart disease (RHD).<sup>1</sup> Inquiries and a coronial inquest have been launched into their care.<sup>2,3</sup> Their stories had a powerful impact on viewers and, on social media, clinicians in primary care expressed feelings of outrage and frustration at the lack of care that led to the preventable deaths of these three women.<sup>4-6</sup>

Health professionals caring for Aboriginal and Torres Strait Islander people with RHD, acute rheumatic fever (ARF) and preceding superficial *Streptococcus pyogenes* (Strep A) infections (sore throats and skin sores) commonly report frustration about health inequalities, fatigue and hopelessness about their own capacity to improve outcomes.<sup>7</sup> Haynes et al interviewed 22 practitioners involved in clinical care and policy related to RHD – including a number of people working in primary care – and analysed these responses using a critical medical anthropology approach.<sup>7</sup> Participating practitioners identified barriers to RHD care mediated through health systems (staff shortages, lack of funding, lack of communication and coordination, limited technology, institutional racism and shame), lived

experience (including poverty, household crowding, unhealthy housing and competing priorities) and their own emotions (specifically hopelessness, frustration and burnout). Researchers found that although participants could identify the impacts of institutional racism and the need for cultural competence, they had little sense of agency in addressing those issues.<sup>7</sup> Few had reflected deeply on their own individual opportunities to improve care delivery. Similarly, a recent eDelphi study about prevention of ARF revealed that primary care staff wanted greater focus on environmental health and housing, employment of Aboriginal and Torres Strait Islander health professionals and genuine community engagement, but they felt they had limited opportunity to influence these factors from primary care roles.<sup>8</sup> Many of these themes mirror the perspectives of hospital-based healthcare workers in tertiary Aboriginal health services in northern Australia, who have expressed dismay at systems barriers to culturally safe care.<sup>9,10</sup>

In the wake of the Four Corners program, this article offers a constructive foundation for reflection by primary care staff and identifies some of the ways that individual practitioners may be able to contribute to better health and healthcare experiences for Aboriginal and Torres

Strait Islander people. These actions are intended to be relevant for individual clinicians in a range of settings and conditions, including people working in settings or services with structural barriers to culturally safe care. Individual actions matter because the beliefs, attitudes and behaviours of clinicians are multiplicative; clinicians contribute to the experiences of individual patients and to the culture and norms of services, health systems and society. This article focuses on clinical issues related to RHD (Box 1) but should be considered in the context of broader work on Aboriginal and Torres Strait Islander sovereignty, racism in healthcare and ending RHD.<sup>11–13</sup>

### Opportunities in primary care

The disproportionate burden of RHD among Aboriginal and Torres Strait Islander people is inexorably linked to the effects of colonisation and racism.<sup>14</sup> Systematic marginalisation, disempowerment, policy and funding decisions culminate in unsafe living conditions with overcrowded, poorly maintained homes that potentiate Strep A infections. Similarly, systemic under-resourcing of remote primary care is also a function of colonisation, which limits access to culturally safe care for Aboriginal and Torres Strait

Islander people. Racism leads to poor care delivery and culturally unsafe experiences for patients. While the burden of ARF and RHD in remote Australia predominantly affects Aboriginal and Torres Strait Islander people, the primary healthcare workforce is predominantly non-Indigenous with Western worldviews, stereotypes and biases, limiting the ability to connect culturally with patients. Additionally, the workforce crisis in remote primary care services is associated with high staff turnover and few trusting relationships that can support engagement in ongoing care.<sup>14,15</sup>

Substantively reducing the impact of RHD requires decolonisation and changes to the way the health system functions, including governance, cultural safety, workforce, payment, and models of care.<sup>13</sup> These changes should be coupled with disease specific management strategies and practical systems changes such as increased interoperability of clinical information systems to safely transmit clinical information. The scale of necessary changes can be overwhelming for individual practitioners who perceive themselves as having limited influence. However, general practitioners and primary care teams often occupy important leadership and norm-setting roles within clinics and communities. The functioning of 'the health system' is the product of individual actions. Primary care staff have a unique opportunity to use micro-level influence to address racial bias and support culturally safe delivery of evidence-based care.<sup>16</sup> These opportunities may be most evident in Aboriginal community-controlled healthcare settings – where leadership by Aboriginal and Torres Strait Islander people is core business<sup>17</sup> – but are equally feasible and relevant in 'mainstream' general practice or government clinics.

### Quality clinical care

Primary care clinicians working with Aboriginal and Torres Strait Islander people have a responsibility to be clinically competent and aware of the implications of Strep A infections, ARF and RHD. This includes being alert to the significance

of seemingly trivial skin sores, sore throat, mild joint pain or restlessness in a child. These respectively can represent streptococcal impetigo, streptococcal pharyngitis, rheumatic fever with mono- or poly-arthritis, and Sydenham chorea. Most people with rheumatic fever do not present at the first clinic appointment with the classical migratory polyarthritides/arthritis of large joints that is characteristic of ARF; the presentation may be subtle, attributed to injury and evolve over days or weeks. Similarly, Sydenham's chorea is a movement disorder affecting approximately a quarter of Aboriginal and Torres Strait Islander people with ARF and people may present with subtle clinical signs or symptoms such as declining school performance and being 'fidgety'.<sup>18</sup> These presentations should prompt diagnostic evaluation for ARF; a process that is time sensitive and requires inpatient evaluation and blood examinations for erythrocyte sedimentation rate, C-reactive protein, antistreptolysin O and anti-DNase B, electrocardiography and consideration of echocardiography.<sup>18</sup> Delay in recognition of ARF symptoms and incomplete diagnostic workup contributes to under-diagnosis of ARF, which precludes people from benefitting from disease-altering secondary prophylaxis. The Guidelines and Diagnosis Calculator App developed by RHDAustralia condenses the full guideline and is a useful resource for primary care clinicians considering the possibility of ARF.<sup>18</sup>

Initiating the diagnostic workup and referrals for possible ARF can be time consuming in busy clinics, which may be a disincentive for clinical staff to begin the process.<sup>7</sup> Reflective practices can help practitioners examine their own drivers and barriers to initiating diagnostic processes and examine the role of their own beliefs and attitudes in these decisions. For example, clinicians may be more likely to dismiss migratory joint pain as a nonspecific symptom for Aboriginal and Torres Strait Islander people than they would for other people. Racism – sometimes described as 'implicit bias' – is well described as predisposing clinicians to dismiss symptoms or results in 'premature diagnostic closure', particularly in busy acute settings.<sup>19</sup>

### Box 1. Acute rheumatic fever and rheumatic heart disease in Australia

Almost 10,000 people live with a history of acute rheumatic fever (ARF) or rheumatic heart disease (RHD) in Australia; the vast majority are Aboriginal and Torres Strait Islander people, largely living in remote Northern Australia.<sup>42,43</sup> The disease begins with a *Streptococcus pyogenes* (Strep A) infection of the throat or, likely, skin.<sup>44</sup> Some people have an abnormal immune reaction to this infection, which presents some weeks later as ARF, with fevers, migratory joint pain, chorea or carditis, or a combination of these. Very rarely, there may be skin involvement. Severe or recurrent episodes of ARF lead to valvular scarring that characterises RHD. Over time, valve stenosis or regurgitation leads to heart failure and increased risk of arrhythmia, stroke and pregnancy complications (Table 1).

This bias may be further amplified when history-taking is conducted cross-culturally and translation of Aboriginal languages reduce the nuances of arthralgia to ‘whole-body paining’ or ‘body aches’. Use of Aboriginal English terms such as ‘lazy’ to mean ‘reduced exercise tolerance’ can result in a clinician not recognising the significance of the presenting symptom. Non-Indigenous clinicians may also internalise beliefs about ill-health and the inevitability of poor outcomes for Aboriginal and Torres Strait Islander people, leading to clinical inertia in offering diagnosis and treatment options.<sup>7</sup> Aboriginal and Torres Strait Islander people are acutely aware of low expectations about their health and identify that delayed diagnosis of ARF and RHD leads to considerable harms.<sup>20</sup> Many Aboriginal patients will have a family member or relative with ARF or RHD and may worry about missed diagnosis. It is good practice to routinely ask people about their ideas, concerns and expectations during clinical consultations.<sup>21</sup> Asking

Aboriginal and Torres Strait Islander people these questions may help to identify concerns about ARF or RHD and support two-way discussion about the diagnostic possibilities.

Clinical education resources, including *The 2020 guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease* and *National healthy skin guideline*, are useful for checking assumptions and considering diagnostic possibilities.<sup>22,23</sup> Other resources may include familiarity with common local language terms and knowing how to access interpreter services or consult with Aboriginal and Torres Strait Islander Health Practitioners to better understand and discuss symptoms. Actively seeking context-specific clinical and cultural knowledge from Aboriginal and Torres Strait Islander Health Practitioners or local cultural experts is particularly important for clinicians who may travel from metropolitan centres to remote locations, where the burden of RHD is highest.

### Reflective practice

Personally mediated racism occurs when assumptions made about people’s abilities, motives and actions lead to differential treatment.<sup>24</sup> Racism and deficit framing of Aboriginal and Torres Strait Islander people can lead to poor delivery of ongoing care. For example, primary care staff may blame patients who have had ARF for failing to attend for secondary prophylaxis injections. As one primary care provider from the Northern Territory remarked during a program to improve secondary prophylaxis delivery:<sup>25,26</sup>

*Either [patients] don’t understand, or they don’t want to listen, and that’s their prerogative really. They expect us to create miracles and keep them alive, yet they’re not doing their part of the bargain.*

These attitudes are infused into clinical encounters and communication, including pejorative terms in clinical notes such as ‘non-compliant’ with secondary prophylaxis.<sup>27</sup> Racism can lead to care that

**Table 1. Overview of *Streptococcus pyogenes*, acute rheumatic fever and rheumatic heart disease pathway and prevention opportunities<sup>45</sup>**

Disease stage	Indicative ages	Prevention and management
<i>Streptococcus pyogenes</i> (Strep A) exposure	From birth	Primordial prevention includes addressing household crowding, poverty and improved access to healthcare. Primary care staff can support primordial prevention through referrals to environmental health or housing services.
Strep A infection	From birth	Primary prevention is antibiotic treatment of Strep A infections among people at risk of developing ARF. Clinicians can support primary prevention by using guidelines for treatment of skin and throat infections and creating a culturally safe and validating environment for people attending for these infections. <sup>34</sup>
Acute rheumatic fever (ARF)	Initial episode most common in children aged 5–14 years	Secondary prevention includes diagnosis of ARF and the regular administration of antibiotics to people with a history of ARF to prevent recurrent episodes of ARF and reduce the probability of RHD. Clinicians can support secondary prevention through awareness of ARF symptoms and diagnosis and through systems that increase secondary prophylaxis delivery such as nominating responsible prophylaxis staff and pain minimisation techniques. <sup>18</sup>
Rheumatic heart disease (RHD)	Can begin in childhood; incidence increases with age and peaks between 25 and 40 years	Tertiary management of RHD includes ongoing secondary prophylaxis, medical management of symptomatic RHD and cardiac surgery for damaged heart valves. Clinicians can support tertiary care through awareness of heart failure presentations, support for self-management and integration with hospital-based specialist care. <sup>18</sup>
Complications of RHD	Thirty per cent of people with RHD progress to heart failure within five years of diagnosis	

is not culturally safe or compassionate, or it can lead to lack of care, which, in turn, means that people may be less likely to attend for ongoing secondary prophylaxis.<sup>22</sup>

Reflective practice may have antiracist outcomes by prompting examination of personal beliefs and attitudes about Aboriginal and Torres Strait Islander people and their experiences in healthcare.<sup>16</sup> Reflexivity was identified as a core principle for improving clinical care during recent qualitative research on RHD, with one Aboriginal participant identifying that non-Indigenous clinicians should be asking themselves:<sup>28</sup>

*Maybe I'm part of the problem? But maybe I can also do something about it as well ... There is a power imbalance, you know, a clinician has power. They also have power to change.*

Reflection on the limits of biomedical approaches and the pervasive effects of trauma, racism and colonisation may improve the quality of clinical interactions.<sup>12</sup> The connection between culturally safe care and personal reflection is made explicit in the Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025 released through the Australia Health Practitioner Registration Authority, which defines cultural safety as:<sup>29</sup>

*the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism. It is judged by the recipient of care, Aboriginal and Torres Strait Islander peoples.*

Cultural safety training can play an important part in reflective practice by providing knowledge and context to prompt personal examinations.

The Royal Australian College of General Practitioners offers a Continuing Professional Development–accredited 'Introduction to Aboriginal and Torres Strait Islander cultural awareness in general practice' online training.<sup>30</sup> This

kind of training may provide a foundation for ongoing listening, reflection and learning but is insufficient in isolation; evidence suggests that continuous self-examination and participation in cultural awareness training needs to occur regularly to achieve a meaningful impact on culturally safe care delivery.<sup>31</sup> For example, 'Ask the Specialist' is a multi-award winning podcast developed as a cultural safety tool to prompt reflective practice for clinicians working in the Northern Territory's Top End.<sup>32</sup> Evaluation has revealed relevance beyond the Top End and the capacity for the podcast to prompt reflective behaviour change by listeners.<sup>32</sup>

Reflective capacity may be augmented by increasing understanding of trauma and trauma-informed care for Aboriginal and Torres Strait Islander people.<sup>33</sup> Wider reading about race and colonisation, learning about local communities and respectful listening to Aboriginal and Torres Strait Islander colleagues can also support continuous reflective practice and understanding. The intellectual and emotional work of delivering culturally safe services is indivisible from day-to-day primary care. Reflexive, trauma-informed care is directly relevant to even seemingly minor, yet frequent, presentations such as skin sores and sore throats in Aboriginal and Torres Strait Islander children, which can lead to ARF.<sup>34</sup>

Reflection may also support GPs to explore and address their own emotional responses in providing care, including the frustrations of systems barriers to delivering the kind of care they would like and discomfort in delivering some interventions. For example, in a survey of nearly 60 care providers, all described administering antibiotic secondary prophylaxis injections as distressing.<sup>35</sup> Self-reflection may help GPs to examine their own experiences, acknowledge the inadequacies of current antibiotic formulations, seek resources and knowledge about pain minimisation techniques (comprehensively detailed in *The 2020 guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease*, page 175)<sup>22</sup> and ultimately deliver better care. Personal

or collegial reflective practices – such as Balint groups or professional supervision – may also be effective in addressing and identifying declines in empathy and compassion, which are associated with professional burnout.<sup>36</sup>

### **Leadership, bystander action, allyship and patient advocacy**

People working in primary care commonly have implicit leadership roles and are influential in setting professional and personal norms. As reflective practitioners, they may become empowered as bystanders and build their capacity to act in their sphere of influence and engage in opportunities to participate in broader initiatives to address institutional racism and other barriers to care.<sup>16,17</sup> This may include role modelling of culturally safe care, undertaking respectful clinical documentation, encouraging cultural safety training as a regular activity, providing opportunistic education to colleagues or identifying and intervening in racist encounters. Some GPs have a formal supervisory role with registrars or other colleagues; it is important that supervisors develop sufficient knowledge and confidence to address cultural considerations in the course of supervision.<sup>37</sup> Non-Indigenous clinicians should be informed in allyship roles by the priorities and guidance of local Aboriginal and Torres Strait Islander colleagues and communities. Useful contributions in one clinic may or may not be welcomed or appropriate in others. Contextual awareness and understanding are critical to appropriate allyship and bystander support.

Primary care staff may also act as advocates for individual patients and families, particularly when liaising from remote settings with secondary, tertiary metropolitan or specialist services. Administrative and logistic systems to safely transfer people and information between different parts of the health system are often inadequate and do not meet the needs of Aboriginal and Torres Strait Islander patients. As one GP in a study from remote services describes, this involves:<sup>38</sup>



*a lot of advocating ... ringing and cutting through the crap, the resistance and the verbal 'rolling of the eyes' and just keeping on pushing until the appointment happens.*

This kind of work is often poorly visualised, under-appreciated, frustrating and time consuming. However, the efforts of GPs and primary care teams to arrange specialist assessment, advocate for accompanying support people to travel with the patient where needed, follow up and provide ongoing care can have a significant impact on the clinical trajectory of individual patients. Additionally, the process of seeking equitable care delivery for Aboriginal and Torres Strait Islander people is a practical demonstration of how healthcare staff can support implementation of the Australian Charter of Healthcare Rights, grounded in international human rights agreements for the highest possible standard of health.<sup>39</sup> Primary care staff who – patiently and respectfully – wrangle patient travel arrangements are role modelling advocacy and the pursuit of equity to their colleagues.

Beyond the clinical domain there is considerable opportunity for primary care staff to act as allies and advocates for the goals of Aboriginal and Torres Strait Islander people. As managers and professional leaders, clinicians can help facilitate broader action in the health sector by pursuing recommendations in the RHD Endgame Strategy,<sup>13</sup> progressing implementation plans for Closing the Gap<sup>40</sup> and committing to addressing racism in health.<sup>41</sup> More broadly, support for the Uluru Statement from the Heart promotes Aboriginal and Torres Strait Islander sovereignty through an invitation to the Australian people to establish a First Nations Voice to Parliament enshrined in the Constitution and a Makarrata Commission for the purpose of treaty making and truth-telling.<sup>11</sup>

## Conclusion

Primary care providers may feel and believe that addressing the health consequences of colonisation and racism – manifest through conditions such

as RHD – is insurmountable. Although transformative change is needed to decolonise Australia and the Australian health system, micro-level actions by primary care staff can have a valuable and immediate impact on the healthcare experiences of Aboriginal and Torres Strait Islander people. Clinicians are accountable for the quality of care they deliver and are responsible for safe clinical practice, reflective engagement and cultural safety. Many have opportunities to elevate this work with local leadership and allyship to support systemic change. A multitude of individual action is a critical step to end the ongoing toll of young Aboriginal and Torres Strait Islander people dying of collective failures.

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