



The RHD Endgame Strategy:
*The blueprint to eliminate rheumatic
heart disease in Australia by 2031*

The *Endgame Strategy* is a product of collaboration between researchers, Aboriginal and Torres Strait Islander leaders, communities and people with lived experience.

The END RHD CRE investigators would like to thank the Aboriginal and Torres Strait Islander people who have shared their stories in the *Endgame Strategy*. We acknowledge that the figures outlined represent the loss of human life with profound impact and sadness for people, families, community and culture.

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Glossary

ABS	Australian Bureau of Statistics
ACCHO	Aboriginal Community Controlled Health Organisation
ACCCHS	Aboriginal Community Controlled Health Service
ACSQHC	Australian Commission on Safety and Quality in Health Care
ACT	Australian Capital Territory
ACW	Aboriginal Community Worker
AF	Atrial fibrillation
AHP	Aboriginal Health Practitioner
AHMAC	Australian Health Ministers' Advisory Council
AHW	Aboriginal Health Worker
AIG	Aboriginal Investment Group
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
AMS	Aboriginal Medical Service
AMSANT	Aboriginal Medical Services Alliance Northern Territory
APSGN	Acute post-streptococcal glomerulonephritis
APY Lands	Anangu Pitjantjatjara Yankunytjatjara Lands
ARF	Acute rheumatic fever
ASR	Age-standardised rate
ASRR	Age-standardised rate ratio
ATSIC	Aboriginal and Torres Strait Islander Commission
ATSIHP	Aboriginal and Torres Strait Islander Health Practitioner
BPG	Benzathine benzylpenicillin <i>Also referred to as LAB, BLA, Bicillin L-A, Bicillin, BPB, Benzathine penicillin G</i>
CABG	Coronary artery bypass graft
CARPA STM	Central Australian Rural Practitioners Association Standard Treatment Manuals <i>A collection of protocols for the management of common conditions seen in remote (mainly Aboriginal and Torres Strait Islander) health practice</i>
CDNA	Communicable Diseases Network Australia
CHC	COAG Health Council
CHCI	Child Health Check Initiative
CHD	Congenital heart disease or childhood heart disease
CHW	Community Health Worker
COAG	Council of Australian Governments
CKD	Chronic kidney disease
CNOS	Canadian National Occupancy Standard
COPD	Chronic obstructive pulmonary disease
CQI	Continuous quality improvement
CSANZ	Cardiac Society of Australia and New Zealand
CTG	Closing the Gap
END RHD CRE	End Rheumatic Heart Disease Centre of Research Excellence
ERASE Project	End RHD in Australia: Study of Epidemiology Project
GP	General practitioner or general practice
HLP	Healthy Living Practice

HPA	Health Policy Analysis
ICOP	Indigenous Cardiac Outreach Program
ITC	Integrated Team Care
IAHP	Indigenous Australians' Health Programme
IHD	Ischaemic heart disease
IREG	Indigenous Regions
MBS	Medicare Benefits Schedule
MDA	Mass drug administration
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSIHP	National Aboriginal and Torres Strait Islander Health Plan
NSQHS	National Safety and Quality Health Service
NATSIHWA	National Aboriginal and Torres Strait Islander Health Worker Association
NHMRC	National Health and Medical Research Council
NTAHF	Northern Territory Aboriginal Health Forum
NPA	National Partnership (or Project) Agreement
NSW	New South Wales
NT	Northern Territory
PCIS	Patient care information system
PBS	Pharmaceutical Benefits Scheme
PCR	Polymerase chain reaction
PHC	Primary healthcare
PoCT	Point-of-care testing
QAAMS	Quality Assurance for Aboriginal and Torres Strait Islander Medical Services
QLD	Queensland
RACGP	Royal Australian College of General Practitioners
RADT	Rapid antigen detection test
RAAHS	Remote Area Aboriginal Health Services
RN	Registered nurse
RFS	Rheumatic Fever Strategy
RFS Communities	Rheumatic Fever Strategy Communities <i>Communities receiving RFS funding and support to prevent and manage ARF and RHD announced in October 2018</i>
RHD	Rheumatic heart disease
RHDA	Rheumatic Heart Disease Australia
SA	South Australia
SDOH	Social determinants of health
SoNG	Series of National Guidelines
SP	Secondary prophylaxis
TAS	Tasmania
VIC	Victoria
WA	Western Australia
WHA	World Health Assembly
WHO	World Health Organization
WoF	Warrant of Fitness

Foreword



To many Australians, rheumatic heart disease (RHD) is a foreign concept – a disease most will have never heard of. But for my people, RHD continues to pose a very real and present threat. Despite having been eliminated in the non-Indigenous Australian population for decades, RHD continues to devastate Aboriginal and Torres Strait Islander communities at some of the highest rates in the world. Starting with a simple Strep A infection of the throat or skin, RHD can be fatal without treatment. There is no cure and children who have the disease must endure a painful penicillin injection every 21–28 days for at least five years or until they are 21, whichever comes first. Many, some as young as five years old, must also have open heart surgery. For these children and their families – who must be taken off country to large tertiary hospitals for months at a time – it is often the emotional scars that last the longest.

In 2016 Professor Jonathan Carapetis came to me in my capacity as the newly appointed CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO) to discuss forming END RHD – an alliance between the Aboriginal Community Controlled Health Sector and health and research bodies, all committed to ending RHD. As he outlined the plan, it became clear that we had an unprecedented opportunity to end this devastating disease.

Professor Carapetis and colleagues had been funded by the National Health & Medical Research Council to develop an *RHD Endgame Strategy*: a blueprint outlining exactly what needed to happen – and who needed to do it – to eliminate RHD for the next generation of Aboriginal and Torres Strait Islander children. But what set this research translation piece apart from previous work was that it was to be created *with* Aboriginal and Torres Strait Islander people, rather than *for* us: it was to be a research-driven strategy that had at its core the voices of those living with and impacted by RHD.

This was significant, because our people already know what needs to happen to eliminate RHD. Communities have long told us they need support to tackle the problems which contribute to the spread of Strep A infection: things like overcrowding and a lack of access to infrastructure such as hot water and running showers – basic amenities most Australians take for granted. Aboriginal Health Workers in communities with the highest RHD burden have told us they need support and resources to grow the workforce and catch more sore throats and skin sores before

they lead to acute rheumatic fever (ARF), the precursor to RHD. Most importantly, people living with ARF and RHD have told us they need better treatments and culturally safe care so they can live their lives to the fullest. The *Endgame Strategy* honours and reflects all these views, adding them to the evidence base that will underpin the work needed to eliminate RHD – work that will further ‘close the gap’ by helping to eliminate linked diseases like otitis media, trachoma and kidney disease.

In my work leading the Coalition of the Peaks – a historic partnership between the Council of Australian Governments (COAG) and Aboriginal and Torres Strait Islander leaders – we are committed to addressing the structural and systemic changes that have led to the gap in outcomes, including life expectancy, between Indigenous and non-Indigenous Australians. The *Endgame Strategy* recommendations echo this new framework and, when implemented, will go a long way to closing this gap.

The *Endgame Strategy* heralds a new chapter where ending RHD is genuinely possible. We have the Aboriginal leadership, community demand, and evidence base to support the work that can make this disease history. All we’re missing is the funding to make this a reality. If the Commonwealth Government is to meet its pledge to eliminate RHD in this decade, Australian governments must act upon this report. The *Endgame Strategy* cannot be consigned to a bookshelf to sit, gathering dust. The actions – or inaction – of today will be felt by the next generation of our people, and for generations after that. It is unconscionable to let them suffer as a result of RHD when we now have an Endgame to prevent it.

Pat Turner AM
CEO, National Aboriginal Community
Controlled Health Organisation

Executive Summary

Rheumatic heart disease (RHD) is preventable. The collective experience of communities, clinicians, Aboriginal Community Controlled Health Organisations, government and non-government organisations, in addition to over 25 years of research, means the knowledge and evidence base now exists to eliminate rheumatic heart disease in Australia.

The *Endgame Strategy* brings together this experience, knowledge and evidence for the first time, presenting an opportunity for Australia to implement a comprehensive, long-term strategy to end RHD.

RHD disproportionately affects Aboriginal and Torres Strait Islander people. Currently, around 420 Aboriginal and Torres Strait Islander people have a diagnosed episode of acute rheumatic fever (ARF) each year,¹ a rate 123 times higher than rates in non-Indigenous people. Of the more than 5,000 people living with RHD in Australia, 71% are Aboriginal and Torres Strait Islander people.¹ This represents one of the highest per capita burdens of RHD in the world.

Without action, it is estimated that a further 8,667 Aboriginal and Torres Strait Islander people will develop ARF or RHD by 2031. Of these people, 1,370 will have severe RHD and 663 will die, with \$273.4 million required to be spent on medical care.² Aboriginal and Torres Strait Islander children are most at risk of developing the disease.

Ending RHD will not just eliminate the disease for the next generation of Aboriginal and Torres Strait Islander children – it will help to close the gap caused by other diseases of inequity.

Eliminating RHD means preventing new cases of disease. The *Endgame Strategy* outlines the best existing evidence-based strategies to prevent new cases of RHD in Australia, in line with the biomedical model of disease:

- **Structural and system considerations:** Central to any disease-specific strategy is a well-resourced, culturally secure primary healthcare system. Local partnerships to support communities also require links to housing, education, meaningful employment and environmental health services.
- **Environmental, social and economic determinants:** Action must be taken to address the environmental and socio-economic causes of Strep A infections leading to ARF and RHD, with investment in collaborative, community-led solutions.
- **Primary prevention:** Strategies which improve the assessment and treatment of skin and throat infections will prevent ARF in people at high risk of the disease.
- **Secondary prevention:** In order to prevent progression of ARF to RHD, strategies are needed to improve the early and accurate diagnosis of ARF and delivery of secondary prophylaxis.
- **Tertiary care:** Australia has a moral imperative to provide high-quality medical and surgical management for people with existing RHD, preventing complications and improving quality of life.

Strategies to eliminate RHD

A snapshot of potential RHD elimination strategies identified in the *Endgame Strategy* is outlined in Table 1. These strategies were identified as having the greatest potential impact, as well as being acceptable, practical and readily implementable with appropriate investment.

What is RHD?

Rheumatic heart disease (RHD) starts with a Strep A infection of the throat or skin. When left untreated, the infection can lead to acute rheumatic fever (ARF), which causes sore joints, rash, fevers, and heart inflammation. While the other symptoms of ARF go away, the heart damage remains – and this is known as rheumatic heart disease

Table 1: Potential RHD elimination strategies as identified within the Endgame Strategy.

Point of intervention	Strategies
<p>Structural and systems considerations</p> <p><i>Systemic enablers needed to reduce the burden of Strep A infections, ARF and RHD</i></p>	<ul style="list-style-type: none"> Support primary care by increased and sustained resourcing of Aboriginal and Torres Strait Islander health services, particularly in remote communities. Invest in training and employment of Aboriginal and Torres Strait Islander people in new and ongoing funded positions to deliver comprehensive primary healthcare. Use of evidence-based mechanisms including increasing Aboriginal and Torres Strait Islander staffing at all levels to reduce turnover of rural and remote staff. Embed Environmental Health within Primary Care. Prepare health providers in all disciplines to provide culturally appropriate services for Aboriginal and Torres Strait Islander people.
<p>Environmental, Social and Economic determinants</p> <p><i>Reducing the risk of Strep A transmission and infection</i></p>	<ul style="list-style-type: none"> Develop, cost and implement a National Aboriginal and Torres Strait Islander Housing and Community Environmental Health Strategy, increasing housing stock to substantially reduce overcrowding, improve housing maintenance and ensure adequate power and water supply. Assess community acceptability and value of shared community infrastructure to facilitate Healthy Living Practices, particularly washing of bodies, clothes and bedding, community swimming pools, ablution blocks and/or laundries. Support households to increase uptake of Healthy Living Practices through health promotion campaigns. Ensure Aboriginal and Torres Strait Islander governance of housing construction, management and maintenance processes through their own institutions and organisations.
<p>Primary Prevention</p> <p><i>Improving the assessment and treatment of Strep A infections</i></p>	<ul style="list-style-type: none"> Develop and evaluate resources for discussing skin sores and sore throats in primary-care settings. Develop a working definition of a 'healthy skin check' to provide guidance on the setting (privacy and environment) and components (skin areas to be examined or self-reported). Establish comprehensive healthy skin outreach programs in settings with a high burden of skin infection. Explore opportunities to increase the use of telehealth for primary prevention of ARF, and opportunities to provide healthcare or referral services from schools for sore throats and/or skin sores. Explore potential to increase access to medication for primary prevention through broader dispensing opportunities, accompanied by training and investment in the Aboriginal and Torres Strait Islander health workforce. Develop a 'look back' review of ARF notifications, with a view to scale up to major referral hospitals accounting for the majority of ARF admissions. Enhance referral systems for sore throat and skin sores, including school-based referral.
<p>Secondary Prevention</p> <p><i>Opportunities to improve prevention and management of ARF and RHD</i></p>	<ul style="list-style-type: none"> Develop training opportunities and resources to increase health worker awareness of ARF symptoms and pathways. Resource peer-support programs to encourage connections and self-management. Resource primary-care providers to provide outreach secondary prophylaxis services where community demand indicates that this is a priority. Continue research to identify more sensitive and specific diagnostic tests for ARF and methods of secondary prophylaxis delivery.
<p>Tertiary Care</p> <p><i>Assisting those living with RHD to live lives to its fullest</i></p>	<ul style="list-style-type: none"> Enhance existing jurisdictional patient assisted travel schemes. Fund permanent care coordination roles to support children and adults who are having heart surgery for RHD, to ensure alignment of clinical, administrative and logistic plans alongside attention to cultural needs and communication between different levels of the health service. Ensure that all people diagnosed with ARF or RHD receive high-quality, culturally relevant education about the condition in their preferred language. Establish clear clinical pathways for women of reproductive age with ARF and RHD. Improve service delivery for Aboriginal and Torres Strait Islander adolescents moving from paediatric to adult services.

An 'indicative bundle' of strategies which might be implemented in communities to reduce RHD consists of reducing household crowding, improving hygiene infrastructure, strengthening primary healthcare, and enhancing the delivery of secondary prophylaxis. These strategies were identified by the END RHD CRE Investigators in consultation with the END RHD Advisory Committee and other stakeholders because they show the greatest promise in preventing new cases of RHD over the next decade to 2031. In particular, these strategies appear to be acceptable, practical and readily implementable with appropriate investment.

Modelling estimates indicate that the strategies proposed in the *Endgame Strategy*, namely reducing household crowding, improving hygiene infrastructure, strengthening primary healthcare, and enhancing the delivery of secondary prophylaxis, would reduce ARF and RHD cases by **69%** and **71%** respectively, **preventing 471 deaths** and saving **\$188.2 million** on ARF- and RHD-related healthcare expenditure.

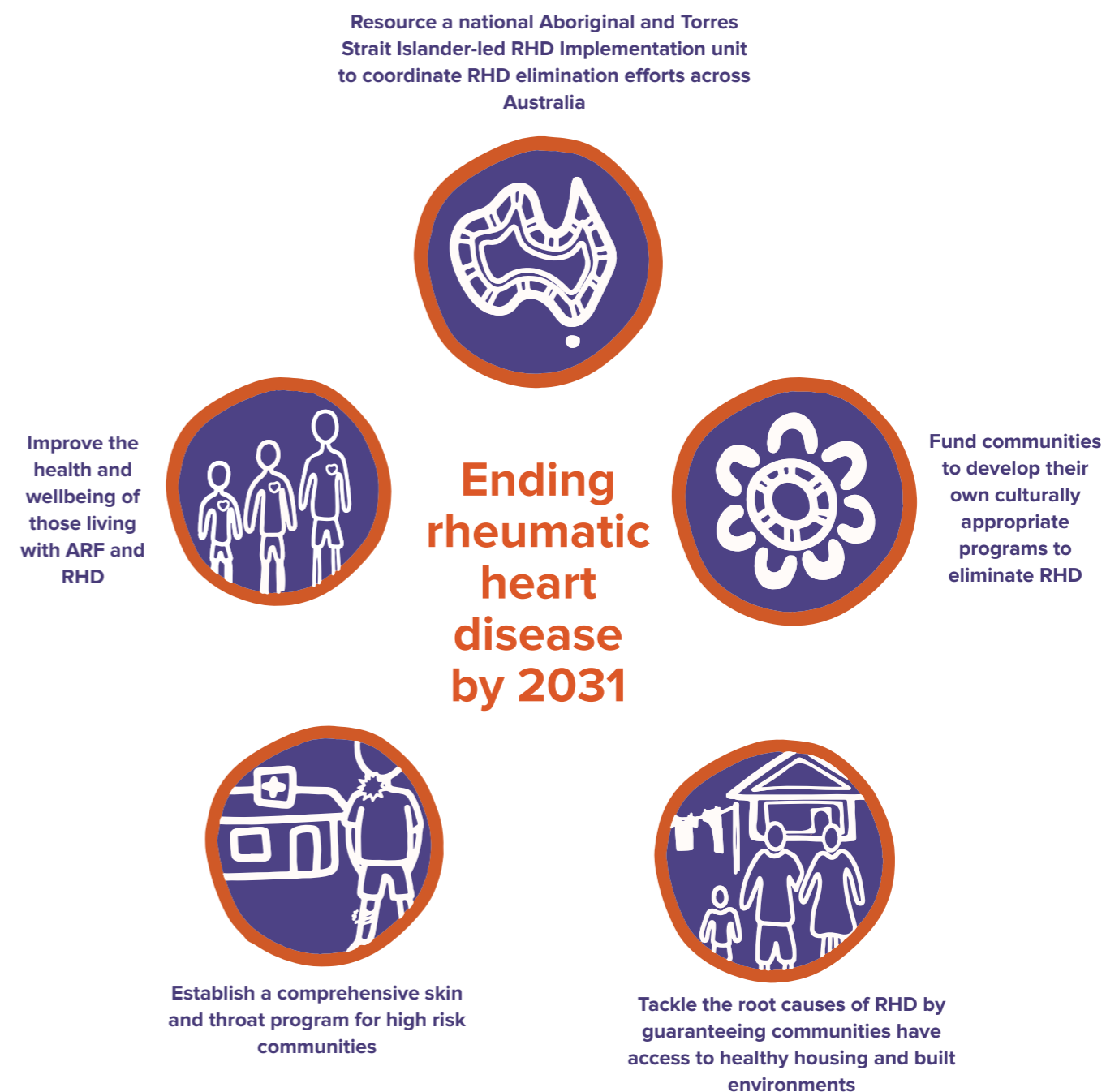


Figure 1: Priority Action Areas.

Priority Action Areas

The *Endgame Strategy* has identified a range of strategies that demonstrate potential to put the elimination of RHD in Australia on track for 2031. No single one of these strategies will eliminate RHD. Instead, a comprehensive approach, applying a number of strategies concurrently, is needed. This will look different across communities and jurisdictions, reflecting the cultural, geographic and political context in which they operate.

Resource an Aboriginal and Torres Strait Islander-led National Implementation Unit to coordinate rheumatic heart disease elimination efforts across Australia

The RHD National Implementation Unit will:

- Work with government at the national, state, territory and local level to address the root environmental and social causes of rheumatic heart disease;
- Deliver technical support to all stakeholders involved in work to end RHD – from communities to policymakers, clinicians, and health workers;
- Support and fund communities across Australia to deliver culturally appropriate strategies to prevent RHD and ensure the best treatment for those already living with the disease;
- Develop resources and guidelines to equip communities, schools and clinicians in their work to end RHD;
- Act as the critical link between researchers and communities – setting research priorities and ensuring translation of evidence and technological advances in acute rheumatic fever and RHD diagnosis and management; and
- Monitor progress and re-evaluate strategies to ensure goals are achieved.



Aboriginal & Torres Strait Islander leadership

Fund communities to develop their own culturally appropriate programs to eliminate RHD

Ending RHD will only be successful if communities are empowered and supported to implement culturally relevant RHD elimination activities aligned to local priorities. There are currently at least 10 communities taking action to address ARF and RHD, with varying levels of funding and support.

With a network of support coordinated by the RHD National Implementation Unit, communities will be able to drive work to:

- Increase awareness about Strep A and the symptoms of ARF so that people:
 - Are diagnosed and receive the right treatment as quickly as possible to prevent RHD developing;
 - Already living with ARF or RHD have access to culturally safe health care within their community.
- Resource peer support networks led by those living with or impacted by ARF or RHD; and
- Evaluate demand for community-based echocardiography screening, ensuring comprehensive follow-up care is available for those diagnosed.

To support this community-driven work, the Commonwealth Government should:

- Provide ongoing investment to better support and grow the Aboriginal and Torres Strait Islander health workforce; and
- Increase funding to community-based health care providers to ensure accessible, best quality care for those living with ARF and RHD.



Community-based programs

Experience and evidence make it clear that community-level action is crucial to eliminating RHD. Therefore, the *Endgame Strategy* proposes a holistic strategy to end RHD with Aboriginal and Torres Strait communities at the core, grounded in local decision-making and with supporting structures to ensure a nationally consistent approach.

Tackle the root causes of RHD by guaranteeing communities have access to healthy housing and built environments

This will involve cross-sector collaboration between national, jurisdictional and local governments and communities to:

- Increase new housing stock and ensure proactive repair and maintenance of existing housing to reduce overcrowding and improve living conditions;
- Ensure access to essential hygiene infrastructure such as hot water, running showers and washing machines, so that people are able to achieve the Healthy Living Practices including washing hands, clothes and bodies; and
- Embed environmental health in community-based health care.



Healthy environments

Establish a comprehensive skin and throat program for high risk communities

The RHD National Implementation Unit will work with communities and their local service providers to:

- Implement comprehensive Strep A outreach activities tailored to the local context;
- Develop tools to better support health workers to diagnose and treat Strep A skin and throat infections, the precursor to ARF and RHD; and
- Explore strategies aimed at making it easier for people in high risk communities to have their skin sores and sore throats checked. For example: flexible appointment systems and after-hours services; school-based screening programs; and offering transport to and from clinics.



Early prevention

Improve the health and wellbeing of those living with ARF and RHD

Communities, researchers, service providers and the RHD National Implementation Unit will together work to:

- Make sure those already living with ARF and RHD have access to clear support pathways throughout their journey. This is especially important for transitional periods such as adolescence to adulthood and for women planning pregnancies;
- Resource positions for regional coordinators to monitor and improve treatment and health promotion activities in high risk communities; and
- Ensure people who require specialist treatment off country receive culturally safe treatment in mainstream services.



Care and support



INTRODUCTION TO THE ENDGAME STRATEGY



Angela Kelly demonstrates to Aboriginal Community Worker, Segora Bauu, how RHD damages the heart valves

Introduction

Across the majority of Australia, sustained improvements to the conditions in which people are born, grow, live, work and age have permanently reduced the rates of preventable infectious diseases. However, this progress is inequitable. Aboriginal and Torres Strait Islander people have not benefited from the same improvements in health and living outcomes as the rest of Australia. Perpetuated by household disadvantage, poor-quality housing and inadequate access to primary healthcare, rheumatic heart disease (RHD) is an exemplar of the 'gap' between Aboriginal and Torres Strait Islander people and non-Indigenous Australians. This is unjust. RHD is a preventable disease.

However, two decades of research linked closely to service delivery and policymaking have put Australia at the forefront of global acute rheumatic fever (ARF) and RHD research, control and advocacy. The results of research and policy lessons signal that definitive disease control is within reach. Implementing the end of RHD necessitates a strategic approach, targeting practical science and development of new interventions with potential for rapid benefits.

Following a proposal of a research-policy-service partnership to plan for the *Endgame Strategy*, in 2014 the National Health and Medical Research Council (NHMRC) provided funding to the END RHD Centre of Research Excellence (END RHD CRE) to develop the *Endgame Strategy: a 'costed, comprehensive approach to end RHD in Australia by 2031'*.

The END RHD CRE offers the first opportunity for any country to build a comprehensive, evidence-based strategy for ending RHD. This project has represented a tremendous challenge and an untold chance to 'Close the Gap' and end the disparity for Aboriginal and Torres Strait Islander communities.

Initially involving collaborators from 16 institutions across Australia, the END RHD CRE has allowed investigators to work closely with individuals and communities living with the condition to fill knowledge gaps and achieve the best possible outcome. Projects funded by the CRE, including those focused on the lived experience, improved methods of diagnosis and treatment, and Strep A vaccine development, have broadened our collective understanding of ARF and RHD and contributed to the overall goal of the *Endgame Strategy*.

In the years since the inception of the END RHD CRE, ARF and/or RHD have become notifiable in four additional Australian jurisdictions,³⁻⁵ the national agency for RHD has received two supplementary funding commitments,^{6,7} control program funding has been extended, and RHD has been prominent in a number of Federal commitments to improve health.^{6,8-10} Specifically, the National Aboriginal Community Controlled Health Organisation (NACCHO), on behalf of END RHD, was commissioned to present a Rheumatic Heart Disease Roadmap to the Council of Australian Governments (COAG) Health Council in 2019 – under review at the time of writing.^{9,10} These national movements have been part of a global commitment towards eliminating RHD, with the World Health Assembly (WHA) passing a resolution in 2018 to end RHD.¹¹

Never before has there been such an intense and concerted effort to eliminate RHD, nationally and globally.

Following five years of research, investigation and advocacy, this document, the *Endgame Strategy*, provides a technical foundation to end the preventable injustice of RHD for Aboriginal and Torres Strait Islander peoples in Australia.

Overview of Strep A, ARF and RHD

Rheumatic heart disease (RHD) is a chronic condition caused by damage to the heart valves.¹² RHD is a downstream result of infection by Group A Streptococcus (Strep A, also referred to as *Streptococcus pyogenes*, GAS).

Most people have a normal immune system response which resolves these infections with no ongoing consequences. A small number of people have an abnormal immune response to Strep A, which is known as acute rheumatic fever (ARF). ARF can cause sore joints, rashes, abnormal movements, fever, and heart inflammation. Most of these symptoms resolve over a few weeks but often heart damage remains. Repeated Strep A infections can cause recurrent ARF and permanent scarring of the heart valves. Damage to the heart valves is called RHD. The causal pathway from Strep A to RHD is described in Figure 2.

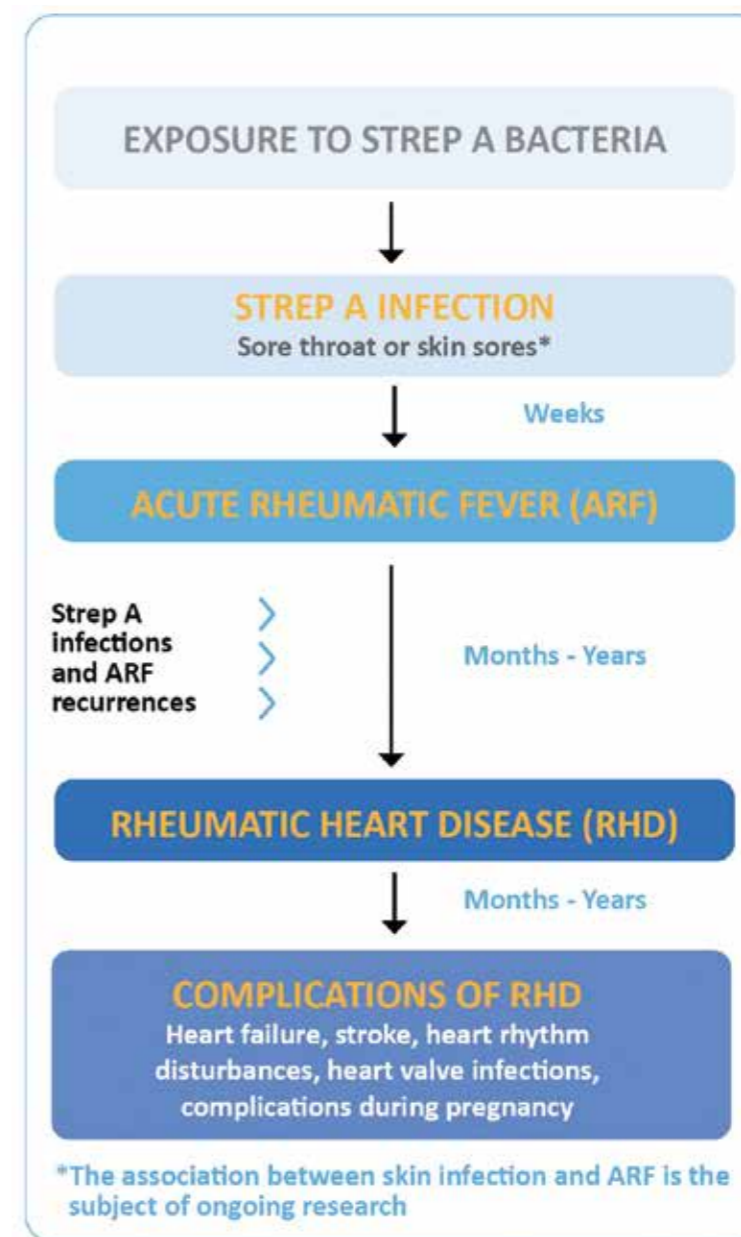


Figure 2: Causal pathway from Strep A to RHD.

Structure and methods of the RHD Endgame Strategy

Scope and structure

The *Endgame Strategy* is intended to identify and evaluate approaches to ending RHD in Australia by 2031. The focus is on preventing new cases of ARF and RHD, therefore the *Endgame Strategy* is weighted towards strategies which act early in the causal pathway from Strep A exposure to ARF. Some areas of biomedical research have been identified as priorities but, in general, the focus is on what can be done now, with existing knowledge, to end RHD. The *Endgame Strategy* is presented in five chapters:

Chapter 1 – Burden of disease

This chapter presents an overview of what is already known about the health and economic burden of Strep A, ARF and RHD in Australia, and projections of the burden of disease over time if no further action is taken.

Chapter 2 – Lived experience of RHD

This chapter presents the human impact of RHD and profiles the lived experience of the disease.

Chapter 3 – The policy context

This chapter addresses the national policy context, including the history of RHD initiatives in Australia and other relevant initiatives. The policy context is intended to inform implementation planning.

Chapter 4 – Strategies to address Strep A, ARF and RHD

This chapter examines each of the opportunities to intervene on the causal pathway from Strep A exposure to advanced RHD, spanning structural determinants of health and health delivery (4a), environmental and social determinants of health (4b), more biomedical approaches in primary prevention (4c), secondary prevention (4d), and tertiary care (4e). Each potential strategy is evaluated according to the evidence framework described later in this section.

Chapter 5 – Modelling, measurement and recommendations

This chapter costs an indicative bundle of strategies selected from Chapter 4, estimates their effectiveness, and uses disease modelling to make predictions about the activities needed to end RHD. Priority recommendations are presented for community, jurisdictional and national stakeholders.

Intended audience and use

This full-length technical report is intended as a guide for community and government decision-makers, health professionals and researchers working to reduce the incidence of Strep A, ARF and RHD among Aboriginal and Torres Strait Islander people in Australia. The primary decision-makers are intended to be remote Aboriginal and Torres Strait Islander communities seeking to weigh up local priorities. For example, communities may seek to evaluate the effect of a community laundry relative to a swimming pool in reducing skin sores. At a jurisdictional level, decisions may be needed about infrastructure investments or resourcing of tertiary care services. Nationally, the *Endgame Strategy* provides a broad overview of policy and service delivery issues relevant to ending RHD. This is intended to provide an evidence base for engaging a broad range of stakeholders to develop a comprehensive approach to ending RHD and help inform priority-making decisions in partnership with community.

It is not possible or desirable for the *Endgame Strategy* to present a single uniform approach to ending RHD across Australia. Decisions made by communities, jurisdictions and government are necessarily contextual and should be guided by the agreed priorities of Aboriginal and Torres Strait Islander peoples in all cases.

Geographic focus

This review focuses on actions needed to reduce the risk of Strep A infections, ARF and RHD for Aboriginal and Torres Strait Islander people living in remote and very remote communities in northern Australia. Almost all (89%) of Aboriginal and Torres Strait Islander people with ARF live in these communities, as outlined in Chapter 1. Therefore, efforts to end the inequality of RHD are most urgent and appropriately focused in these areas. A smaller proportion of people with a history of ARF or RHD live in urban settings or are not Aboriginal or Torres Strait Islander. This includes Māori and Pacific Islander people, and refugees and migrants from countries with a high burden of ARF and RHD. Many prevention recommendations are likely to be relevant to these population groups.

Methods

The scope and structure of the *Endgame Strategy* has been developed by END RHD CRE Investigators. Content experts have led the development of each chapter of the *Endgame Strategy* and the methods used by each group are briefly outlined at the start of each chapter. Literature reviews were concluded by 1 November 2019 unless otherwise specified.

Data Sources

The *Endgame Strategy* draws from a number of data sources, primarily the ERASE data set¹ for modelling purposes, but also referencing the foundational Cost of Inaction report² and Australian Institute of Health and Welfare data.⁷⁷ Various methods are used to collect and report data on ARF and RHD in Australia, including hospital admission and death datasets, disease notification systems, ARF/RHD registers, cardiology clinics, and echocardiography screening studies. Variances in reported figures within the Endgame reflect differences in the way data systems operate and variations in modelling methods used. These differences include the period of time under analysis and inclusion or exclusion of people who already have the disease in initial forecasts. More detailed information on Data Sources is provided in Appendix One.

Review process

The END RHD *Endgame Strategy* Review Working Group (Review Working Group) was established with the approval of the END RHD Advisory Committee at the request of the CRE Aboriginal Investigators who contributed to the process and, based on feedback from the Working Group, made final recommendations for consideration and document revision to the broader CRE investigator group. The purpose of the Review Working Group was to review *Endgame Strategy* recommendations for feasibility and acceptability, inclusive of review from a cultural perspective. The Review Working Group:

- Provided feedback and recommendations to the END RHD CRE;
- Provided advice to the END RHD Advisory Committee; and, ultimately
- Provided a recommendation to the Advisory Committee on END RHD's endorsement of the Strategy.

Language and terminology notes

The language used to discuss the end of RHD is important. Wherever possible, language used by Aboriginal and Torres Strait Islander peoples and groups has been prioritised and the context and origin of specific terms acknowledged. Where the most appropriate terms are not widely agreed upon, this review uses the most common terminology for clarity. Some terms and concepts remain problematic and a summary of some of these issues is provided below:

Primary healthcare (PHC)

Primary healthcare (PHC) was a concept elaborated on in the 1978 Declaration of Alma-Ata, focusing on the principles of equity, participation, intersectoral action, adequate and appropriate technology, and a central role played by the health system.¹³ PHC comprises the first interaction that individuals, families and the community have with the healthcare system. For Aboriginal and Torres Strait Islander people, PHC includes the collective effort of the community to achieve and maintain cultural wellbeing, integrating a holistic approach incorporating body, mind, spirit, land, environment, custom and socioeconomic status.¹⁴ Additional services comprise PHC, including environmental health, provision of pharmaceuticals, counselling, preventative medicine, health promotion, antenatal and postnatal care, and maternal and child care, among others.¹⁴ PHC is provided in a number of different models in Australia.

Aboriginal Community Controlled Health Service (ACCHS)

An ACCHS is an incorporated Aboriginal organisation initiated by a local Aboriginal community within a local Aboriginal community, governed by an Aboriginal body which is elected by the local Aboriginal community and delivering a holistic and culturally appropriate health service to the community which controls it.¹⁴ ACCHSs are unique in their governance, in that they are '*culturally appropriate, autonomous primary health services initiated, planned and governed by local Aboriginal communities through their elected Aboriginal board of directors.*'¹⁴ ACCHSs evolved from a need to meet the needs of Aboriginal and Torres Strait Islander people and communities, and generally provide comprehensive programs that incorporate treatment and management with prevention and health promotion, as well as addressing the social determinants of health.¹⁵

Aboriginal Medical Service (AMS)

An Aboriginal Medical Service (AMS) is a health service funded principally to provide services to Aboriginal and Torres Strait Islander individuals. If these providers are not community controlled, they are generally run by a State or Territory government, most commonly in the Northern Territory and the northern part of Queensland.¹⁴

General Practice

General practice is a term synonymous with primary care and family medicine and refers to the delivery of nine levels of care: prevention, pre-symptomatic detection of disease, early diagnosis, diagnosis of established disease, management of disease, management of disease complications, rehabilitation, palliative care, and counselling. General practice generally is facilitated by a general practitioner and associated personnel.¹⁴

'Mainstream' Practices

'Mainstream' is sometimes used colloquially to distinguish primary healthcare services which are not ACCHSs or government-run Aboriginal Medical Services. Mainstream services are generally run as private businesses in some regional towns and most Australian cities. Out-of-pocket gap payments may be required to attend these practices.

Aboriginal and Torres Strait Islander Health Practitioner (ATSIHP)

Aboriginal and Torres Strait Islander Health Practitioner means a person registered by the Aboriginal and Torres Strait Islander Health Practice Board of Australia. Only persons who are Aboriginal and/or Torres Strait Islander are eligible for registration as an Aboriginal and Torres Strait Islander health practitioner, with the aim to enhance the quality of holistic healthcare that is provided by Aboriginal and Torres Strait Islander health practitioners to the community in a culturally safe manner.¹⁶

Primordial prevention

Primordial prevention is a widely used term to describe risk-reduction strategies in cardiovascular disease that prevent the development of risk factors.¹⁷ Primordial prevention has been particularly used in RHD control to address the social determinants of health which drive Strep A, ARF and RHD risk.¹⁸ However, primordial prevention can imply a passive transmission of risk. Therefore, this review uses the term 'social and environmental determinants of health' in a positive sense to reflect opportunities for community-driven intersectoral action for health and wellbeing.

Health promotion

Health promotion is defined by the Ottawa Charter as *'the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities.'*¹⁹

Some of the programmatic examples presented in Chapter 4 are simple health education programs and do not reflect the holistic, enabling and empowered approach implied by health promotion activities as defined by the Ottawa Charter. The generation of posters, flipcharts or advertisements, while important in isolation, is not health promotion. These resources may provide health information and improve health literacy. However, superficial 'information only' activities which do not account for the cultural, social and economic context for remote-living Aboriginal and Torres Strait Islander people are unlikely to be effective and may contribute to undermining Aboriginal and Torres Strait Islander knowledge and culture.^{20,21} Work to better define, describe and evaluate appropriate health promotion approaches for Aboriginal and Torres Strait Islander people has been conducted and is the subject of active ongoing research.^{22,23}

For the purposes of this review, health education programs have been presented as they relate to each Healthy Living Practice (HLP). This inclusion is necessary given that relatively little information is available about how the risk of Strep A infection can be reduced through health education and health promotion activities. However, sustained and high-impact change is only possible if future iterations of health promotion more clearly account for the context in which these programs are delivered. Ecological approaches can help to consider the context of health promotion activities more holistically and in the settings where they occur.²⁴

There is a need to develop and trial comprehensive, community-wide, ecological health promotion models that can be utilised and sustained in the long term to change health behaviours in Aboriginal and Torres Strait Islander communities.

Housing

In this review, the use of the term 'housing' refers to new constructions, upgrades, repair and maintenance, appropriate designs and standards, as well as culturally appropriate tenancy management.

Household crowding

Household crowding is considered by some authors to be an accurate description of large numbers of people living in confined environments with limited household resources. However, the impacts of people living together are a result of biological, psychological and cultural determinants.

The term 'close living' is also used to describe arrangements where many family members live together. Close living may have value culturally, and there is evidence that strong culture is central to Aboriginal children's wellbeing.²⁵ Examples of the benefits from living with many family members include potential support, connection, and protective influence of extended family.²⁶ For example, close living contributes to a learning environment in which Yolŋu children grow up learning from family members of different ages, including cultural knowledge.²⁶

However, the benefits from living with extended family only have value when people have sufficient control over how many and who they choose to live with, and there is adequate housing design and infrastructure to support the numbers.²⁶ Overcrowding is therefore the result of inappropriate housing, or even lack of adequate housing, for large families which is not culturally appropriate.

Importantly, *'cultural preferences and practices must be understood if housing and health improvements are to be appropriate and sustainable.'*²⁶ In some cases, structural improvements to housing may lead to unintended adverse consequences.²⁶ For example, when tenants of sub-standard housing are moved into a new, improved home, there is also loss of community, disruption of social networks, and unsatisfied social aspiration – factors that can counteract positive health effects of moving.²⁷

It has been argued that in Aboriginal communities, rights and obligations around accommodating extra people in a house must be respected in interventions to reduce household crowding.²⁸ Where close living is important culturally, ways to live safely in larger households, focusing on ensuring adequate health literacy and washing facilities, need to be implemented.²⁹

On this basis, 'overcrowding' could equally be considered 'close living' behaviour.^{28,30,31} The term 'household crowding' is used in this review, with acknowledgment that crowding is often the result of culturally and climatically inappropriate housing design, and that the relationship between overcrowding and infectious disease is complex.

Health hygiene hardware and software

The idea of 'Health Hardware' was first used in the Australian context by renowned ophthalmologist Fred Hollows, following international exposure to the concept.³² Health hardware is commonly defined as the physical infrastructure required for healthy living (including electrical systems, fans, toilets, showers, taps, kitchen cupboards and benches, stoves, ovens, fridges, and washing machines collectively).³²

In Australia, the term 'health software' has been adopted as a derivation of this to refer to consumables for health behaviours (for example: soap, washing powder, tissues). However, internationally, health software more commonly refers to human elements, including health promotion and behaviours.³³ The term 'health hardware' is used throughout this document, while the term 'health software' is avoided given the confusion about its meaning in different geographic settings.

Primary prevention

In Australia, primary prevention can reasonably be described as the *'assessment of skin and throat infections and treatment with appropriate antibiotics to prevent ARF in people at high risk of the disease'*.

Sore throat and skin sores

The words used by health professionals and community members to describe skin sores and sore throats can overlap and have different meanings to different audiences. This can lead to miscommunication and confusion. For instance, qualitative data suggests that, in the Pilbara region, the term 'sores' is used by community members to refer to all kinds of skin infection – potentially encompassing fungal infections, scabies infections, boils and abscesses.³⁴ Qualitative data suggests that, in the Pilbara region, health professionals use the terms 'boils' and 'sores' interchangeably.³⁴ In other clinical settings, the term 'boil' or 'abscess' indicates an infection – and generally implies that a collection of pus is present which increases the likelihood that the bacteria *Staphylococcus aureus* is causing the infection. In this document, 'sore throat' is used to refer to symptomatic throat pain, synonymous with pharyngitis, while 'skin sore' is used to describe an infected lesion, synonymous with impetigo and pyoderma.

Wound

Used in this document to describe uninfected damage to the skin such as a cut, graze or scratch.

Secondary prevention

Used in this document to refer to comprehensive care needed for people living with ARF and RHD, including regular antibiotic delivery, immunisations, avoidance of and prompt management of Strep A infections, regular clinical review, and prevention of comorbidities.

Secondary prophylaxis

In this review, secondary prophylaxis specifically refers to the regular administration of antibiotics to reduce the risk of ARF recurrence.

Secondary prophylaxis adherence

This is used to refer to the proportion of scheduled injections of benzathine benzylpenicillin delivered to prevent ARF recurrences. Historically, the term 'compliance' has been used to communicate about whether secondary prophylaxis injections have been received. However, this term implies a value judgement about whether an individual has been 'compliant' with recommended treatment and fails to account for the many social, cultural and economic determinants of people accessing medical care. The concept of 'poor compliance' must also be viewed in the context of resourcing of primary healthcare and workforce. As one author identifies *'within this context the term 'poor compliance', oft-used by health professionals and administrators, would best be replaced by 'poor service' in the majority of circumstances'*.³⁵

Tertiary care

In this review, tertiary care is used to describe the surgical and medical management of RHD. The goal is to prevent the complications of established disease. In the case of RHD, this means reducing symptoms to minimise disability and prevent premature death, with examples including heart valve surgery, management of heart failure, and prevention of stroke.⁶

Disability-adjusted life year (DALY)

Disability-adjusted life year (DALY) is a measure of the overall disease burden. According to the World Health Organization (WHO); *'one DALY can be thought of as one lost year of 'healthy' life. The sum of these DALYs across the population, or the burden of disease, can be thought of as a measurement of the gap between current health status and an ideal health situation where the entire population lives to an advanced age, free of disease and disability.'*³⁶

Health states

Across the lifespan, an individual may transition through a number of different health states that have a varying degree of wellbeing and functionality. The WHO provides health state valuations on a scale of 0 to 1, where 0 is equivalent to death, and 1 is equivalent to full health.³⁷ Health states have been used in the *Endgame Strategy* to demonstrate the transition of health from Strep A infection to death from severe RHD.

Cohort

A cohort refers to a group of individuals sharing a defining subject and/or characteristic within a given period of time.

Birth cohort

A birth cohort is a group of individuals born during a given calendar time period within a specified geographical region.³⁸

1 BURDEN OF STREP A, ARF AND RHD



Tenaya, diagnosed with RHD aged just seven, looks down at the scar caused by surgery to repair her heart valves

Strep A infections

Introduction to Strep A

Strep A is a human-only bacterial pathogen which causes a range of different infections, outlined in Figure 3.

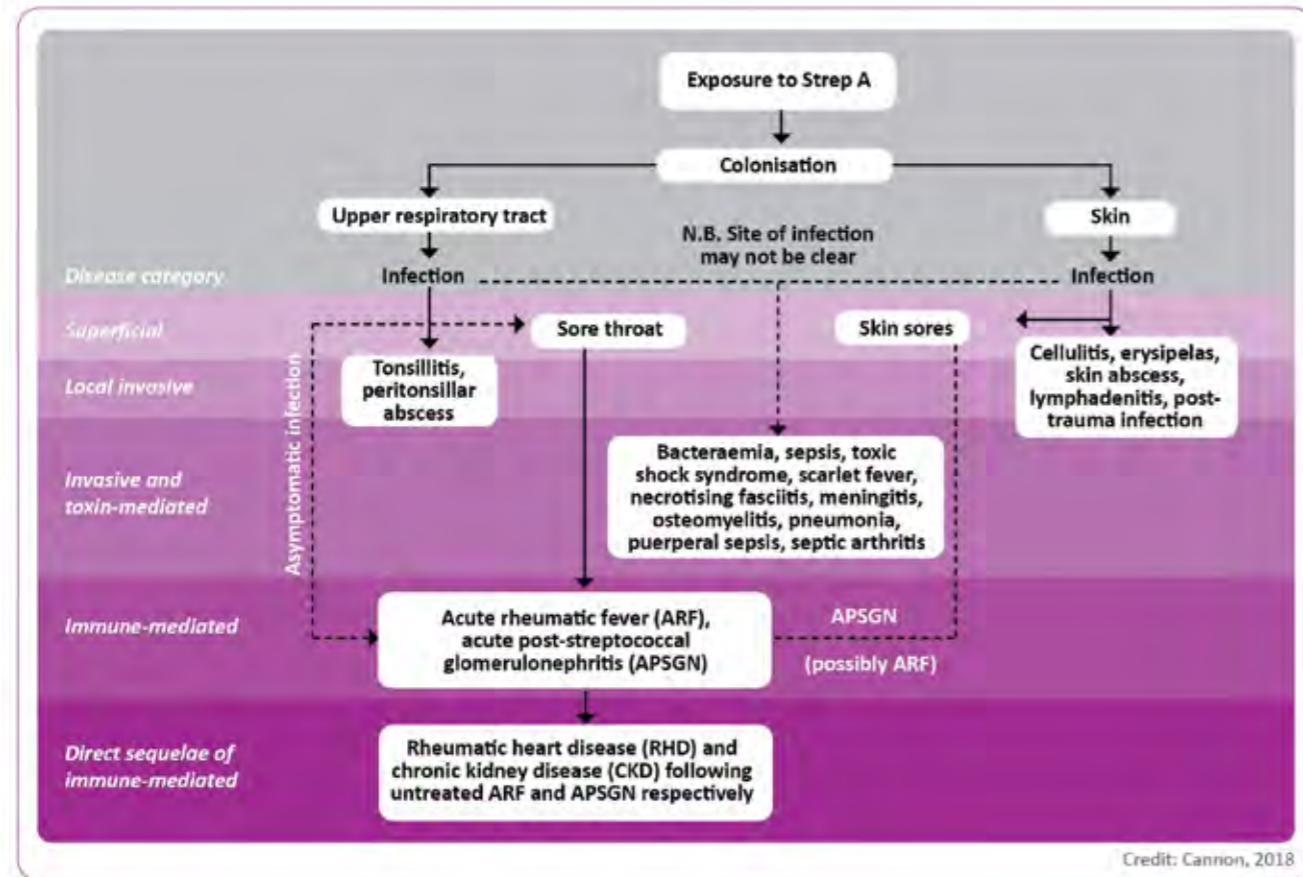


Figure 3: Diseases caused by Strep A.³⁹

People are exposed to Strep A through contact with other people. Strep A lives in the back of the throat (nasopharynx) of humans who are colonised with the bacteria.⁴⁰ Transmission occurs through close contact, predominantly via large respiratory droplets. Transmission may also occur via skin surfaces contaminated by settled respiratory droplets and from infective discharge from skin sores and nasal secretions.

Strep A can cause superficial infections of the throat ('strep throat') or skin (skin sores, impetigo, pyoderma). Medical and colloquial use of these terms is discussed in the language notes at the beginning of the *Endgame Strategy*.

Box 1: Introduction to Strep A carriage

Some children have Strep A bacteria detectable from swabs of their throat without having signs (throat redness, swollen tonsils, enlarged tender lymph nodes) or symptoms (pain or fever) of active infection. Some do not have evidence of an immune response (elevated ASOT or Anti-DNase B) on blood tests either.^{41,42} These children without signs, symptoms or an immune response are described as having 'Strep A carriage'.

There is no evidence that children with persistent Strep A carriage are at risk of acute rheumatic fever (ARF), provided they remain asymptomatic.⁴³ It is possible that children with persistent Strep A pharyngeal carriage could be infectious to close contacts, although carriers are thought to be substantially less contagious than actively infected children.⁴³

The mechanism by which some children have Strep A present in their throat without active infection is unclear.^{41,43} The proportion of children with Strep A carriage varies in different communities and with age. For example, Strep A was isolated from the throats of 1.1%, 7.6% and 12.7% asymptomatic Aboriginal and Torres Strait Islander children in three studies conducted in remote communities.⁴⁴⁻⁴⁶ Overall, in an international meta-analysis of asymptomatic children in a variety of settings, 12% were found to have Strep A carriage.⁴⁷ A 2006 Australian study found that about 10% of Aboriginal and Torres Strait Islander children have Strep A carriage.⁴⁸

Burden of Strep A infections in Australia

Sore throat

Sore throat (pharyngitis) is a common childhood illness accounting for about 3% of presentations to mainstream general practitioners in Australia.^{49,50} There is little existing data about sore throat presentation in remote Aboriginal and Torres Strait Islander settings. Sore throat is caused by a range of pathogens, most commonly respiratory viruses.⁵¹ The bacterial pathogen is Strep A, which is isolated in up to 20% of symptomatic children and in about 10% of asymptomatic children.^{47,51,52}

Skin sores

Skin sores occur when a break in the skin surface becomes infected. These infections are sometimes known as school sores, pyoderma or impetigo. Generally, the sores are round in shape, beginning with pus-filled bumps which become blisters or release a clear, crusting fluid. The underlying skin is reddened.⁵³ Almost all skin sores among Aboriginal and Torres Strait Islander people in Australia are caused by Strep A. Simultaneous infection with another bacteria, *Staphylococcus aureus*, is common but *S. aureus* generally does not cause the primary infection.⁵⁴

Box 2: The association between skin sores and ARF

Some Aboriginal and Torres Strait Islander communities have high rates of skin sores and ARF but relatively few reports of sore throat. This raised the possibility that Strep A skin infections may cause ARF. This possibility was investigated in a prospective surveillance study of 1,172 people in 49 households across three remote Aboriginal and Torres Strait Islander communities from 2003 to 2005. No symptomatic cases of Strep A throat infection were identified and a low-point prevalence carriage of Strep A in the throat was reported (3.7%).⁴⁸ However, 37% of children had at least one Strep A skin infection during the study, isolated on swabbing from 93% of cases. There was a very high incidence of ARF, with seven cases identified during the study period (equivalent to 350/100,000 per year).⁴⁸

Supporting the hypothesis that ARF can follow Strep A skin infection is the repeated observation that strains of Strep A more typically associated with skin infection than throat infection dominate in endemic tropical regions with a high burden of ARF. More recently this was confirmed in New Zealand⁵⁵⁻⁵⁷ and has also been demonstrated in a cluster of ARF cases relevant to the model cohort in a remote Aboriginal community in northern Australia.⁵⁸ Case reports of ARF following skin infection include a contemporary case report from New Zealand with confirmatory microbiological testing.^{59,60}

Although there is evidence of a causal association between Strep A skin infection and ARF, there are no data as to whether antibiotic treatment of skin infections can prevent subsequent ARF, whereas these data do exist for prevention of ARF following Strep A throat infections. For the purposes of the *Endgame Strategy* the potential for antibiotic treatment of skin sores to provide primary prevention of ARF has been proposed.

Scabies

Infection with the *Sarcoptes scabiei* (scabies) mite causes intense itching, leading to picking of the skin and subsequent damage. Skin lesions resulting from scabies infestation most commonly affect the hands, wrists, ankles and feet.⁶¹ Spread of scabies usually occurs from skin-to-skin contact, with higher risk of transmission in areas of higher population density and crowded housing conditions.⁶¹

Crusted scabies is a rare condition which occurs when the spread of scabies mites is not controlled by the host immune system. It is highly infectious and disfiguring, characterised by thick skin crusts and infestation with thousands to millions of mites, compared with five to 15 mites in common scabies.⁶² Rates of crusted scabies in remote Aboriginal and Torres Strait Islander communities of northern Australia are the highest in the world.⁶³

Secondary infection with Strep A following scabies infestation is common and has been demonstrated in a range of study designs and settings.⁶⁴⁻⁶⁶ Therefore, scabies control is an important aspect of ARF prevention.

Burden of skin infections in primary care

Skin infections are one of the most common reasons for Aboriginal and Torres Strait Islander children to present to clinics for primary care. A retrospective review of clinic presentations of all children aged up to five years, presenting to four clinics located in the Western Desert region of Western Australia between 2007 and 2012, found that skin infections (including sores, scabies and fungal infections) accounted for the largest proportion of presentations (16%).⁶⁷ Almost three-quarters (72%) of children presented at least once with skin infections during this period.⁶⁷

Burden of skin infections in hospital admissions

Scabies and impetigo infections are acknowledged to be under-recognised and therefore under-treated by clinicians. A prospective, cross-sectional study was conducted which assessed the burden of skin infections (scabies, impetigo, tinea and pediculosis) in children admitted to two regional Australian hospitals from October 2015 to January 2016. One hundred and fifty-eight patients with median age 3.6 years (74% Aboriginal and Torres Strait Islander) were prospectively recruited. A retrospective chart review of patients admitted to the same hospitals in November 2014 was also performed; 77 patient records were reviewed.⁶⁸ Scabies (8.2% vs 0.0%) and impetigo (49.4% vs 19.5%) were more prevalent in the prospective analysis. Skin examination was only documented in 45.5% of cases in the retrospective review.⁶⁸

A larger retrospective cohort study of all children born in WA between 1996 and 2012 (n=469,589, 6.7% Aboriginal and Torres Strait Islander) also assessed the occurrence of skin infections.⁶⁹ Hospitalisation rates for skin infections in Aboriginal children were 15 times higher than in non-Indigenous children.⁶⁹ The highest rates for all skin infections were observed in infants, and admissions increased with the remoteness of the child's residential address.⁶⁹

Strep A infections by age

Strep A infections among Aboriginal and Torres Strait Islander people usually begin in childhood. On average, Aboriginal children in remote communities have their first skin infection at seven months of age, which is predominantly caused by Strep A.⁷⁰ Strep A skin infections continue throughout childhood and into adolescence. Strep A throat infections begin in later childhood, peaking between 5 and 14 years of age (Figure 4).⁷¹

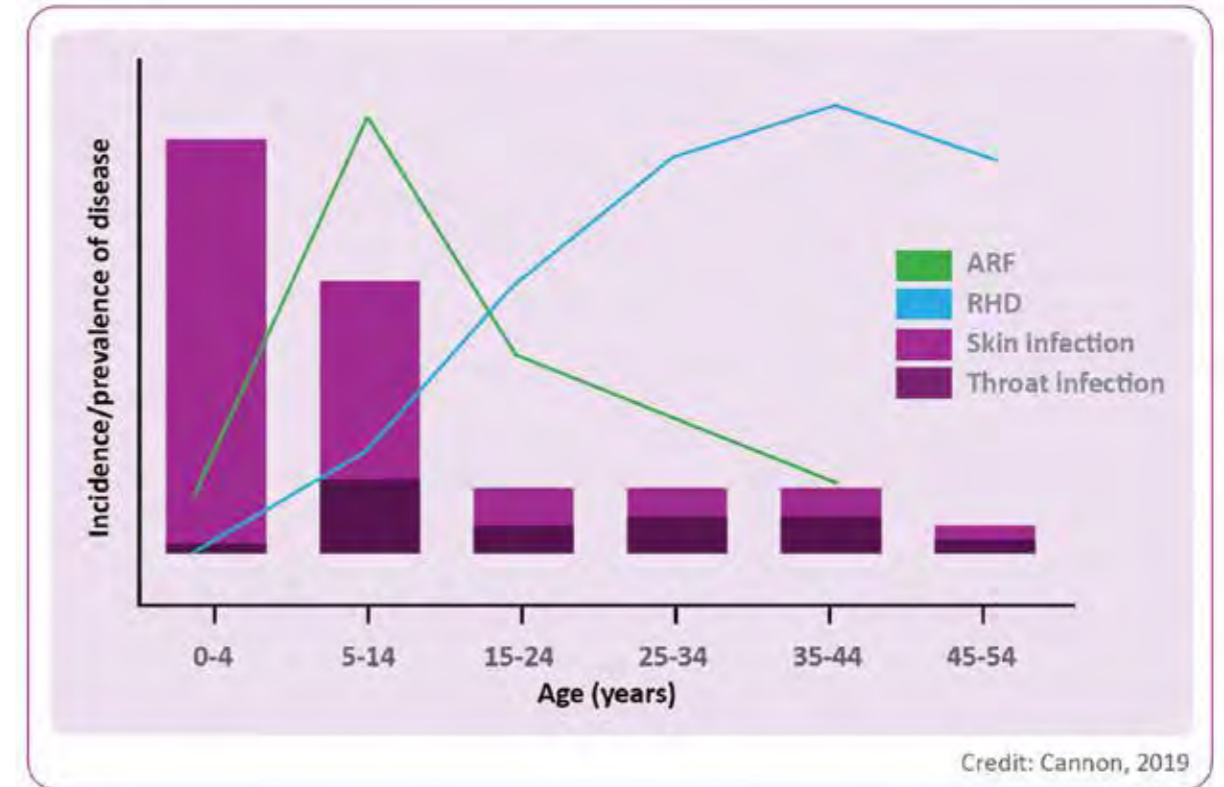


Figure 4: Skin and throat infection incidence, ARF incidence, RHD prevalence by age (schematic representation only, not based on real data).

Acute rheumatic fever

Introduction to ARF

ARF is caused by an abnormal immune response to an untreated Strep A infection. In a normal immune response, the body forms antibodies against the Strep A bacterium and is able to fight off the infection. In the abnormal immune response, these antibodies attack other parts of the body.¹⁸ This antibody response leads to inflammation which causes the symptoms of ARF. Symptoms occur 10 days to six weeks after a Strep A infection.

Symptoms of ARF are associated with the joint lining, brain, skin and heart. Joints become red, swollen, painful and tender. Typically, the large joints are affected, including ankles, knees, shoulders and elbows. Sydenham chorea presents as abnormal movement of the hands, feet, tongue and face, and indicates that there is brain involvement. The uncontrollable movements are thought to be caused by abnormal antibody effects on the basal ganglia part of the brain. Chorea occurs in about 28% of Aboriginal and Torres Strait Islander people with ARF, and more commonly in females.⁷² Skin rashes and nodules occur less frequently. These symptoms are usually accompanied by fever, raised markers for inflammation in the blood, and a general feeling of being unwell. Swelling of the heart, or carditis, is commonly associated with chorea, and is present in most recurrences of ARF. A heart murmur may be heard using a stethoscope; however, carditis is often missed using auscultation alone, and an echocardiogram is the most accurate method of diagnosis.

The ARF illness can be severe and disabling. On average, symptoms last two to three weeks but the damaging effects on the heart may persist.¹⁸ Chorea can appear after other signs and symptoms have resolved, and tends to persist for longer, with resolution usually within weeks to months.^{18,73,74}

Diagnosis of ARF

There is no single, diagnostic test for ARF. The diagnosis is made on the basis of a combination of symptoms, signs, investigations and clinical history as outlined by the modified Jones Criteria.⁷⁵ The Jones Criteria divide the clinical features of ARF into major and minor manifestations. Major manifestations are signs and symptoms strongly associated with ARF. Minor manifestations are clinical indicators that are not specific for ARF but when considered with major manifestations, increase the likelihood of ARF.⁷⁵ The Jones Criteria have undergone several revisions, the most recent in 2015.⁷⁶

To meet the case definition for definite ARF, an individual must demonstrate a specific combination of signs and symptoms and have evidence of a recent Strep A infection.⁷⁵ However, ARF can be difficult to diagnose; presenting symptoms may be subtle, or the presentation to healthcare may be delayed so symptoms may be subsiding. To capture ARF that is highly suspected but cannot be confirmed using the modified Jones Criteria, in Australia the categories of probable and possible ARF have been included, with relevant treatment pathways.⁷⁵ This approach helps to ensure that people at highest risk of ARF are managed according to their likelihood of having ARF.⁷⁵

Management of ARF

The Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (Australian Guideline) recommend that people suspected to have ARF should be referred to a hospital as soon as possible for investigations, treatment and education.⁷⁵ Admission to a hospital with echocardiography services is strongly recommended so that a correct diagnosis is reached, since this informs the recommended treatment plan, including the duration of secondary prophylaxis. While in hospital, people should be registered with the jurisdictional ARF/RHD register (where it exists). This is discussed in greater detail in Chapter 4c, specifically Figure 33).

Burden of ARF

The incidence of ARF peaks in childhood. RHD develops from one or more prior episodes of ARF, and prevalence peaks between the ages of 35–44 years (Figure 5).

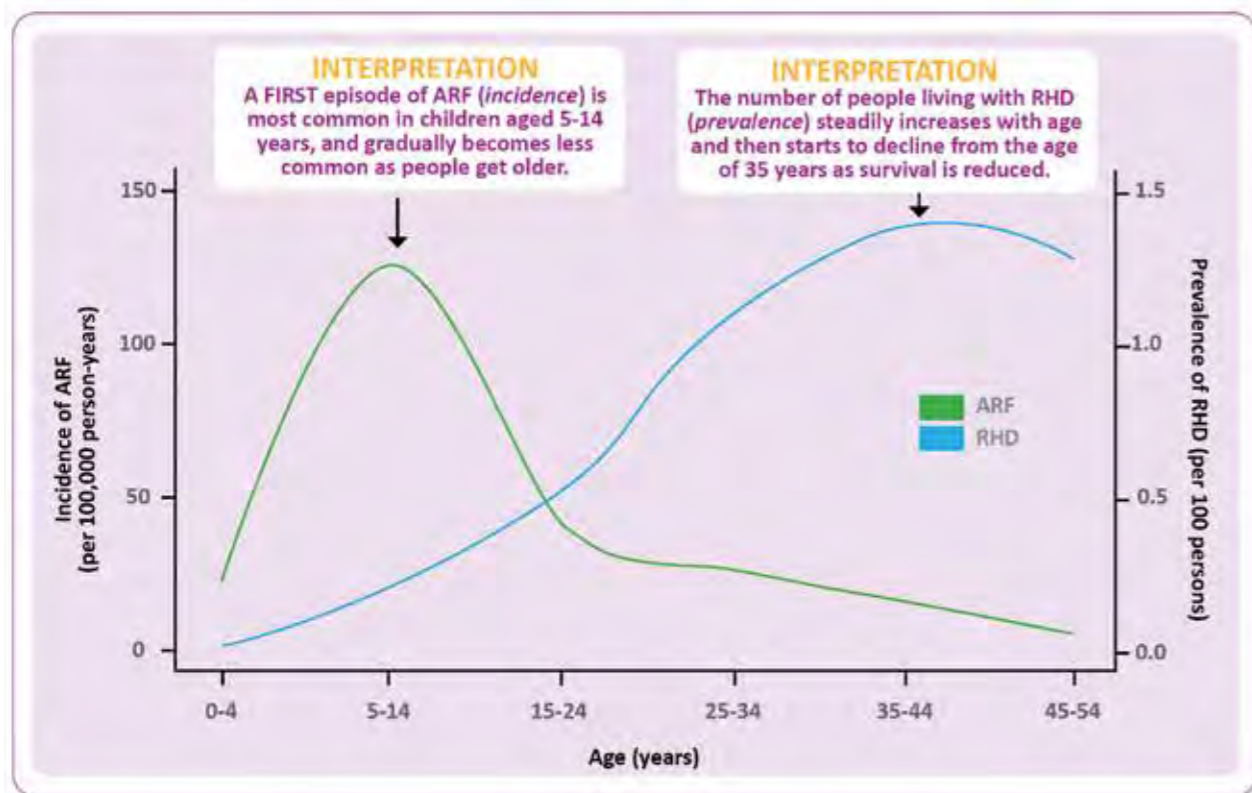


Figure 5: Incidence of ARF between 2014 and 2016 and prevalence of RHD in mid-2016, in the NT, QLD, SA and WA (Preliminary analysis of data from NHMRC PG 1146525).²

Between 2015 and 2017 in the Australian jurisdictions recording ARF and RHD rates (NT, SA, QLD, WA and NSW), there were on average 476 diagnoses of ARF recorded each year. This represents an age-standardised rate of 4.9 per 100,000 population.¹ Of the people diagnosed, the vast majority (89%) were Aboriginal and/or Torres Strait Islander people.¹ The overall rate of ARF diagnosis in Aboriginal and Torres Strait Islander people was 72 per 100,000 population, making them 123 times more likely to be diagnosed with ARF than non-Indigenous people of the same age.¹ People being diagnosed with a first episode of ARF made up the vast majority (71%) of ARF diagnoses (Table 2).¹

Table 2: Annual incidence counts (average over three years) and rates per 100,000 of all ARF episodes and first-ever ARF, by age and Indigenous status: NT, SA, QLD, WA* and NSW (2015–2017).¹

	Age Group	All ARF episodes			First-ever ARF episodes		
		Indigenous	Non-Indigenous	Total	Indigenous	Non-Indigenous	Total
Average Counts Per Year	0-4	13	2	15	12	2	14
	5-14	217	23	240	171	20	191
	15-24	104	15	119	66	12	78
	25-34	62	8	70	33	7	40
	35-44	26	6	32	14	5	19
All	0-44	422	54	476	296	46	342
Rates	0-4	15.7	0.2	1.3	14.5	0.2	1.2
	5-14	136.2	1.1	11.2	107.4	1.0	8.9
	15-24	75.8	0.7	5.3	48.5	0.6	3.5
	25-34	61.3	0.3	2.8	32.5	0.3	1.6
	35-44	33.8	0.3	1.4	18.4	0.2	0.9
Crude rate	0-44	75.7	0.5	4.6	53.2	0.5	3.3
ASR	0-44	71.9	0.6	4.9	49.3	0.5	3.6
ASRR	0-44	123.3			98.0		

*WA mid-2014 to mid-2017
ASR Age-standardised Rate (World Standard Population); ASRR Age-standardised Rate Ratio
Figures in this table have been rounded to the nearest whole number

Credit: Katzenellenbogen et al., 2019

Children aged 5–14 years are the most commonly affected by ARF.⁷⁷ Aboriginal and Torres Strait Islander children in this age group accounted for more than a third of all diagnoses.^{1,77} The incidence of ARF declines steadily by age group thereafter.⁷⁷ As the burden of disease accumulates in early life, 2016 statistics demonstrated that almost two-thirds of those who had been hospitalised with ARF in their lifetime were under 25 years of age.² This is evident in Figure 6.

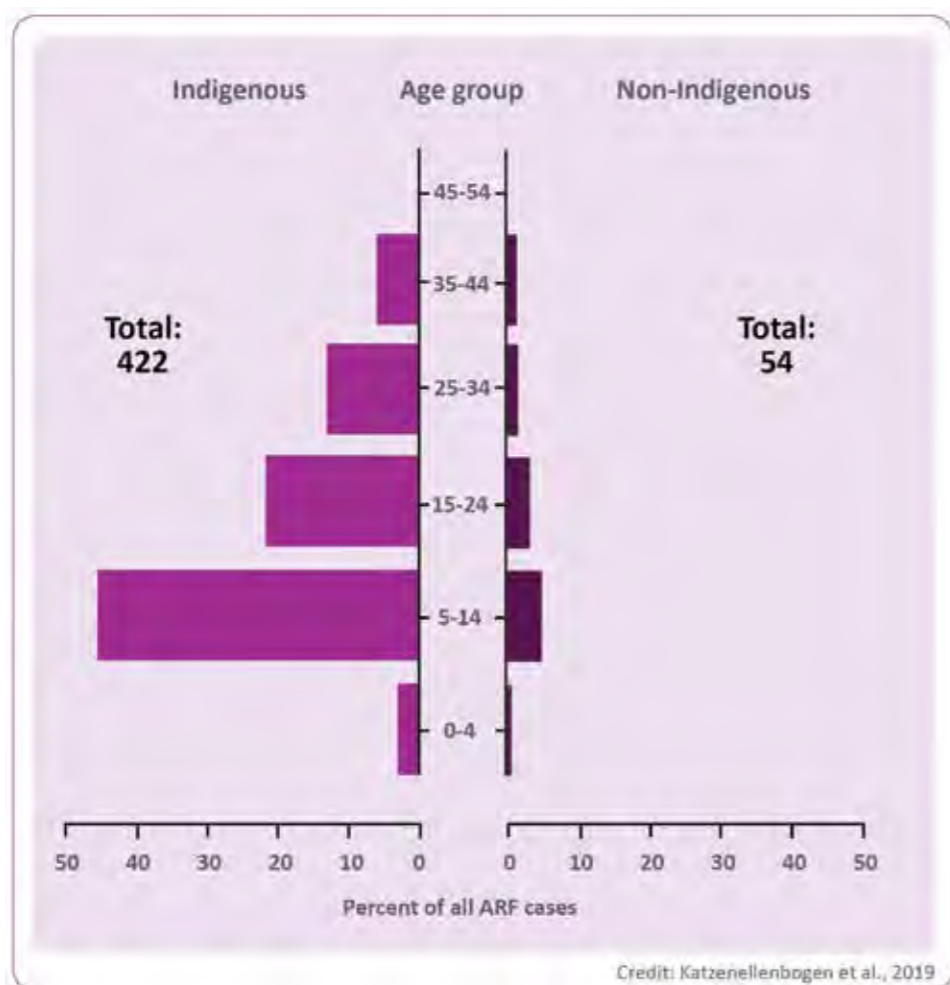


Figure 6: Age pyramid of the distribution of people with ARF (first-ever and recurrent combined), by age group and Indigenous status: NT, SA, QLD, WA and NSW (annual average of 2015–2017*).¹
*WA data covers 07/2014 to 06/2017

Women are more likely to be diagnosed with ARF than men, representing 55.3% of all episodes between 2015 and 2017.¹ Women were most likely to be diagnosed with ARF during childbearing years (63% of all episodes).

Geographically, the highest age-standardised rates of ARF are seen in the NT, with 413 diagnoses of ARF per 100,000 population.¹ This accounts for more than half (58%) of all ARF episodes in the five jurisdictions studied. Overall, there is a clear pattern of markedly higher ARF rates in northern Australia (Figure 7).

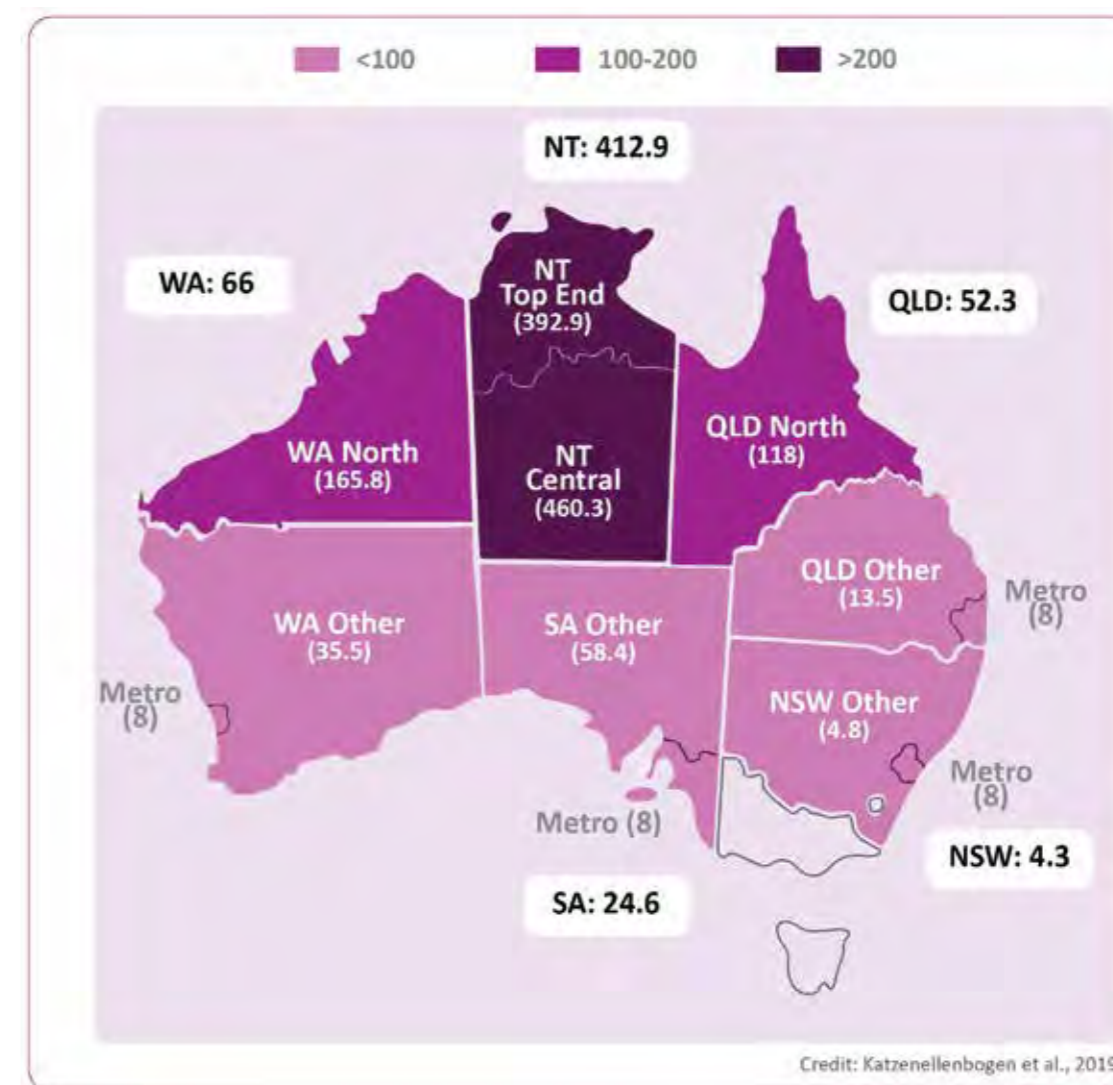


Figure 7: Map of age-standardised rates of acute rheumatic fever per 100,000 Indigenous people under 45 years, by Indigenous Region Group and jurisdiction (2015-2017*).¹
*Data only analysed and shown for Northern Territory, Queensland, Western Australia, South Australia and New South Wales.

Rheumatic heart disease

Introduction to RHD

RHD is the long-term damage to heart valves following carditis (inflammation of the heart) during ARF. RHD can result from a single severe episode of ARF or from multiple recurrent episodes of the illness.^{12,18} About two-thirds of people with ARF will develop RHD.⁷⁸

RHD occurs when the valves of the heart – most commonly the mitral or aortic valves – become thickened and scarred following an abnormal immune response to Strep A infection. This scarring damages the function of the heart valves, preventing them from closing properly and causing blood to flow in the wrong direction (regurgitation), or preventing them from opening properly and causing increased pressure within the heart (stenosis). In turn, the abnormal blood flow around heart valves damaged by RHD causes heart failure and increases the risk of other complications, including stroke, abnormal heart rhythm and infections on the heart valves.

Echocardiography (an ultrasound of the heart valves) is the best way to diagnose RHD.⁷⁵ Clinical examination, including cardiac auscultation using a stethoscope, can help diagnose RHD by detecting heart murmur but is not sufficiently accurate to diagnose RHD without confirmatory echocardiography.⁷⁵

The manifestations of RHD occur across a spectrum of severity in clinical symptoms and echocardiographic findings. Terms and concepts to describe this spectrum have evolved over a number of years, with a range of different terms in use.^{79,80} For the purposes of this chapter, concepts and associated terms are summarised in Figure 8 reflecting the following usage:

- Subclinical RHD occurs when the signs and symptoms are not detectable, but changes are detectable within the heart valves by echocardiography. These echocardiographic changes may represent borderline RHD or definite RHD, as defined by the World Heart Federation criteria for echocardiographic screening for RHD.⁸⁰
- Clinical RHD refers to valve disease which causes clinical symptoms (breathlessness or other symptoms of heart failure) or clinical signs (detectable to examination, including a murmur on cardiac auscultation).

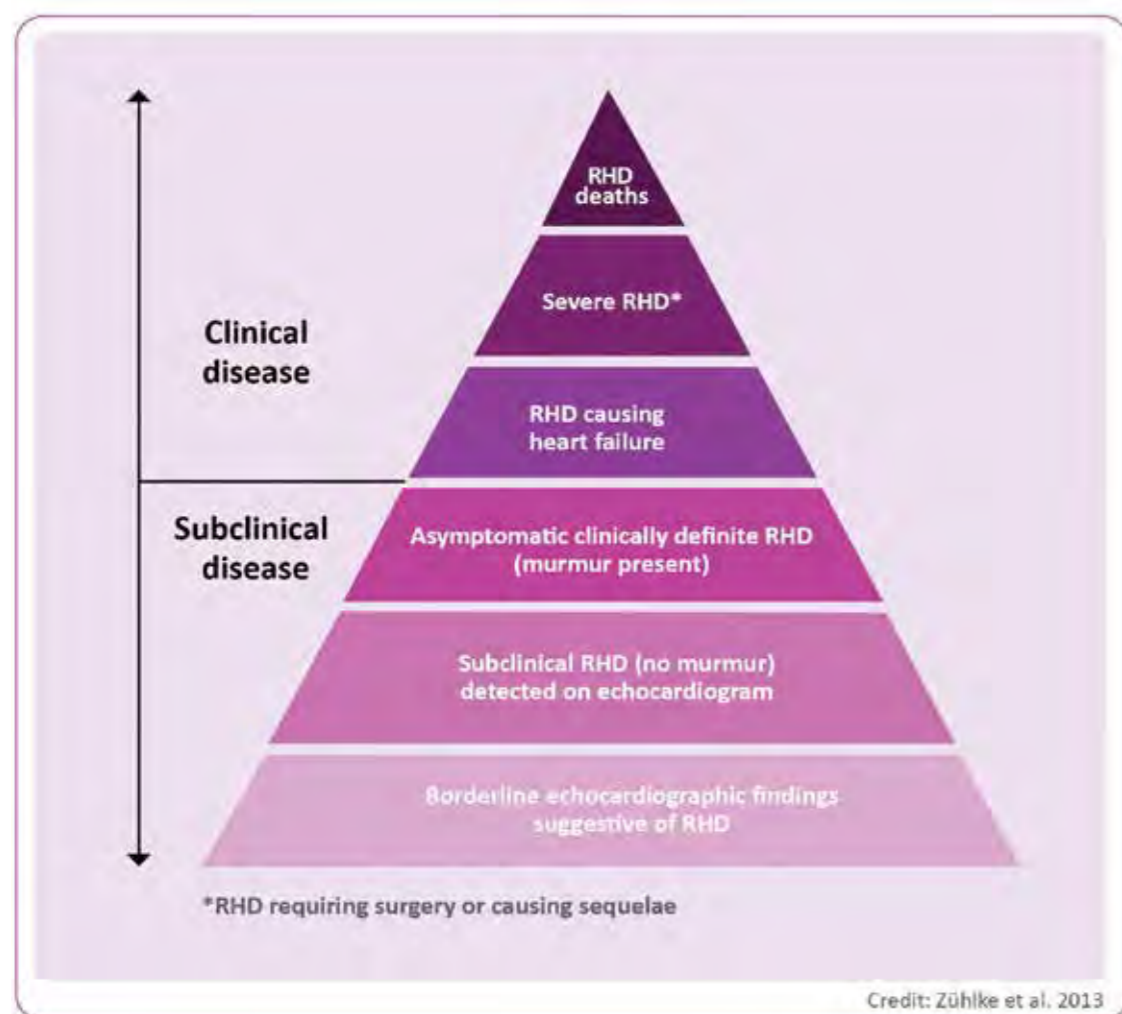


Figure 8: Population model of RHD progression.⁷⁹

Burden of RHD

In Australia as of mid-2017, there were 5,307 people under 55 years of age living with RHD. Two-thirds of those were female.¹⁷⁷ More than 2,200 (43%) of people living with RHD have severe disease. Despite making up 5% of the total population in this age range, 71% of people with RHD were Aboriginal and Torres Strait Islander people.¹ This makes the age-standardised prevalence of RHD 60 times higher in Aboriginal and Torres Strait Islander people (674 per 100,000) than in non-Indigenous people (11.1 per 100,000, Table 3).

Table 3: Annual average prevalence counts and proportions of RHD and severe RHD, by age and Indigenous status: NT, SA, QLD, WA and NSW (2015–2017, midyear).¹

	Age Group	All RHD			Severe RHD*		
		Indigenous	Non-Indigenous	Total	Indigenous	Non-Indigenous	Total
Average Counts Per Year	0-4	4	1	5	1	1	2
	5-14	356	55	411	76	28	104
	15-24	907	116	1,023	190	67	257
	25-34	978	224	1,202	301	135	436
	35-44	850	398	1,248	310	265	575
	45-54	684	734	1,418	329	557	886
All	0-54	3,779	1,528	5,307	1,207	1,053	2,260
Prevalence Per 100,000 population	0-4	4.4	0.1	0.4	1.2	0.1	0.2
	5-14	223.1	2.8	19.1	47.4	1.4	4.8
	15-24	663.2	5.6	46.0	139.2	3.2	11.6
	25-34	972.6	9.3	47.9	299.2	5.6	17.4
	35-44	1,089.7	18.1	54.8	397.2	12.0	25.3
	45-54	963.5	33.9	63.7	462.9	25.8	39.8
Crude prevalence ASP	0-54	601.2	12.9	42.5	191.9	8.9	18.1
	0-54	674.0	11.1	40.0	223.1	7.5	16.3
ASPR	0-54	60.6			29.6		

* Defined as heart failure and/or receipt of a valvular intervention as documented in hospital data, RHD register data or in the ANZSCTS; Severe RHD is a subset of All RHD
 ASP Age-standardised prevalence (World Standard population); ASPR Age-standardised prevalence ratio
 Figures in this table have been rounded to the nearest whole number

Credit: Katzenellenbogen et al., 2019

RHD is endemic among young Aboriginal and Torres Strait Islander people. RHD is primarily seen in age groups 15 years and older, with people aged 25–34 having the highest rate. In these age groups, Aboriginal and Torres Strait Islander people are about 100 times more likely to have RHD than non-Indigenous people of the same age¹ (Figure 9).

Between 2013 and 2017, 1,261 people were newly diagnosed with RHD.⁷⁷ Of these, 1,041 were Aboriginal and Torres Strait Islander people at a rate of 49.9/100,000.⁷⁷ This compares to 0.4/100,000 among non-Indigenous Australians.⁷⁷ By far, the highest prevalence of RHD and diagnoses of new RHD in Aboriginal and Torres Strait Islander people are seen in the NT (Figure 10).

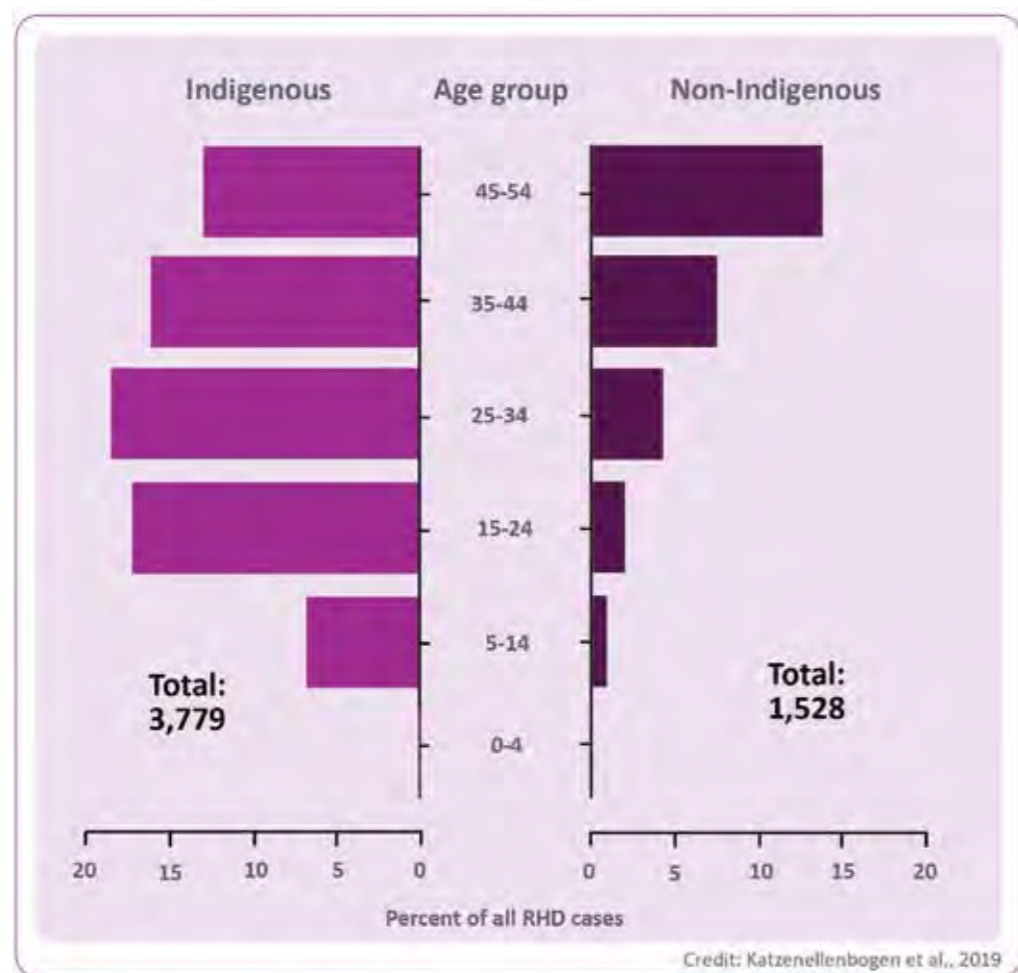


Figure 9: Age pyramid of the distribution of people diagnosed with rheumatic heart disease, by age group and Indigenous status: NT, SA, QLD, WA and NSW 30 June 2017).¹

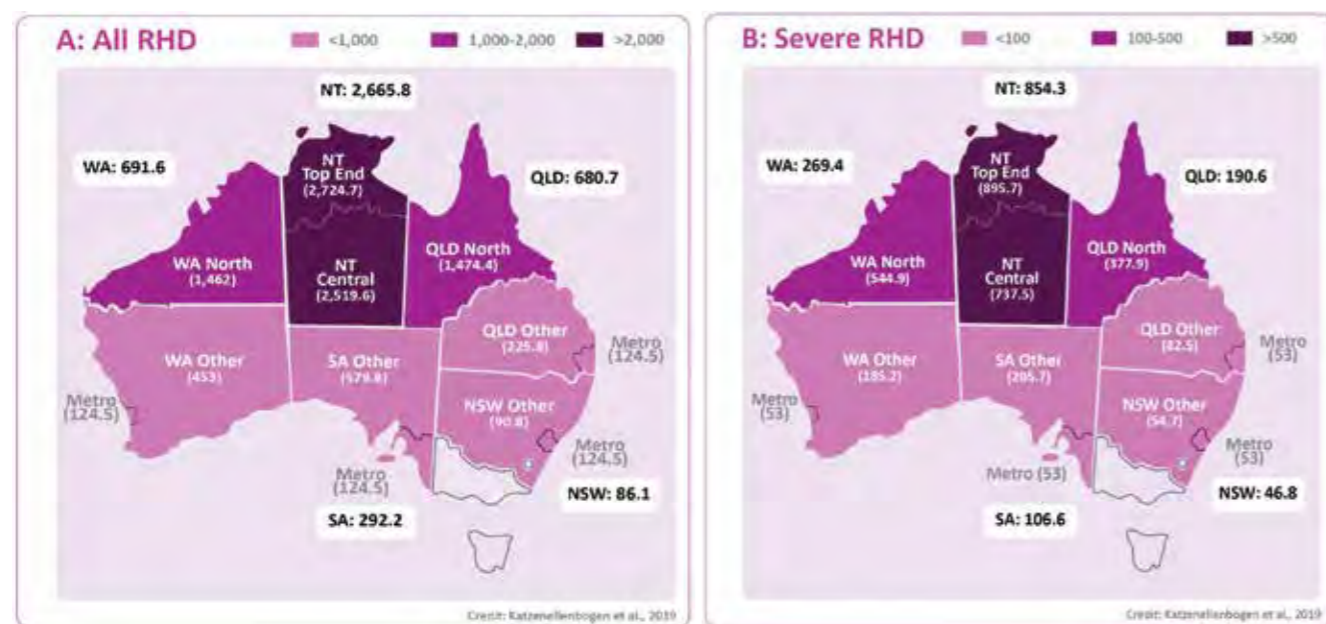


Figure 10: Indigenous age-standardised prevalence per 100,000 of total RHD and severe RHD, by Indigenous Region category and jurisdiction: NT, SA, QLD, WA and NSW (2015–2017).¹

Consequences and complications of RHD

Severe and untreated RHD can lead to a range of complications, which can in turn cause disability, reduced quality of life and premature death. These complications include heart failure, arrhythmia and stroke, and occur in younger people affected by RHD (see Figure 11).

Heart failure

Over time, heart valves damaged by RHD do not work effectively, causing pressures to rise within the chambers of the heart and the heart to fail as a pump. Without a well-functioning heart, fluid builds up in the lungs and body, causing symptoms of breathlessness, swelling and fatigue. These symptoms tend to worsen over time without treatment, becoming a condition known as heart failure.

Heart failure is the most common complication experienced by Aboriginal and Torres Strait Islander people with RHD. In total, 663 (17%) of the 4,013 Aboriginal and Torres Strait Islander people with RHD in 2017 had been hospitalised with heart failure. The rates of heart failure increase with age but are seen even in young people with RHD. Of Aboriginal and Torres Strait Islander people living with RHD in 2017, 5% in the 0–14 age group and 31% of the 40–54 age group had been admitted to hospital because of heart failure.

Arrhythmia

Atrial fibrillation (AF) is an abnormal heart rhythm (arrhythmia) and a complication particularly associated with mitral stenosis. People with RHD are at risk of AF because of the structural heart changes caused by RHD. AF tends to make heart failure worse, increasing shortness of breath and may cause palpitations. AF also significantly increases the risk of stroke. Of those living with RHD in 2017, 10% of people aged 25–39 years and 28% of people aged 40–54 years had been admitted to hospital for AF.

Infective Endocarditis

Endocarditis is a bacterial infection on the valves of the heart. People with valves that are already scarred or damaged by RHD are more likely to develop bacterial endocarditis than people with undamaged valves. Infective endocarditis is a dangerous complication of RHD and may occur following prosthetic valve replacement. One in 20 (5%) Aboriginal and Torres Strait Islander people aged 25–54 years with RHD in 2017 had been admitted to hospital with infective endocarditis.

Stroke

Stroke occurs when a part of the brain does not receive adequate blood supply. Strokes can be ischaemic (from a blocked blood vessel or clot) or haemorrhagic (from a burst blood vessel or bleed). People with RHD are at increased risk of ischaemic stroke because blood clots can form in the heart around damaged heart valves. These clots may become dislodged and block blood flow to parts of the brain. Consequently, people with RHD may be prescribed blood-thinning medications (anticoagulants). Bleeds can also occur among people with RHD receiving these medications, so careful monitoring of anticoagulation levels is required.

Aboriginal and Torres Strait Islander people are 1.5 times more likely to have a stroke than non-Indigenous people in Australia. Of the 4,013 Aboriginal and Torres Strait Islander people who had been living with RHD for less than 5 years in 2017, 3% of those aged 25–39 years and 8% aged 40–54 had been hospitalised with a stroke. Over all ages, the median age of stroke is 58 for Aboriginal and Torres Strait Islander people, relative to 75 years for non-Indigenous people.⁸¹ The disproportionate burden of RHD for Aboriginal and Torres Strait Islander people contributes to this stroke rate, though the magnitude of that effect is unknown.^{82,83}

Pregnancy and maternal health outcomes

Women with RHD may have an increased risk of complications during pregnancy. Pregnant women have an increased circulating blood volume and cardiac effort. In the setting of RHD, pregnant women with moderate or severe RHD are at risk of complications such as preterm delivery and foetal growth restriction.¹⁸ Additionally, blood-thinning medications which may be needed in patients with mechanical valves to prevent stroke are associated with increased risks to both mother and foetus.⁷⁵ Of 2,546 women with RHD in the ERASE study in 2017, 1,204 women (47%) were identified as having had a pregnancy-related admission to hospital.¹ In Australasia, 4.3 in 10,000 women giving birth have RHD.⁸⁴



Figure 11: History of admissions for rheumatic heart disease-associated complications and pregnancy among Aboriginal and Torres Strait Islander people with RHD who were alive at 30 June 2017 (WA, SA, QLD, NT and NSW): percentages with comorbidity and distribution of these people.¹

Comorbidities

When a person lives with two or more diseases (morbidities), these diseases are called comorbid. Management of one disease can sometimes impact the management of other diseases. This is often the case in RHD, particularly as advances in medical therapy mean that people live longer with a range of chronic medical conditions.

The burden of comorbid disease for Aboriginal and Torres Strait Islander people with RHD is high. For example, in Australia, 40% of people having heart valve surgery for RHD also required a coronary artery bypass graft (CABG) for ischaemic heart disease (IHD).⁸⁵ In contrast, only 21.2% of people having heart valve surgery unrelated to RHD required a CABG. Aboriginal and Torres Strait Islander people having heart valve surgery for RHD were also more likely to have hypertension or chronic kidney disease (CKD) than non-Indigenous people having RHD-related valve surgery (Figure 12).⁸⁵ These comorbidities complicate management and often require more medications, more specialist input and more complexity in primary care, and may be associated with worse clinical outcomes. For example, surgical outcomes following valve surgery for RHD are worse for people with comorbid diabetes and CKD.⁸⁶ Similarly, Aboriginal and Torres Strait Islander people with RHD who have renal failure or harmful consumption of alcohol also have an increased risk of death.⁸⁷

Comorbidities are more common in older people with RHD. However, CKD, chronic obstructive pulmonary (lung) disease (COPD, including asthma) and, to a lesser extent mental illness (e.g. depression and anxiety), are all relatively common in children with RHD. Of the 3,379 Aboriginal and Torres Strait Islander people with RHD, 668 (20%) had histories of admissions to hospital for diabetes. The same number had admissions due to CKD, although CKD affected people at younger ages than diabetes. IHD was rare under 25 years but increased sharply from 25 years, showing that at least 449 people (13%) have both rheumatic and ischaemic heart disease. A history of alcohol-related admissions (including for conditions caused by alcohol) was relatively common (959 people, 28%), and was highest in the oldest age group. More than a quarter (25.8%) of Aboriginal and Torres Strait Islander people aged 15–24 with RHD had a history of smoking, with much higher smoking rates (65.8%) in those aged 25–54 years.

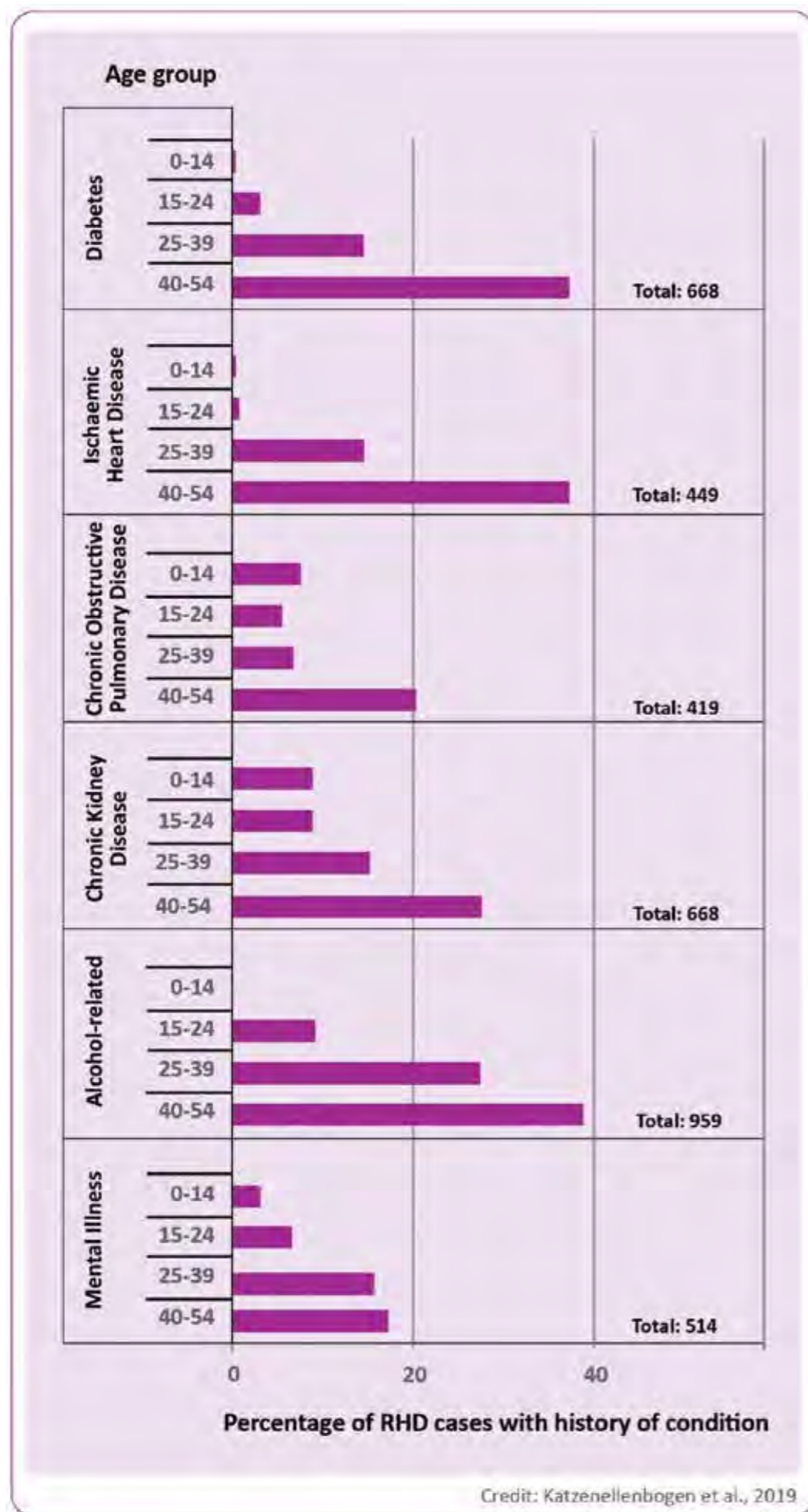


Figure 12: History of admissions for selected comorbidities among Aboriginal and Torres Strait Islander people with rheumatic heart disease alive at 30 June 2017 (WA, SA, QLD, NT and NSW): percentages with comorbidity and distribution of these people by age.¹

Severe RHD requiring surgery

In people with severe RHD, surgical intervention to repair or replace a damaged heart valve is often needed.¹⁸ A study that analysed data on young people in the NT diagnosed with RHD between 5 and 24 years of age found that more than 40% of children with severe RHD underwent valvular surgery within one year of diagnosis; 60% had undergone valvular surgery within five years of diagnosis.⁸⁸

Between July 2002 and June 2017, 3,205 valvular interventions were performed on 2,725 people with RHD living in the NT, WA, SA, QLD and NSW – an average of 214 per year. A total of 112 (3.8%) of those who had surgery died within a year of the intervention. This mortality varied across age groups, from 2% in those aged 0–14 years to 4% in those aged 35–50 years.

Mortality from RHD

Of the 275 deaths recorded in people with RHD between 2013 and 2017, 80.3% were Aboriginal and Torres Strait Islander people.⁷⁷ Almost 50% of the Aboriginal and Torres Strait Islander individuals living with RHD were 45–64 years old when they died, and just over one-quarter were aged 25–44 years.⁷⁷ Thirteen deaths (5.9%) were in young adults aged 15–24 years.⁷⁷ The median age of death was 50 years and about two-thirds of deaths (145 deaths) were among females.⁷⁷

The financial burden of RHD

Australia will need to spend at least an estimated \$344 million to provide medical care to people with a recent history of ARF or RHD (hospitalised between 2007 and mid-2016) and people projected to develop these diseases from mid-2016 to 2031.⁸⁹

For people with a recent history of ARF or RHD, the estimated cost to the health system of medical care from 1 July 2016 to the end of their recommended follow-up was \$26.5 million, comprising \$24.8 million in annual disease management cost and \$1.7 million in hospitalisations for people with ARF estimated to progress to RHD.

The estimated cost of medical care for people projected to develop ARF between mid-2016 and 2031 totalled \$141 million. This included the cost of care in a proportion of people that were expected to progress from ARF to RHD, with most of the total cost (\$85 million, 60.6%) to be incurred by children 5–14 years old. For people projected to develop RHD with no history of ARF hospitalisation (due to lack of access to health services or misdiagnosis, for example), the estimated cost of medical care was \$176 million. In total, a cost of \$317 million was estimated for the medical care of all people projected to develop ARF and RHD between mid-2016 and 2031 (see Figure 13 and Figure 14).

The figures below are drawn from the 2018 report, *Cost of Inaction on Rheumatic Heart Disease*, which predicted the financial costs of RHD based on existing cases at 2016, and projections of new cases. This foundational work, in conjunction with the ERASE dataset, AIHW data and other sources of data, informed the Endgame human and economic impact modelling.

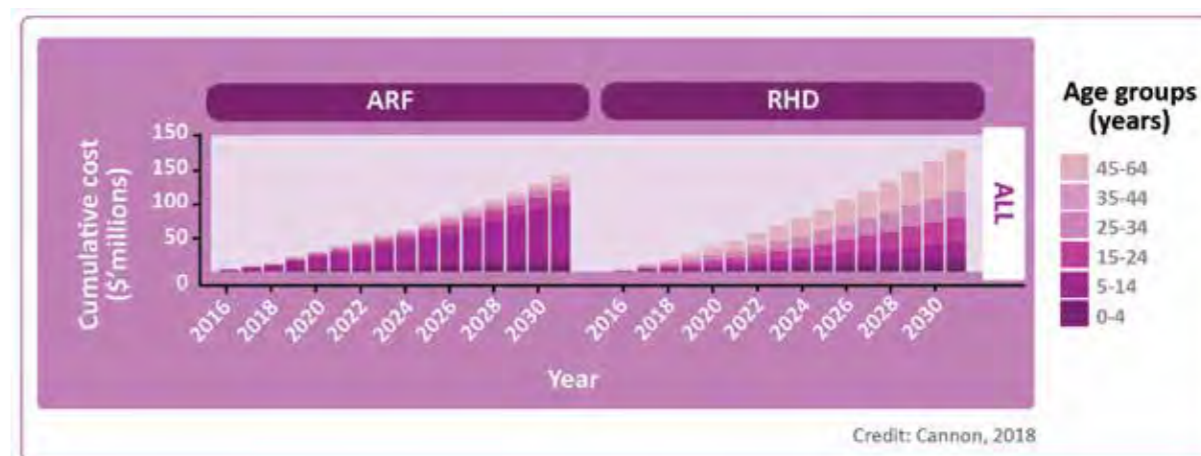


Figure 13: The estimated cumulative cost of national medical care for people with ARF or RHD projected to occur between mid-2016 and 2031.⁹⁰

2 THE LIVED EXPERIENCE OF ARF AND RHD

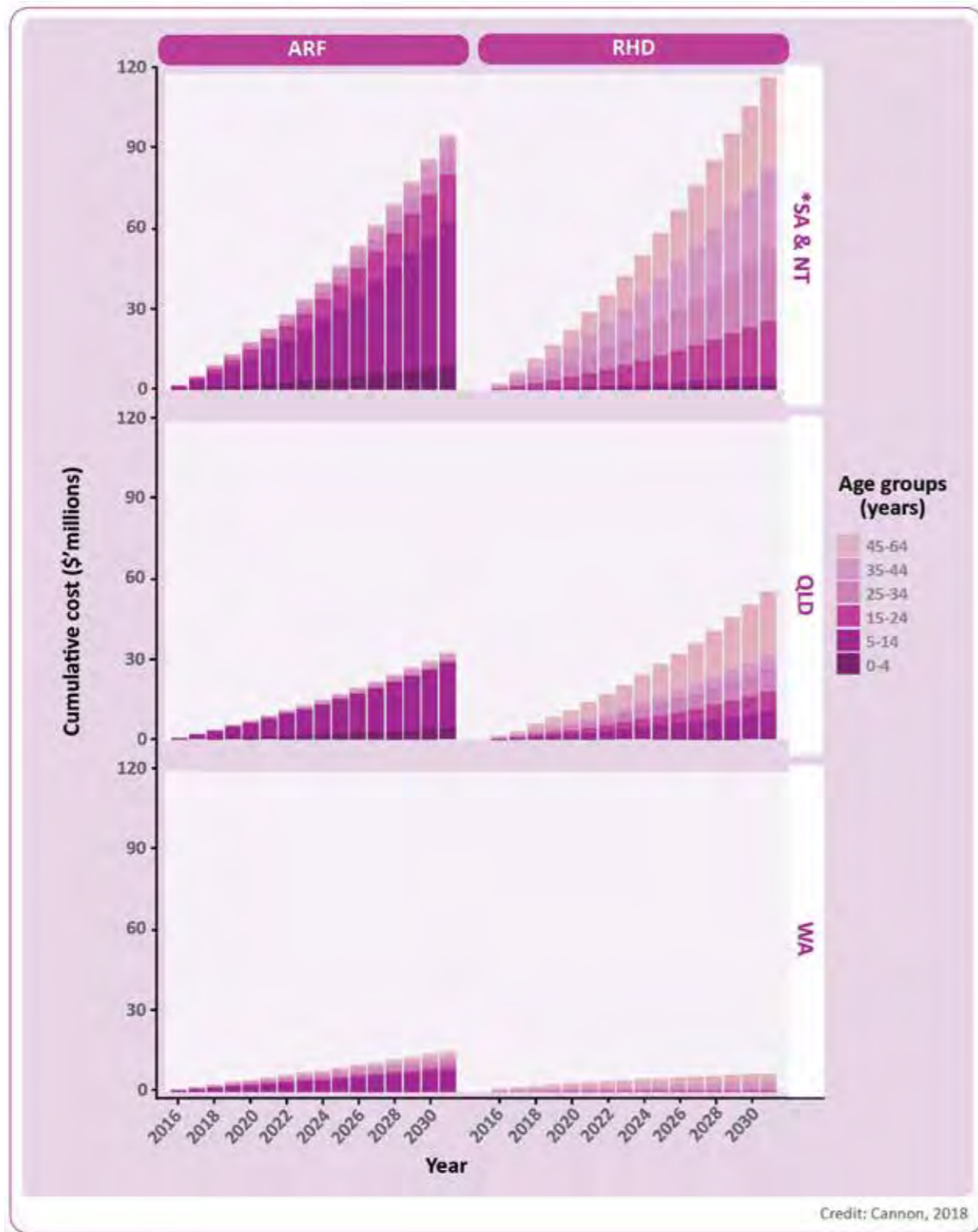


Figure 14: The estimated cumulative cost of medical care for people with ARF or RHD projected to occur between mid-2016 and 2031 by jurisdiction.⁹⁰

Notes on data sources used to complete this chapter can be viewed in Appendices One to Three.



Goldie was diagnosed with RHD aged just six. She lives with her mother in a remote Aboriginal Community in northern Australia and must travel 1,000km to visit the nearest cardiologist

Finding answers for Tenaya: from a sore throat to open-heart surgery

When Katrina Walley took her seven-year-old daughter Tenaya to the local emergency department for the fourth time within a month, she was determined she wouldn't be leaving without answers.

Tenaya had been complaining of a sore throat, stomach pains, and breathlessness. At night-time, she found it hard to lie down flat to sleep – a sign of heart failure.

“I knew something wasn't right,” Katrina said. “We got to the hospital around 8 or 9pm. At this point, her oxygen levels started dropping, so she was put on oxygen.”

By 11pm, they were being flown to Perth Children's Hospital where upon arrival, Tenaya was rushed to the intensive care unit (ICU) and put on a life-support machine – where she would remain for the next two weeks.

“I will never forget any of that – seeing my baby in the ICU,” Katrina said.

Katrina was told Tenaya's heart was failing as a result of rheumatic heart disease, and that the little girl urgently needed surgery to have one of her heart valves repaired.

“I was in shock at first. I just went and sat in one of the rooms by myself,” Katrina said.

Tenaya was in hospital for a month before she was strong enough to have the surgery. She hated being away from her school, friends, and family, and was scared about having to have surgery.

“

“By the second month, she started to cry every time she saw a nurse,” Katrina says.

”



“[On the day of the surgery] she was crying when they put the oxygen tubes in, but when she was asleep, I felt better that she was resting and that something was going to get done.”

The surgery to repair Tenaya's heart valve went well and after two months in hospital, she was finally discharged. However, just a few days later, she had to be rushed back into surgery due to complications.

Two months on from two rounds of open-heart surgery, and Tenaya and her family are in the process of relocating permanently to Perth so she can be closer to specialist medical care. Every four weeks, Tenaya must have a penicillin injection to prevent her condition getting worse, and Katrina says Tenaya is struggling to understand that she will need to have them until she is at least 21.

“She doesn't like having them, but she'll go to get them done – but then she starts crying,” she said. “After the injection she is always in pain for two days.”

A ray of sunshine for other kids living with RHD:

Billi Joh's story

When aged eight, Billi-Joh started to complain of a sore ankle, her family weren't too worried as she had just returned from a trip to a neighbouring community where she had been playing with other kids.

But a few days later, her condition had deteriorated so much that she was unable to walk. Panicked, her mum Belinda rushed her to the local clinic, who referred them to the nearest hospital in Broome – three hours drive away.

After three weeks in hospital Billi-Joh was diagnosed as having RHD – a diagnosis Belinda says took them all by surprise. “I never thought it would happen to us” she says.

Being so young, Billi-Joh did not understand what rheumatic heart disease was, and how it would impact her life. She just missed her family and friends and struggled being confined to a hospital room.

“She wanted to jump around but she couldn't do that. It was hard for her to stay in the bed” Belinda says.

Treatment for rheumatic heart disease involves one injection every 21 – 28 days for a minimum of ten years, and Billi-Joh has been told by doctors that she will need the injections until she is at least twenty-one.

While the monthly injections remain a painful and inconvenient part of Billi-Joh's life, they are something that she has come to accept.

“Having the injections had both of us in tears at first. It took four people to hold her down. She did not understand the injections were there to help her. But now, she takes herself into the clinic” Belinda says.

Not only does Billi-Joh adhere to her own treatment schedule, she is instrumental in making sure other kids with RHD in her community receive their treatment on time too.



“She has been in positions where younger girls have been diagnosed with RHD, and she has held their hand, taken them in, and gone into the clinics with them. She has been that person to talk to, who is going through the same thing as them.”

Beyond the regular injections and appointments, RHD has impacted Billi-Joh's life in a range of ways. Her mum says there is no doubt that the disease has held her back at times. She has had to take time off school, and while she refuses to let the disease get in the way of playing football and basketball, she struggles at times and can tire easily.

“

But her mum says she is a ray of sunshine despite the challenges she faces living with RHD.

”

“She is a beautiful young girl who has her health in mind. She gets down like any other teenager but looks forward to every day.”

Billi-Joh loves school, and her mum says she wants to be a counsellor or psychologist when she finishes school – so she can continue to help other children living with RHD.

Introduction

[Twenty-year-old] Elijah died only minutes after he had been laughing with us... Such inexplicable events occurred with tragic frequency. The statistics dissolved into the face of people we knew – at work, in the street, down at the shop, hanging around the playground.'

Doctors living in an Aboriginal community, quoted in Gruen & Yee, 2005.⁹¹

The consequences of Strep A infections, acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are enormous, significantly impacting the lives of Aboriginal and Torres Strait Islander children, adolescents, young adults, adults, families, and communities in Australia. This chapter explores these impacts through a systematic review of publications that include information regarding the lived experience of ARF and RHD. Throughout the chapter, the term 'people' is used for ease and consistency with the majority of the publications. However, thinking more critically, the term 'people' tends to distract from the fact that it is children and their families who are largely affected.^{1,92,93} While statistically there are more adults with RHD, the impacts on families are considerable. This chapter argues that to end RHD, the focus for prevention needs to be on children and families.

Methods

A systematic search of peer-reviewed and grey literature databases in 2019, using a range of terms related to qualitative research, was conducted to identify sources that included any evidence regarding the lived experience of people, families and communities at risk of and living with ARF and RHD in Australia. The New Zealand literature was also included due to having similar widespread social and socioeconomic marginalisation, gross health inequities, and colonised Indigenous peoples. We therefore expected to find some common experiences that would add greater depth to the limited Australian literature. Additionally, Australia and New Zealand collaborate closely on RHD prevention.

Conventional systematic review inclusion criteria were broadened to include publications that might otherwise have been omitted (such as editorials and case studies) that were authored by an Indigenous person or included Indigenous people as co-researchers. Details of the search strategy are available in Haynes et al. 2019.⁹⁴ The quality of all reviewed publications was assessed according to a hierarchy of evidence from qualitative research for clinical decision-making.⁹⁵ This allowed us to determine the reliability/generalisability of the evidence drawn from the publications to policy and practice.

Using a critical decolonising lens, all review authors (one senior Aboriginal and Torres Strait Islander research leader and two non-Indigenous researchers with extensive experience in Aboriginal and Torres Strait Islander health) contributed to an inductive thematic analysis of the lived experience evidence from all publications. This included iteratively developing, refining and validating themes and sub-themes. In all discussions, the input and expertise of the Aboriginal researcher was prioritised. Further, in addition to the thematic analysis of publications as a whole, a sociolinguistic analysis was undertaken of Aboriginal and Torres Strait Islander research participants' direct quotations extracted from the reviewed publications. This was done to prioritise direct Aboriginal and Torres Strait Islander voices over publication authors' analysis and reporting of interview data.⁹⁶

In the analysis process, despite considerable thematic similarities, it was recognised that the significant differences in primary healthcare delivery between Australia and New Zealand impacted differently on lived experience. Therefore, the Australian literature is primarily reported on here, and findings from the New Zealand literature are only included where they are notably different or, conversely, add depth to themes from the Australian literature. Only one sub-theme relating to medication costs was specific to New Zealand.

Results

In all, 24 publications were identified for review: 15 focused on Australia^{2,91,97-109} and nine on New Zealand,¹¹⁰⁻¹¹⁸ with the majority (19) published since 2013. Eight of the 15 Australian publications were driven by logistical research goals – to address functional, managerial or evaluation questions, while seven either intentionally or indirectly explored the lived experiences of ARF and RHD independently of other research agendas. Despite these differing aims, an assessment of quality found that six publications were Level 1 of the hierarchy, that is, they provide strong, generalisable evidence (more detail in Haynes et al⁹⁴). Publications were predominantly from within medical or clinical science disciplines (6), with only three considered 'social science' publications (anthropological, linguistic or sociological), and six publications demonstrating a clear partnership between biomedical and social researchers in the undertaking of the investigation.

The immediate disease-specific health and logistical impacts of Strep A infections, ARF and RHD cannot be separated easily from contextual factors related to both the sociological (socioeconomic, political, historical and cultural) and health service factors. Hence, the nine primary themes identified during the analysis have been organised into three domains that cumulatively impact on lived experience: sociological; disease-specific; and health service domains. The layered interactions between these factors are expressed diagrammatically as concentric circles, demonstrated in Figure 15. The results of the sociolinguistic analysis of 129 quotes from Aboriginal and Torres Strait Islander people included in the 15 publications (estimated to represent at least 171 people) articulate the combined impact of these factors.

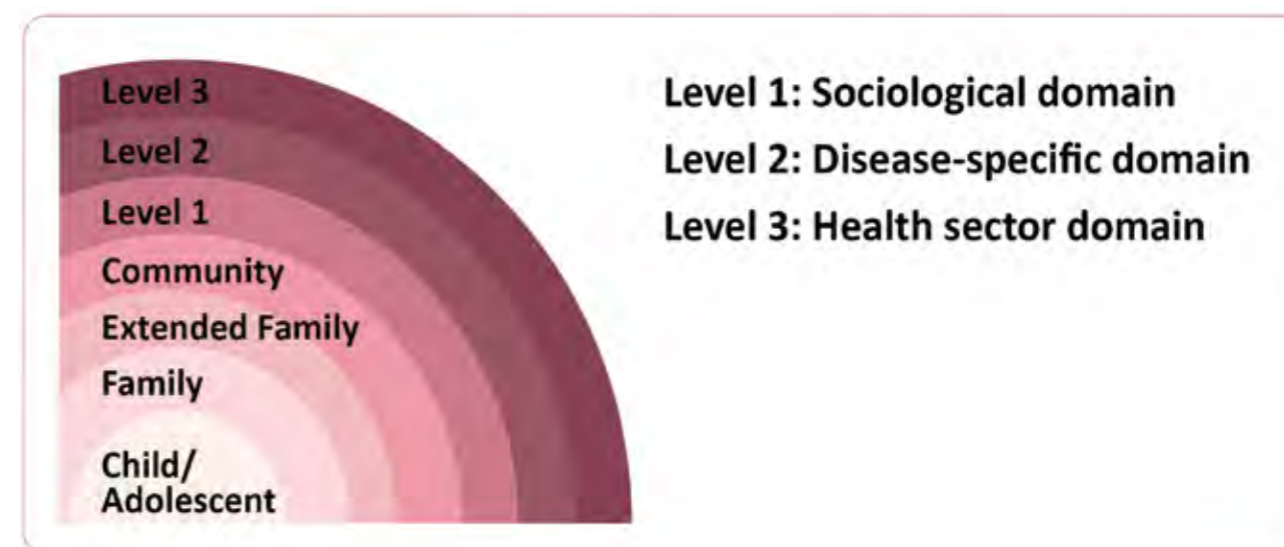


Figure 15: The layered interactions between sociological, disease-specific and health service factors on the lived experience.

Sociological domain

Many of the reviewed publications included a description of RHD as 'a disease of poverty' or more broadly as a disease that is impacted by the social determinants of health (SDOH). Given the biomedical nature of most publications, it is not surprising to find a relatively unquestioning use of the term SDOH that associates poverty/deprivation with RHD. As noted by Coffey et al (2018),²⁹ the lack of research and interventions aimed at unravelling poverty as a mechanism is at odds with the widespread acceptance of ARF and RHD as diseases of poverty. This gap masks the complexities, trauma and practices of life experiences, the neglect of which '*leaves the root causes unchanged*'.²⁹

Analysis of the reviewed publications revealed two themes (discussed further in this chapter) that demonstrate the extent to which sociological factors, including experiences related to racism and powerlessness, fundamentally impact on the 'lived experience' of disease (Figure 16). Finally, to disrupt the tendency to problematise Aboriginal and Torres Strait Islander health, our analysis identified publications that recognised/described social and cultural strengths that have positive impacts on health of people with ARF/RHD. The evidence of social and cultural strengths drawn from the reviewed publications is the third theme in the sociological domain (Figure 17).

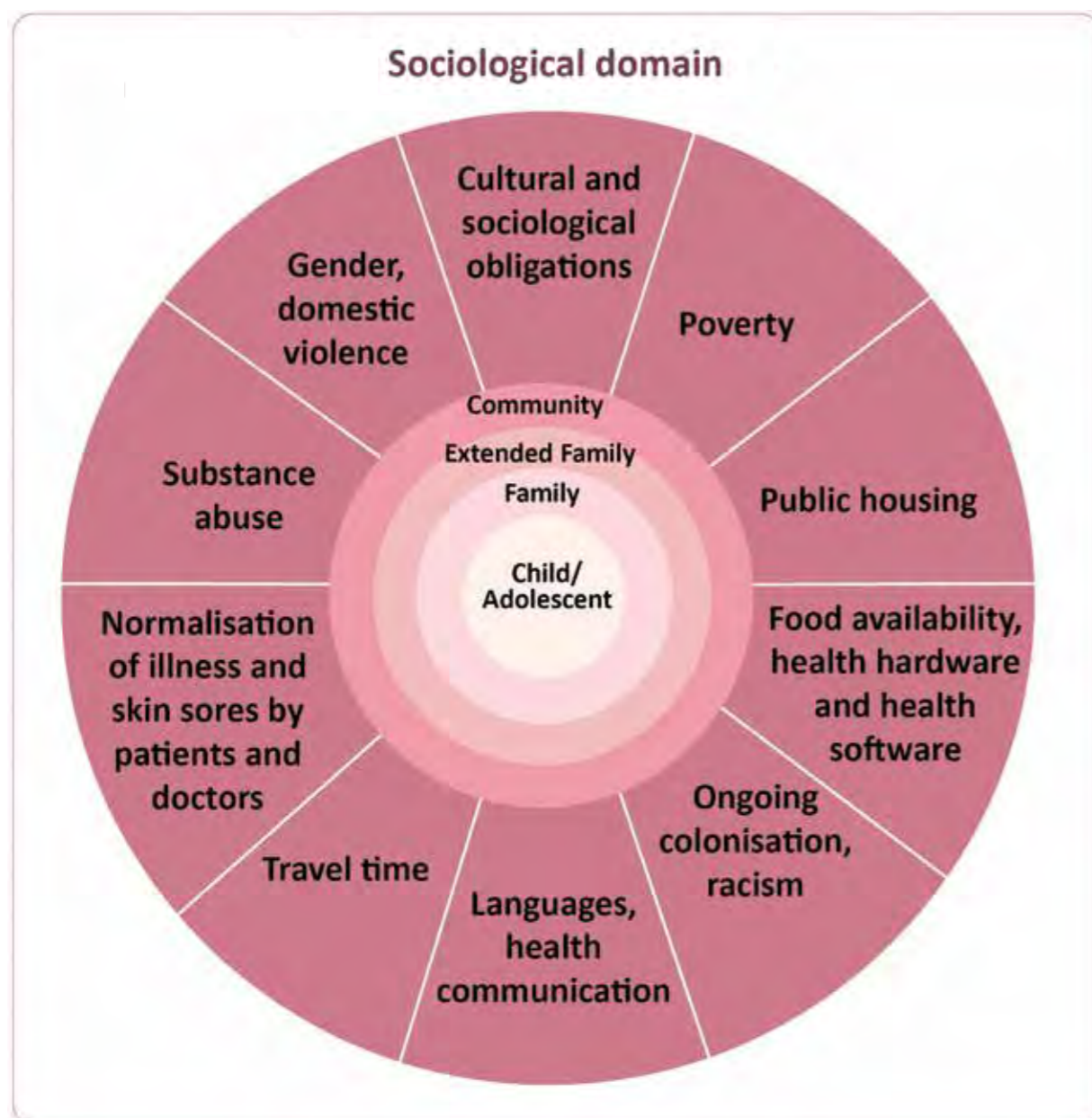


Figure 16: Sociological factors impacting on lived experiences.

Lived realities of children, adults and families affected by RHD

The majority of publications identified that the sociological factors impacting on people affected by RHD were a major determinant of their experience of the disease. Five sub-themes emerged in this domain. The lack of discussion of factors conventionally thought to impact on RHD (e.g. health hardware, overcrowding) indicates the extent to which other issues are more pressing.

Impact of poverty on capacity to manage wellbeing and health

Poverty was described as a significant barrier to making health-enhancing choices, including food choices.^{97,98,101,102} As stated in Gruen,⁹¹ there is no 'escape from the hardship of daily existence and few opportunities to improve their situation' in settings of poverty.⁹¹

'No car to go hunting, an intermittent supply of food, no phone, no money for a bus fare were all mentioned as impacting either on the patient's wellbeing, or on their ability to access medical services.'

Harrington et al., 2005.¹⁰¹

Lack of transport

The reviewed publications described stresses related to a lack of transport, particularly when there are frequent requirements to travel to access healthcare.^{2,91,97,98,100,103}

Cultural mismatch in perceptions of overcrowding

Families described having a large number of people in the house as causing hunger, being equated with children getting sick, and feeling judged or 'spied on' by healthcare providers regarding not meeting expectations in housing standards.^{91,98,100,101} Greater emphasis was placed on the impacts of housing on lived experience in the New Zealand literature and included impacts of family issues, parents being incarcerated, being in foster care, and needing to draw on whānau (family) support.^{111,113,115}

Intersection of inequities

A feature of entrenched disadvantage is the experience of multiple intersecting challenges, both individual and collective, often resulting in conflicting priorities. The reviewed literature described the intersection of inequities including the impact of poverty, indifference born out of lack of opportunities, social and cultural obligations, gender sensitivities, domestic violence, language and communication difficulties, service access issues, and illness as adding to the complexities of living with RHD.^{91,97,98,108}

Experiences of power differences and racism

The overall collective voices in the publications show that connecting with primary healthcare is fraught with experiences of racism and powerlessness. Ongoing colonisation and the impact of systemic racism was described as contributing to poor experiences of RHD and difficulties in accessing primary healthcare.^{91,98,99,102,105,106} It was suggested that the dominant culture background and biomedical worldview of healthcare providers contributes to this power imbalance,^{91,97,99,101,105,106,108,109} with the result that participants felt 'alienated by the very services intended to care for them'¹⁰⁷ and a lack of trust; 'they tell us a lying story'.¹⁰⁹ The perception, held by healthcare providers, individuals, families and communities, regarding the inevitability of illness and skin sores, contributes to care being neither sought nor offered, and a sense of powerlessness for individuals and families.^{91,97,98,102,106,109}

'Like you can get that from generation to generation, passing it down. It's in our family.'

Pregnant Aboriginal participant quoted in Belton et al., 2016.⁹⁷

The New Zealand literature gave more depth to descriptions of the impacts of power differentials, describing a lack of trust, feeling judged, having to 'push' to have throat swabs taken, and diagnosis failures even when family members suspected ARF.^{111,114,117}

Aboriginal and Torres Strait Islander culture, knowledge and strengths

Whilst cultural obligations add to the many competing demands of daily life, they also provide positive experiences¹⁰⁰⁻¹⁰² and living in communities can strengthen this connection to culture.^{91,97,100-102,109}

In nearly half of the reviewed publications, we found descriptions of protective factors of Aboriginal and Torres Strait Islander ways of being and doing,^{91,97,100-102,108,109} and these social and cultural strengths within Aboriginal and Torres Strait Islander groups may mitigate some of the difficulties of living with RHD.

'I don't feel sick back home. Yeah, because of that bush medicine. Yeah, and I got my grandmother like, cook for a person when they're sick. With the medicine from the tree, yeah.'

Pregnant Aboriginal participant in Belton et al., 2016.⁹⁷

These strengths, as described above, are culturally mandated and connect to local knowledge/languages. They are also relationship-based and include ways of caring for one another and the strengths gained from being cemented within a collective group (Figure 17).^{91,97,101,102,108}

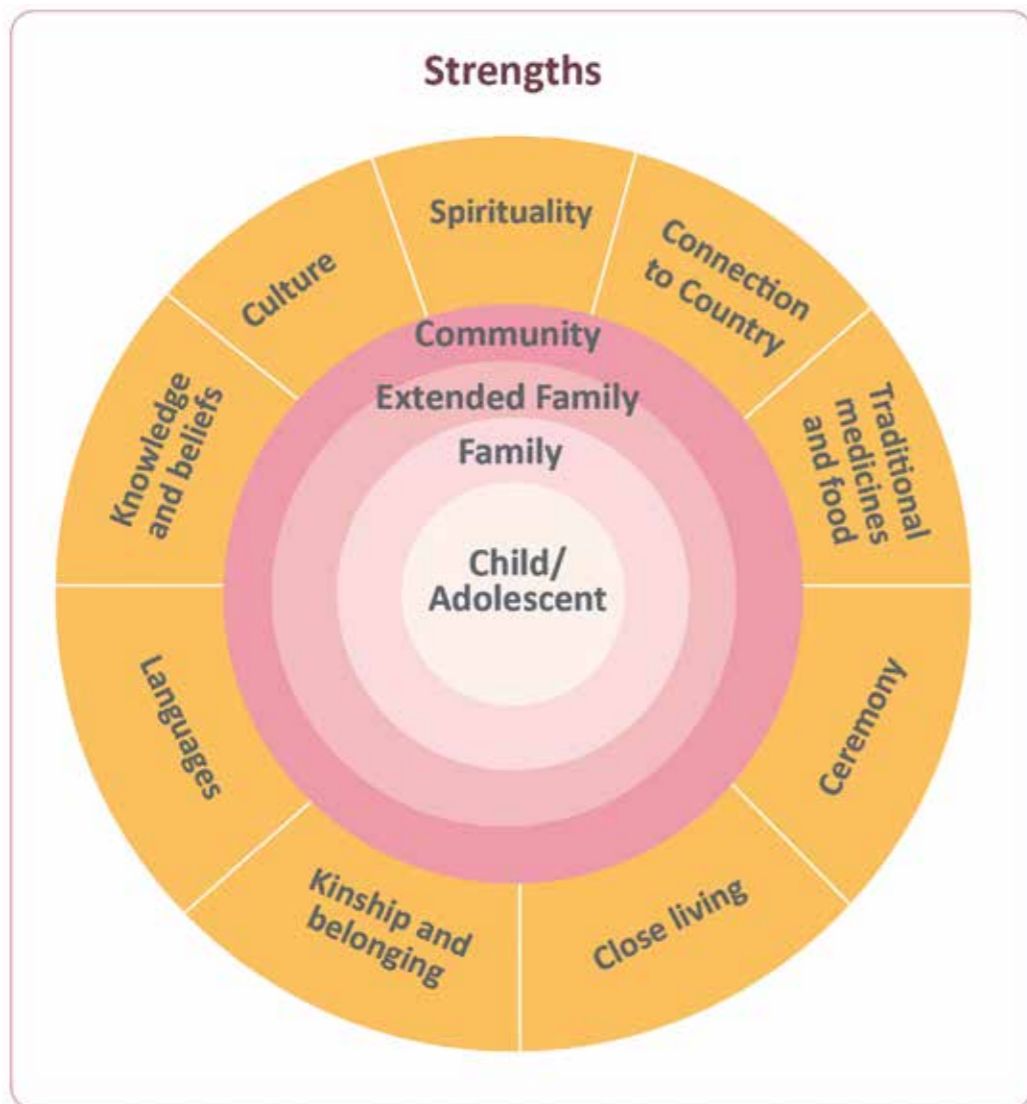


Figure 17: Social and cultural strengths of individuals and families.

Disease-specific domain

Many factors associated with RHD are common to other health experiences (for example, poor communication, inadequate access to primary healthcare, lack of appropriate information), however, some of the reviewed publications reflected specific issues associated with RHD. In particular, the complexities of RHD require adhering to a long-term, often painful, secondary prophylaxis regimen; suffering restrictions on normal activities; travelling long distances for heart valve surgery; and negotiating the transition from paediatric to adult care.^{2,102,104,106,107,109} Further, an RHD diagnosis impacts the whole family. Impacts on children include: not being able to do what other children can; the pain and inconvenience of injections in the context of school and sports; missing out on parents who are travelling for care because of their RHD; and growing up without parents who die from RHD-related causes. Finally, deaths in hospital may mean people are buried off country.² These factors are presented in Figure 18.

‘One of the biggest implications of her disease was that we were taken off country... because of her condition, we lived all over Australia at different missions and communities and, sadly, my mum is buried off country.’

Adult child of an RHD patient quoted in Wyber et al., 2018.²

Three themes related to RHD-specific lived experience were identified: experiences of medication and adherence; experiences of pain associated with medication; and collective trauma.

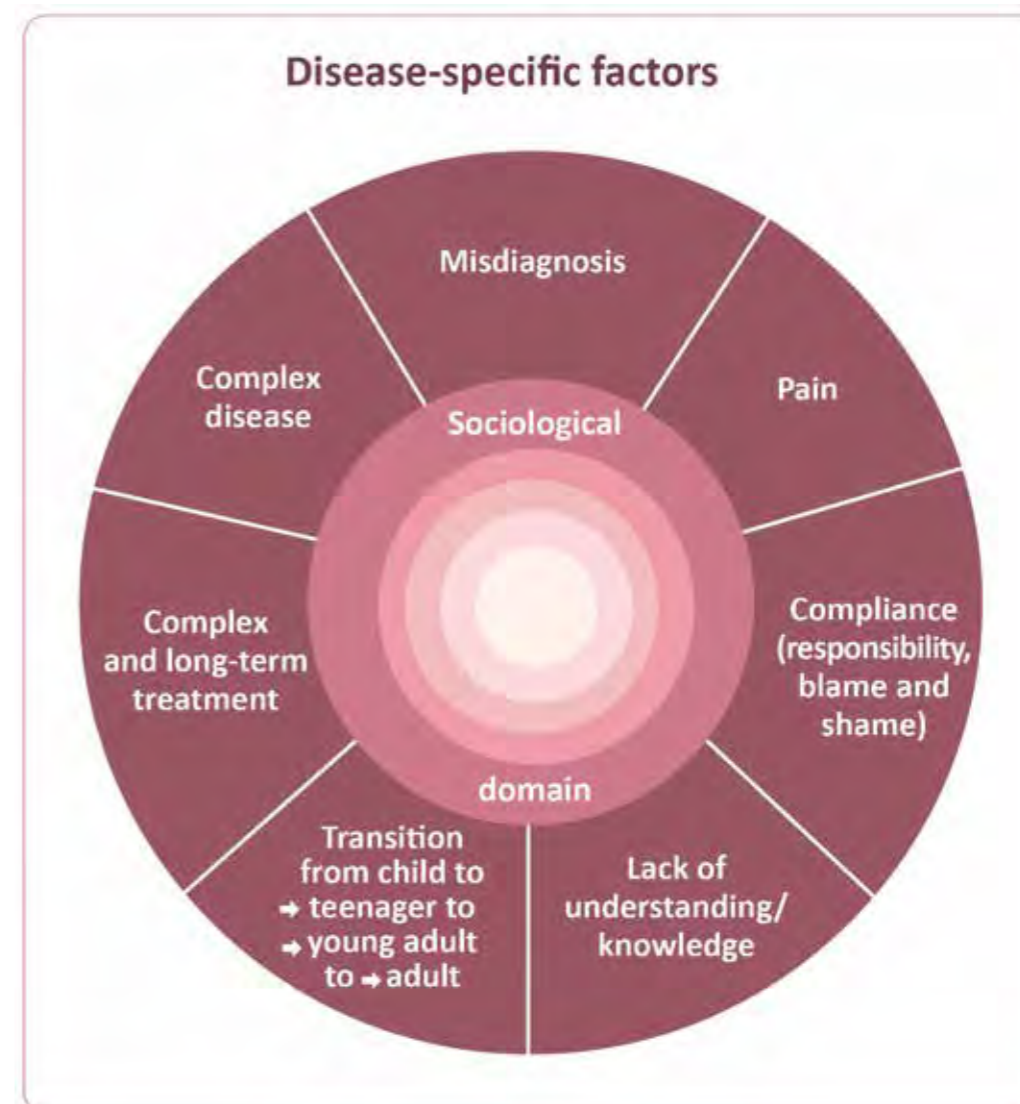


Figure 18: Disease-specific factors impacting on lived experiences.

Experiences of medications and adherence

Much of the reviewed literature focuses on the delivery of secondary prophylaxis injections. This reflects a strong focus of the reviewed publications on service delivery, identifying barriers to adherence, and program evaluation assessments. This relatively well-developed body of literature revealed three sub-themes related to a shifting locus of responsibility that was variously attributed to the health service (invoking the need for good recall systems, good connection with clients, timeliness and flexibility);^{100,101,103,106} or parents (who are often considered responsible for their children’s welfare in all matters) and/or the patient themselves.^{99,103,107}

Constant shifting of locus of responsibility for medication adherence

The reviewed publications reflect a tension regarding who has ultimate responsibility for medication adherence.^{98-103,106} This tension was often described in terms of blame (service provider attitudes)^{101,103,107} and powerlessness (community perceptions).^{91,97,104,109} For example, there was a juxtaposition between parents wanting their children to receive their injections and yet not wanting to inflict a painful and distressing procedure upon them against their wishes.⁹⁹ In one study, a preference for healthcare workers to actively seek out those requiring secondary prophylaxis to the point of delivering home care was preferential to parents taking their children to the clinic for injections.¹⁰¹ This shifted the locus of responsibility to a healthcare provider and removed the parents’ sense of inflicting pain on their children, but still ensured care was provided for the child.

Health provider attitude to low medication adherence

It was reported that health service providers associated non-compliance, particularly in younger children, with a parental failure to care for their families.^{99,101,103,107,109} One publication provides an example of negative language used by healthcare providers with regard to compliance and illness.¹⁰⁷

'Either they 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.'

Healthcare provider quoted in Read et al., 2018.¹⁰⁷

Family and individual perceptions of low medication adherence

In interactions with the healthcare system, parents interpreted 'victim blaming' messages from health professionals as cited above, who implied parents' circumstances were directly under their control and not influenced by external, unpredictable factors.^{2,97,99-101,108} The New Zealand literature adds depth to this, describing families' experiences around expectations that they could ensure children's adherence to prophylaxis without exception.²⁰ Another described parental remorse at not realising the extent of their child's illness, and not seeking care earlier.¹¹⁷

Non-compliance was not perceived as a problem by some Aboriginal people^{101,105,108} and in fact may sometimes be observed as a powerful act: *'without power to be heard or to negotiate, Aboriginal children and young people may use the only power they have, which is to refuse or avoid injections.'*¹⁰⁵

Experiences of pain associated with medication

The mainstay of management for ARF remains the long-term and regular regimen of penicillin injections which makes the issue of injection pain unavoidable, and for many children and their families, a central issue. A subset of papers explored pain associated with injection delivery, generally in the context of evaluating barriers to adherence.^{2,99-101,105} Several publications described insights from Aboriginal and Torres Strait Islander adolescents on their experiences of pain, finding that there were variable experiences and fears associated with uncertainty around the injection regimen.^{99,104-106,109}

Healthcare providers spoke about vicarious trauma in the process of giving injections as 'intrusive', patronising, exploitative of the power differential, painful, 'persistent', unpredictable and chaotic.^{99,101,105} In contrast, the clinical management of injection pain was found to be perfunctory and haphazard^{99,102,103,105,109} or poorly informed, for example accepting patient stoicism as normal.¹⁰⁵ Injection pain experiences indicated that there were deficits in clinicians' skills to manage episodes competently through child-focused care or adolescent care.^{99,104,105} The fact that it is predominantly Aboriginal children requiring the injections, and the majority of healthcare providers giving the injections are non-Indigenous, thus representing the dominant and the privileged, means the repeated painful episodes have potential to deepen already-felt inferiority and lack of power among Aboriginal families.¹⁰⁵

'The hardest part of living with rheumatic heart [disease] is to keep having the injections. It makes me feel really sad and sometimes mad. It's really, really hard.'

Five-year-old female post heart surgery quoted in Wyber et al., 2018.²

'When I get the injection, it is painful for two to three days. I limp and it sometimes keeps me awake at night. It leaves a lump in buttock that is painful to touch.'

Eighteen-year-old female on regimen of seven years quoted in Mitchell et al., 2018.¹⁰⁵

Box 3: The experience of 'pain'

In the literature, the realities of the injection pain for children and adolescents reflected all three domains of the lived experience of RHD. For instance:

- Angst and uncertainty about who holds responsibility for the injections (Disease-specific domain);
- Parents' anguish seeing children in pain makes it difficult for them to assume responsibility for treatment, particularly when their child is unwilling to receive it (Disease-specific domain);
- Lack of long-term appropriate support and counselling for the regular painful procedure (Health service domain);
- Lack of power to communicate and negotiate with healthcare providers on managing their child's injection pain (Sociological domain); and
- Inadequate opportunities to gain health literacy about the injections in the context of trauma (all three domains).

Collective trauma

Analysis of the 129 combined extracted quotes revealed an overwhelming sense of collective trauma around RHD experiences within Aboriginal and Torres Strait Islander families. This was expressed as feelings such as children's fears about death, anger towards healthcare services, a sense of unfairness at poor treatment, a sense of abandonment, unworthiness and devaluing as a person, and especially as experiences of institutional racism.

Health Service domain

In addition to the sociological factors (socioeconomic disadvantage, racism, powerlessness) and RHD disease-specific factors discussed above, the reviewed publications described the impact of a range of health service-related factors. Dominant themes were inadequate access to primary healthcare (including that services don't meet needs)^{91,97,101,103,107} and the impact of poor health communication, including that RHD care is not in healthcare providers' repertoire, and they are therefore unprepared and problems appear intractable.^{97,98,101-103,106,107,109} Finally, not all publications reported negative experiences, with some describing factors that can contribute to positive experiences and high-quality care delivery. These included when healthcare providers were aware of the feelings of those living with RHD and engaged with families, increasing treatment uptake.^{91,99-102,105,107} Figure 19 outlines these factors.

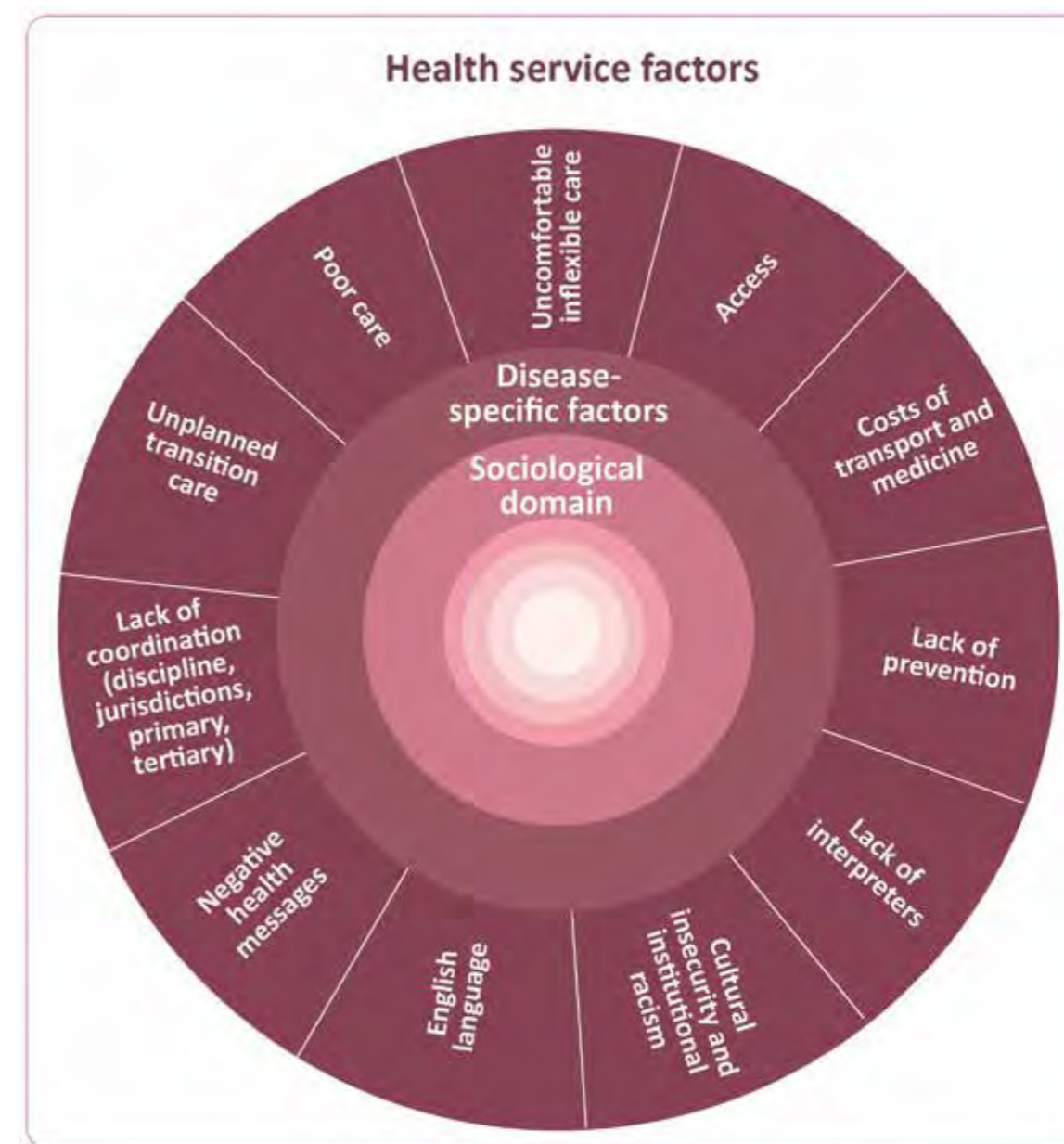


Figure 19: Health service factors impacting on lived experiences.

Inadequate delivery of primary healthcare

The literature commonly reflected that access to primary healthcare was considered inadequate and culturally unsafe. Reviewed publications identified impediments to accessing healthcare, including part-time availability of services, doubts about confidentiality, inappropriate gender of healthcare providers, and questions of competence. The identified failure of services to take into account factors such as poverty, unemployment, powerlessness, and social obligations identified in early themes as significantly impacting lived experience is particularly troubling.^{2,91,98,108}

The New Zealand literature described additional impediments to accessing essential primary care, including the incidental costs of seeking care, such as taking time off work to attend a GP appointment with a child, transport to services, or the cost of medications.^{111,112}

At a system level, insufficient resources and policy decisions result in limitations to healthcare provided to RHD patients, particularly in remote and regional areas.^{91,97-99,105} Limitations include treating only the disease as opposed to comprehensive care, and having a lack of understanding of the lived realities of hardship, suffering and invisibility of the day-to-day struggles of Aboriginal and Torres Strait Islander people.^{91,97,99,101,109} One specific area of health service gap is for young people transitioning from paediatric to adult care (both at primary and tertiary levels). Particularly given inadequate expertise in Adolescent Health, this results in young people getting lost in the system with poor to no follow-up due to lack of communication between health professionals.^{99,104,106,109}

Health communication

While health staff often recognised that a clear understanding of ARF and RHD was important, complex disease management and barriers to effective health communication were identified.^{97-104,106-108} This theme was cited significantly more frequently than any other in our review (49 instances compared to 21 for the next most cited theme of experiences of pain), and every publication discussed some aspect of communication. Three sub-themes emerged, discussed below.

Poor communication

Access to knowledge and information was discussed in most publications. Nearly all publications found that family members and people living with ARF and RHD self-identified a limited understanding of the disease, its causes and methods of prevention.^{97-104,106,107,109} Many Aboriginal and Torres Strait Islander people are not proficient in reading or speaking English,^{91,97,98,100-102,104,106,108,109} and there is a sociocultural/linguistic disconnection between largely non-Indigenous healthcare systems and Aboriginal people.^{91,97,103,104,106,107}

‘During research interviews with interpreters the women said there were no words for ‘RHD’ or ‘heart valves’ in Aboriginal languages. These biomedical disease descriptions were new concepts that were poorly explained in the health education materials offered to women.’

Belton et al., 2018.⁹⁸

Additionally, the requirement for patients to access multiple health professionals and retell their stories numerous times compounds communication difficulties, particularly in the context of dealing with different healthcare levels (primary, tertiary); disciplines (maternity, cardiac); and jurisdictions (government, non-government and across States).^{97,98,100}

Impacts of poor communication on families

Poor communication compromised ongoing engagement with healthcare and was often attributed to health staff providing biomedical explanations of the disease, which had no functional or conceptual meaning for people receiving health information.^{97,99,104,107} People affected by ARF and RHD reported feeling bad/shame and powerlessness associated with limited understanding of the disease due to healthcare providers using complex medical explanations.^{97,100,101,104,107} People living with ARF and RHD and their families often felt unable to question healthcare providers or say that they didn’t understand, and frequently indicated a strong, unmet desire for meaningful information and communication about ARF and RHD. Knowledge was viewed as a valuable commodity that would be of benefit to community and family.^{97,101-103,107,109} Arguably, the denial of Aboriginal people’s languages within health institutions is

a denial of their identities and a demonstration of white dominance,¹⁰⁶ because languages are clan and country identity markers within localised populations.^{97,99,104,106,107} One paper proposed that failure to communicate may result in non-compliance; people *‘not fluent in English, who do not understand medical terminology, and who are not forthcoming with questions, are all at risk of being neglected’*.¹⁰³

Effective communication

In contrast, some of the reviewed publications discussed examples of effective communication such as being empowered,⁹⁹ using own language,¹⁰⁵ and being at the right place and time.¹⁰⁷ Information also needs to be delivered in a manner familiar to the individual or group to ensure understanding and in a manner that avoids producing negative feelings.¹⁰² The ideal way of sharing information was described:

‘We have our own ways of understanding illness and health. Only by using our own words, metaphors that are meaningful to us, and a communication style that is respectful, can we hear the messaging from health professionals. This means the health messages need to be made with us rather than for us.’

Aboriginal participant quoted in Haynes et al., 2019.¹⁰²

Factors contributing to positive experiences of healthcare

Not all publications reported negative experiences. Some described factors that can contribute to positive experiences and high-quality care delivery; for instance, when families and/or healthcare providers were actively considerate of the feelings of those living with ARF and RHD, treatment uptake increased.^{99-102,105} Families were viewed as important facilitators of this, be it via emotional support, material resources such as transport, or reminding people when their injections were due.^{97,98,100-102,106,109} The Australian literature placed more emphasis on healthcare providers who engaged with families and offered a ‘pastoral’ care role, including visiting people at home, talking to families, and encouraging and caring for people living with ARF/RHD emotionally, like a family member (relational care).^{91,99-103,105,109}

It was noted that while it might be expected that people living with RHD would benefit from the services provided by Aboriginal Community Controlled Health Services (ACCHS),¹⁰⁰ none of the publications involving ACCHS as study sites mentioned quality of service, nor was there any indication that having Aboriginal and Torres Strait Islander staff mitigated against poor experiences or improved knowledge.^{91,101}

“‘Good care’ for patients with RHD was often discussed using the terms djäka, meaning to care for physically, and gungga’yun, translated as to encourage or to nurture.’

Harrington et al., 2006.¹⁰⁰

The role of the wider community in the provision of care was also important. Local community navigators who spoke local languages and understood cultural and community issues were viewed as essential collaborators with health service providers, complementing and enhancing service delivery through the relationship.^{101,102,104} Community members in one study advocated for a collectivist, whole-of-community approach to tackle RHD as opposed to an individualistic process.¹⁰² Further, when providers acknowledged the wider community and the challenges contained within community living, they became more willing to engage with the complex lives of people living with ARF/RHD and their families by undertaking non-health service activities, and delivering care more frequently at home; becoming an asset to them.⁹¹

Discussion

Findings from the systematic review providing information about factors impacting on the lived experience of RHD were reported across three domains: the sociological factors; disease-specific factors; and health service-related factors. These domains were observed to interact cumulatively, magnifying the difficulties of life with RHD. Additionally, the analysis of participants' quotes from all reviewed publications revealed an overwhelming sense of collective trauma around RHD experiences within Aboriginal and Torres Strait Islander families. Taken together, these findings provided considerable evidence of negative lived experiences rather than positive ones. Many factors contribute to negative lived experiences of RHD, however, without the capacity to influence socioeconomic factors or provide a 'cure' for RHD, health system factors are the domain most amenable to change to improve the lived experience of RHD.

While RHD management is significant during childhood and adolescence, there was a large gap in the literature related to children's and adolescents' lived experience. Notable exceptions in the reviewed literature were the work of Mitchell et al.^{104,105,109} and Spray et al.¹¹⁸ from the New Zealand literature. This reflects a noteworthy knowledge gap. While recognising the devastating impacts of RHD on families and communities, particularly when adults with RHD are also caring for children, there are strong arguments for taking a child and adolescent focus in preventing RHD overall. This focus would also build on the Aboriginal and Torres Strait Islander cultural strength that recognises the place of children in the continuity of Indigenous society; they grow up to be adults with the responsibility to care for their culture and country.¹¹⁹ This requires different resourcing and co-design of health systems in order to prioritise local community input and recruit healthcare providers with training in Adolescent and Child Health.

Gaps in the literature, such as just described, are likely to be the result of a biomedical focus. The reviewed literature, despite having qualitative research as primary search criteria, is nonetheless very biomedical both in its focus and in the background of researchers, and correspondingly there is a lack of attention to sociological complexities. In addition, the reviewed literature was mostly published in biomedical journals so that even if authors had done sound qualitative lived experience research, reported findings tended to be limited by journal requirements.

The dominant biomedical lens also predisposes service providers to uncritically accept information or not ask how things might be different. This was reflected in the tendency of the reviewed literature to reinforce negative stereotypes and hold a problematised view of Aboriginal and Torres Strait Islander people and issues. We attempted to disrupt this deficit discourse by looking for instances of social and cultural strengths. As a result, we identified two themes that have positive impacts on health: 'what works for good communication' and 'evidence of social and cultural strength'. A greater body of research with a strong social science lens may result in more strengths-based findings.

Similarly, the literature commonly reinforced perceptions that non-compliance was a failure of families to provide care. This is despite strong evidence to suggest non-compliance is rather more about families' lack of understanding about RHD and the failure of healthcare providers to provide a clear explanation.¹⁰⁷ That is, failure to communicate was related to non-compliance.

Finally, as noted above, while it might be expected that people living with RHD would benefit from the more culturally appropriate services provided by ACCHS, none of the publications involving ACCHS as study sites^{91,100,101} provided any evidence regarding the quality of service, nor was there any indication that having Aboriginal and Torres Strait Islander staff mitigated against poor experiences or improved knowledge.^{91,100,101} This lack of evidence should be considered a research omission rather than a reflection of ACHHS and Aboriginal and Torres Strait Islander staff, again reflecting the biomedical nature of the publications reviewed. Others have noted the difficulty in evaluating the work of ACCHS, including ethics and governance barriers and ACCHS not having time or funds to do this type of research.¹²⁰

Providing good-quality care requires health service providers to overcome the issues of inequity, cultural inappropriateness, complexity, and institutional racism. Consequently, *'a decolonising approach to primary healthcare in remote services is needed in order to improve shared decision-making and alleviate power imbalances between healthcare providers and Aboriginal patients'*.¹⁰⁹ This requires changes to standard biomedical approaches. In particular, we need community-led and co-designed research. The collective trauma revealed by analysing participant quotes points to the need for

recognition of ongoing trauma experiences and for this to be addressed in care models for families such as Trauma Informed Care (Mitchell et al, in press).

Conclusion

While this is the first time a systematic review has been undertaken on the lived experiences of RHD, many of the findings that emerged have been available for some time but have yet to be implemented within primary healthcare or strongly inform policy. To improve care for children, young people, families and communities living with RHD, earnestly addressing the results of this review is critical, in particular focusing on healthcare service design and operation. Such improvements will require shifts in care focus, authority and control so that services are flexible, culturally safe, adaptive to local contexts, and family/community-based, as expressed by people living with ARF and RHD.

Diagnosed at four, Chad is learning to live with RHD

Even though he was just four years old at the time, Chad can still vividly recall the moment his journey with rheumatic heart disease (RHD) began.

He woke up one morning with joint pain – a symptom of acute rheumatic fever, the precursor to rheumatic heart disease.

“I couldn’t feel anything in one leg. I had to hop around. Then the next morning my other leg did the same – so we had to go to hospital,” Chad says.

Chad’s mum rushed him to their local hospital in regional Western Australia where, due to the severity of his condition, doctors made the decision to fly him down to Perth that night. It was his first time on a plane and he found it very overwhelming.

It was a frightening time for his parents, too. His dad, Shannon, says he’d never heard of rheumatic heart disease before.

“We’d never heard about it, never knew about it – but we did know it was serious,” Shannon says.

— “ —
“It was scary to hear he had a hole in his heart.”
— ” —

Chad was in hospital for a total of three weeks, and says he struggled being away from his friends, brothers and sisters.

Although Chad didn’t end up having to have heart surgery, he was told that in order to keep his heart strong he must have an injection of penicillin (Bicillin) every 28 days until he is at least 21. Now aged eight, he’s been having these painful injections for half his lifetime.



For a range of reasons – including the pain of the needles and inconvenience of having to attend the clinic every month – many people living with RHD do not receive their injections on time. In 2017, only 36 per cent of those prescribed preventive penicillin received 80 per cent or more of their prescribed doses, putting them at risk of heart failure, stroke and death.

Despite the fact that Chad’s family has moved frequently since his diagnosis, no matter where they are, they always make sure Chad gets his life-saving injection when he needs to.

“He has them every month, on time. It’s a priority,” Shannon says. “And we see the cardiologist every 18 months. This time he said everything looks good – the Bicillin is doing its job. I’m glad it has worked out and it’s going good. You can’t mess around with the heart.”

But while Chad knows the importance of getting his needle every month, it hasn’t always been easy.

“When they do it slow, it stings,” Chad says.

“He used to cry at the start but now he’s very tough – but I still see him wincing – it does hurt,” Shannon adds. “He hasn’t cried for a while – he’s getting used to it. He knows he has to have them.”

3 THE POLICY CONTEXT



Introduction

This chapter situates the goal of rheumatic heart disease (RHD) elimination in the current Australian policy context. Prevention strategies to achieve this goal are complex and interrelated, which means a comprehensive strategy will be enabled, or hindered, by policies across multiple portfolios, and responsibility must be taken by Federal, State and Territory governments.

The chapter is structured in five parts:

- RHD prevention in Australia;
- Health system and policies;
- Monitoring and reporting;
- Critical enabling policies; and
- The reform agenda.

The history of RHD prevention in Australia provides the context for a different, comprehensive approach and the increased and sustained investment required if RHD is to be eliminated. The limitations of the *Rheumatic Fever Strategy*, as the keystone policy for RHD control, are evident through the continued high rates of acute rheumatic fever (ARF) and RHD.²

The disease trajectory and opportunity for prevention of Strep A, ARF and RHD necessitate a policy response across all sectors of the public healthcare system, from the primary to tertiary level. The fragmented and complex nature of the system and the impact of numerous policies at all levels of government present challenges for the implementation of the *Endgame Strategy*. However, timing for implementation is ideal, with the Closing the Gap refresh process and negotiations for a post-2020 national health agreement presenting opportunities for the *Endgame Strategy* to positively influence policy decisions.

Descriptions of the mechanisms for monitoring and reporting on health policy point to deficits in current practice. These deficits and broader failures in evaluation of Aboriginal and Torres Strait Islander social policy highlight the need for a robust monitoring and evaluation plan for the *Endgame Strategy*, developed in conjunction with the implementing organisations. Integral to this is the need for policies around the collection and sharing of data which prioritise community-led data governance and ownership, enshrined in the concept of Indigenous Data Sovereignty.

With social determinants – the conditions in which people live, work and play – responsible for at least 34% of the health gap for Aboriginal and Torres Strait Islander people,¹²¹ the *Endgame Strategy* must align with, or seek to influence, not just health policy but other critical enabling policies such as housing and environmental health. Failures of remote-area housing policy, currently mired in political debate, to meet the needs of Aboriginal and Torres Strait Islander communities, and the lack of consistent, well-resourced environmental health services nationally, are barriers to the success of RHD prevention strategies. Recommendations of the *Endgame Strategy* prioritise structural and systems changes to mitigate this and drive change.

Finally, the reform agenda in Aboriginal and Torres Strait Islander-government relations, initiated by leading Aboriginal and Torres Strait Islander organisations, have set principles and priorities for a co-design approach. These will guide the implementation of the *Endgame Strategy* and provide a basis for the Aboriginal and Torres Strait Islander-led consultation process which will be the first stage of implementation.

This chapter does not make specific policy recommendations, which are made throughout the following chapters. The overview of systems and policies provides context for these recommendations.

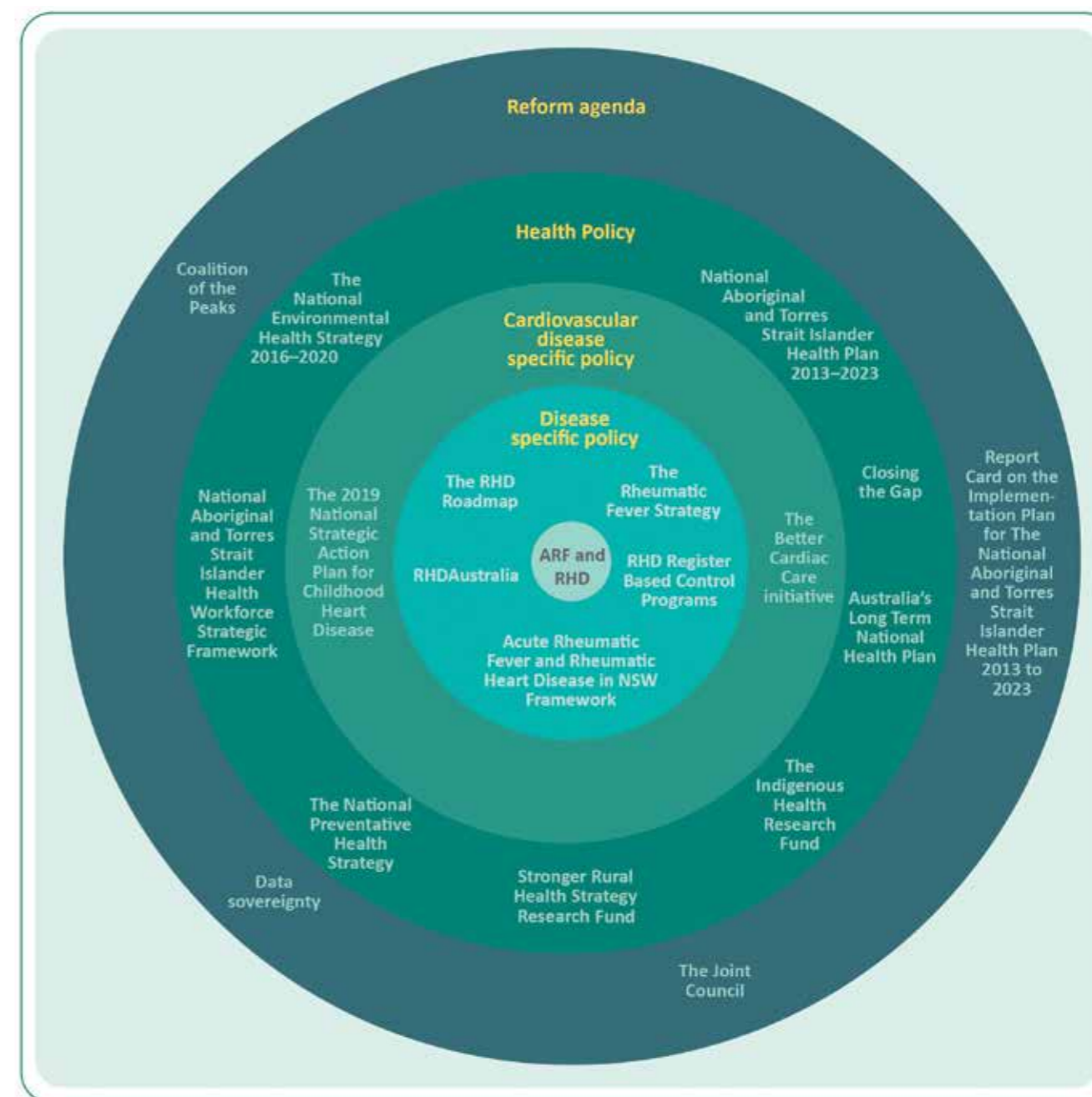


Figure 20: The policy context of ARF and RHD in Australia.

RHD Prevention in Australia

Prior to the launch of the Rheumatic Fever Strategy¹²² in 2009, policy action on the prevention and management of RHD in Australia was limited, with the Northern Territory leading control activities. In recent years, activity has incrementally increased through community-driven prevention projects and State government initiatives.

The Rheumatic Fever Strategy

The prevention of RHD in Australia has focused on register-based control programs and investment in evidence-based education and training resources. Since 2009, this has been governed by the Australian Government's *Rheumatic Fever Strategy* (RFS),¹²² comprising a National Partnership Agreement (NPA) with four jurisdictions (Queensland, Western Australia, South Australia and the Northern Territory), funding for RHD Australia and, more recently, funding for community-led primary prevention projects.^{6,122}

The major limitation of the RFS is that it is a strategy in name only. There is no policy framework or implementation plan; disease reduction targets and evaluation measures were never established. Under the NPA, which has an overriding focus on secondary prevention to prevent ARF recurrence and therefore progression to or worsening of RHD, output metrics are used to assess performance of the jurisdictional control programs.¹²² Evaluation measures for RHD Australia are not articulated in its funding agreement with the Australian Government; these are instead developed by RHD Australia and subsequently endorsed by the Government. Now in its tenth year, the RFS has been subject to only one evaluation in 2017,⁶ expanded upon below, although the current funding agreement makes provision for a government review of the RFS.^{6,122}

RHD register-based control programs

RHD prevention in Australia has been influenced by jurisdictional, national and international developments, as presented in Table 4 at the end of this chapter. The Northern Territory (NT) was the first Australian jurisdiction to implement formal policies for RHD control targeting Aboriginal and Torres Strait Islander people, with legislation introduced in 1996 to make ARF a notifiable condition,¹²³ followed by the establishment of the NT RHD Control Program in 1997.¹²⁴

Prior to the introduction of the RFS, the Australian Government's involvement with RHD control was limited to the Australian Institute of Health and Welfare's (AIHW) support of the NT program. The AIHW's seminal report on RHD in 2004 was entitled '*Rheumatic heart disease: all but forgotten in Australia except among Aboriginal and Torres Strait Islanders peoples*'.¹²⁵ While the report acknowledged the social determinants of drivers of the high rates of RHD, it described the immediate aim of disease management as identifying ARF and preventing progression to RHD; a possible precursor to the focus on secondary prevention under the RFS NPA.

The *Rheumatic Fever Strategy National Partnership Agreement (NPA)*,¹²² initially funded programs in the Northern Territory, Queensland and Western Australia, with a subsequent expansion to include the existing South Australian program in 2013. The required outputs of the jurisdictional programs are the improved detection, monitoring and management of ARF and RHD through:

- Improved clinical care, including improved delivery of and adherence to secondary prophylaxis antibiotics;
- Provision of education and training for healthcare providers, individuals, families and communities;
- Collection and provision of agreed data annually to the AIHW for national monitoring and reporting of ARF and RHD, and measuring program effectiveness in the detection and management of ARF and RHD; and
- Maintenance of a dedicated state-wide patient register and recall system for ARF and RHD.

NSW also operates a RHD register under a State framework initiated and funded by the NSW Government in 2017.¹²⁶ The characteristics of a register-based control program and the outputs of the programs are discussed in further detail in Chapter 4d. The current NPA expires in mid-2021.

In 2018, Queensland became the first jurisdiction to develop an RHD Action Plan independent of, but incorporating elements of the RFS, with the plan seeking to build on the collective will and commitment of the entire health system to reduce the number of people with ARF and RHD.¹²⁷ The Northern Territory will release a Strategic Action Plan for RHD control in 2020 (personal correspondence, Kate Robertson, 2019).

RHDAustralia

The national stakeholder of the RFS is RHDAustralia, which has been funded since 2009 through a series of consecutive funding agreements between Menzies School of Health Research and the Australian Government's Department of Health. The remit of RHDAustralia has evolved over its 10 years of operation. Initially funded as the National Coordination Unit for the RFS, its primary focus was the revision of the *Australian Guideline for the Prevention, Diagnosis and Management of ARF and RHD*, and the development and dissemination of a related suite of high-quality, evidence-based education and training resources for clinicians.¹²⁸ RHDAustralia now describes its three key areas of work as:

- Updating, disseminating and integrating the *Australian Guideline for the Prevention, Diagnosis and Management of ARF and RHD*;
- Developing and implementing high-quality, evidence-based education and training resources for health professionals, people with ARF/RHD, their families, and communities; and
- Supporting health systems to achieve evidence-based best practice for focused prevention activities in high-risk communities.¹²⁹

In recent years, RHDAustralia has increasingly invested its efforts in working with patients, families and communities and applying a cultural lens to its work.¹³⁰

Community-led primary prevention activities

The 2017 evaluation report⁶ acknowledged key achievements of the RFS (again mainly limited to outputs rather than impact) and made a number of recommendations, including expanding activities to include primordial and primary prevention and strengthening the role of primary care.³ As a response, the RFS was expanded, with an additional \$6.1 million committed for primary prevention activities for six communities across Australia, plus an evaluation of the activities. This community-level action is discussed further in Chapter 4c.⁶

Funding

Since 2009, the Australian Government has invested approximately \$54 million in RHD control (Figure 21) through the RFS NPA (funded under the Federal Financial Relations framework) and contractual agreements for the operation of RHDAustralia and implementation of community-level projects (funded from the Indigenous Australians' Health Programme). This figure includes funding committed to 2021.¹²² The most comparable jurisdiction to have implemented an RHD control policy is New Zealand, which invested approximately \$65 million over six years between 2011 and 2017 under the Better Public Services program and set targets to reduce ARF by two-thirds.^{6,131}

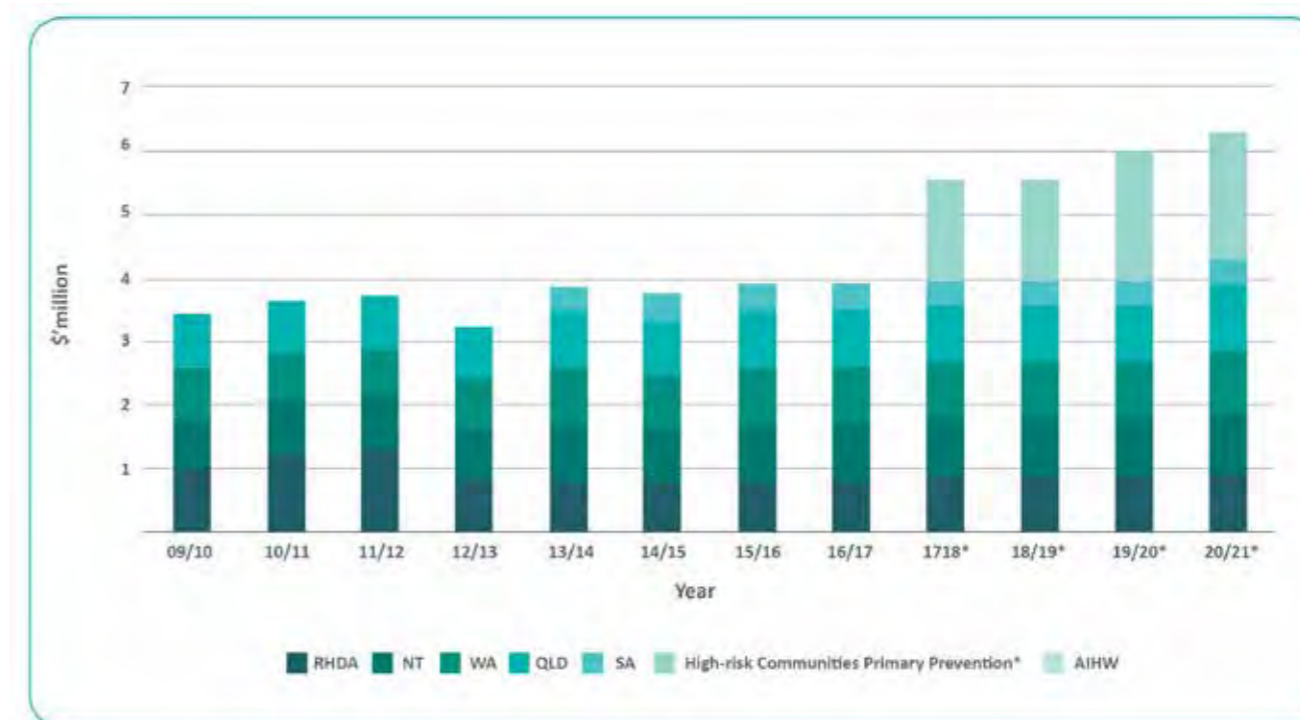


Figure 21: Federal RHD funding in Australia since 2009.

Other RHD policy commitments

Since 2018, the Australian Government has made the following new commitments to RHD elimination. It is worth noting that, to date, there is no funding associated with these most recent policy commitments.

The RHD Roadmap

In 2018, under the leadership of The Hon. Ken Wyatt, MP, the then Federal Minister for Indigenous Health, the RHD prevention agenda was progressed through the development of an RHD Roadmap: a plan for elimination of RHD by 2031. END RHD, contracted through the National Aboriginal Community Controlled Health Organisation (NACCHO), was commissioned to write the Roadmap which was presented to the Council of Australian Governments (COAG) Health Council in March 2019 and subsequently referred to the Australian Health Ministers' Advisory Council (AHMAC).¹³² The RHD Roadmap was one of four Indigenous Health Roadmaps considered by the COAG Health Council, the others being trachoma,¹³³ kidney disease,¹³⁴ and hearing loss.¹³⁵

In 2019, two of the Australian Government's flagship health policies identified RHD as priorities.

- In August 2019, RHD was included in Australia's *Long Term National Health Plan*. A priority under measures to strengthen primary healthcare is to 'eradicate rheumatic heart disease by 2030.' This is the first time the Australian Government has committed to an absolute target for RHD eradication or elimination. The Long Term National Health Plan is the Government's reform plan (over 10 years) for mental health, primary care, hospitals, preventative health and medical research.¹³⁶
- The revised Implementation Plan for the *National Aboriginal and Torres Strait Islander Health Plan (NATSIHP) 2013–2023* (due for full release in 2020 and discussed in more detail below), has identified the elimination of RHD over the course of the decade as a priority.¹³⁷

These are discussed in more detail under Health System and Policies.

The World Health Assembly Resolution on RHD

In 2018, the World Health Assembly adopted a resolution on RHD, recognising the elimination of RHD as a global health priority for the first time.¹¹ Australia played a lead role in drafting the resolution, which commits Member States to take action to prioritise and fund RHD control. Notably, the resolution calls on Member States to put people living with RHD at the centre of the prevention and control agenda. Progress on the implementation of the Resolution will be reported at the 74th World Health Assembly in 2021.

Related cardiovascular policy

RHD control is also identified as a priority through inclusion in two national strategies to improve overall cardiovascular health:

- The *Better Cardiac Care* initiative was established in 2014 under the auspices of the Australian Health Ministers' Advisory Council (AHMAC) to 'reduce mortality and morbidity from cardiac conditions'. RHD was one of its priority areas. The *Better Cardiac Care* reports are primarily a descriptor of Aboriginal and Torres Strait Islander peoples' cardiac health, reporting annually on 14 measures.¹³⁸ *Better Cardiac Care* drew on the *Essential Service Standards for Equitable National Cardiovascular (CVD) Care for Aboriginal and Torres Strait Islander peoples* (ESSENCE),¹³⁹ which proposed minimum service standards for prevention, risk factor management, and acute and chronic care. It was intended to provide a framework for evaluating progress in overcoming CVD inequalities in Australia.¹⁴⁰ Standards for specific diseases such as RHD were included.^{140,141}
- The *2019 National Strategic Action Plan for Childhood Heart Disease* aims to reduce the impact of childhood heart disease (CHD) in Australia and achieve the goal that those with CHD live longer, healthier and more productive lives through effective management of CHD across the life course.¹⁴² Development was led by HeartKids. The action plan was designed to be complementary to the RFS, acknowledging that while ARF and RHD are acquired heart disease, they are lifelong and burdensome. The primary focus of the plan is management, care and support, community support, and increased research and surveillance. At the time of writing, no RHD-specific activities have been initiated under the action plan.

Health system and policies

Understanding the complex structure of the Australian health system, which operates under the principle of universal healthcare for all, is important in understanding the barriers and enablers to RHD policy development and implementation.

The Australian health system

Australia's Federal, State and Territory and local governments have shared responsibility for the health system. The National Healthcare Agreement (NHA) sets out the responsibilities of governments with the overarching goal to 'improve health outcomes for all Australians and ensure the sustainability of the Australian health system'.²¹ The NHA also commits governments to deliver a health system that 'promotes social inclusion and reduces disadvantage, especially for Indigenous Australians'.¹⁴³

The foundation of the health system is Medicare, allowing for universal healthcare for all Australians since 1984.¹⁴⁴ Funded by the Federal Government, Medicare covers the cost of all public hospital services and subsidises or fully costs services provided by GPs, medical specialists and allied health.¹⁴⁴ The Medicare Benefits Schedule (MBS) establishes costs, and therefore funding, for services and procedures under Medicare. The Pharmaceutical Benefits Scheme (PBS) is a complementary scheme, subsidising certain medicines.¹⁴⁴ Further detail and analysis on the complexities of healthcare funding, in particular for the primary care and Aboriginal Community Controlled Health Organisation (ACCHO) sector, is provided in the discussion on structural and system considerations (Chapter 4a).

On these foundations there is a 'multifaceted web of public and private providers, settings, participants and supporting mechanisms'.¹⁴⁵ The Organisation for Economic Cooperation and Development (OECD) found that Australia's complex health system, with funding and responsibility split across different levels of government for the different healthcare sectors, can lead to a duplication of services and leave gaps in care and provision.¹⁴⁶

The Australian Healthcare and Hospital Association's *Blueprint for a Post-2020 National Health Agreement* calls for 'a nationally unified and regionally controlled health system that puts patients at the centre, performance information and reporting that is fit for purpose, a health workforce that exists to serve and meet population health needs and funding that is sustainable and appropriate to support a high-quality health system'.¹⁴⁷

Health policies

The complexity of the Australian health system, and broader government structures, means that policy is formulated at all levels of government. The following contextualises the *Endgame Strategy* primarily in current Australian Government policy but acknowledges that RHD control, and elimination, is influenced by multiple intersecting (and potentially conflicting) Federal, State and Territory, and even local government policies.

Closing the Gap

The overarching framework for Aboriginal and Torres Strait Islander health policy is the *Closing the Gap strategy*. In 2008, Australian governments and Aboriginal and Torres Strait Islander peoples committed to 'work together to achieve equality in health status and life expectancy between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians by the year 2030'¹⁴⁸ when they signed the *Indigenous Health Equality Summit Statement of Intent*. The *Closing the Gap strategy*,¹⁴⁹ established under the National Indigenous Reform Agreement, was the Government's policy response, setting targets for reducing disadvantage among Aboriginal and Torres Strait Islander peoples. A decade on, only two of the seven health, education and employment targets are on track to be met.¹⁵⁰

The Australian Government 'Refresh' of the *Closing the Gap strategy*, announced in 2016, recognised the failings of the policy and committed to establishing new targets.¹⁵¹ The 'Refresh' has been a catalyst for Aboriginal and Torres Strait Islander organisations to demand a new model of shared decision-making with governments, culminating in the signing of the Partnership Agreement on Closing the Gap between Australian governments and the Coalition of Peaks.¹⁵² The 'Refresh' and associated reforms have informed the development, and will have implications for the implementation of the *Endgame Strategy*.

National Aboriginal and Torres Strait Islander Health Plan 2013–2023

Under the *Closing the Gap* strategy, the *National Aboriginal and Torres Strait Islander Health Plan 2013–2023* was designed as a long-term, evidence-based policy framework to achieve an Australian health system ‘free of racism and inequality and all Aboriginal and Torres Strait Islander people have access to health services that are effective, high quality, appropriate and affordable’.¹³⁷

The related Implementation Plan articulated the actions needed to meet the Plan’s objective and assigns responsibility to the various stakeholders, including the Australian Government and the Aboriginal Community Controlled Health Organisation (ACCHO) sector.¹⁵³ The Aboriginal and Torres Strait Islander sector was critical of the lack of dedicated funding to support the Implementation Plan.¹⁵⁴ A series of consultations, known as ‘*My Life My Lead*’¹⁵⁵ were held in 2017 to inform the development of a revised Implementation Plan, with a strengthening focus on the social and cultural determinants of health.¹⁵⁵ The resulting themes of these consultations, consistent with current *Closing the Gap* refresh priorities, were:

- Putting culture at the centre of Aboriginal and Torres Strait Islander wellbeing;
- Addressing racism across health and other systems; and
- Acknowledging the impact of intergenerational trauma and the importance of place-based approaches.¹⁵⁵

A revision of the Implementation Plan commenced in 2019, and culture remains at the centre of a life-course approach with activities in six focus areas contributing to the vision of Aboriginal and Torres Strait Islander peoples enjoying long and healthy lives.¹⁵⁶ The revised Implementation Plan framework is used to assess the structural and systems considerations in Chapter 4a. Report cards assess progress against the 20 goals of the *Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013 to 2023*.¹⁵³

Australia’s Long Term National Health Plan

Australia’s Long Term National Health Plan was released in 2019, as the Australian Government’s flagship policy to reform, modernise and improve the health system.¹³⁶ The plan is modelled on four pillars.¹³⁶

1. Guaranteeing Medicare, stronger primary care and improving access to medicines through the PBS.
2. Supporting our public and private hospitals, including improvements to private health insurance.
3. Mental health and preventive health.
4. Medical research to save lives and boost our economy.

As previously noted, ‘to eradicate rheumatic heart disease by 2030’ is identified as a priority under Pillar 1.¹³⁶ Other policies, either in existence or flagged for development, included in the *Long Term Health Plan* and of direct relevance to the *Endgame Strategy* are:

- Under the Medical Research Future Fund the Indigenous Health Research Fund will, over 10 years and with \$160 million in funding, support research into the ‘best approaches prevention, early intervention and treatment of the health conditions of the greatest concern to Aboriginal and Torres Strait Islander communities’.¹⁵⁷ Ending RHD is one of its flagship priorities, with \$35 million already invested in the acceleration of a Strep A vaccine.¹⁵⁸
- The *Stronger Rural Health Strategy* will continue with a \$550 million investment in building a sustainable workforce, delivering approximately 6,000 additional doctors and nurses to high-need rural areas within the decade.¹⁵⁹
- The *National Preventive Health Strategy* will be designed to help Australians improve their health at all stages of life, through early intervention, better information, and targeting modifiable risk factors and the broader causes of poor health over 10 years.¹⁶⁰ In November 2019, at the NACCHO annual conference, it was announced that this will include the *Indigenous Preventive Health Plan*, to be developed in a co-design process by an Aboriginal and Torres Strait Islander-led reference group headed by NACCHO.

National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework

The key workforce policy is the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework 2016–2023*, a framework focusing on prioritisation, target-setting and monitoring of progress against growing and developing the capacity of the Aboriginal and Torres Strait Islander health workforce.¹⁶¹ The Framework aims to ‘contribute to the achievement of equitable health outcomes for Aboriginal and Torres Strait Islander people through building a strong and supported health workforce that has appropriate clinical and non-clinical skills to provide culturally safe and responsive healthcare’.¹⁶¹ The critical importance of the Aboriginal and Torres Strait Islander health, and environmental health, workforce is discussed under structural and systems considerations in Chapter 4a.

Health system monitoring and reporting

A number of mechanisms are in place to measure progress towards health policy aims and objectives

The Australian Health Performance Framework

The *Australian Health Performance Framework* (AHPF) aims to ‘provide a single, enduring and flexible vehicle to support system-wide reporting on Australia’s health and healthcare performance, to support the assessment and evaluation of value and sustainability, and to inform the identification of priorities for improvement and development’.¹⁶² The AHPF attempts to conceptualise the complexities of the health system into a model which acknowledges the public/private funding mix, core delivery components, and evolving policies and programs. The model includes both the broader determinants of health and the concept of equity as key domains. AHPF data can be analysed at a jurisdictional level or by population, including Aboriginal and Torres Strait Islander status.

Aboriginal and Torres Strait Islander Health Performance Framework

Similarly, the *Aboriginal and Torres Strait Islander Health Performance Framework* (ATSIHPF) is intended to measure outcomes not only against ‘traditional’ health outcome and system measures, but puts equal emphasis on the socioeconomic determinants of health and behavioural factors.¹⁶³ The biennial reports against 68 performance measures (including ARF and RHD rates) are used by Government as the ‘authoritative evidence base for Aboriginal and Torres Strait Islander health policy’. The ATSIHPF is also used to track progress against both *Closing the Gap* targets and the implementation of the *National Aboriginal and Torres Strait Islander Health Plan*. While the AHPF is overseen by the Australian Institute of Health and Welfare (AIHW), the ATSIHPF is the responsibility of the Department of the Prime Minister and the Cabinet (with AIHW assistance) and is sponsored by the Australian Health Ministers’ Advisory Council (AHMAC).

Report Card on the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013 to 2023

The most recent Report Card on the *Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013 to 2023*¹⁵³ (NATSIHP) indicates that 12 of the 20 goals named in the Plan are on track to be achieved by 2023.^{164,165} However, in recognising that further work is required before widespread reform, the Co-Chairs acknowledge ‘it is important to maintain, expand and strengthen Aboriginal and Torres Strait Islander community controlled health organisations while also ensuring that mainstream health providers are delivering culturally safe care for Aboriginal and Torres Strait Islander people’.^{153,164,165} It is not clear whether the Report Card will continue in its current format under the revised Implementation Plan.

Aboriginal Community Controlled Health Organisations

All Aboriginal Community Controlled Health Services report against national key performance indicators (KPIs), which are used to measure progress towards the Government’s *Closing the Gap* targets.

This data is published regularly, with the program currently reporting on 21 KPIs that inform understanding of population health outcome trends, identify factors influencing these trends, and allow for appropriate planning and policy development.¹⁶⁶ In addition, services have obligations to report at a jurisdictional level. The Northern Territory, for example, measures these via the Northern Territory Aboriginal Health Key Performance Indicators Information System (NT AHKPI) reporting on both government and non-government health services.¹⁶⁷

National Key Performance Indicators (nKPIs) are overseen by the AIHW. Presently, five reports on nKPIs data collection have been released, with the latest reporting on 2017 data. This most recent report used data collected from 231 primary healthcare organisations that receive funding from the Australian Government's Department of Health to provide services primarily to Aboriginal and Torres Strait Islander peoples. Twenty-four 'process-of-care' and 'health outcome' indicators are assessed with a focus on maternal and child health, preventative health, and chronic disease management.¹⁶⁸

ARF and RHD-specific data collection and monitoring

As previously noted, the *Rheumatic Fever Strategy* and associated NPA have never set targets for ARF and RHD control. The articulation of RHD elimination as a priority within this decade in both the *Long Term Health Plan* and the NATSIHP-revised *Implementation Plan* is the first time a definitive target has been set in national policy. The *Endgame Strategy* proposes targets and how these will be measured in Appendix Six.

National KPIs for ARF and RHD have been agreed by the Australian Government (through the AIHW) and participating jurisdictions.^{77,169} The AIHW is responsible for reporting ARF and RHD-related data through triannual ARF and RHD, annual *Better Cardiac Care for Aboriginal and Torres Strait Islander People* reports and the biannual *Aboriginal and Torres Strait Islander Health Performance Framework report*.

Evaluation of Aboriginal and Torres Strait Islander policy and programs

The shortcomings, or absence of, the evaluation of Aboriginal and Torres Strait Islander policy and programs have been highlighted through the *Closing the Gap* refresh process. In 2019, an Australian National Audit Office (ANAO) audit of the arrangements for monitoring, evaluating and reporting progress towards *Closing the Gap* found that while robust processes have been established for data collection and reporting against targets, these high-level reports in themselves did not provide 'an objective assessment of the Australian Government contribution to Closing the Gap'.¹⁷⁰ The audit found that governance arrangements lacked the necessary oversight and stakeholder engagement, there was no overarching implementation plan or evaluation framework, and this had limited the effectiveness of the *Closing the Gap* framework.¹⁷⁰

In part as a response to this critical ANAO report, the Australian Government legislated the establishment of the Indigenous Evaluation Strategy through the Productivity Commission. This Strategy, due to be released in 2020, will establish a principles-based framework and has as its key objective the delivery of better outcomes for Aboriginal and Torres Strait Islander peoples.¹⁷¹ The Productivity Commission has situated the new Strategy in a human rights context: the *United Nations Declaration on the Rights of Indigenous Peoples* will be used as a framework for establishing principles governing the Strategy.¹⁷¹

The 2017 the *Aboriginal and Torres Strait Islander Health Performance Framework* report found 'a clear gap in robust evaluation evidence on effective interventions across a range of program areas' and that 'high-quality evaluation evidence is vital for informing policy and program development and planning'.¹⁶³ There are also challenges in reporting on some NATSIHP measures due to inconsistencies in data reporting and collection, variations between years preventing comparisons, and a failure to appropriately sample the population.¹⁶⁵

Critical enabling policies

Improvements in living conditions are acknowledged as a key driver for RHD elimination in developed countries^{172,173} (including the elimination of the disease for the majority of Australia's non-Indigenous population); therefore housing and environmental health policy can be considered as critical enabling policies for any RHD elimination strategy. Chapter 4a provides an overview of other systemic enablers of RHD elimination. The role of housing and environmental health in the prevention of Strep A, ARF and RHD is discussed in further detail in Chapter 4b.

Housing

Housing of a standard adequate for health and wellbeing is considered a basic human right, enshrined in Article 25 of the *United Nations Universal Declaration of Human Rights*, yet housing in many remote Aboriginal and Torres Strait Islander communities – those communities most at risk of ARF and RHD – consistently fails to meet this standard.¹⁷⁴ The link between housing and health is widely accepted^{175,176} and evidence supports the association between housing crowding and Strep A infection, ARF and RHD.²⁹

Strategies to reduce the negative impact of overcrowding, and to assess the impact of adequate new housing stock and the modification of existing housing stock are discussed in Chapter 4b.

In the past decade, the *National Partnership Agreement on Remote Indigenous Housing* (NPARIH) and subsequent *Remote Housing Strategy* have been the keystone policy for the provision and maintenance of Aboriginal and Torres Strait Islander housing in remote communities. Implemented in 2008 with an investment of \$5.4 billion over 10 years through an agreement by the Council of Australian Governments,¹⁷⁷ the agreement for investment in Aboriginal and Torres Strait Islander housing was described as a 'central plank to achieving the targets for 'Closing the Gap' on Indigenous disadvantage'.¹⁷⁷ However, only output measures were included in the NPA, with no attempt to articulate potential health, social or education outcomes with the *Closing the Gap* targets. The Agreement included performance indicators for reduced overcrowding, number of new dwellings constructed or upgraded, repairs and maintenance targets, tenancy management process measures, and increased employment in housing-related jobs created for Aboriginal and Torres Strait Islander peoples.¹⁷⁷ The NPARIH was replaced, in 2016, by the *Remote Housing Strategy* through an agreement between the Federal Government and Queensland, South Australia, Western Australia and the Northern Territory.¹⁷⁸

The 2017 Remote Housing Review includes a comprehensive history of Australian Government investment in remote Indigenous housing, since the 1960s when it first provided funding, which will not be replicated here. The recommendations of the Review are covered in detail in Chapter 4b. The Review evaluated lessons learned in more than 50 years of housing provision for Aboriginal and Torres Strait Islander peoples and noted that 'policy change has been the norm'.¹⁷⁶

Since the expiry of the *Remote Housing Strategy*, the Federal Government has been unable to reach a unilateral agreement with the States (WA, QLD and SA) and the Northern Territory for the funding and split of responsibility for remote-area housing. Negotiations have been contentious and grievances have been publicly aired with accusations of negated responsibility from both sides.^{179,180} The 2017 Review recommended that the Australian Government and jurisdictions share the cost of any Indigenous housing program 50:50. The Northern Territory reached an agreement through the National Partnership for Remote Housing Northern Territory, with a \$550 million commitment from the Federal Government matched by the Northern Territory (total investment of \$1.1 billion over five years), but disputes continue. In April 2019, the Northern Territory's Chief Minister relinquished the remote housing leases of 44 remote communities back to the Federal Government, resulting in the Federal Government withholding funding and accusing the Northern Territory of mismanagement of the program and funds.¹⁸¹ Western Australia accepted a lump sum of \$121 million for 2018–19, noting the Federal Government held the view during negotiations that this would be a final funding contribution before the State Government took over complete responsibility for WA's remote housing.^{182,183} To date, the Federal Government has failed to reach a new agreement with either Queensland or South Australia. All sides of governments have been criticised by Aboriginal leaders for politicising the issue of Aboriginal and Torres Strait Islander housing.^{181,184}

One of the failings of remote-area housing policy, and at odds with current reform priorities in Aboriginal and Torres Strait Islander affairs, has been the loss of funding to the Indigenous Community Housing Organisations (ICHOs) as the transfer of responsibility has slowly shifted from the ICHO sector to the States and Territories. The number of ICHOs fell from 616 in 2001 to 330 in 2012.¹⁸⁵ In addition, the Australian Government has abandoned a specific 'housing for health' approach. The Housing for Health approach and associated programs, widely endorsed by Aboriginal and Torres Strait Islander organisations, are discussed in Chapter 4b.

The *National Indigenous Housing Guide* (3rd Edition) shared the same safety and health principles as the Housing for Health and had the endorsement of all governments. It was due for renewal in 2009 but the scheduled review, committed to by the Australian Government, never occurred.¹⁸⁶ The *Fixing Houses for Better Health Program*, implemented using the Housing for Health approach, was discontinued in 2011. This was despite an independent review recommending it be continued.¹⁸⁷ New South Wales is the only jurisdiction to have a comprehensive Housing for Health policy and program which has shown that 'those who received the Housing for Health intervention had a significantly reduced rate of hospital separations for infectious diseases – 40% less than the hospital separation

rate for the rest of the rural NSW Aboriginal population who did not receive the Housing for Health intervention'.¹⁸⁸

Environmental health

As in the above example of the implementation of the Housing for Health approach by the New South Wales Department of Health, environmental health policy and practice is largely governed at a jurisdictional level, with priorities and resources driving decision-making by States and Territories. National policy is governed through the COAG processes with the Environmental Health Standing Committee (enHealth) responsible for providing national coordination and policy advice. Departments of Health from each jurisdiction have representation on the Committee which, as stated by the Committee in the *National Environmental Health Strategy 2016–2020*, presents an opportunity for harmonising environmental health approaches between jurisdictions. There is little evidence of this in practice. The Strategy articulates a commitment to 'addressing inequalities in health status due to environmental health factors, particularly in Aboriginal and Torres Strait Islander communities'.¹⁸⁹ The Strategy also acknowledges major challenges such as shortages in the environmental health workforce, and specifically the shortage of Aboriginal and Torres Strait Islander environmental health professionals. Specific environmental health strategies and programs and the impact of a lack of a consistent national framework and investment in environmental health are discussed in Chapter 4a and 4b.

Reform and guiding principles

There is a widespread acknowledgment that a new way of working is needed if there are to be meaningful improvements in outcomes for Aboriginal and Torres Strait Islander peoples.¹⁹⁰

There is a growing recognition of the need for solutions tailored to communities and of the critical role of local, resident knowledge. There are numerous community-based and community-led initiatives occurring across Australia at a grassroots level (community-led activity specifically relating to ARF and RHD are discussed in Chapter 4) but it is imperative that the Government respond through systemic change and in its policy responses to this increased demand for community control and decision-making.¹⁹¹

In early 2019, a review was undertaken to examine the capability, culture and operating model of the Australian Public Service (APS).¹⁹² It was recognised that the APS lacked a systematic understanding of local solutions and failed to appropriately combine architecture across agencies.¹⁹² Further, it was noted that the APS prioritised frontline perspectives as opposed to local communities' experiences and expertise.¹⁹² The overarching recommendation was to combine approaches to meeting local needs with working directly with citizens and communities to achieve agreed outcomes.¹⁹² No recommendations specific to Aboriginal and Torres Strait Islander communities were made. However, the review acknowledged that a new way of operating with a community-centred focus would have positive implications for ways of working and better involving communities to make strengths- and evidence-based decisions.

An example of how this idea is being put into operation is Empowered Communities, an organisation by Aboriginal or Torres Strait Islander people, for Aboriginal or Torres Strait Islander people. Aboriginal or Torres Strait Islander leaders from eight regions across Australia are working together with government and corporate Australia to reform how Aboriginal or Torres Strait Islander policies and programs are designed and delivered.¹⁹³ Primarily, the organisation seeks a shift towards an Aboriginal and Torres Strait Islander Empowerment agenda with a 10-year Empowerment framework.¹⁹⁴ Empowered Communities recommend national and regional institutions only support an enabling framework for place-based development agendas.¹⁹⁴

Critical to this community empowerment and informed decision-making is the governance of data. Indigenous Data Sovereignty is a global movement concerned with the right of Indigenous peoples to govern the creation, collection, ownership and application of their data.¹⁹⁵ In Australia, this work is being driven by the Maïam nayri Wingara Indigenous Data Sovereignty Collective. At the Indigenous Data Sovereignty Summit in 2018,¹⁹⁶ delegates asserted that Aboriginal and Torres Strait Islander peoples have the right to:

- Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure;
- Data that is available and accessible at individual, community and First Nations levels;
- Data that is relevant and empowers sustainable self-determination and effective self-governance;
- Data structures that are accountable to Indigenous peoples and First Nations; and
- Data that is protective and respects their individual and collective interests.^{195,196}

Local decision-making is discussed further in Chapter 4a and with regards to proposed Strep A, ARF and RHD metrics in Appendix Six.

The *Closing the Gap* refresh process has been the stimulus for a reform of Aboriginal and Torres Strait Islander-government relations. Through this process, with the leadership of Aboriginal and Torres Strait Islander organisations, two sets of priorities and principles have been articulated which will guide the implementation of the *Endgame Strategy* – the Implementation Principles agreed by COAG in December 2018 and the three reform priorities agreed by the Joint Council in August 2019.^{190,197}

COAG Implementation Principles

In 2018, COAG committed to a formal partnership with Aboriginal and Torres Strait Islander peoples to progress the Closing the Gap refresh. This included endorsing the following Implementation Principles and was formalised in March 2019 through the Partnership Agreement between COAG and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations ('Coalition of Peaks').

- *Shared Decision-Making* – Implementation of the Closing the Gap framework, and the policy actions that fall out of it, must be undertaken in partnership with Aboriginal and Torres Strait Islander peoples. Governments and communities should build their capability to work in collaboration and form strong, genuine partnerships in which Aboriginal and Torres Strait Islander peoples can be an integral part of the decisions that affect their communities.
- *Place-based Responses and Regional Decision-Making* – Programs and investments should be culturally responsive and tailored to place. Each community and region has its own unique history and circumstances. Community members, Elders and regional governance structures are critical partners and an essential source of knowledge and authority on the needs, opportunities, priorities and aspirations of their communities.
- *Evidence, Evaluation and Accountability* – All policies and programs should be developed on evidence-based principles, be rigorously evaluated, and have clear accountabilities based on acknowledged roles and responsibilities. Governments and communities should have a shared understanding of evidence, evaluation and accountability.
- *Targeted Investment* – Government investments should contribute to achieving the Closing the Gap targets through strategic prioritisation of efforts based on rigorous evaluation and input from Aboriginal and Torres Strait Islander communities, especially as it relates to policy formation, outcomes and service commissioning.
- *Integrated Systems* – There should be collaboration between and within governments, communities and other stakeholders in a given place to effectively coordinate efforts, supported by improvements in transparency and accountability.

Joint Council Reform Priorities

The Partnership Agreement between COAG and the Coalition of Peaks established the Joint Council on Closing the Gap. The Joint Council has agreed on the following three reform priorities:

1. Developing and strengthening structures to ensure the full involvement of Aboriginal and Torres Strait Islander peoples in shared decision-making at the national, State and local or regional level and embedding their ownership, responsibility and expertise to close the gap.
2. Building the formal Aboriginal and Torres Strait Islander community-controlled services sector to deliver *Closing the Gap* services and programs in agreed priority areas.
3. Ensuring all mainstream government agencies and institutions undertake systemic and structural transformation to contribute to *Closing the Gap*.

*A New Way of Working: Talking about what is needed to close the gap in life outcomes between Aboriginal and Torres Strait Islander people and other Australians*¹⁹⁰ expands on these priorities.

Table 4: RHD programs and significant events.

Year	RHD-related significant events
1944	<ul style="list-style-type: none"> Jones Criteria for ARF and RHD diagnosis developed by Dr. T. Duckett Jones.¹⁹⁸
Pre-1950	<ul style="list-style-type: none"> Rheumatic fever widespread throughout Australia's Aboriginal and Torres Strait Islander and non-Indigenous population.^{199,200}
1951	<ul style="list-style-type: none"> Benzathine benzylpenicillin (BPG) is developed and becomes the primary method of RHD prevention and ARF control.²⁰¹ With successful diagnostic and treatment methods, rates of ARF and RHD decline but remain high in developing nations and areas of high need.²⁰²
1952	<ul style="list-style-type: none"> Difference in incidences of rheumatic fever and streptococcal infection observed among different social groups in Melbourne.²⁰³
1969	<ul style="list-style-type: none"> High rates of streptococcal infection, heart reactive antibody and subclinical rheumatic carditis observed among Aboriginal school children.²⁰⁴
1981	<ul style="list-style-type: none"> 60 case records from ARF admissions to Derby Regional Hospital 1970–1979 are reviewed. Estimated ARF incidence of 227 to 353 per 100,000 person years. Very high rates of recurrence.²⁰⁵
1990	<ul style="list-style-type: none"> Retrospective case review of 976 clinical records from the Aboriginal community between 1978 and 1987, incidence of ARF 815/100,000 person years. Prevalence of RHD 1.9-12.3/1000 people.²⁰⁶
1992	<ul style="list-style-type: none"> Jones Criteria reviewed by the American Heart Association (AHA).²⁰⁷
1994	<ul style="list-style-type: none"> Oracle database of ARF and RHD patients developed for research by Jonathan Carapetis during PhD studies.²⁰⁸
1995	<ul style="list-style-type: none"> The World Health Organization (WHO) recommends register-based programs for RHD control.²⁰⁹
1996	<ul style="list-style-type: none"> ARF becomes notifiable in the Northern Territory.¹²³
1997	<ul style="list-style-type: none"> First report on National Health Priority Areas. RHD not identified as a priority.²¹⁰ Northern Territory RHD control program established, initially covering the Top End population and fully functional by June 1998. Funding provided by the Australian Institute of Health and Welfare (AIHW).¹²⁴
1999	<ul style="list-style-type: none"> <i>National Health Priority Area Report on Cardiovascular Health</i> – frequent reference to RHD in the Aboriginal and Torres Strait Islander population. Aim to 'reduce mortality from RHD by 50% by 2008.'²¹¹ ARF becomes notifiable in Queensland and active surveillance begins.²¹²
2000	<ul style="list-style-type: none"> Northern Territory RHD control program extended to cover people in Central Australia.¹²⁴
2001	<ul style="list-style-type: none"> The first Technical Report on Rheumatic Fever and Rheumatic Heart Disease is released by the WHO.²¹³
2002	<ul style="list-style-type: none"> Northern Territory RHD control program fully functional.¹²⁴ 0.7 FTE co-ordinator funded by the Federal Department of Health and Aging. Formal consent process for registration established. <i>Can skin infection with group A streptococcus cause acute rheumatic fever?</i> NHMRC Project Grant (funded until 2005).
2004	<ul style="list-style-type: none"> <i>Should acute rheumatic fever and rheumatic heart disease be nationally notifiable?</i>²¹⁴ Explores the criteria and issues around RHD as a notifiable disease. <i>Rheumatic heart disease: all but forgotten in Australia except among Aboriginal and Torres Strait Islanders peoples.</i> Report published by AIHW.¹²⁵ Data from the Northern Territory register is heavily cited.
2005	<ul style="list-style-type: none"> New DVD resource for RHD education in Northern Australia developed with support of the Australian Rotary Health Research Fund and the National Heart Foundation of Australia.²¹⁵

Year	RHD-related significant events
2006	<ul style="list-style-type: none"> Queensland register commences and is fully operational by 2009. <i>Benzathine penicillin – down but not out.</i>²¹⁶ Outlines access to medicines challenges for BPG in Australia. <i>National guidelines for diagnosis and treatment of ARF and RHD</i>, published by National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand (CSANZ) released (1st edition).²¹⁷ 'National program for prevention and management of acute rheumatic fever and rheumatic heart disease: business case' produced by the Menzies School of Health Research (unpublished). Formation of a Working Group to advise branches of the Australian Health Workforce Ministerial Council on national control of RHD.²¹⁸
2007	<ul style="list-style-type: none"> Three-year study of ARF in Australian children conducted by Menzies in conjunction with Australian Paediatric Surveillance Unit (APSU) begins.²¹⁹ ARF becomes notifiable in Western Australia.¹²³
2008	<ul style="list-style-type: none"> <i>Cardiovascular disease and its associated risk factors in Aboriginal and Torres Strait Islander peoples 2004–05</i> released by the AIHW. Extensive national coverage of RHD burden for Aboriginal and Torres Strait Islander people.²²⁰
2009	<ul style="list-style-type: none"> Australian Government funds Rheumatic Fever Strategy (RFS) as part of its <i>New directions: an equal start in life for Indigenous children</i> policy in NT/WA/QLD.²²¹ Western Australia register commences.¹²³ Australian Government funds the National Coordinating Unit (NCU) under the RFS and Menzies launches RHD Australia (RHDA), with \$2.5 million of funding.²²² Additional funding to a total of \$11.2 million is later provided to the NCU (via RHDA) to work with three jurisdictions – NT, WA and QLD. Funded until 2012.¹⁴³
2010	<ul style="list-style-type: none"> <i>Surgical challenges in rheumatic heart disease in the Australian Indigenous Population.</i>²²³ Long-term post-operative outcomes for Aboriginal and Torres Strait Islander Australians inferior to non-Indigenous Australians. RHD control program begins in South Australia, fully operation by 2012 with development support from the Northern Territory.²²⁴
2011	<ul style="list-style-type: none"> <i>World Heart Federation (WHF) criteria for echocardiographic diagnosis of RHD – an evidence-based guideline</i> released.²²⁵ Australian Government refunds QLD, WA and NT RHD Control programs (July 2013 – June 2017). \$15 million allocated to State-based register and control programs until 2016.⁶ RHD register developed in SA.⁶ CSANZ Indigenous Cardiovascular Health Conference in Alice Springs includes substantive discussion on RHD.²²⁶ RhFFUS (Rheumatic Fever Follow-Up Study). NHMRC Project Grant (funded until 2013).²²⁷
2012	<ul style="list-style-type: none"> Second edition of National Guidelines for ARF/RHD released by RHD Australia.⁷⁵ <i>Australasian Maternity Outcomes Surveillance System (AMOSS) RHD in pregnancy study</i> commences (Qualitative and Quantitative research). NHMRC Project Grant (funded until 2016).²²⁸ <i>Improving delivery of secondary prophylaxis for rheumatic heart disease.</i>²²⁹ NHMRC Project Grant (funded until 2015). <i>Genetic associations of rheumatic heart disease in Australian Aboriginal and Torres Strait Islander communities.</i>²³⁰ NHMRC Project Grant (funded until 2015).
2013	<ul style="list-style-type: none"> World Heart Federation (WHF) and its Working Group on ARF and RHD declare a WHF institutional strategic goal – a 25% reduction in premature deaths from ARF and RHD among individuals aged <25 years by the year 2025.²⁰² AIHW publishes <i>Rheumatic heart disease and acute rheumatic fever in Australia: 1996–2012.</i>¹²⁴ Strep A vaccine developed and enters phase 1 human clinical trial in healthy adults to assess safety and immunogenicity of formulation (Griffith University/Queensland Institute of Medical Research (QIMR)).²³¹ \$2.4 million funded by Australian and New Zealand governments over two years to identify potential Strep A vaccines that could progress to clinical trials.²³²

Year	RHD-related significant events
2014	<ul style="list-style-type: none"> REACH (Rheumatic Heart Disease. Evidence. Advocacy. Communication. Hope) launched.²³³ Third RHD forum held by the World Congress of Cardiology (WCC) – 5x5 Path toward RHD Control developed.²³⁴ Australian Government extends funding to South Australia under RFS.⁶ The END RHD CRE funded by the NHMRC (launched in 2015 and funded until 2020).²³⁵ <i>Better Cardiac Care for Aboriginal and Torres Strait Islander</i> forum, under auspices of Australian Health Ministers' Advisory Council (AHMAC), launched in Sydney. RHD listed as one of five priorities. Report released the following year.⁸
2015	<ul style="list-style-type: none"> Jones Criteria again reviewed by the AHA.^{76,236} RHDAustralia refunded under RFS (July 2015–June 2017).⁶ RHD becomes notifiable in Western Australia.³ NSW RHD Coordinator appointed, and New South Wales register commences (funded by NSW). ARF becomes notifiable in New South Wales.⁴
2016	<ul style="list-style-type: none"> ARF and RHD become notifiable in South Australia.⁵ RHD becomes notifiable in New South Wales (<35 only).⁴ Department of Health <i>Evaluation of the rheumatic fever strategy: final report released</i>.⁶
2017	<ul style="list-style-type: none"> RHDAustralia funding continued (July 2017–June 2021). RHDAustralia now required to develop and deliver evidence-based guidance, education and training, as well as create resources and conduct education and training sessions to support health systems.⁷ RHD Control program re-funded (July 2017–June 2022).¹²² NSW <i>Acute Rheumatic Fever and Rheumatic Heart Disease in NSW Framework released</i>.²³⁷
2018	<ul style="list-style-type: none"> World Health Assembly (WHA) passes resolution to END RHD.¹¹ Additional funding announced for primordial prevention efforts through Aboriginal Medical Services (AMS). Rheumatic Fever Communities funded through RFS in the NT, QLD, WA and SA.²³⁸ RHD becomes notifiable in Queensland. The Queensland RHD Action Plan is also launched.²³⁹ National Aboriginal Community Controlled Health Organisation (NACCHO) on behalf of END RHD commissioned to present an RHD Roadmap to the COAG Health Council.^{9,10} Communicable Diseases Network Australia (CDNA) ARF and RHD Series of National Guidelines (SoNG) published.²⁴⁰
2019	<ul style="list-style-type: none"> RHD Roadmap presented to the COAG Health Council and endorsed.⁹ \$35 million awarded to Telethon Kids Institute to lead a national consortium to develop a vaccine to prevent Strep A-related diseases.¹⁵⁸ <i>Australia's Long Term National Health Plan is released, with the eradication of RHD by 2030</i> identified as a priority.¹³⁶ The 2019 Report Card on the <i>Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013 to 2023</i>¹⁵³ found that 12 of the 20 goals named in the Plan are on track to be achieved by 2023.^{164,165} The revised plan (due for full release in 2020) will identify the elimination of RHD over the course of the decade as a priority.¹³⁷

4

STRATEGIES TO END RHD

- 4a STRUCTURAL AND SYSTEM CONSIDERATIONS IN ADDRESSING STREP A INFECTIONS, ARF AND RHD
- 4b ADDRESSING ENVIRONMENTAL, SOCIAL AND ECONOMIC DETERMINANTS OF STREP A INFECTIONS
- 4c PRIMARY PREVENTION OF ARF
- 4d SECONDARY PREVENTION OF ARF AND RHD
- 4e TERTIARY CARE FOR PEOPLE WITH RHD



Children in a remote school make paper hearts while learning about rheumatic heart disease

Introduction

The trajectory of RHD and its causal roots within the social determinants of health necessitate a response from all sectors of the health system. Therefore, the *Endgame Strategy* has undertaken a biomedical approach, aligning the review by undertaking evidence-based assessments at the primordial, primary, secondary prevention and tertiary care levels, with the structural assessment of health service and delivery within an Aboriginal and Torres Strait Islander context at the forefront (Figure 22).



Figure 22: The Endgame Strategy structure.

The subsequent five sub-chapters aim to identify the best available evidence-based strategies that have potential to eliminate RHD at each of these levels of prevention using a systematic method of assessment, discussed below.

Evidence grading

Many of the strategies to reduce Strep A, ARF and RHD addressed in the *Endgame Strategy* are more appropriately described as fundamental human rights, including access to adequate housing and health.^{241,242} Fulfilment of these rights does not require evidence of an association with Strep A, ARF and RHD in order to be prioritised. However, where evidence of an association does exist, this is presented to help communities and decision-makers prioritise and advocate for action. Where this occurs, the evidence and other considerations are presented in a structured evidence synthesis table throughout Chapters 4b–4e.

There are multiple grading systems for evaluating different kinds of evidence and forming clinical recommendations, including guidelines from the National Health and Medical Research Council (NHMRC) and GRADE assessment of evidence.²⁴³⁻²⁴⁵ These grading systems provide a structured approach to assessing and synthesising evidence into transparent recommendations.²⁴⁶

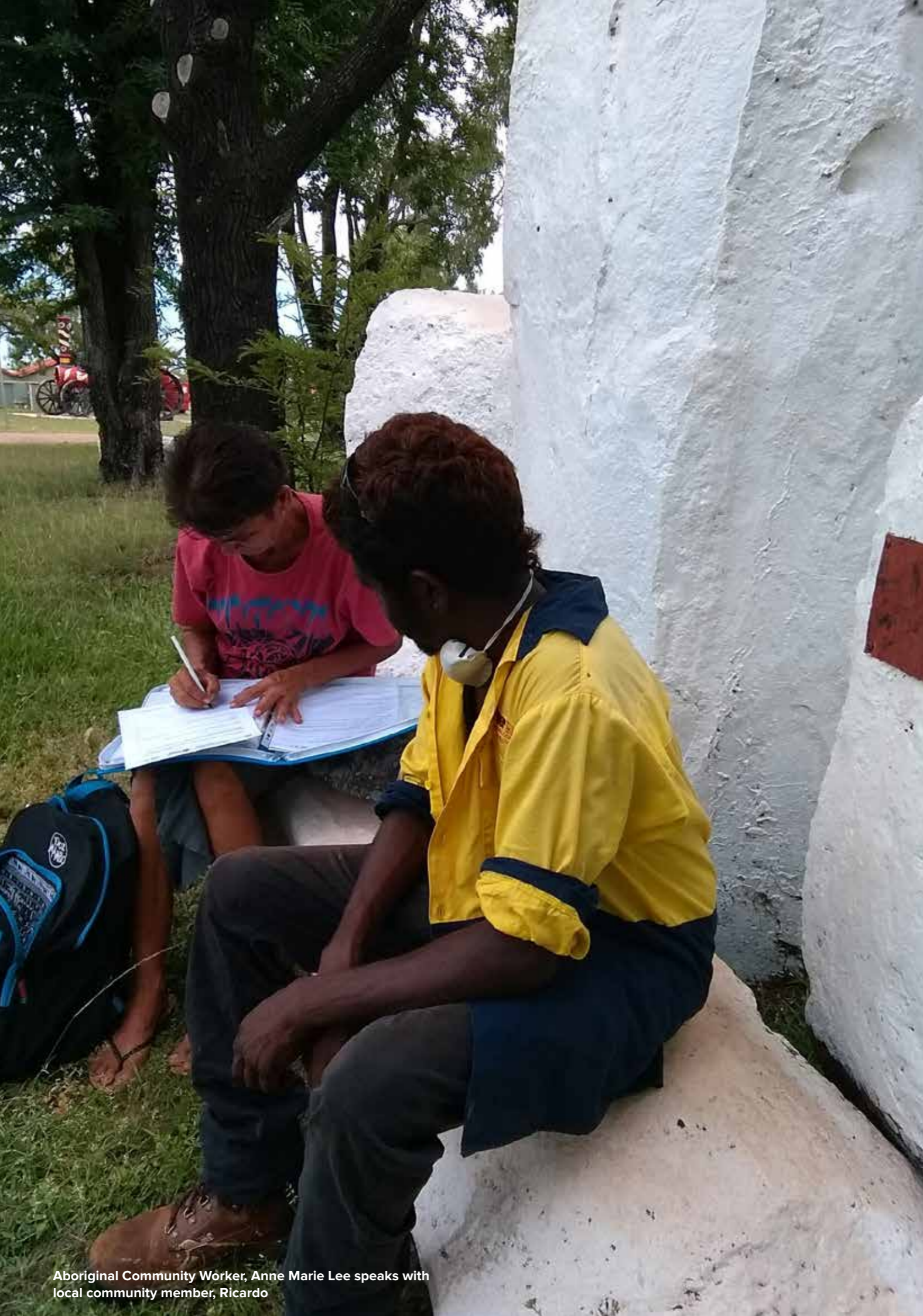
Established grading systems are most often used for assessing biomedical approaches which are amenable to evaluation with rigorous interventional studies.²⁴⁶ Few of these systems address the external validity of the proposed intervention – including context, barriers to implementation, cost or sustainability.^{245,246} Acknowledging these limitations, and the need to assess public health strategies differently to clinical guidelines, a new grading scale for population-level decision-making has emerged in recent years from the GRADE consortium.²⁴⁷ The GRADE Evidence to Decision (EtD) framework is intended for use in population-level decisions, even when the evidence base is limited.²⁴⁷

The GRADE EtD framework for public health interventions is new and, at time of publication, there are few examples of how the framework has been applied in practice. Although it was developed in close consultation with decision-makers, it is not yet clear whether the rigour of the framework meets the expressed needs of policymakers to have clear, concise summaries.

The END RHD CRE has chosen to use the categories of the GRADE EtD framework as a basis for simplification in the absence of the full EtD methodology of online consensus decision-making. This is a pragmatic decision to account for very limited evidence base, limitations of time and resources for individuals to contribute to the online decision-making, and the needs of end-users, including the needs of Aboriginal and Torres Strait Islander communities making community-level decisions.

END RHD domain	Key question	Scale			
Evidence	How strong is the evidence that the strategy will reduce Strep A infections?	High	Medium	Low	Unknown
Benefits	How significant are the potential benefits of the strategy?	High	Medium	Low	Unknown
Risks	How significant are the potential risks of the strategy?	Low	Medium	High	Unknown
Acceptability	How acceptable is the strategy to Aboriginal and Torres Strait Islander people and organisations?	High	Medium	Low	Unknown
Feasibility	How feasible is it to implement the strategy?	High	Medium	Low	Unknown
Costs	How much will the proposed strategy cost?	Low	Medium	High	Unknown
Timeline	How long is the lead time before the strategy can be implemented?	Short	Medium	Long	Unknown
Positive externalities	What other benefits may be associated with the strategy?	High	Medium	Low	Unknown
Equity	Will the proposed strategy improve health equity?	High	Medium	Low	Unknown

Figure 23: END RHD evidence evaluation scale.



Aboriginal Community Worker, Anne Marie Lee speaks with local community member, Ricardo

4 STRATEGIES TO END RHD

4a STRUCTURAL AND SYSTEM CONSIDERATIONS IN ADDRESSING STREP A INFECTIONS, ARF AND RHD

An overview of the systemic enablers needed to reduce the burden of Strep A infections, ARF and RHD for Aboriginal and Torres Strait Islander people in Australia



Aboriginal Health Worker Taylor Matthew checks the heart of a client at Danila Dilba Health Service's clinic in Darwin
Photo credit: Danila Dilba Health Service

Introduction

The biological cause of rheumatic heart disease (RHD) is a reaction to Strep A infection. Yet this alone does not account for the disproportionate burden of the disease among Aboriginal and Torres Strait Islander people. Social, economic and structural inequality also accounts for the 125-fold increased risk of acute rheumatic fever (ARF) for Aboriginal and Torres Strait Islander peoples compared to non-Indigenous people in Australia.¹⁶⁹ While preventing and treating Strep A infections will reduce new infections, only addressing the broader determinants of health can definitively end RHD.

Until equity in the broad determinants of health has been achieved for Aboriginal and Torres Strait Islander people, specific strategies are needed to address these underlying drivers of ill health. Reducing the burden of Strep A infections, ARF and RHD for Aboriginal and Torres Strait Islander people requires attention to both the direct and indirect determinants of health, which increase the risk of Strep A infection in households and communities. Many Aboriginal and Torres Strait Islander organisations have identified political and policy priorities to address the broad economic, social and cultural determinants of health. For example, the 2019 Lowitja Institute Close the Gap Report identifies three priorities: targeted, needs-based primary healthcare; a responsive healthcare system; and good housing for health.²⁴⁸

Many Aboriginal and Torres Strait Islander groups also support the voice, treaty, truth approach enshrined in the Uluru Statement from the Heart.²⁴⁹ A 2019 Partnership Agreement between a Coalition of Aboriginal and Torres Strait Islander Peak Organisations and the Council of Australian Governments identifies priority areas and ways of working.²⁵⁰ This work towards structural change throughout Australia is critical to address the indirect determinants of inequality which contribute to the burden of Strep A infections, ARF and RHD. The priority needs for improving outcomes for Aboriginal and Torres Strait Islander people with Strep A infections, ARF and RHD are common to many conditions in remote communities: improving housing and environmental health, addressing inequality, and improving clinical service delivery.

'Failure to provide secondary prophylaxis can be due to missed diagnoses, poor continuity of care, a lack of trust and communication between patients and care providers, high staff turnover, a lack of appropriate health education and, perhaps most importantly, a lack of political and bureaucratic commitment to solving the problem.'

'Failure in primary prevention of ARF and RHD (i.e. in preventing the acquisition of group A streptococcal infections) reflects the failure to provide Indigenous communities with the appropriate type and level of housing and environmental conditions that all Australians should expect.'

Alex Brown, Malcolm McDonald & Tom Calma.¹⁷³

The services, infrastructure and local capacity needed to prevent new diagnoses of ARF and RHD are currently fragmented. People at greatest risk of these diseases have inadequate opportunities to identify and implement solutions. Clinical services are often delivered in isolation from other providers of housing, education and employment. Health promotion messaging may be culturally inappropriate or inconsistent and, too often, RHD is addressed biomedically as a clinical disease rather than through a systems-based public health approach and patient-centred care which will deliver much greater impact.

While the systems and structural considerations outlined in this chapter are not unique to RHD, they are integral to successfully implementing the actions outlined in the *Endgame Strategy*. Prompt access to care for sore throat or skin sores relies on well-resourced, culturally secure systems in health and other service providers.

Disease-specific programs are doomed to failure unless core primary-care services are appropriately resourced and delivered. Indeed, in isolation, disease-specific programs may be harmful.²⁵¹ Local partnerships to support communities also require links to housing, education, meaningful employment and environmental health services.

Approach, structure and scope

A large number of reports and recommendations have been produced to identify the critical elements to improve the health of Aboriginal and Torres Strait Islander peoples. Many of these have been developed by peak bodies of Aboriginal and Torres Strait Islander peoples and professional groups. Recommendations are broadly consistent and repeated. No more reports are needed for meaningful action to begin.

Therefore, this chapter is a distillation of key priorities repeatedly researched, consulted and expressed by expert bodies in Aboriginal and Torres Strait Islander primary care, workforce and service delivery. An exhaustive review of literature or a comprehensive plan to reform primary care and workforce is out of scope for the Endgame. Rather, the Endgame seeks to amplify priorities expressed by Aboriginal and Torres Strait Islander peak bodies, subject experts and lived experience leaders. This chapter presents a high-level overview of the health system challenges, an overview of actions proposed by leading bodies to address these, and a commentary on how they relate to the goal of ending RHD in Australia.

The chapter is structured around the focus areas of the revised *Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan (IAHP) 2013–2023*.¹⁶¹ A revision of this plan was updated in late 2019 to embed social and cultural determinants of health, align with refreshing *Closing the Gap*, address focus conditions, and simplify goals and actions (discussed in Chapter 3).¹⁵³ There is an emphasis on the focus areas which are fundamental to achieving implementation of the *Endgame* strategies – namely, resourcing of primary healthcare and the Aboriginal and Torres Strait Islander workforce. The revised IAHP focus areas are illustrated in Figure 24.

This chapter reviews the evidence of association between each National Aboriginal and Torres Strait Islander Health Plan (NATSIHP) focus areas, and Strep A, ARF and RHD. However, the issues addressed in this section – such as access to healthcare and cultural safety – are human rights issues. They are not amenable to evaluation using a biomedical assessment model. As such, a narrative review has been provided to highlight their importance.

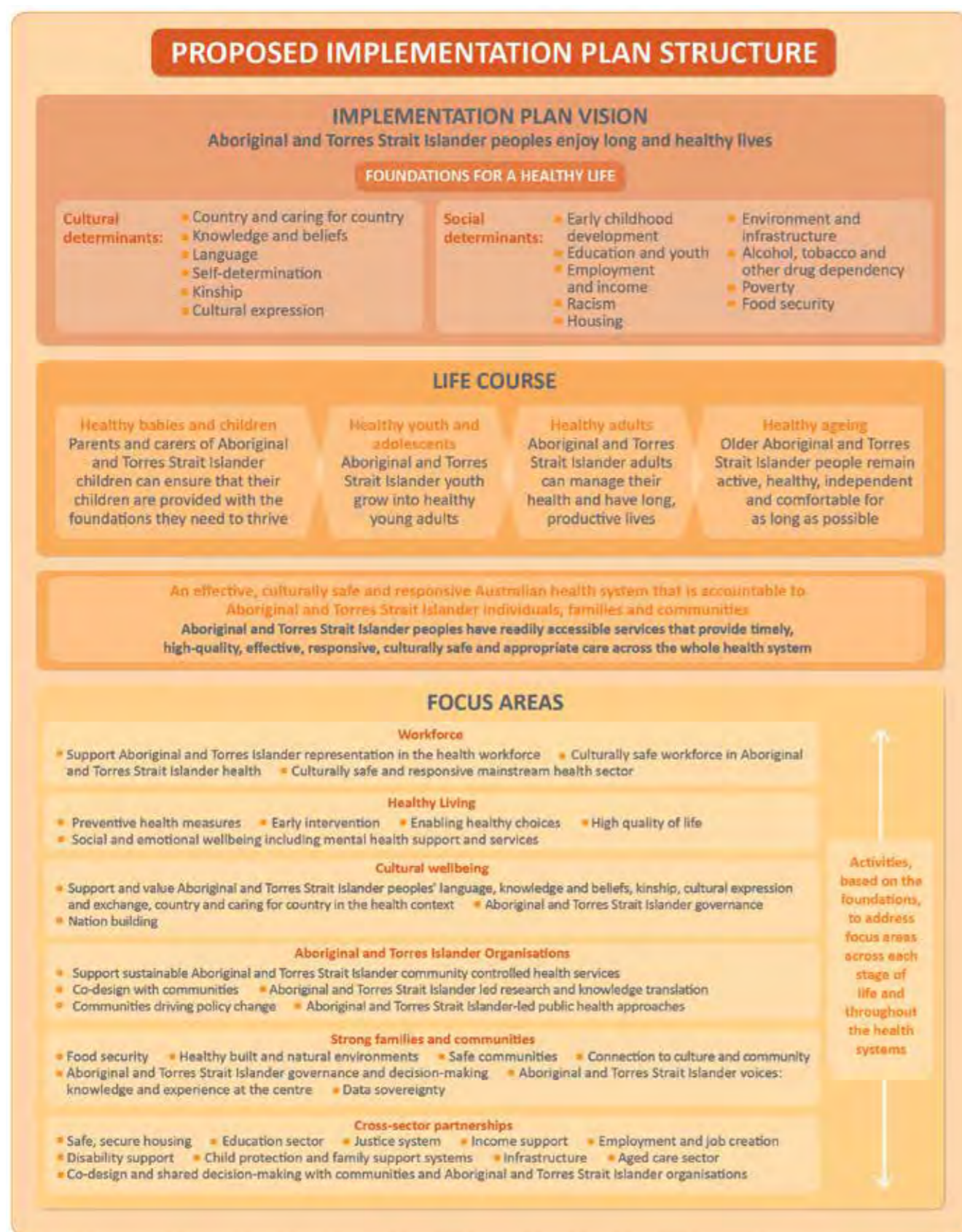


Figure 24: Revision of the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023.¹⁵⁶

NATSIHP Focus Area: Aboriginal and Torres Strait Islander Health Workforce

Baseline situation

There is compelling evidence that a high-functioning, well-resourced and culturally outstanding health workforce is essential to reduce the burden of Strep A, ARF and RHD among Aboriginal and Torres Strait Islander people. Many studies have identified the importance of the workforce for care delivery for RHD, particularly in frontline primary-care roles. For example:

- Evaluation of a two-year study to improve delivery of secondary prophylaxis injections to prevent ARF recurrence found that *'the most pressing needs of healthcare providers related to improved staffing levels'*. One healthcare provider participant reflected on strategies to improve secondary prophylaxis that: *'all of these processes take thought and time and a lot of planning. And we just don't have it.'*¹⁰⁷
- A qualitative consultation with 64 primary-care staff reflecting on 80 systems assessments and 2,581 individual clinical records for people with ARF and RHD care found that *'staffing and workforce'* were a major barrier to providing quality care for ARF and RHD.²⁵² Specifically: *'Most respondents indicated that there were inadequate numbers of staff in PHC services. In terms of staff roles, most agreed that there were inadequate numbers of ATSIHPs (Aboriginal and Torres Strait Islander Health Practitioners) and administrative staff. In terms of support systems for recruitment and retention, respondents felt there were inadequate systems in relation to all types of staff (nursing, medical specialists, allied health workers and administrative staff), but in particular more work needed to be done to recruit and retain ATSIHPs.'*²⁵²
- External evaluation of the Australian Government's Rheumatic Fever Strategy found that clinician knowledge about ARF and RHD was adversely affected by high rates of staff turnover, *'contributing to gaps in clinical care.'*⁶

There are direct and indirect effects from an insufficient and unstable primary-care workforce. Directly, health promotion campaigns encouraging people to attend clinic to treat Strep A infections are meaningless unless the clinic is staffed with people to receive them. Similarly, referral systems to address housing for health cannot function without environmental health staff and services. Guidelines for specialist review and assessment of people living with RHD cannot be followed if specialists are not available and waitlists are impossibly long.

Indirect effects are more insidious but equally serious. For example, in the Northern Territory, half of nurses working in the remote primary-care workforce in government primary-care clinics have left within four months.²⁵³ This makes it impossible to form critical relationships with community members, build trust with people living with RHD, establish new programs, or undertake continuous quality improvement projects.

Fundamentally, the strategies to end RHD and recommended in this *Endgame Strategy* are predicated on sufficient health workforce. Current and potential workforce roles related to Strep A, ARF and RHD and identified in Chapter 4 are summarised in Table 5.

Aboriginal and Torres Strait Islander Health Workers/Health Practitioners

'The Aboriginal and/or Torres Strait Islander Health Worker/Health Practitioner workforce evolved from a need to provide culturally safe clinical and primary healthcare services to Aboriginal and/or Torres Strait Islander people whose health needs were not being met by mainstream services.'

National Aboriginal and Torres Strait Islander Health Worker Association, 2016.²⁵⁴

Aboriginal and Torres Strait Islander Health Practitioner (ATSIHP) roles have existed informally for many decades.^{255,256} Initial conceptions of the ATSIHP role were similar to that of community or primary healthcare workers, with a focus on primary healthcare tasks such as health education, basic healthcare, and community health action. However, with the development of the ATSIHP role in the Northern Territory, a distinct feature of ATSIHP practice became the emphasis placed on *'cultural brokerage'* and the focus on provision of culturally safe and comprehensive primary healthcare

services to Aboriginal and Torres Strait Islander people.²⁵⁵ The tasks and responsibilities expected of ATSIHPs have increased since the creation of the role, incorporating clinical duties, community care and cultural brokerage.²⁵⁷

The ATSIHP role evolved in the Northern Territory and was recognised by the structured health system in the 1950s.²⁵⁵ It was formally incorporated into Australia's national health system in 2008.²⁵⁴ In 2012, the Aboriginal and Torres Strait Islander Health Practice Board of Australia was formed, regulating the profession nationally.²⁵⁴ Activities of ATSIHPs are defined by legislation at a jurisdictional level. ATSIHPs may be employed by State or Territory health departments to work in government hospitals or primary-care services; by Aboriginal community-controlled health services; or by other organisations delivering health and allied services.

According to the Productivity Commission as at June 2017, Aboriginal and Torres Strait Islander primary healthcare services employed a total of 686.8 FTE Aboriginal Health Workers (AHWs) and 300.0 FTE ATSIHPs.^{258,259}

Community Health Workers

Community Health Workers (CHWs) are people who work towards improving health in their communities in a range of ways. Titles of CHW roles vary, including of 'lay health educators', 'community health representatives', 'peer advisors' and 'multicultural health workers'.²⁶⁰

The Aboriginal CHW role in health promotion is distinct from, but complementary to, that of ATSIHPs in clinical settings.²⁶¹ While ATSIHPs are typically employed by and work through health services, CHWs complement this work in a community setting, for example within schools and with families. Benefits of this model included ensuring inclusivity by reaching the entire community, creating common goals, and reducing potential stigma associated with targeting programs to at-risk groups in a small community.²⁶¹ These CHWs tailor messaging and adapt resources to make health promotion content culturally appropriate, improving the relevance of the program to the local context.

Environmental Health Workers and Officers

Environmental determinants of health underlie the disproportionately high rates of Strep A infection, ARF and RHD. These are described in detail in Chapter 4b. An effective environmental health workforce, especially Aboriginal and Torres Strait Islander Environmental Health Practitioners, is critical to addressing the root causes of Strep A infections and other health outcomes related to environmental health.^{262,263}

Box 4: Environmental health workforce to support Healthy Living Practices

The Australian Department of Health defines environmental health as addressing 'all the physical, chemical, and biological factors external to a person, and all the related factors that can potentially affect health'.²⁶⁴ In some jurisdictions, environmental health staff have a major role in supporting Healthy Living Practices (HLPs) of remote Aboriginal and Torres Strait Islander communities where issues of sanitation, housing-related environmental issues, the built environment, waste disposal and regulation are on the front line of disease control.²⁶² Most Environmental Health Officers (EHOs) in Australia are employed by local councils, though funding constraints and increasing demand mean the small number of EHOs are increasingly stretched to support and deliver critical services, generally focused on the built environment rather than housing.²⁶² Training opportunities for new environmental health staff, scope of work and retention of EH practitioners are variable between jurisdictions.^{265,266}

Despite these challenges, Aboriginal and Torres Strait Islander Environmental Health Officers and Aboriginal and Torres Strait Islander Environmental Health Worker programs show some of the greatest promise in supporting healthy living practices. The 2010 Environmental Health Practitioner Manual: a resource manual for Environmental Health Practitioners working with Aboriginal and Torres Strait Islander communities, provides practical guidance about germ theory, dog management, pest control, water supply and community education.²⁶⁷ Employment of Aboriginal and Torres Strait Islander Environmental Health Practitioners may provide a mechanism for communities to have meaningful, direct impact on access to HLP, increase local employment, and build workforce capacity.

The lack of housing-related Environmental Health Services provided to Aboriginal and Torres Strait Islander communities is a substantial ongoing concern to peak Aboriginal health organisations. In Australia in 2017, there were only 32.9 FTE Environmental Health Workers employed by Aboriginal and Torres Strait Islander primary healthcare services nationally.^{258,259}

The structure and resourcing of environmental health programs vary widely between jurisdictions, as does the employment of Aboriginal and Torres Strait Islander Environmental Health Practitioners. Some of these variations include:

- Service delivery arrangements: Environmental health is the responsibility of State government public health units or agencies, local government councils, Aboriginal Community Controlled Health Organisations, or other Aboriginal and Torres Strait Islander organisations.
- The remit of environmental health programs and services delivered: While some have a strong focus on housing related environmental health, other jurisdictional areas are serviced by State or Local Government Environmental Health Officers (EHOs) who service Aboriginal Communities with a focus on all aspects of the built environment.
- The activities that can be performed by Indigenous Environmental Health Workers (IEHWs).

Specialist medical workforce

The specialist workforce required to provide care for Aboriginal and Torres Strait Islander people with RHD includes cardiologists, paediatric cardiologists, cardiothoracic surgeons, specialist cardiology nurses and sonographers, and access to paediatricians, obstetricians and general medical specialists. However, access to specialist services for Aboriginal and Torres Strait Islander people, particularly those in remote areas, is often poor. In 2013–14, Aboriginal and Torres Strait Islander access to specialist care was 43% lower than for non-Indigenous Australians.²⁶⁸

Strategies

It is rarely possible, or desirable, for PHC health staff to *solely* deliver services for people living with ARF and RHD. With the exception of a small number of care coordination roles, most care is delivered by generalist providers. Attempting specific initiatives for Strep A infections, ARF and RHD when the health workforce is inadequate is doomed to fail. Staff who are employed to focus on ARF/RHD alone will inevitably be needed to provide acute care services if immediate clinical care roles are unfilled. A comprehensive approach is therefore needed to provide a sustained and comprehensive PHC workforce.

Increase and support the Aboriginal and Torres Strait Islander primary-care workforce

Aboriginal and Torres Strait Islander people with long-term community connections are the most appropriate health workforce in primary care. Aboriginal and Torres Strait Islander healthcare providers should be supported by a workforce equipped to provide culturally excellent care in primary, secondary and tertiary settings.

A number of initiatives are under way to increase and strengthen the Aboriginal and Torres Strait Islander health workforce. These speciality approaches and agencies are appropriately identifying priority-setting with Aboriginal and Torres Strait Islander leadership, including:

- *The National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework (2016–2023)*.¹⁶¹
- *National Aboriginal and Torres Strait Islander Health and Medical Workforce Plan*.²⁶⁹
- *National Medical Workforce Strategy*.²⁷⁰

National workforce initiatives articulate with jurisdictional activities, including the *Primary Health Care Workforce Strategy* in the Northern Territory,²⁷¹ *South Australian Health Aboriginal Workforce Framework 2017–2022*,²⁷² *Western Australia Health Aboriginal Workforce Strategy 2014–2024*²⁷³ and the *Queensland Aboriginal and Torres Strait Islander Health Workforce Strategic Framework 2016–2026*.²⁷⁴

Similarly, the Career Pathways Project (CPP) is a national workforce project, which aims to provide insights and guidance to enhance the capacity of the health system to retain and support the development and careers of Aboriginal and Torres Strait Islander people in the health workforce.²⁷⁵ It is a collaborative project, initiated by ACCHOs, and has leadership at all levels by Aboriginal and Torres Strait Islander investigators, partners and researchers.²⁷⁵ The CPP will develop a set of evidence-

based guiding principles to assist health service managers and policymakers across sectors in pillars of support. It will also outline a proposed monitoring mechanism to track progress in policy and practice to address the barriers and improve the recruitment, retention and career pathways of Aboriginal and Torres Strait Islander health staff.²⁷⁵

Focused initiatives to increase Aboriginal and Torres Strait Islander employment in the health workforce can be effective. For example, Danila Dilba, an ACCHS in Darwin, employs approximately 170 staff and operates seven clinics in the Greater Darwin area.²⁷⁶ Danila Dilba introduced an Indigenous Employment and Career Pathways program aimed at increasing Aboriginal and Torres Strait Islander staffing at all levels. This focus on staff retention has resulted in a more stable workforce, with a reduction in staff turnover from 36% in 2015–16 to 22% in 2017–18. As well as optimising patient care, reduced turnover saved the service about \$400,000 on casual or agency staff in one year. Investing in professional development, mentorship and career planning has been successful in attracting and retaining staff. In 2017–18, Aboriginal and Torres Strait Islander staff made up 65% of the Danila Dilba leadership team and 63% of non-GP clinicians and community, social and clinical support staff.²⁷⁶

Increase the environmental health workforce

The environmental health workforce in Australia is not well defined or supported. While tertiary qualifications in environmental health – degree, diploma and a certification scheme – are available in some jurisdictions, there is no clear pathway into environmental health employment.²⁶² Models of environmental health workforce and provision of services varies considerably between jurisdictions, and workforce planning for environmental health is significantly behind other parts of the health workforce.

A national plan for a trained environmental health workforce, including establishing workforce benchmarks, is needed to complement the *COAG Health Council National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework*.¹⁶¹

Recommendations

The RHD National Implementation Unit should:

- Continue to collate experience and evidence about the role of the Aboriginal and Torres Strait Islander health workforce to address Strep A infections, ARF and RHD;
- Contribute to the development and implementation of the national *Aboriginal and Torres Strait Islander Health and Medical Workforce Plan* initiated by the COAG Health Council and the *National Medical Workforce Strategy*;¹⁶¹ and
- Work with sectorial partners including NACCHO, National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA), and professional colleges to advocate for workforce expansion, support and resourcing.

NATSIHP Focus Area: Aboriginal and Torres Strait Islander Organisations

Baseline situation

The majority of strategies needed to prevent Strep A infections, ARF and RHD must happen through primary care: health promotion, preventing and treating skin sores, diagnosing ARF, and managing chronic care needs and secondary prophylaxis of people with RHD.²⁷⁷ Therefore, PHC is the cornerstone of ending RHD.

PHC services must be adequately funded to provide comprehensive and culturally appropriate care. However, PHC services for Aboriginal and Torres Strait Islander people in rural and remote areas of Australia do not currently receive sufficient funding or support to achieve this.

Funding model

Funding for remote Aboriginal and Torres Strait Islander PHC is provided from a range of sources. The largest of these sources are:

Indigenous Australians' Health Programme (IAHP)

Since 2014, funding for remote Aboriginal and Torres Strait Islander primary care has been administered through the Indigenous Australians' Health Programme (IAHP).²⁷⁸ IAHP consolidated a number of earlier funding streams into a more unified funding mechanism. Activities funded through IAHP have included

Primary Care Activity for clinical service delivery, along with Tackling Indigenous Smoking, the Remote Area Health Corps, and Integrated Team Care.²⁷⁹

Data from the Productivity Commission for 2016–17 demonstrated that \$672.7 million was spent on Aboriginal and Torres Strait Islander primary health services by the Australian Government.²⁵⁹ Over that year, there were 196 Aboriginal and Torres Strait Islander primary health services funded, providing more than 3.2 million episodes of healthcare. Almost half (42.6%) of the Aboriginal and Torres Strait Islander primary healthcare episodes provided were in remote or very remote areas.²⁵⁹

In 2019, IAHP contributed \$800 million for Aboriginal and Torres Strait Islander health, of which approximately 60% was directed to the ACCHO sector.²⁵⁹ In November 2019 the Australian Government announced an additional investment in the IAHP of \$90 million over three years for comprehensive primary healthcare.²⁸⁰ This is to be combined with annual indexation and three-year funding agreements for greater workforce continuity and planning. This November 2019 announcement also indicated that changes to the distribution of funding to ACCHSs would be introduced in mid-2020, to be developed in partnership by the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Australian Medical Association.²⁸⁰

Medicare

Medicare is an Australian Government-funded health insurance scheme intended to provide universal access to affordable, accessible and high-quality healthcare for all Australians.^{281,282} The Medicare Benefits Schedule (MBS) is a list of professional medical services for which the Australian Government pays a Medicare rebate to individual consumers. Each professional service is assigned an item number. The Medicare funding model mechanises a 'fee-for-service' approach to primary care. This is supplemented by a smaller amount of practice incentive payments (outcomes-based funding), including for Aboriginal and Torres Strait Islander health.²⁸³ The largely fee-for-service Medicare funding model has major constraints for remote Aboriginal and Torres Strait Islander PHC because:

- The majority of MBS rebates are for services provided by a doctor, usually general practitioners in PHC. However, there is a substantial shortage of doctors in rural and remote areas. More than 46,000 Aboriginal and Torres Strait Islander people (6.9% of the Aboriginal and Torres Strait Islander population) live in areas of GP supply shortages.¹²¹ Therefore, in remote areas, most PHC services are delivered by Remote Area Nurses or ATSIHPs. However, fewer than one-third of these services are reimbursed through MBS rebates.²⁸⁴ In 2010, Medicare expenditure on PHC services in very remote areas was only 57% of expenditure in urban settings.²⁸⁵ Limited access to MBS rebates in remote settings leads to underfunding for PHC in the areas of greatest need.²⁸⁶⁻²⁸⁸
- MBS rebates do not account for the real cost of delivering PHC services in remote locations. Providing PHC in small, remote clinics is considerably more expensive than in other settings.^{284,287} For example, remote PHC providers report significant ongoing cost to provide core services, including \$220,000 annually for after-hours services, annual staff accommodation costs of \$40,000, satellite internet costs of \$50,000, and freight costs of \$20,000 annually. These kinds of costs mean that even when MBS rebates are paid, the true cost of providing PHC services in remote settings is not covered by rebates.²⁸⁸

Other smaller funding sources for PHC come from State or Territory government grants, and Federal government and commissioning agencies for various disease- or activity-specific programs. These ad hoc funding streams vary in amount over time and can be administratively complex with short funding horizons.²⁸⁸

Service delivery model

Delivery of PHC in remote Aboriginal and Torres Strait Islander settings is very different to urban or non-Indigenous settings. There are clear differences in PHC services between 'mainstream' GP and Aboriginal Community Controlled Health Services in the Indigenous Health Service Delivery template (reproduced in Box 5).²⁸⁹

A systematic scoping review of Indigenous PHC service delivery models globally identified the characteristics that distinguished them from mainstream health services. Culture underpinned all aspects of service delivery. Other key distinguishing features included greater accessibility, community participation, continuous quality improvement, culturally appropriate and skilled workforce, a flexible and holistic approach to care, and self-determination and empowerment.¹⁵ ACCHSs also have an important role in addressing the negative effects of racism and intergenerational trauma on health.²⁹⁰

Box 5: The Indigenous Health Service Delivery Template components (reproduced from Ong et al., 2012)²⁸⁹

Differences in how health interventions are delivered between ACCHSs compared to 'mainstream' GP practices:

- Basic health intervention delivery characteristics:
 - Role substitution – a patient may be seen by an Aboriginal Health Worker or a nurse before, or instead of, a doctor.
 - Compliance management – e.g. medication dosing and appointment recalls.
 - Staff training activities – e.g. cultural in addition to professional training for non-Indigenous staff.
 - Emphasis on social determinants and relationships with the community, including home visits.
 - Time spent on paperwork, case conferencing and the management of complex medical conditions.
 - Seeing of other family members as part of routine consultations.
- Population health, social and community activities:
 - Provision of holistic healthcare and wrap-around services – e.g. social work and counselling.
 - Provision of services usually provided by outside agencies – e.g. pharmacy, financial and housing assistance.
 - Health promotion and community development activities.
 - Provision of a community space.
- Management and governance structures:
 - Presence of a community management board and the associated need for community capacity building in management.
 - Additional management resources required for overseeing larger staff numbers and multiple projects.
 - Differences in rates of Indigenous utilisation of services and adherence to treatments.
 - Differences in rates when interventions are delivered from ACCHSs compared to mainstream GP clinics due to improved access.

These differences map closely to the expressed needs priorities for improving care of Aboriginal and Torres Strait Islander peoples with Strep A infections, ARF and RHD – namely, culturally excellent, responsive and accessible primary-care services.

Funding gaps

The culturally grounded service delivery models of ACCHSs means they have a different cost profile relative to 'mainstream' services. This is the case for management of Strep A infections, ARF and RHD, as for all other conditions. A qualitative consultation with 64 primary-care staff reflecting on 80 systems assessments and 2,581 individual clinical records found that for ARF and RHD care 'most respondents disagreed that there were sufficient financial supports from government or health authorities to support best practice in ARF/RHD healthcare'.²⁵² Illustrative primary-care activities relevant to the *Endgame Strategy* are presented in Table 5.

Table 5: Illustrative primary-care activities for Strep A infections, ARF and RHD and associated funding.

Treatment of scabies and skin sores	Costs	Funding
<p>ATSIHP or RN review of skin sores</p> <p><i>With most remote ACCHS PHC providers, the initial assessment for common conditions such as skin sores is conducted by an ATSIHP or nurse. In the Northern Territory, this is guided by the CARPA Manual; similar operational arrangements exist in other settings.²⁹¹ Complex skin sores may be referred to a GP, if available, for additional assessment. Assessment and treatment of skin sores does not currently attract an MBS rebate unless a GP consult occurs.</i></p>	ATSIHP or RN salary costs	Potential partial May be partially funded through IAHP grants or other core funding sources.
<p>General Practitioner review of skin sores, assessment and treatment</p> <p><i>Where a GP is available, assessment and treatment of skin sores can be funded through time-based general practice MBS rebates.</i></p>	GP salary costs	Funded Time-based MBS rebate can be claimed if a GP is available to provide the service.
<p>Dispensing medication from the clinic under s100 scheme</p> <p><i>Antibiotics are recommended to treat skin sores in Aboriginal and Torres Strait Islander populations.⁵³ Oral medication may be used – which must be retrieved from the onsite pharmacy in s100 settings, labelled and dispensed to the consumer with instructions on use.</i></p>	ATSIHP, RN or GP salary costs	Partial s100 funding Costs partially covered though s100 funding scheme.
<p>Wound dressing by ATSIHP or RN</p> <p><i>A waterproof dressing is recommended for skin sores – this may improve healing and is likely to reduce transmission of Strep A infections.⁵³ Consumable wound dressing costs are not funded.²⁹²</i></p>	ATSIHP or RN salary and consumable costs (dressings and wound care)	Partial MBS funding MBS rebate (item number 10989) if 'on behalf of and under the supervision of, a medical practitioner'. ²⁹³ Consumable costs not funded through MBS. Wrap-around services and health promotion activities required for the client and the family may not be funded.
<p>Referral to environmental health services to identify modifiable risks for future skin sores</p> <p><i>Improving the integration of PHC and environmental health services is necessary to help prevent recurrent skin sores. Referring to environmental health services (where they exist) and other administrative arrangements are not currently formally funded.</i></p>	ATSIHP, RN or GP salary costs	Unfunded Not funded through MBS unless the referral is arranged by a GP during a time-based consultation with the patient in attendance.
<p>Other activities associated with prevention and management of skin sores include training of health staff to assess skin sores and sore throats (recommended in Chapter 4c), use of interpreters where necessary to provide health education, health promotion to families about Healthy Living Practices (recommended in Chapter 4b), and addressing the role of scabies in skin infection. These additional activities are largely unestablished or unfunded in current primary-care models.</p>		

Delivery of secondary prophylaxis injections	Costs	Funding
<p>Maintenance of secondary prophylaxis injection recall list by nominated ATSIHP, RN or administrative staff member</p> <p><i>Most remote ACCHS clinics have a list of people receiving secondary prophylaxis injections and a system for following up people on this list. In some jurisdictions, this list is triangulated with information sent to and from the RHD register. These administrative tasks are time- and resource- intensive.</i></p>	<p>ATSIHP, RN or administrative salary costs</p>	<p>Potential partial funding May be partially funded through IAHP grants or other core funding sources.</p>
<p>Reminders to people living with ARF/RHD that injections are due – by phone, home visit or outreach services</p> <p><i>Most remote ACCHS clinics provide reminders to let people know their secondary prophylaxis injection is due. As outlined in Chapter 4d, some of these reminder systems appear to increase secondary prophylaxis delivery. These reminder services receive no dedicated funding.</i></p>	<p>Administration, driver and ATSIHP or RN salary costs</p>	<p>Potential partial funding May be partially funded through IAHP grants or other core funding sources.</p>
<p>Secondary prophylaxis injection delivery</p> <p><i>Delivery of secondary prophylaxis injections includes collecting medication from an onsite pharmacy in s100 settings, education and pain- reduction techniques and injection delivery.</i></p>	<p>ATSIHP, RN or GP salary costs</p>	<p>Potential MBS funding Secondary prophylaxis injections administered by a GP in the course of a consultation are eligible for time-based MBS item number rebates. However, most injections are provided by ATSIHP or RNs in remote ACCHS settings. Services delivered by practice nurses or ATSIHP may be eligible for MBS funding (item number 10987) for up to 10 episodes a year if the person has a valid health assessment.²⁹⁴</p>
<p>Other activities associated with delivery of secondary prophylaxis may include the use of clinic drivers to transport people for injections or provide outreach services and liaising with the RHD register and other clinics to establish whether injections have been given elsewhere. These additional activities are largely unfunded in current primary-care models.</p>		

Diagnosis of ARF	Costs	Funding
<p>Preliminary assessment of suspected ARF in primary care</p> <p><i>The Australian Guideline recommends the following investigations for people with suspect ARF: history and physical examination, blood tests (which blood cell count, inflammatory markers, blood culture, Strep A serology), throat swab and ECG.</i></p>	<p>ATSIHP, RN or GP salary costs Consumables for taking blood, swabs and ECG</p>	<p>Partial MBS subsidy MBS item numbers provide time-based rebate for a GP providing assessment and management of suspected ARF. RN or ATSIHP time for supporting this role and taking bloods or swabs is not covered. MBS item numbers for investigations (bloods, swabs and ECG) provide some funding towards consumables but not necessarily staff time or logistic arrangements to transport samples out of community.</p>

Diagnosis of ARF	Costs	Funding
<p>Referral to hospital for assessment and management</p> <p><i>The Australian Guideline recommends that all people with suspected ARF are admitted to hospital for further investigation and diagnostic confirmation, particularly with echocardiography. In most remote settings this means arranging medical evacuation.</i></p>	<p>ATSIHP, RN or GP salary costs to arrange referral. PATS officer or administrative support to arrange transport.</p>	<p>Partial MBS subsidy MBS item numbers provide time-based rebate for a GP to make referrals to specialist services while the person with suspected ARF is present. Medicare funding does not account for logistics arrangements including phone calls to specialists and transport specialists while the person is not present.</p>
Management of patients with existing RHD or history of ARF	Costs	Funding
<p>Coordination of specialist appointments, such as echocardiography, cardiology, cardiac surgery, dental care</p>	<p>ATSIHP, RN or GP salary costs. Administrative support to arrange specialist visits and transport.</p>	<p>Potential Partial MBS subsidy Management of RHD may be eligible for a GP Management Plan (721) and Team Care Arrangement (723) and subsequent review arrangements (732).</p>

The amalgam of MBS rebates and primary-care grants does not meet the true cost of delivering best-practice clinical care for Aboriginal and Torres Strait Islander people in remote communities. A number of studies have explored this funding gap:

- Economic evaluation of Phase 1 of the NATSIHP found that the cost of providing a long primary-care consultation in a remote ACCHS was \$403, relative to \$163 for a long consultation in a remote ‘mainstream’ general practice.²⁹⁵
- Similarly, a review of the actual cost of managing diabetes and chronic kidney disease in a remote Aboriginal community, according to best-practice clinical guidelines, identified a projected funding gap of \$1,733 per patient per annum.²⁹⁶
- A 2006 study from the Northern Territory attempted to model the operational costs of a remote Aboriginal and Torres Strait Islander PHC relative to an average Australian solo general practice. Modelling identified that costs in the Northern Territory were almost double those of an average solo general practice and that MBS rebates covered about 30% of the actual cost of service delivery.²⁹⁷
- A 2012 study used a mixed-method approach to estimate the cost of ACCHS consultation relative to a ‘mainstream’ GP consultation. This indicated that a short consultation in the remote Aboriginal and Torres Strait Islander population costs five times more than the equivalent Medicare benefit.²⁸⁹
- A 2017 study used expenditure data from 11 high-performing remote PHC centres in the Northern Territory in a model to predict remote PHC funding based on population size.²⁸⁸ Its analysis suggested that economies of scale take effect in communities with a catchment population of approximately 800 and decrease significantly in communities with populations less than 200. Cost estimates from this model were compared to the actual expenditure from the Productivity Commission and estimates provided by the above studies.

Collectively, these studies conclusively demonstrate that current funding for remote Aboriginal and Torres Strait Islander PHC is grossly insufficient to delivery of best-practice care. This inequality is unjust and is a missed opportunity to offer disease-altering, cost-effective primary care for Strep A, ARF, RHD and other conditions.^{298,299}

Strategies

Increase funding quantum

An increase in funding for remote Aboriginal and Torres Strait Islander primary care is needed for the sector to be able to provide effective clinical care.^{288,300}

In its 2018 report card dedicated to Aboriginal and Torres Strait Islander health, the Australian Medical Association (AMA) concluded that ‘... overall Commonwealth Government spending is only 53 per cent of the needs-based requirements. Spending less per capita on those with worse health, and particularly on their primary healthcare services, is dysfunctional national policy. It is not ‘special treatment’ to provide additional health funding that is proportional to additional health needs. Further, the relative lack of spending on primary healthcare results in increased hospitalisation costs. It is a highly inefficient way to spend health dollars. This too must change.’³⁰¹

More work to identify the best mechanism for increasing funding to Aboriginal and Torres Strait Islander PHC is needed. It may be possible for loading to be added or increased to Medicare rebates for services delivered in remote locations or to Aboriginal and Torres Strait Islander people.³⁰² New MBS item numbers for ATSIHP or registered nurse services may increase MBS income for remote PHC sites. Conversely, increases in core funding or capitated payments may provide more opportunity for local priority-setting about funding allocations.

Optimise funding for different models of care delivery

Increasing care coordination

Care coordination has significant potential to improve outcomes from ARF and RHD, by increasing specialist follow-up, timely echocardiography, and timely access to cardiac surgery where required. Care coordination is recommended in the *Endgame Strategy* Chapter 4d and Chapter 4e for people with severe RHD and people receiving secondary prophylaxis.

Some funding for care coordination for Aboriginal and Torres Strait Islander people is provided through the Integrated Team Care (ITC) funding stream of the NATSIHP.²⁷⁹ External evaluation of the ITC program found a range of benefits and recommended ongoing funding.³⁰³ The General Practice and Primary Care Clinical Committee of the MBS Review Taskforce recommended an increase in funding for care coordination.³⁰⁴ Block funding for care facilitation, directly to ACCHSs, could more effectively resource care coordination.

Increasing use of telehealth

Telehealth has potential to improve care for people with Strep A infections, ARF and RHD as outlined in Chapter 4d and 4e. This includes capacity for increased GP review in remote primary-care settings and increased access to specialist services.

The General Practice and Primary Care Clinical Committee of the MBS Review recommended that telehealth items be expanded to be available to GPs as specialists, enabling them to provide direct-to-patient telehealth services. As of 1 November 2019, 12 new MBS items were added for GP telehealth consultations for patients living in rural and remote areas.³⁰⁵ The new items are only available to doctors who have an established clinical relationship with the patient requesting the telehealth consultation, defined as at least three face-to-face consultations in the past 12 months. Items which facilitate GPs to provide telehealth consultations to support Nurse Practitioners and Aboriginal and Torres Strait Islander Health Practitioners consulting with patients in remote and rural settings would also be beneficial. The telehealth MBS items should also be extended to remote areas nurses as well as nurse practitioners.

Increasing use of interpreters

Appropriate care for Aboriginal and Torres Strait Islander people includes the use of interpreters in relevant Aboriginal and Torres Strait Islander languages.³⁰⁶ Use of interpreters is commonly needed in remote settings to deliver culturally excellent care and to ensure that critical health education is possible. There is currently no additional rebate for MBS services provided with the aid of an interpreter. There is inadequate funding for the use of interpreters in primary care and other healthcare settings; arranging access to interpreters requires administrative time, and longer and more complex consultations. Introduction of additional MBS item numbers to be used in consultations with interpreters may go some way to offsetting these costs.³⁰⁷

Optimise funding disbursement

In addition to increasing the quantum of PHC funding, the disbursement of funds should be optimised to best reflect the needs of remote Aboriginal and Torres Strait Islander people and communities. This includes facilitating local priority-setting and governance.

Health Care Homes (HCH)

The HCH project began in 2016 following the Primary Health Care Advisory Group recommendations to improve care for people with complex chronic health conditions.³⁰⁸ The premise of HCH is that people can enrol with a practice and have all care coordinated through that practice. This service is funded through a single annual payment, replacing chronic disease-planning MBS items. Additional one-off funding for training and project initiation was provided. A nationwide pilot began in 2017 and a detailed evaluation framework has been developed.³⁰⁹ A number of remote ACCHS PHC providers are participating in this pilot and preliminary research has identified major cultural and service aspirations for the HCH model.³¹⁰ The HCH model may allow for more capitated core funding for Aboriginal and Torres Strait Islander people in remote locations. Further evaluation of this model is required.

Other partnerships

Effective governance or advice arrangements in funding disbursement can help ensure that PHC funding is used most appropriately and effectively. For example, the Northern Territory Aboriginal Health Forum (NTAHF) is a longstanding partnership between the Australian Government, Northern Territory Government, Northern Territory Primary Health Network and the Aboriginal Medical Services Alliance Northern Territory (AMSANT).^{311,312} The NTAHF has provided strategic leadership in the planning and implementation of an effective service delivery model for Aboriginal and Torres Strait Islander PHC together with leadership and innovation from the Aboriginal community-controlled health sector.³¹²

Consolidated funding streams

The administrative cost and complexity of multiple funding streams handicaps access to funding for small and remote PHC providers. Consolidating different funding into a single core funding model would reduce this complexity and allow primacy-care agencies to make best use of funds for local needs. A number of Aboriginal and Torres Strait Islander health bodies and research agencies have called for consolidated funding on this basis.^{300,312}

Recommendations

The RHD National Implementation Unit should:

- Work with jurisdictional agencies and primary-care providers to help understand the costs of delivering best-practice care for Strep A infections, ARF and RHD in the setting of comprehensive primary care;
- Work with other stakeholders in primary-care provision to understand how to best support comprehensive, culturally excellent primary care; and
- Support initiatives which increase resources to achieve equitable funding of PHC, accounting for population size, health need and complexity, and geographic remoteness. This may include innovations in funding models and streamlined funding disbursement.

NATSIHP Focus Area: Cultural Wellbeing

Baseline situation

Culturally competent care is central to ending RHD in both prevention and management.^{155,313} Biomedical approaches to Strep A infections, ARF and RHD are not meaningful unless they are developed and delivered within Aboriginal and Torres Strait Islander cultural realities.

‘Cultural competence is more than cultural awareness – it is the set of behaviours, attitudes, and policies that come together to enable a system, agency, or professionals to work effectively in cross-cultural situations... A culturally competent system of care acknowledges and incorporates – at all levels – the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally unique needs.’

Cross et al., 1989.³¹⁴

The centrality of cultural competency in addressing Strep A infections, ARF and RHD is articulated in a wide range of studies, reports and priority-setting initiatives:

- In the *NATSIHP 2013–2023*, cultural competency is described through the concept of respect, defined as ‘ensuring that the cultural diversity, rights, views, values and expectations of Aboriginal and Torres Strait Islander peoples are respected in the delivery of culturally appropriate health services.’³¹⁵
- Cultural competency in the delivery of health services for Indigenous people.³¹³

Strategies

Culturally safe and responsive mainstream health sector

Cultural safety is a concept which was originally defined in New Zealand, developed in response to the harmful effects of colonisation and its ongoing legacy on the health and healthcare provided to Māori people.³¹⁶ One widely accepted definition of ‘cultural safety’ is the ‘effective nursing or midwifery practice of a person or family from another culture, and is determined by that person or family.’³¹⁶ *Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual.* Importantly, cultural safety is defined by the end-users of the services, i.e. Aboriginal and Torres Strait Islander people, not by the non-Indigenous providers of that care.³¹⁶

Cultural safety in healthcare requires acknowledgment of the impact of colonisation and the ongoing systemic disenfranchisement and racism experienced by Aboriginal and Torres Strait Islander people. In 2019, a *Cultural Safety in Healthcare Monitoring Framework* was established (Figure 25), covering three domains:

1. How healthcare services are provided.
2. Aboriginal and Torres Strait Islander patients’ experience of healthcare.
3. Measures regarding access to healthcare.³¹⁶

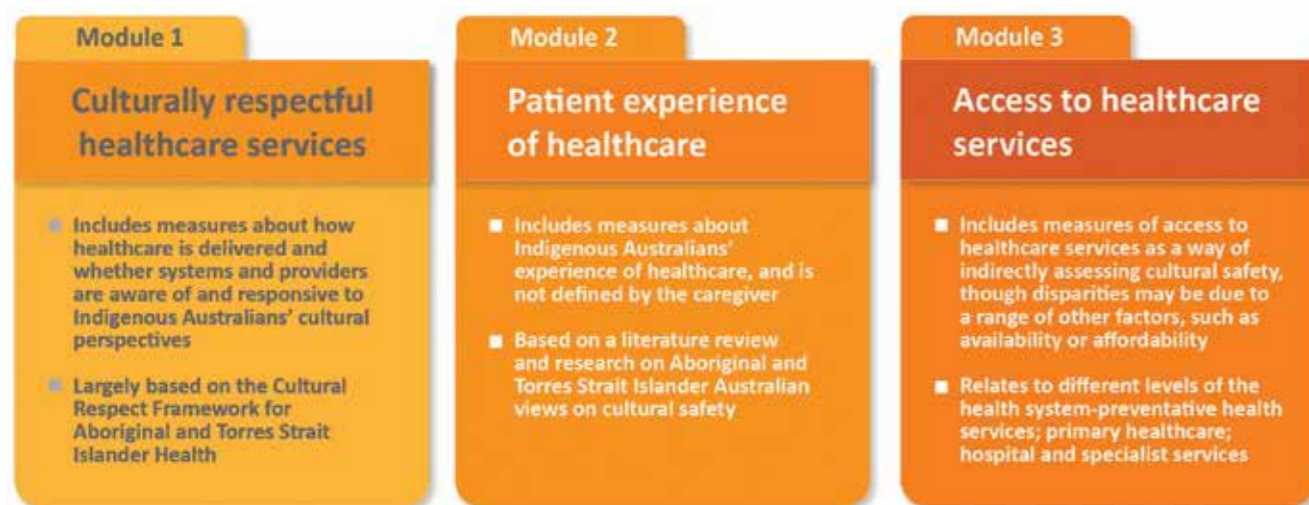


Figure 25: Cultural safety in healthcare monitoring framework domains.

There has been increasing recognition in Australia that improving cultural safety for Aboriginal and Torres Strait Islander people can improve access to, and the quality of, healthcare. This means a health system where Aboriginal and Torres Strait Islander cultural values, strengths and differences are respected, and racism and inequality are addressed.³¹⁶

Culturally respectful health services

ACCHSs are well-recognised as providing holistic, culturally appropriate care. Mainstream health services – particularly in an acute or tertiary setting – may not provide appropriate care for Aboriginal and Torres Strait Islander people. Restructuring of mainstream healthcare teams is needed to develop culturally secure relationship-based care, rather than disease-centred care.³¹⁰ In a qualitative study of 60 Aboriginal health service users in the Northern Territory, it was expressed that patients wished for a focus on culturally competent relationship-based care, as well as a reorientation of the Aboriginal and Torres Strait Islander Health Practitioner role from acute care management to strengths-based competencies.

Care should be focused within communities, engaging local cultural navigators and brokers, and ensuring local reference groups have ongoing and considerable input into service design.

The *National Safety and Quality Health Service (NSQHS) Standards User Guide for Aboriginal and Torres Strait Islander Health* was launched in 2018.³¹⁷ The guide aims to assist health services to improve the quality of care and health outcomes for Aboriginal and Torres Strait Islander people.³¹⁷

Culturally appropriate health communication

While interpreters speaking Aboriginal and Torres Strait Islander languages are of use, especially within tertiary settings, they are frequently underutilised to the detriment of patient care.^{318,319} The use of interpreters may also be unsuitable in some settings, such as when an interpreter would be required to interpret for a relative or acquaintance, or for gendered issues.

Health communication can also be improved by applying empowering, strengths-based approaches for care and health communication that values social and cultural strengths as well as Aboriginal and Torres Strait Islander languages.³²⁰

Other methods of effective communication to enhance cultural security can include developing rapport, being conscious of non-verbal communication, respecting personal space, avoiding touch unless permitted, allowing time for decisions about treatment to be made with family, and refraining from using local language or terms unless confident about their applicability in context.³²¹ Importantly, strong Aboriginal and Torres Strait Islander leadership at the senior levels is essential to planning and designing culturally safe healthcare services for Aboriginal and Torres Strait Islander people.

Recommendations

The RHD National Implementation Unit should:

- Work with jurisdictional agencies and primary-care providers to help understand the relationship between culture and care delivery for Strep A infections, ARF and RHD;
- Support the implementation of the National Safety and Quality Health Service (NSQHS) Standards User Guide for Aboriginal and Torres Strait Islander Health; and
- Engage in national efforts to increase access to culturally appropriate health communication, including the use of interpreters.

NATSIHP Focus Area: Cross-sector partnerships

Baseline situation

The main drivers of Strep A infections are environmental, social and economic; particularly household overcrowding, poverty and inadequate access to functional health hygiene infrastructure. These determinants mean that preventing new cases of Strep A infection requires action outside the health sector. However, mechanisms for addressing determinants of health outcomes in other sectors are generally weak.

Strategies

Service delivery partnerships need to be developed between housing, health, environmental health, and education sectors. This will ensure a collaborative approach with each provider fulfilling their service responsibility in a coordinated, complementary and timely manner to achieve the best possible health outcome.

Housing

Chapter 4b outlines the link between housing and Strep A, ARF and RHD. It identifies in particular the increased risk of Strep A infection associated with overcrowding. Housing policy is discussed in Chapter 3.

Education

The *Endgame Strategy* has identified multiple intersections between education providers and opportunities to address Strep A infections, ARF and RHD. These include infrastructure issues such as provision of adequate handwashing facilities in remote schools, health literacy and health education in schools, and opportunity to provide health screening or health services directly in education settings.

Recommendations

The RHD National Implementation Unit should:

- Work proactively with people living with ARF and RHD, jurisdictional agencies, healthcare providers and researchers to identify cross-sector partnerships relevant to Strep A, ARF and RHD;
- Highlight to Federal and jurisdictional governments the health impacts of different sectors and facilitate interdepartmental action to address these issues;
- Promote the establishment of regional Housing for Health forums – involving representation from housing, health, environmental health and education sectors; and
- Support service delivery partnerships between housing, health, environmental health and education providers

NATSIHP Focus Area: Strong families and communities

Baseline situation

Central to achieving strong families and communities are Aboriginal and Torres Strait Islander governance and decision-making, with Aboriginal voice, knowledge and experience front and centre. Data sovereignty is an increasing priority for communities in order to effectively lead action around ARF and RHD. This is discussed in Chapter 3.

Local decision-making

The most important determinant of project success is community support. Aboriginal and Torres Strait Islander people consistently identify community engagement, consultation and ownership of health activities as a prerequisite for programmatic success.^{322,323} This need is supported by high-quality evaluations across a very wide range of programs over many years in Australia.³²⁴⁻³²⁶ For example, in a synthesis of contributors to success in Aboriginal and Torres Strait Islander health programs, the following characteristics were identified: community control, community participation and involvement, resourcing, sustainability, partnerships, workforce, evaluation, accountability and capacity building.³²⁷

These recommendations are further supported by the experience and evaluation of skin and RHD programs in Australia. In the RHD Secondary Prophylaxis (RHDSPP) study across 10 remote Aboriginal and Torres Strait Islander communities (2012–2016), a collaborative approach was used to develop Action Plans for improving SP adherence with health providers. The approach was most successful and most sustainable in clinics with strong community relationships, engaged staff, and resources allocated for programmatic service delivery.^{107,229} Similarly, the sustainability of community-based scabies and skin health control programs have been predicated on long-term relationships, awareness, engagement and local leadership.³²⁸ In developing a Coordinated Healthy Skin Program for the Top End, a feasibility study found that:

- Communities that have implemented their own programs have developed skills, community capacity and confidence to identify the advantages of working with neighbouring communities to implement a regional healthy skin program;
- Communities that had not planned or run their own programs expressed an interest in the program but wanted to gain their own experience before committing to a larger regional program; and
- There is a clear need for evaluated resource materials and programs to support communities which are planning their own programs.³²⁹

Recommendations

The RHD National Implementation Unit should:

- Ensure that local decision-making underpins all strategies to end RHD;
- Commit to governance structures and ways of working which prioritise local decision-making; and
- Support initiatives which facilitate access to local decision-making, including access to local data on the burden of Strep A, ARF and RHD.

NATSIHP Focus Area: Healthy Living

Baseline situation

The factors which determine whether someone lives healthily are wide ranging and have effect throughout the lifespan. Priorities within the IAHIP Implementation Plan focus area of Healthy Living include preventive health measures, early intervention, enabling healthy choices, social and emotional wellbeing, and health literacy.

Health literacy

Health literacy is increasingly recognised as a key social determinant of health. It is a driver of patient self-management, empowerment and engagement with their healthcare team. Low levels of health literacy have been identified as a hindering factor in the management of chronic disease.²⁹⁶

Improving health literacy and health knowledge through health promotion is equally important in preventing the development of ARF and RHD. This is discussed in detail in Chapter 4c.

Recommendation

The RHD National Implementation Unit should:

- Work with communities to develop health promotion materials which are tailored to local contexts.
- Fund communities to implement health promotion programs around the Healthy Living Practices and primary prevention of ARF and RHD.
- Support the development and dissemination of patient education materials to strengthen self-management of ARF and RHD.

Synthesis of structural and system recommendations in addressing Strep A infections, ARF and RHD

- Support primary care by increasing resourcing of Aboriginal and Torres Strait Islander health services, particularly in remote northern Australia. This can be achieved through a range of mechanisms including MBS rebates, increased use of telehealth, and investment in the health workforce.
- Invest in training and employing Aboriginal and Torres Strait Islander people in new and ongoing funded positions to deliver comprehensive primary healthcare. In addition, dedicated positions according to community needs may be considered for ARF and RHD case management, Integrated Team Care coordination roles, Environmental Health Officers, Aboriginal and Torres Strait Islander Health Practitioners, and Community Health Promoters.
- Reduce turnover of all staff through a range of evidence-based mechanisms including increasing Aboriginal and Torres Strait Islander staffing at all levels.
- Prepare health providers from all disciplines to work effectively in culturally appropriate services for Aboriginal and Torres Strait Islander people.



4 STRATEGIES TO END RHD

4b ADDRESSING ENVIRONMENTAL, SOCIAL AND ECONOMIC DETERMINANTS OF STREP A INFECTIONS

An overview of primordial prevention strategies to reduce the risk of Strep A transmission and infection



A new community laundry has been welcomed by those living in Barunga, including Reggie (pictured)

Introduction

Primordial prevention strategies focus on the prevention of risk factors and generally address the social and environmental determinants of health which increase the risk of Strep A associated disease^{17,29} (Figure 26).

Social determinants are defined as ‘the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces’.³³⁰ Improvements in living conditions have been widely credited for reducing the burden of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in most developed countries, including Australia.^{172,173} Internationally, improvements in living conditions have generally occurred at a population level through economic development, policy and regulatory changes.^{172,331,332}

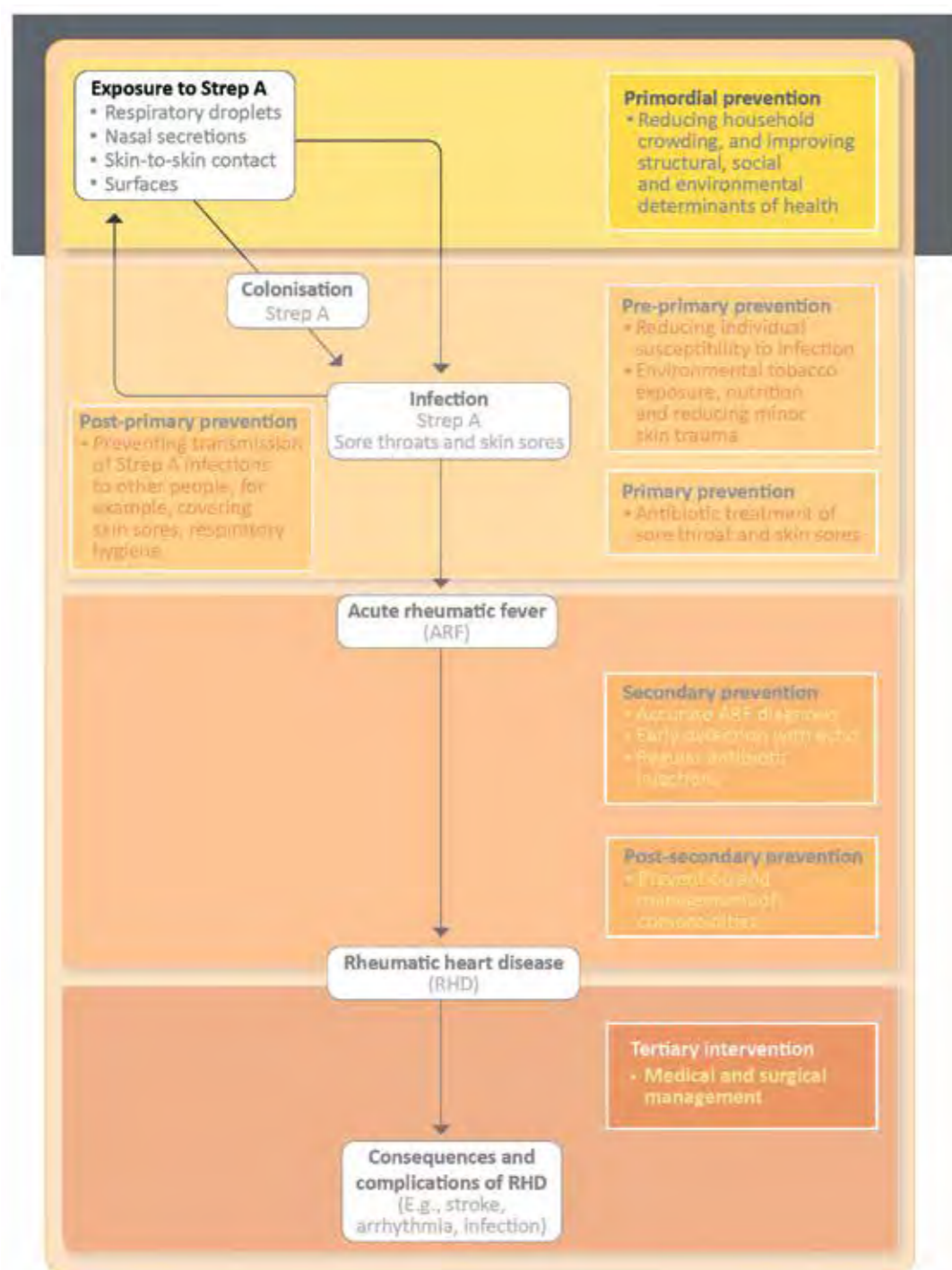


Figure 26: The role of primordial prevention in the causal pathway of Strep A infection.

In Australia, the health benefits of economic, social, political and cultural inclusion have been inequitable and have not been adequately realised by many Aboriginal and Torres Strait Islander people. The legacy of colonisation and the continuation of challenging public policy means that social determinants drive at least a third of the gap in health outcomes between Aboriginal and Torres Strait Islander people and other Australians.¹⁶³ Until parity of opportunity has been achieved for Aboriginal and Torres Strait Islander people, specific strategies are needed to address these underlying drivers of ill health.

Social, environmental and economic determinants of health can exert their influence directly (for example, when families prioritise buying food over soap to reduce the risk of skin sores) or indirectly (when families are unable to find employment because of systemic racial or educational exclusion and therefore cannot afford soap). The effect of indirect social determinants of health are real and measurable. For example, in a Northern Territory study, Aboriginal children were more likely to have had an infectious disease if their caregivers self-reported experiences of racism, even when confounding variables were accounted for.³³³

Some of these direct and indirect social determinants which influence health outcomes for Aboriginal and Torres Strait Islander people are illustrated in Figure 27. It is also necessary to acknowledge that poor health outcomes resulting from social disadvantage are often cyclic, challenging to break free of, and perpetuate further inequity throughout generations.³³⁴ Conversely, other determinants, including strong cultural identity, can have a positive effect on health outcomes.^{335,336}

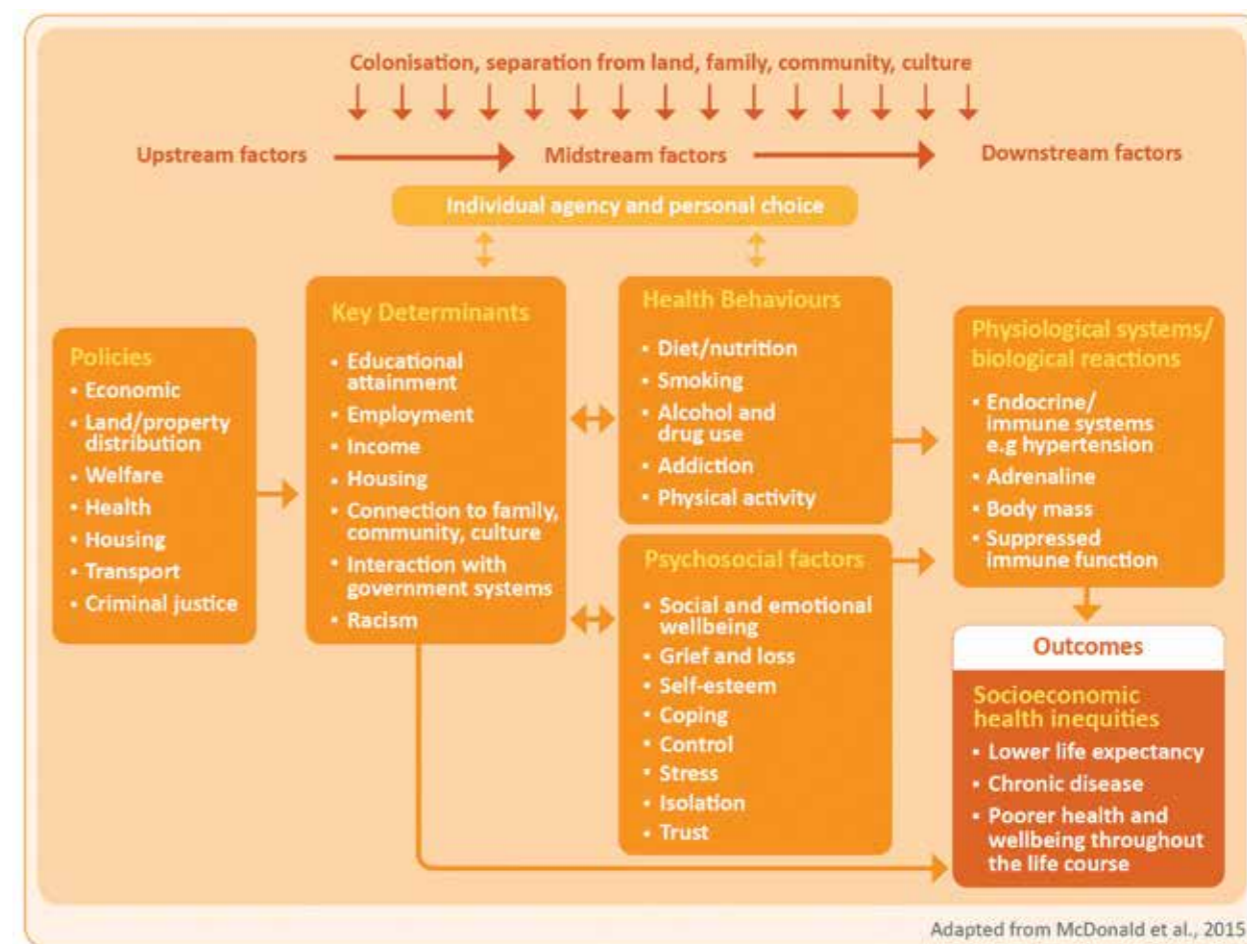


Figure 27: Overview of social determinants of health for Aboriginal and Torres Strait Islander people.^{337,338}

Alongside structural change, this review addresses the direct determinants of Strep A infection risk and opportunities for risk reduction. This review focuses on opportunities to reduce the risk of Strep A infection at a household and community level. Adequate housing is prioritised to reflect the widely expressed primacy by Aboriginal and Torres Strait Islander groups that improving housing is the key step to improving health.²⁴⁸ The importance of housing has also been expressed by communities, academics and health experts as the first priority.^{339,340}

Chapter 4b is intended to provide a technical foundation for community-level action on Strep A, ARF and RHD, with comment on the myriad strategies presented as a package as opposed to individual methods. This technical guidance can only ever be an adjunct to broad social change, led by Aboriginal and Torres Strait Islander peoples, to achieve equity in Australia.

Structure of this chapter

A wide range of environmental health strategies could have an impact on Strep A transmission and infection. To provide a framework for considering different options, this review is structured around nine Healthy Living Practices (HLPs). The development of the HLPs began more than 30 years ago and is outlined in Box 6.

Box 6: Introduction to Healthy Living Practices

The Nganampa Health Council has provided health services to Aboriginal people in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands since 1983.³⁴¹ In the 1980s, Yami Lester and other Nganampa Health Council Directors called for a project to 'stop people getting sick'.

This request initiated Uwankara Palyanku Kanyintjaku – a review of environmental and public health in the APY Lands, funded by the South Australian Minister of Health, jointly conducted by the Nganampa Health Council, South Australia Health Commission, and the Aboriginal Health Organisation South Australia (later, AHCSA), in conjunction with technical experts.³⁴²

The review was based on three main sources of information:

- Field survey of household circumstances of Anangu people in all major communities and selected homelands. This incorporated 90 houses with an average of 8.3 residents/house.
- Nutrition survey of dietary practices.
- Analysis of data which had already been collected, including clinic information, healthy survey records, housing details and evaluations of previous projects.

Recommendations from the Uwankara Palyanku Kanyintjaku review were intended for use by government and service agencies, Anangu Pitjantjatjara people and communities. Once immediate life-threatening dangers associated with electrical, gas, fire, sewerage and structural threats were addressed,³⁴³ the primary recommendation of the review was to use nine Healthy Living Practices (HLPs) to describe, define and focus on what people need to live healthy lives:

- Healthy Living Practice 1 - Washing people.
- Healthy Living Practice 2 - Washing clothes and bedding.
- Healthy Living Practice 3 - Removing wastewater safely.
- Healthy Living Practice 4 - Improving nutrition, the ability to store, prepare and cook food.
- Healthy Living Practice 5 - Reducing the negative impacts of overcrowding.
- Healthy Living Practice 6 - Reducing the negative effects of animals, insects and vermin.
- Healthy Living Practice 7 - Reducing the health impacts of dust.
- Healthy Living Practice 8 - Controlling the temperature of the living environment.
- Healthy Living Practice 9 - Reducing hazards that cause trauma.

These nine HLPs have been widely adopted as a foundation for communities and governments to consider the conditions related to housing, the built and natural environment, and help guide priorities for action. Dissemination of the HLP framework has been amplified by the not-for-profit company Healthhabitat, guided by directors who were involved in the initial Uwankara Palyanku Kanyintjaku evaluation.³⁴⁴ This included development of the *Housing for Health* approach and enshrining the concept of 'no survey without service' promulgated by Professor Fred Hollows.³⁴⁵

In 2000–2001, Healthhabitat was funded by the Australian government to assess and fix 11,000 houses nationally, using the *Housing for Health* processes.³⁴⁵ By March 2002, 792 houses in four jurisdictions had been assessed, with the vast majority of required work and maintenance completed by local Aboriginal and Torres Strait Islander staff. Most repairs were able to be completed within the project budget of \$3,000 per house.³⁴⁵

New South Wales subsequently adopted the *Housing for Health* program and provided jurisdictional funding through the NSW Department of Health in partnership with the Department of Aboriginal Affairs.³⁴⁴ The NSW Housing for Health program aimed to undertake repairs and maintenance of Aboriginal community housing, focusing specifically on improving safety and health for residents.¹⁸⁸ A 10-year evaluation of this NSW program was published in 2010: 71 community projects had been undertaken with 2,230 houses fixed to the benefit of 9,528 individuals. More than 51,700 items were repaired during this period.¹⁸⁸

Health outcomes were encouraging. People receiving the *Housing for Health* intervention had 40% fewer hospital separations for infectious diseases.¹⁸⁸ Guided by the HLPs, the program also demonstrated more than a twofold improvement in the ability to wash people, bedding and homes, and a twofold improvement in the safe removal of waste from homes.¹⁸⁸ Two companion principles developed; 'no survey without service' (the survey-fix approach) and a 'no service without survey' approach to provide data for ongoing improvements.³⁴⁶

HLPs have also been used as a framework for research initiatives (including the *Housing Infrastructure and Child Health Study* in 10 Northern Territory communities),³⁴⁷ for the National Indigenous Housing Guide³⁴⁸ and in reporting on the *Aboriginal and Torres Strait Islander Health Performance Framework*.¹⁶³ The *Housing for Health* approach was endorsed by the National Aboriginal and Torres Strait Islander Housing Authority, on behalf of jurisdictional partners, in their 2018 submission on the *Closing the Gap refresh*. The *Housing for Health* approach also has been endorsed as the most appropriate housing repairs and maintenance regime by NACCHO and affiliates from five jurisdictions. The approach is most effective when run in conjunction with an existing responsive repairs and maintenance program. The HLP framework provides a well-recognised model for considering Strep A risk reduction strategies. The framework was developed as a result of work done in an Aboriginal community and is therefore suitable for direct inclusion into existing policy frameworks.

Chapter 4b considers how each of the HLPs relate to Strep A transmission and infection, and outlines the baseline status of that HLP and the evidence for the association between the HLP and Strep A outcomes. Potential strategies to increase access to HLPs are presented and reviewed using the adapted evidence to decision-making framework.

Chapter 4b is not intended to identify *individual* strategies to be completed to reduce Strep A, ARF and RHD. Rather, Chapter 4b demonstrates the importance of each HLP as part of a comprehensive package of strategies to reduce the burden of disease.

Methods

1. A focus group to explore potential environmental, social and economic prevention priorities was convened in May 2018 at the END RHD CRE Annual Meeting with approval from The University of Western Australia Human Research Ethics Committee (RA/4/20/4489). Six participants, including two people identifying as Aboriginal and/or Torres Strait Islander people and two from New Zealand, participated. Housing, community empowerment and health and other services emerged as priority themes and key directions helped to inform the structure of this review.
2. A systematic review of global social determinants of Strep A infection, ARF and RHD was also published in 2018, providing a critical synthesis of international research.²⁹ A review of Strep A transmission mechanisms was undertaken to provide biological context, and a systematic review on transmission mechanisms is under way.⁴⁰ The HLP framework was identified as a way to synthesise these inputs into tangible, actionable opportunities which would be useful for communities and decision-makers.
3. A brief literature review was conducted to explore the relevance of each HLP to:
 - Define the baseline circumstances of access to each HLP for Aboriginal and Torres Strait Islander people living in remote communities;
 - Define the evidence for an association between each HLP and Strep A infections, ARF and RHD; and
 - Identify different strategies for improving access to each HLP.

Relatively few peer-reviewed publications were available for each HLP. A search of the grey literature to identify other programs and evaluations was undertaken using similar search terms in Google. References from peer-reviewed publications and evaluation reports were hand-searched for other relevant examples, and chapter reviewers provided direction to additional resources and case studies.

Population-level approaches were considered and examples from Australia were prioritised. Management of individuals who have Strep A infections was not included, as this is covered in the Primary Prevention (4c) chapter.

Healthy Living Practice 1 – Washing people

Baseline situation

Many people in remote Aboriginal and Torres Strait Islander communities have insufficient access to functioning health hardware (e.g. taps and sinks), consumables (e.g. soap and clean towels), and water for effectively washing hands and bodies.

A survey of houses in Aboriginal and Torres Strait Islander communities across Australia between 1999 and 2006 found that 65% of houses did not have a functioning shower, and it was impossible to wash a child in a tub or bath in 50% of homes.³⁴⁰ A smaller study from the same era in the Northern Territory identified that very few houses had a tub for washing children, with variable access to showers and handwashing basins.³⁴⁹ Similarly, a survey of 75 houses in a Central Australian community in 2000 found only 33% of houses had adequate facilities for washing people.³⁵⁰ In the mid-2000s, a study exploring the housing circumstances of children under seven years of age in three remote Aboriginal and Torres Strait Islander communities found that 28% of houses did not have facilities for washing children.³⁵¹

These health hardware limitations are only some of the barriers to hand and body washing. A broad array of social, structural, mechanical and cultural practices contribute to washing behaviours as outlined in Figure 28.^{351,352} These underlying determinants can include household crowding, climatic and structural disruptions to consistent water supply, and limited hygiene education.³⁵³⁻³⁵⁵ A comprehensive, multiple-exposure, multiple-effect approach to addressing these determinants is needed before change is likely to occur.³⁵²

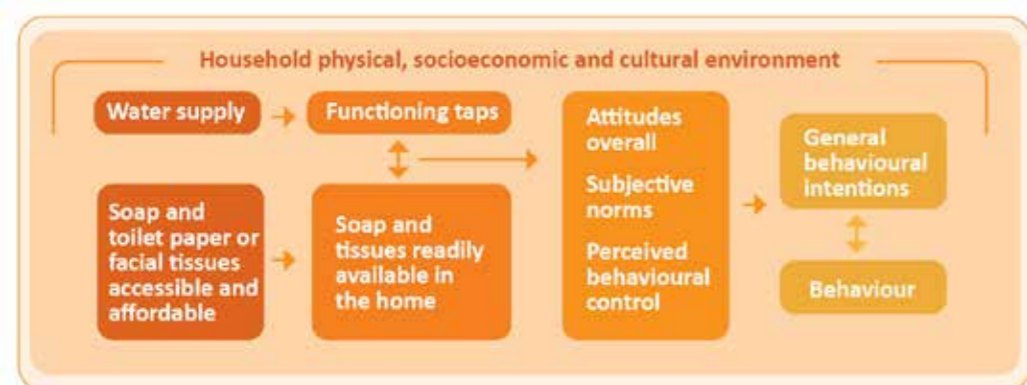


Figure 28: Conceptual model of factors relate to handwashing and face-cleaning behaviour of Aboriginal and Torres Strait Islander children.³⁵²

Studies in a number of remote Aboriginal and Torres Strait Islander communities suggest that washing and handwashing are not common practices.^{356,357}

Evidence of association with Strep A, ARF and RHD risk

There is strong evidence from international studies that daily handwashing by children with soap and water reduces skin infections.^{358,359} A recent systematic review of these studies concluded that daily handwashing can be recommended for treatment and prevention of skin sores in Australia (Level 1A evidence).³⁶⁰ This has been included as a recommendation in the National Healthy Skin Guidelines for Aboriginal and Torres Strait Islander communities.⁵³

Some evidence from New Zealand is emerging to support the application of these results. In a rigorous case-control study, lack of access to hot water for showering or delaying showering was associated with an increased risk of ARF. Further analysis of New Zealand data is under way at time of writing.³⁶¹

There is no evidence that hygiene, hand or body-washing practices reduce scabies infections.³⁶² Scabies outbreaks occur in communities with vigorous hygiene practices, including in coastal communities with frequent bathing and access to health services.^{362,363} A detailed overview of transmission mechanisms for scabies is presented in Appendix Four.

Evidence for different strategies to achieve this Healthy Living Practice

A range of approaches to increase washing practices among Aboriginal and Torres Strait Islander people have been proposed.³⁵¹ Few have been implemented and even fewer have been evaluated. A summary of different strategies, implementation experiences and evaluations are presented below.

Health promotion to increase washing hands and bodies

No Germs on Me

The No Germs on Me (NGoM) handwashing campaign was initially trialled between February 2006 and May 2008 in two Aboriginal communities in the Northern Territory, one in the Top End and one in Central Australia.³⁵⁶ The goal of the project was to increase handwashing in order to reduce transmission of pathogens associated with diarrhoea, skin sores and respiratory infections. Baseline assessment revealed that handwashing was not the social norm in the communities, and that soap and functioning health hardware were generally not available. However, participants were positive about the idea of washing hands and felt that soap was cheap in the communities.³⁵⁶

Strategies to increase handwashing centred around social marketing, including television advertisements, posters, stickers and soap display stands in community stores.³⁶⁴ Local community members were filmed for television advertisements. A hip-hop song, educational DVD, community service announcement and school-based educational activities were also developed and disseminated.³⁶⁴

After two years, some increase in self-reported handwashing behaviour and awareness about handwashing was demonstrated, though this was variable between the two communities. Television education campaigns did not affect beliefs or behaviour. Evaluation of NGoM suggested social marketing elements could be effective if people had access to health hardware and other resources to implement the recommendations.³⁵² However, for most participants this was not the case; 75% of people reported they would buy more soap, toilet paper and facial tissues if they were not so expensive.³⁵² Overall, the results of this evaluation confirm that widespread social and economic change is required to achieve sustained change in washing behaviour. Health promotion campaigns which are not coupled with improvements in infrastructure are unlikely to be effective in isolation.

In 2011, the NGoM resources were made available nationally by the *National Working Group on Aboriginal and Torres Strait Islander Environmental Health* (now the *Expert Reference Panel on Aboriginal and Torres Strait Islander Environmental Health*).³⁵² In 2013, the NGoM campaign was expanded and three new television commercials were produced, focusing on face washing and the importance of washing hands before touching young babies. Evaluation findings highlighted the socioeconomic and physical barriers to meeting children's hygiene needs.³⁵² As of mid-2019, the NGoM education resources continued to be provided by the Northern Territory Government.³⁶⁵

Mister Germ

Mister Germ was developed by Queensland Health to reduce bacterial transmission and improve community health. One of the aims of Mister Germ was to reduce illness by increasing handwashing after toileting and use of soap. It was delivered to children in the first three years of formal schooling in Aboriginal and Torres Strait Islander communities.³⁶⁶

The Mister Germ program was adapted by Environmental Health Officers and Aboriginal Medical Service to meet the needs of a preschool population in North Coast NSW. In 2007, four preschools trialled the program. Mister Germ was structured around an activity guide with classroom activities. An accompanying resource kit was provided to each preschool at an estimated cost of less than \$1,000 per kit.³⁶⁷ No formal evaluation was conducted. Measured comparison of daily absence due to illness between the four participating preschools and four non-participating preschools did not reveal any difference in absences. Participant feedback suggested an increase in handwashing frequency by children and staff.³⁶⁷

Mister Germ has been formalised into a hand hygiene education package focused on 3 to 12-year olds and now includes interactive activities to demonstrate sufficient handwashing using glow-in-the-dark gel. In 2011, Mister Germ was endorsed by the Working Group on Aboriginal and Torres Strait Islander Health

(now the Expert Reference Panel on Aboriginal and Torres Strait Islander Health). As of mid-2019, Mister Germ was being offered in more than 60 childcare centres in NSW and through community events.³⁶⁸

Take Pride in Personal Hygiene

Take Pride in Personal Hygiene was developed jointly by the Cairns Public Health Unit (Queensland Health) and the Northern Pride Rugby League Club and launched in 2011. The program used sporting role models to educate Aboriginal and Torres Strait Islander children in Far North Queensland communities on the importance of personal hygiene to combat high rates of skin, ear, diarrhoeal and respiratory diseases.³⁶⁹

The program used the NGoM handwashing campaign and Mister Germ to facilitate classroom sessions. Students were introduced to germ theory (where germs are found, their spread and how they can be controlled), and a member of the local rugby team was interviewed about the effect of germs and associated infections and illnesses on their ability to play rugby. Mister Germ was then removed by the ‘Germinator’ in a short skit.³⁶⁹

Students were also asked to pass around a football covered in a glitter lotion. Holding their hands under a UV box, they were able to visualise the transfer of the glitter, or ‘germs’ from the football to themselves. Following a lesson on washing their hands correctly, students used the light box to determine how well they had washed their hands.³⁶⁹

Project evaluation in 2012 indicated an improvement in germ theory knowledge, handwashing practices and knowledge of the environmental health worker.³⁶⁹ The Northern Pride representatives were evaluated as having a high impact among two-thirds of the students, and student attention was high during the program compared with regular classes.³⁶⁹

Breathe Blow Cough

Breathe Blow Cough (BBC) was first trialled in the Northern Territory during the early 1990s and aimed to reduce ear infections among school-aged children.³⁷⁰ The 10-minute program was delivered at the start of the school day, with structured deep breathing, nose-blowing, and coughing activities performed by the whole classroom with teacher guidance.^{371,372} BBC was also designed to encourage students to practise other germ-controlling strategies such as coughing into elbows, hand and face washing and drying to limit the spread of the pathogens causing colds, ear infections and coughs.³⁷³

A formal evaluation of BBC was conducted in the 1990s in eight schools in the Northern Territory among children aged 7–9 years who were exposed to the program over eight months. The study identified improvement in signs of upper and lower respiratory tract disease and pulmonary function measurements but no significant change in hearing levels.³⁷⁴ Further survey feedback from teachers participating in another BBC program identified anecdotal reduction in ear infections and nasal discharge, improved hearing and behaviour in the classroom, clean faces, and improved independence of children to blow their own nose. Poor school attendance was identified as a barrier to implementation.³⁷⁴

A qualitative study of BBC in 2010 identified additional barriers to the implementation, including poor school attendance, staff turnover, inconsistent implementation, and a lack of handwashing facilities in the classroom for after nose-blowing.³⁷¹ Some feedback suggested that health promotion and initiatives such as BBC take place after ‘core’ classroom priorities have occurred, and are often not prioritised.³⁷⁵

The BBC program has continued to develop, including new resources such as an animation available in nine Aboriginal and Torres Strait Islander languages, developed with assistance from Hearing Australia and the Menzies School of Health Research.³⁷⁰

Clean Faces, Strong Eyes program

The Clean Faces, Strong Eyes (CFSE) program was designed to reduce the incidence of trachoma, an eye infection caused by the *Chlamydia trachomatis* bacteria. Trachoma can spread through direct or indirect contact with infected eye and nose secretions, indirect contact with these secretions through surfaces, or through flies which are attracted to these secretions.³⁷⁶ Children with an ‘unclean face’ have an increased risk of trachoma because of eye secretions, which are infectious and can be spread by hands, clothes or flies.³⁷⁶

The program was developed by researchers at the Melbourne University Indigenous Eye Health Unit as part of the Indigenous Eye Health Program,³⁷⁷ and was aligned with the WHO-recommended SAFE Strategy, which included surgery for turned-in eyelashes, antibiotics to treat active infection, facial cleanliness and environmental modifications.³⁵⁰ CFSE used ‘Trachoma Story Kits’ in schools, workplaces and clinics around the Northern Territory, South Australia, Western Australia, Queensland and New South Wales.³⁷⁸ These resources provided consistent messages about how the spread of trachoma could be reduced.³⁷⁸ Community adaptations of the resources emphasise empowerment, and reflect the diversity of culture and language.³⁷⁹ CFSE also used a mascot – Milpa the goanna – which was easily recognised by community children and assisted in spreading the health promotion messages during visits.³⁸⁰

Evaluation of community-based health promotion using CFSE key messages was published in 2017.³⁸⁰ The evaluation comprised a cross-sectional, pre- and post-exposure study in 63 remote Aboriginal communities identified as being at risk of trachoma in the Northern Territory. The study assessed the efficacy of the health promotion strategy, which aimed to increase the knowledge, attitudes and behaviours of health and community staff.³⁸⁰ Increases in trachoma-related knowledge were observed across all measures, specifically the actions required to improve facial hygiene.³⁸⁰ The perception of dirty faces as normal within communities also declined.³⁸⁰ These benefits accrued despite high staff turnover within schools, workplaces and clinics.³⁸⁰

Targeting trachoma through facial cleanliness

Targeting trachoma through facial cleanliness is one of the methods of the WHO-endorsed SAFE Strategy.³⁵⁰ In 2005, a program was run in schools at two Central Australian communities by teachers and staff from the local clinics.³⁸¹ Students were actively encouraged to wash before coming to school by posters on the walls of the classroom containing drawings depicting children bathing. A song advocating this behaviour was also written and sung in English and local language. Aboriginal Health Workers also assisted with medical examinations, promoting health education at the clinic, and conducting the health education campaign in homes where applicable, specifically encouraging facial cleanliness.³⁸¹ No detailed evaluation was identified.

Summary: Health promotion to increase washing of hands and bodies		
Domain	Summary	Rating
Evidence	Evidence comes from reports and evaluations from No Germs on Me, Mister Germ, Breathe Blow Cough, Clean Faces Strong Eyes and similar programs. Overall, these programs increased awareness of washing behaviours in some circumstances. Evidence of changes in behaviour is less clear and probably does not occur as a result of isolated health education activities.	Medium
Benefits	Empirical evidence for the benefit of health promotion campaigns for washing is weak in Australia. Health promotion campaigns conducted in isolation, without addressing household infrastructure, are unlikely to be effective. ³⁵⁷	Low
Risks	Health promotion resources may inadvertently contribute to stigma, shame or blame for families and communities with Strep A infections and other conditions. ^{112,356,382} In New Zealand, intensive social marketing about ARF and RHD resulted in reports of racism and shame associated with the condition. ¹¹² The risk of stigmatising people appearing in washing advertisements has also been identified in the NGoM program. ³⁵⁶ Carefully co-designed health promotion campaigns are needed to manage this risk and should be iteratively evaluated. Multiple health promotion programs may also address different diseases, potentially leading to message confusion and fatigue. In consultations for the My Life, My Lead report, participants identified that ‘ <i>inconsistent hygiene messaging is hampering prevention activities with regard to the spread to trachoma, otitis media, scabies and acute rheumatic fever</i> ’. ¹⁵⁵	Medium

Summary: Health promotion to increase washing of hands and bodies		
Domain	Summary	Rating
Acceptability	No explicit examples of communities seeking to learn more about handwashing were identified. Programs do seem to be acceptable when implemented.	Low
Feasibility	Health promotion approaches are relatively feasible to develop and deliver. However, the programs with the most impact use local people, local languages and local metaphors in health promotion initiatives. This level of co-design takes time and resources.	Medium
Costs	Costs for developing health promotion programs vary depending on the medium used and the need for translation and local adaptation.	Medium
Timeline	Co-design, development and testing of health promotion resources take time, particularly when local actors are used or translation into local languages is required. Sustainability of impact may be challenging. Health promotion programs are usually implemented for a limited time and are unlikely to have long-term impact in the absence of change in beliefs, attitudes and behaviours about handwashing. Health promotion activities also have to be sustained in the long term to effect behavioural change.	Medium
Positive externalities	Effective health promotion of hand and body washing is likely to yield benefits for a wide range of other health outcomes, including gastrointestinal disease and respiratory tract infections. ^{383,384} Well-developed health promotion approaches in Aboriginal and Torres Strait Islander languages would have broad-ranging health and equity benefits if effectively implemented.	High
Equity	Handwashing-focused health promotion is common in non-Indigenous settings and extending these messages in culturally appropriate, non-stigmatising ways to Aboriginal and Torres Strait Islander people is likely to be equity enhancing.	Medium
Recommendations	<ul style="list-style-type: none"> Health education and health promotion may be an important adjunct to other initiatives to improve HLP1. Programs which are most likely to have impact are long-term initiatives coupled with improvements in infrastructure and delivered in locally meaningful ways and languages. Further evaluation of health promotion programs in Aboriginal and Torres Strait Islander health is required to further define and disseminate best practice. Health promotion initiatives for HLP1 should be aligned to maximise relevance to a number of disease endpoints. 	

Box 7: The importance of using Aboriginal and Torres Strait Islander languages and knowledge in health promotion

While the operational language of many health services across the north of Australia is English, very few Aboriginal families in remote locations speak this language at home.¹⁰⁴ The predominance of English language in the health system is a common barrier for families and children gaining knowledge about health and illness in remote Aboriginal communities. The absence of a shared language reduces the ability of clinicians to successfully educate on these conditions.³⁸⁵ This is compounded when health services are predominantly biomedically focused.

For example, research in the Northern Territory indicates that almost all information about ARF and RHD is provided in English, yet unfamiliarity with medical terms means not even the names of the diseases are recognised and acknowledged by people living with ARF or RHD or their communities.¹⁰⁶ Although English words may have meaning for symptoms to a specific sickness, the communication process is limited without a shared starting point between clinician and patient.^{106,385} These barriers also manifest in population-level messaging which is insufficiently tailored to the language and cultural needs of communities.

A recent Australian study noted the importance of local language in the delivery of health information: a non-Indigenous woman able to speak the local language acted as a liaison in explaining to the family of a young child the process of heart surgery. *'When information is given in English, they don't understand enough. When told why in language, then it can change your life,'* she stated. Similarly, a senior Aboriginal woman and former Aboriginal Health Worker emphasised this necessity, saying *'talk to them in their own language. When I talk to them in English, it's hard. It's clear when I talk to them in language, it's like a picture.'*¹⁰⁶

It is only through the acknowledgment of and active engagement with the language of Aboriginal and Torres Strait Islander people that health literacy and empowerment become achievable.³⁸⁶ Recognising the local knowledge base and worldview allows for language/conceptual equivalents to be found for new English health and biomedical terms and supports improved communication between health professionals and the community.³⁸⁶

Improve access to soap and other consumables for washing hands or bodies

A small number of programs have been established to distribute or improve access to consumable hygiene equipment for Aboriginal and Torres Strait Islander people.

Internationally, a small number of programs have explored the effects of providing soap to households. Few of these have been evaluated. One study of soap distribution in a refugee camp in Malawi in 1993 did not demonstrate increased handwashing but did show reduced incidence of diarrhoeal disease among households who received soap relative to those who did not.^{387,388} A more contemporary study from South Africa in 2018 found that distributing soap (including bars with and without a novelty toy inside) increased handwashing behaviour.³⁸⁸ A small number of programs have been implemented to improve access to consumable hygiene equipment for Aboriginal and Torres Strait Islander people.

Squeaky Clean Kids

The Squeaky Clean Kids initiative was funded in 2017 to distribute 200,000 bars of free soap to 63 Aboriginal communities in Western Australia over a two-year period.³⁸⁹ The focus of Squeaky Clean Kids is to reduce the incidence of trachoma and other diseases, including skin infections and diarrhoea.³⁹⁰ Soap is distributed in conjunction with a health promotion campaign.³⁹⁰ Evaluation of the project is under way.³⁹¹

Bush medicine and soaps

Some initiatives are under way to explore the role of traditional bush medicines and soaps to increase washing behaviour. These programs may offer a participatory, strengths-based approach to increasing the use of soap made by and for Aboriginal and Torres Strait Islander people. Positive externalities may include the opportunity to produce soap for sale. For example, in two New South Wales communities, the leaves of a native plant historically used to treat a range of infections and illnesses have been incorporated into a soap recipe, with the resulting soap cakes well accepted by the local communities.³⁹² While anecdotal reports indicate positive results, an evaluation of this approach is pending. Research is also under way to investigate the use of 'soap trees,' or traditional medicinal plants by primary healthcare in remote communities. It is hypothesised that these plants could be promoted within schools by Aboriginal and Torres Strait Islander Elders to increase handwashing with soap.³⁹³

Product distribution

Rotary has supported distribution of face washers to Aboriginal and Torres Strait Islander communities through a 'Chamois' program. An additional 33,500 mirrors have been provided to remote communities to support self-care.³⁹⁴ No evaluation of this approach was identified.

‘The store is too expensive. People buy in order – food, toilet paper, but they don’t think washing hands is an emergency. People think that hand soap, shampoo, deodorant, are luxury items.’

Aboriginal participant quoted in McDonald et al., 2015.³⁵²

Summary: Improving access to consumable hygiene products		
Domain	Summary	Rating
Evidence	There is no evidence that providing soap or other consumables for washing hands or bodies is effective in reducing skin sores in the Australian setting. International evidence for soap provision as part of a comprehensive health hygiene intervention suggests that positive impacts are possible. ³⁸⁷	Low
Benefits	In theory, providing hygiene products should support increased use of those products. However, no evaluation has demonstrated that this is the case in Australia.	Unknown
Risks	Distributing hygiene consumables may be stigmatising, particularly if recipients are perceived as ‘dirty’ or unclean, or that hygiene is solely a behaviour or choice.	Medium
Acceptability	Households with limited financial resources may not prioritise health hygiene resources. ³⁹⁵ Products may not be available, may be prohibitively expensive, or may be perceived to be too expensive relative to other needs. ^{357,396} Without the ‘consumables’ for healthy living practices, handwashing and clothes washing is not likely to be effective. There are anecdotal reports that some Aboriginal and Torres Strait Islander people want better access to soap and other hygiene consumables and ask health clinics to provide them. ³⁵²	Medium
Feasibility	The existence of some small-medium scale programs indicates that distribution of consumables is feasible.	High
Costs	The cost of hygiene consumables distribution is likely to be low relative to other strategies. However, ongoing consumable costs could be vulnerable to changes in funding arrangements without robust evaluation of program success.	Low
Timeline	Distribution processes for hygiene consumables could be scaled up relatively promptly.	Short
Positive externalities	The provision of consumables to encourage hand or body washing can assist in reducing the prevalence of other illnesses. The strongest evidence of impact is for reduction of diarrhoeal disease when soap is distributed among crowded refugee populations. ³⁸⁷ Community-initiated soap manufacture and distribution programs may bring economic benefits for the community in addition to increased washing.	High
Equity	The cost of groceries in remote Aboriginal and Torres Strait Islander communities is generally higher than in non-remote locations. ³⁹⁷ Reducing costs or improving access to health hygiene consumables in remote settings would therefore be equity enhancing.	Medium
Recommendations	Soap and other hygiene consumables distribution may be a useful adjunct to other programs aiming to improving HLP1 but should not be used in isolation.	

Improve construction and maintenance of household health hardware for washing hands and people

Develop and enforce building and environmental health standards for remote community housing

Poor design and construction, low-quality materials and poor maintenance of housing contributes to equipment failure of plumbing-related health hardware. Plumbing and other health hardware failures limit capacity for families to undertake HLP1.¹⁷⁵ Establishing and enforcing design, construction and functionality standards for housing in remote Aboriginal and Torres Strait Islander communities could provide an opportunity to improve the functionality of houses.

‘A female Aboriginal Elder on one of the communities said to me ... “How can we wash hands when we don’t have hand basins that work and we don’t have showers that work and we don’t have the infrastructure?”’

Representative from Aboriginal and Torres Strait Islander organisation #1 quoted in Hall, 2018.³⁹⁸

The *National Indigenous Housing Guide* was developed by the Australian Government in 1999 to supplement the Building Code of Australia, Australian Standards and jurisdictional documents.³⁹⁹ The guide was updated regularly until 2007 but a scheduled review of the document was abandoned by the Government in 2011.^{400,401} Archived versions of the document are now fading from use.^{400,401} The impact of the *National Indigenous Housing Guide* was limited because – although the *COAG National Partnership Agreement on Remote Housing* required housing to comply with the Guide – there was no legal enforcement of standards.⁴⁰⁰ In 2012, Healthabitat published ‘*Housing for Health – the Guide*’ online to address the absence of the planned fourth edition of the *National Indigenous Housing Guide*.⁴⁰² Further updates of this publication are planned but are not endorsed by any Australian government.

There are widespread concerns that many of the houses in remote Aboriginal and Torres Strait Islander communities do not meet the standards of the *National Indigenous Housing Guide*.^{399,403} The 2017 review of the *National Partnership Agreement on Remote Housing* found that this should be addressed. The review recommended that properties undergo independent certification (throughout construction and subsequent use) as compliant with legislation, which is challenging in remote settings.³⁹⁹ It was also recommended that the *National Indigenous Housing Guide* should be considered ‘not negotiable’.³⁹⁹ The need for enforceable national and jurisdictional remote-housing standards has been identified as a priority by the review of the *National Partnership on Remote Housing*.³⁹⁹

A variety of other guidelines and standards have been developed at a jurisdictional level:

- *The Environmental Health Standards for Remote Communities in the Northern Territory and the Code of Practice for Housing and Environmental Infrastructure Development in Aboriginal Communities in Western Australia* were developed to provide jurisdictionally specific guidance.^{404,405} However, these documents were released in the early 2000s and are now outdated and difficult to enforce.
- *Design and Construction Standards for Remote Housing* were published in Queensland in 2016 with more contemporary content.⁴⁰⁶
- The *Housing for Health Guide* provides additional specifications and functional standards for houses to support the HLP. While this document is widely applied in New South Wales, it has limited impact throughout the rest of Australia.³⁴³
- *New Housing and Health Guidelines* were released in 2018, potentially providing a new foundation for considering Australian standards in the context of international housing policy.⁴⁰⁷

Other household infrastructure issues, including household maintenance, are addressed in HLP2.

Summary: Develop and enforce design, construction, building and environmental health standards for remote community housing	
Comments	There is a well-demonstrated need for building and environmental health standard in housing. There is insufficient evidence to evaluate the effect of enforceable housing standards on infectious disease outcomes including Strep A. However, mechanising the human right to adequate housing can be reasonably expected to improve health outcomes including for Strep A, ARF and RHD.

Increase access to swimming pools and water parks in remote communities

Swimming pools may provide a mechanism for washing skin which appears to be acceptable and accessible in Aboriginal and Torres Strait Islander communities.

Ten studies have been conducted in remote Australian communities exploring the impact of community swimming pools on skin health outcomes for Aboriginal and Torres Strait Islander people. All described a drop in skin sore prevalence and severity (when measured).⁴⁰⁸ One study indicated a 51% decrease in skin disease, a 44% decrease in the incidence of ear infections, a 41% reduction in antibiotic prescriptions, and a 63% decrease in respiratory diseases in the years following the opening of the swimming pool in a remote community.⁴⁰⁹ Although the lack of control groups makes it difficult to be sure that swimming pools caused these changes, the consistent findings across studies provides some indication that the relationship may be causal.⁴⁰⁸ The mechanism of any skin sore effect from swimming pools also remains uncertain given many pools also require showering before pool use.⁴¹⁰ Several studies also suggest broad benefits including for social and emotional wellbeing, improved school attendance and water safety skills.⁴⁰⁸

Water parks, such as the innovative approach in Punmu community, may have a similar effect without the need for extensive maintenance and supervision, but this has not been empirically demonstrated.^{411,412}

'You need to use the showers so you can swim...the showers are important for hygiene while in the water swimming...using showers are good for keeping the pool and everyone clean.'

High school student quoted in The Photovoice Project, Juniper et al., 2016.⁴¹⁰

Summary: Providing increased access to swimming pools or water parks		
Domain	Summary	Rating
Evidence	There is evidence that access to a swimming pool is effective at reducing skin sores. ^{408,409,413-415}	Medium
Benefits	It is plausible that swimming pool use may be associated with reductions in skin sores through showering, chlorinated water or other mechanisms. The magnitude of effect is likely to depend on swimming pool exposure.	Medium
Risks	Exposure to swimming pools may be hazardous for those unable to swim. Between 2010 and 2012, drowning was the third leading cause of death among children aged 1–14 years in Australia. ⁴¹⁶ Swimming may also not be accepted for cultural reasons, such as wearing bathers in front of the opposite sex. Pools may only be open during the warmer months of the year. ⁴¹⁰ The cost of management and maintenance may cause financial stress to community management budgets.	Medium
Acceptability	Qualitative research undertaken in three communities with a pool indicates the intervention is effective at enhancing social cohesion and providing a mutual and safe meeting place. ⁴¹⁰ The pools were more popular among younger children (a group more susceptible to skin sores and associated infections) than teenagers and adults. ⁴¹⁰ Local schools were able to use access to the pool as a reward for school. ⁴¹⁰	Medium
Feasibility	Where community desire and commitment to the facility exists, building and managing a swimming pool may be feasible. However, the logistic requirements of pool management are high. A 2010 survey of swimming pools in remote Northern Territory communities found that many required remedial work or had significant structural issues. Inadequate toilet and shower facilities, incomplete or missing risk management plans, inadequate fencing and chemical storage were all noted as issues. ⁴¹⁷	Medium

Summary: Providing increased access to swimming pools or water parks		
Domain	Summary	Rating
Costs	The cost of installing swimming pools in rural and remote regions is high, with recent costings indicating in excess of \$7 million per pool development, excluding maintenance. ⁴¹⁸ Adequate funds are needed to ensure sufficient pool opening hours and maintenance. ⁴¹²	High
Timeline	The timeframe to design, build and open a swimming pool in rural and remote communities is several years. ⁴¹⁹	Long
Positive externalities	Pools provide communities with an environment for recreation and physical activity. Community capital is boosted. Other benefits to the community include physical activity, heat relief and increased school attendance. ⁴⁰⁸	High
Equity	Providing easier access to recreational infrastructure, which is readily available to Australians in most parts of the nation, would enhance equity for those living in under-served regions.	High
Recommendations	<ul style="list-style-type: none"> Swimming pools and water parks are likely to reduce skin sores in remote communities and have other benefits, but require costs, governance and sustainability to be addressed in order to achieve these benefits. The decision to build and run a swimming pool or water park requires significant community consultation and oversight. 	

Increase access to ablution blocks or shower facilities

Some communities have built or suggested ablution blocks to improve access to showers and washing facilities.⁴²⁰ For example, the Nganampa Health Council designed and built an ablution block based at the local arts centre (in conjunction with washing machines provided at the community clinic).⁴²¹ Management and cleaning of ablution blocks may be challenging in remote communities. Portable ablution blocks for community visitors have been explored in Western Australia.⁴²² In other places, the health clinic provides shower facilities. In larger centres and urban areas, shower facilities may be provided as part of homelessness services. For example, the Katherine Doorways Hub offers access to showers, clothes washing and sanitary products.⁴²³

No evaluation of health effects of ablution facilities has been identified to date.

Summary: Increase access to ablution blocks or shower facilities	
Recommendations	Information on examples of successful facilities in similar settings and resulting evaluation of use and acceptability could help communities make decisions about new infrastructure investments.

Strengthen school and childcare infrastructure, policies and procedures about handwashing

There are limited data on access to hygiene facilities in remote schools, including soap and running water for handwashing. Multiple anecdotal reports suggest that access to soap and water, sinks and functional washing facilities in schools is limited.^{382,424-426} Cost barriers to providing soap and drying facilities appear to be an issue for individual schools.^{425,426} No comprehensive program for school-initiated/encouraged handwashing appears to be operational beyond those identified in the health promotion section of this chapter.

The Australian Children’s Education and Care Quality Authority maintains a National Quality Framework to guide and support education and care services.⁴²⁷ Monitoring and enforcement of this National Quality Framework is the responsibility of jurisdictional governments. Quality Area 2 of the framework addresses children’s health and safety and Standard 2.1, element 2.1.3 requires that ‘effective illness and injury management and hygiene practices are promoted and implemented’.⁴²⁷

Meeting the requirements for this area includes supporting appropriate hygiene practices for handwashing, coughing, dental hygiene and ear care.⁴²⁸ Some jurisdictions provide more explicit guidance, including best-practice guidelines from Western Australia, though these identify that there is *'no specific policy or procedural statement which identifies minimum requirements for provision by schools of handwashing materials or facilities for students'*.⁴²⁹ Guidelines from Victoria indicate that some funding is available in that jurisdiction for hygiene consumables in schools.⁴³⁰

Anecdotal reports from remote Aboriginal and Torres Strait Islander communities suggest improving infrastructure – including sinks in school bathrooms – increases handwashing behaviour at schools.³⁹⁵ Campaigns to increase legislative standards for handwashing facilities in schools have identified this issue as a community priority.⁴³¹

There is little information about how schools in remote Aboriginal and Torres Strait Islander communities enshrine handwashing behaviour into daily classroom routines. Beyond isolated health promotion initiatives, there are no clear examples of schools where handwashing is a routine part of classroom activity. The role of schools and teachers in supporting washing behaviour is complex, with some reviews suggesting this is considered outside the scope of the education system.⁴³² Opportunities to support increased handwashing behaviour appear to be an area of outstanding need.

Summary: Strengthen school infrastructure, policies and procedures about handwashing

Recommendations	Insufficient evidence to evaluate the health impact of school washing approaches. Clarification and implementation of existing standards can be confidently recommended. Development of standards should be pursued with jurisdictional governments where they do not exist.
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Additional strategies

Improving access to water for washing

Access to sufficient water is necessary to undertake washing of hands and bodies. A number of Aboriginal and Torres Strait Islander communities do not have sufficient access to water to fulfil the Healthy Living Practices.³⁹⁵ This is discussed in Box 8.

Mandating face washing

Shared Responsibility Agreements were instituted between the Australian Government and a number of remote Aboriginal and Torres Strait Islander communities in the mid-2000s.⁴³³ One of the first of these agreements – with the Mulan community in Western Australia in 2004 – included a range of activities by the community in return for funding for petrol bowsers.⁴³⁴ The agreement included a requirement for the community to ensure that children would shower daily and wash their faces twice daily to reduce rates of trachoma. None of the other recommended elements of trachoma control (screening, treatment or environmental health programs) were included or provided.⁴³⁵ This attempt to mandate personal behaviours, in isolation from other structural and behavioural recommendations, saw rates of trachoma in the community rise. Programs which attempt to change community activities or behaviour through punitive or coercive measures do not appear to be effective and are not acceptable to communities.⁴³⁶ They can be counterproductive by reducing self-efficacy and self-esteem.⁴³³⁻⁴³⁷

HLP 1 – Summary and recommendations

- An international randomised control trial provides high-quality evidence that daily washing of children's hands reduces the incidence of skin sores. Therefore, it is likely that regular washing of hands and bodies can reduce the incidence of ARF and development of RHD. The relationship between handwashing and sore throats is unknown.
- No single approach is likely effective in increasing uptake of HLP1.
- Given the multiple barriers to regular washing of hands and bodies, a combination of improving health hardware, consumables and health promotion are needed to increase daily washing behaviours.
- Therefore, communities should have the opportunity to design locally relevant programs which may include:
 - Improvements in household and school health hardware and consumables for washing;
 - Exploring community infrastructure opportunities including an ablution block, water park or swimming pool; and
 - Health promotion initiatives which support healthy living practices.
- Structural, national and jurisdictional-level actions also are needed to support community-level initiatives. These include:
 - Improving design, construction and maintenance of houses to achieve agreed environmental health standards in remote communities; and
 - Ensuring that housing improvements occur in the context of improving the community environment for health.
- These approaches should be integrated with other health promotion activities to ensure consistent health messages which are relevant for a number of different infectious diseases.

Healthy Living Practice 2 – Washing clothes and bedding

Baseline situation

Ensuring that people have facilities to wash clothes and bedding may reduce the rates of Strep A skin infection by reducing the risk of transmission of Strep A (particularly from heavily contaminated clothing), scabies, and crusted scabies. Access to sufficient resources for people to wash clothing and bedding is limited in many remote Aboriginal and Torres Strait Islander communities.

A 2000 study in a Central Australian community of 75 houses found only 45% of houses had adequate facilities for HLP2.³⁵⁰ A 2001 study of nearly 5,000 remote houses in the Northern Territory revealed 32% of households did not have functional hot water taps in the laundry.⁴³⁸ A smaller study from the same area in the Northern Territory identified that in three communities, fewer than 50% of houses had a functional washing machine.³⁴⁹ In a detailed study of one Northern Territory community between 2000 and 2003, only one of the three main family groups had specific access to washing machines, with others using machines owned by either the clinic or local women's centre.⁴³⁹ Housing for Health figures from 2013 suggest that the number of houses with secure laundry tubs (not washing machines) had reached 91%, with 73% having functional hot water and 77% functional cold water.⁴⁴⁰

Contemporary data on household washing machine ownership come from the East Arnhem Spin Project ('Washing machine djäma') conducted across five East Arnhem communities in 2013. A total of 450 households were surveyed: 49% had a functional washing machine, 17% had a partially functioning machine, 16% had a non-functioning machine, and 17% of households did not have a washing machine.⁴⁴¹

The soap and detergent required to wash clothes and bedding may be prohibitively expensive. In one study in a remote community, households reported they primarily completed their laundry in the days following payday when laundry soaps were able to be purchased. Households then completed as many loads as possible before the detergent ran out, stalling further laundry until more soap was affordable.⁴³⁹

Heavily mineralised water in many locations leads to a build-up of scale which can damage washing machine function.⁴⁴² Mineralised water may also require the use of expensive water softeners and

other speciality products for effective lathering.³⁹⁶ Transport of washing machines to communities on bumpy, dusty roads may contribute to damage before installation. In crowded households, large numbers of people using washing machines can mean that whitegoods intended for smaller domestic use break down rapidly.⁴⁴² Heavy use, in conjunction with poor installation, mineralised water and limited maintenance, means an estimated average lifespan of two years for household washing machines in remote communities.⁴⁴¹ Commercial-grade washing machines may last longer in houses with many people. However, these larger commercial machines tend to be less efficient and more expensive to maintain/repair, increasing costs and potentially creating a barrier to use in households with limited access to power and water.⁴⁴³ Box 8 explores issues related to power and water access for household washing.

Evidence of association with Strep A, ARF and RHD risk

Overall, the association between hygiene and skin infections is well recognised in remote communities. For example, in the Kimberley region, a survey of healthcare providers indicated that 100% of the burden of skin infections and 95% of scabies infections were considered attributable to environmental factors, including poor water quality, inadequate sanitation and non-functioning health hardware.⁴⁴⁴

In general, Strep A bacteria are not transmitted person to person via clothes or bedding. Transmission may occur if clothing or bedding is heavily contaminated with body fluids, including pus or serous discharge from skin sores or nasal secretions.⁴⁴⁵ Rarely, scabies mites may be spread through clothes or bedding used by someone who has scabies. Scabies transmission through bedding and clothing may be more likely from people with crusted scabies and very high mite burden.⁴⁴⁶ Fleas, lice and fungal infections may also have some mechanism of transmission through clothes or bedding and cause skin irritation, which predisposes to Strep A infections. An overview of the evidence for transmission is presented in Appendix Four: Transmission mechanisms for Strep A infections, scabies and crusted scabies.

Effective washing practice

Not all washing practices effectively kill the scabies mites and body lice. Technical requirements for effectively killing scabies mites and lice are summarised in Table 6.

Table 6: Specifications of washing practices to kill scabies mite and body lice.

Organism	Washing practices necessary to ensure pathogens are killed
Scabies ⁴⁴⁷	<ul style="list-style-type: none"> Wash at ≥ 50°C and <i>expose</i> for at least 10 minutes or; Place in clothes dryer for at least 30 minutes or; Place in freezer for at least five hours. Detergent or Ozone treatment have no killing effect
Head Lice and body lice ⁴⁴⁸	All headlice are killed when: <ul style="list-style-type: none"> Washed at 50°C (with or without detergent); or Dried at high temperature for more than 40 minutes.

Evidence for different strategies to achieve this Healthy Living Practice

Increasing access to household washing machines

Household access to washing machines may be limited in some communities. Increasing access via households has been attempted through a number of programs.

Washing machine djäma (East Arnhem Spin Project)

The East Arnhem Spin project was an initiative of the East Arnhem Scabies Control Program in collaboration with One Disease at a Time and Miwatj Health Aboriginal Corporation, with funding from the Office of Aboriginal and Torres Strait Islander Health in 2013. The Spin Project operated in five communities in East Arnhem land and included:

- Regular service visits to each community to inspect household washing machines and conduct on-the-spot repairs. As part of the first phase of the project, 87 existing machines were repaired;⁴⁴¹

- Promotion of loans for families to be able to buy washing machines;
- Advocacy to standardise locally sold washing machines;
- Stocking spare parts in communities to facilitate on-the-spot repairs;
- Social marketing to improve the operation of washing machines; and
- Training for community members to install, service and support washing machine use.

An ongoing program of washing machine repairs was also conducted by Nganampa Health Council in the APY Lands. Environmental Health Workers repaired 37 household machines in 2017.⁴⁴⁹

Other initiatives to improve household ownership of washing machines and other electrical goods are run by government agencies, philanthropic groups and Aboriginal and Torres Strait Islander organisations. The No Interest Loan Scheme for low-income families – offered in 625 locations by 175 community organisations – is one of the largest of the finance schemes addressing whiteware ownership and other essentials.⁴⁵⁰ No evaluation of the health impact of these initiatives to improve washing machine ownership has been conducted.

A randomised controlled clinical trial evaluating tea tree oil treatment options for scabies in Aboriginal and Torres Strait Islander children was registered in 2017.⁴⁵¹ This study includes a plan to distribute 30 washing machines in participating communities and will be evaluated as part of a comprehensive approach to scabies control.

Summary: Increased access to household washing machines		
Domain	Summary	Rating
Evidence	No evidence was identified to compare the health effect of living in a household with or without a functioning household washing machine. There is a theoretical basis to believe that access to a household washing machine may increase washing of clothes and bedding and potentially reduce the risk of transmission of Strep A (particularly from heavily contaminated clothing), scabies and crusted scabies.	Low
Benefits	Unable to assess benefits of household washing machines relative to other kinds of washing machines or washing facilities.	Unknown
Risks	There is a theoretical risk of spreading infectious diseases if washing machines are not operating at sufficient temperatures to kill pathogenic organisms. ^{452,453} Misuse of machines (such as overloading) through a lack of knowledge or irresponsible use can heighten the risk of mechanical failure. There is a need to provide education on washing machine use to all potential users within a household.	Unknown
Acceptability	The acceptability of providing washing machines is unknown.	Unknown
Feasibility	Provision of washing machines is likely to be feasible. However, plumbing for hot water to laundry tubs and capacity for ongoing maintenance is unclear.	Medium
Costs	Provision of washing machines may be relatively low cost, but installation and maintenance costs are ongoing and may be prohibitive for households. The cost of power, water and consumables for washing may also be prohibitive.	Medium

Summary: Increased access to household washing machines		
Domain	Summary	Rating
Timeline	Washing machines can be purchased at short notice but sufficient plumbing for household installations is likely to take longer.	Short
Positive externalities	Opportunities for private and timely washing of clothes are likely to enhance dignity.	Medium
Equity	Most Australian households outside of remote Aboriginal and Torres Strait Islander communities have a washing machine. Ensuring similar access for Aboriginal and Torres Strait Islander people would be equity enhancing.	Medium
Recommendations	<ul style="list-style-type: none"> Household washing machines are likely to be beneficial in improving access to HLP2. Further research is required to assess benefits, risks and acceptability of household washing machines relative to other kinds of washing facilities. 	

Increase access to community laundromats

Lack of access to household washing machines has prompted a range of initiatives to build laundromats in remote Aboriginal and Torres Strait Islander communities. Many community laundries have been built, although there has been little evaluation of the health impacts.⁴⁵⁴⁻⁴⁵⁶

A study in the 1990s in the Anangu Pitjantjatjara Yankunytjatjara installed 44 commercial washing machines across two communities. Usage of the machines was very high, indicating strong community demand. Health outcomes were not assessed.⁴⁵⁷

One study from the Northern Territory in the mid-2000s explored use of machines available for public use, including at the clinic, school or women’s centre. These machines were primarily used by those whose household or those of their family members did not have a washing machine for personal use.⁴³⁹

Remote Laundries Project

A contemporary laundromat program has recently been initiated by the Aboriginal Investment Group (AIG). The AIG Remote Laundries Project aims to reduce instances of scabies, trachoma and RHD while improving school attendance and contributing to community employment opportunities through the provision of community laundromats. Large shipping containers are converted to fit four washers and dryers linked to soap and water, with room for laundry preparation and folding. As of early 2019, AIG manages one project in the NT community of Barunga and is scoping out further locations in consultation with local groups.⁴⁵⁶

Attempts to maximise the impact of community laundromats have involved the development of construction standards in the Northern Territory. Environmental health standards indicate that commercial-grade washing machines are needed in at least two locations within a community at a ratio of one machine/trough for every 50 people.⁴⁰⁴ The optimum model for providing community laundry services has not been identified.

Summary: Increase access to community laundromats		
Domain	Summary	Rating
Evidence	No evidence was identified to compare the health effect of living in a community with or without a communal washing machine. There is a theoretical basis to believe that access to a communal washing machine may increase washing, reduce scabies transmission and therefore reduce skin infections.	Low
Benefits	Unable to assess the benefits of community washing machines relative to other kinds of washing machines or washing facilities. ⁴⁵⁸ In some communities there may be a preference for shared facilities rather than individual or household washing machines, which may be prone to breakdown and require expensive maintenance. ⁴⁵⁸	Unknown

Summary: Increase access to community laundromats		
Domain	Summary	Rating
Risks	Community consultation ahead of recent laundry construction identified vandalism as a risk to the project. ⁴⁵⁹ The risk of transmitting pathogenic organisms through shared washing machines should be low in the setting of sufficient water temperature.	Low
Acceptability	The continued construction of community laundries over many years points to strong community demand. Communal services may be more acceptable in some Aboriginal and Torres Strait Islander communities than individual health hardware. ⁴⁵⁸ Consultation with Aboriginal and Torres Strait Islander women in the 1990s by ATSIC identified ‘coin-operated washing machines in women’s centres’ as a priority for self-determination. ^{458,460}	High
Feasibility	A number of commercial companies support construction of community laundries, which demonstrates and enhances feasibility. ⁴⁶¹ However, maintenance and supervision of facilities can be challenging.	High
Costs	Construction of a new laundry in a remote community in 2018 was \$242,000. ^{462,463} The cost of use is currently \$4 per wash and \$4 per dry. ⁴⁵⁴ This may be a barrier to regular use, though ongoing maintenance costs may be covered by user fees.	Medium
Timeline	Construction of modular laundries can be quickly achieved but community consultation and governance arrangements may take some years.	Medium
Positive externalities	Some community laundries are owned by local organisations which draw a small profit from the project. Employment opportunities may also be possible. Reduction in other infectious diseases spread through clothing may be possible. Other potential externalities may include improved hygiene self-esteem, opportunity for laundromat as social centre.	High
Equity	Access to laundromats may enhance equity between Aboriginal and Torres Strait Islander people and non-Indigenous people if they improve access to washing. Risks of inequality may occur if not all members of a community have access to the laundromat. Some laundromats require coin use which may be challenging if income management precludes the use of cash, for example through the BasicsCard. ⁴⁶⁴	Medium
Recommendations	<ul style="list-style-type: none"> There is no empirical evidence about the health impact of community laundries. However, community demand appears to signal an unmet need. The construction of laundromats requires significant community consultation. Evaluation of existing community laundromat programs is required to understand impact and develop effective models of operation. 	

Box 8: Access to power and water for Healthy Living Practices

Water is required for HLPs 1 and 2, in order to wash people, clothes and bedding. Electricity supplies are needed to run household appliances including washing machines for HLP2, along with power for storing and cooking food in HLP4 and for controlling temperature in HLP9.

Power

Power supplies in a number of remote Aboriginal and Torres Strait Islander communities are operated via card-operated, prepayment meters.^{443,465} Households must purchase power cards to access electricity. These prepayment meters are generally popular with community members but are both expensive and not equipped to provide information about electricity use, faults or disconnections.⁴⁶⁵ Household power outages are common in remote communities, because there are insufficient funds to buy power cards or because of central outages, faults, or mismanagement of power usage. Hence, power to run washing machines, fridges or air conditioning is not always available.

Options for heating water without power (though ideally through solar exposure or over fire) as part of health-enhancing approaches are poorly understood and warrant further exploration. A stable supply of power at low cost is essential for health-related infrastructure.

Water

Access to sufficient quantity and quality of water for washing is constrained in a number of Aboriginal and Torres Strait Islander communities.³⁹⁵ Limited water access has direct and indirect impacts on health, including reducing the capacity for washing.⁴⁶⁶ An estimated 100–400 litres of water per person per day is needed for washing people, clothes and safely removing waste.⁴³⁹ Demand can be increased by ineffective water management, temperature and other climate events; therefore strategies for reducing demand are an area of active research.⁴⁶⁷

A stable supply of high-quality water at low cost is essential for health-related infrastructure.

Build or repair houses which support washing of clothes and bedding

The need for construction and maintenance standards for housing are addressed in HLP1.⁴⁶⁸ Houses which do not have functional plumbing cannot support the use of washing machines. Additional facilities, including for drying of clothes and disposing of used wastewater, are also needed.⁴⁶⁸

Summary: Build or repair houses which support washing of clothes and bedding

Summary	Houses with adequate plumbing and infrastructure for washing clothes and bedding are likely to increase HLP2 and therefore contribute to reduced skin damage, Strep A infection, ARF and RHD.
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Improve maintenance of household health hardware for washing clothes and bedding

A range of approaches to increase access to plumbing and housing repairs and maintenance are possible. Increasing resourcing for remote housing maintenance is critical, coupled with enforceable housing standards for design, construction and maintenance.

Box 9 outlines legislative approaches to allow trained community members to undertake minor plumbing repairs. Other enablers to improving maintenance services in remote Aboriginal and Torres Strait Islander communities are likely to include:

- Developing proactive scheduled maintenance programs which do not rely solely on the tenant reporting faults³⁹⁹;
- Ensuring decentralised maintenance services which support community engagement and enable employment of local people to undertake these activities⁴⁶⁹; and
- Tenancy management to support and skill household members to report housing maintenance issues, educate about batching of non-urgent repairs, and ensure prompt reporting.^{357,469}

The governance of housing and maintenance arrangements underpins many of these issues. Aboriginal and Torres Strait Islander organisations are widely identified as the most appropriate and effective leaders to develop and deliver remote household maintenance programs.⁴⁷⁰

Summary: Improve maintenance of household health hardware for washing clothes and bedding

Summary	A wide range of strategies to improve remote housing maintenance have been identified. It is not possible to individually evaluate the direct effect of each of these on health outcomes. However, proactive maintenance schedules coupled with an effective routine repairs and maintenance program, developed and delivered in partnership with Aboriginal and Torres Strait Islander communities, appear most likely to be effective in supporting infrastructure for people to access HLP2.
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Alternatives to washing clothes and bedding

'We're going to help you put all your sheets in the washing machine. I'll help you hang them out because I know you've got little kids. I asked a mother already, 'would you allow me to come in and help you move the mattresses out in the sun?' She said yes because I can't lift them on my own.'

Aboriginal Registered Nurse quoted in Thomas, 2017.⁴⁷¹

Cleaning strategies which do not rely on washing clothes and bedding have been suggested to accrue some of the benefits of HLP2. For example, it may be possible to accelerate the death of scabies mites, which occurs once the mite is off a host. Isolating bedding and clothing in a plastic bag and exposing to sunlight for one week is a commonly recommended alternative to washing in order to kill the scabies mite.^{472,473} Other resources recommend the sun exposure of blankets and mattresses.²⁹¹

Summary: Alternatives to washing clothes and bedding

Domain	Summary	Rating
Evidence	There is reasonable laboratory evidence that scabies mites are killed in heated conditions. ⁴⁷⁴ No evaluation of this approach in practical, real-world settings was identified.	Medium
Benefits	Effective killing of scabies mites could be expected to reduce the incidence of skin sores.	High
Risks	The effectiveness of this approach may be reduced in settings of high humidity or low temperatures.	Low
Acceptability	Acceptability of wash-free substitutes for HLP2 is unknown.	Unknown
Feasibility	Almost all households can access plastic bags or containers and sunlight – although exclusion of household items for a period of time may be inconvenient. Wrapping items in plastic is likely to be laborious and may be particularly difficult to implement during cultural and other gatherings when transmission risk may be higher. Community leadership in healthy skin days is critical for maximising uptake.	Medium
Costs	Direct costs for occlusion of items are low but time for community engagement, inconvenience and opportunity costs relative to other approaches may be high.	Medium
Timeline	Education on this approach is required but can be delivered rapidly and as part of comprehensive scabies management.	Short
Positive externalities	Wrapping clothing/bedding in plastic and then heating is likely to kill other pathogenic bacteria. ⁴⁷⁵	Medium
Equity	Wrapping clothing/bedding in plastic and then heating does not address other benefits of washing (cosmetic removal of stains, heavy biologic contamination or odours). These benefits are widely available to non-Indigenous people in Australia and equitable access to these additional benefits should be prioritised.	Low
Recommendations	<ul style="list-style-type: none"> • Wash-free approaches are possible to kill scabies mites but do not provide all the benefits of washing clothes and bedding. • There may be a role for wash-free strategies in some circumstances, but these should not be pursued in isolation from longer term wash-based approaches. 	

Other strategies

Other strategies may increase washing of clothing and bedding and thereby reduce Strep A infection. Effectiveness would depend on these being positioned as part of a comprehensive approach which addresses the broad ecological contributors to health outcomes.

Increased access to soap and detergent to increase washing of clothes and bedding.

The cost of soap and detergent has been identified as a barrier to the use of washing machines in some settings.^{395,439} Providing or subsidising washing powder may reduce this barrier, although is likely to be subject to the same risks and limitations as providing soap for hand and body washing, addressed in previous sections.

Provide education about washing clothing and bedding for health

Ensuring community and provider knowledge about healthy living behaviours with the maximum potential impact on health may be important. For example, in an energy conservation project conducted with Yolŋu households in the Northern Territory, laminated flip charts were used to encourage households to use cold water for clothes washing and save hot water for showers. This may increase washing behaviour through the use of more appealing warmer showers but the advice does not necessarily maximise the effectiveness of HLP1 and HLP2 for improving health.⁴⁷⁶ Aligning health promotion messages to maximise impact on a range of disease endpoints is likely to have greatest impact.

Hand-operated washing machines

In the 1980s, programs to develop hand-operated washing machines were explored and some manual machines have been used in communities.^{339,477} EzyWashing machines appear to have been trialled and found acceptable in Alice Springs in 2018, although results are unpublished.⁴⁷⁸ The utility of machines which function without power is unclear but the machines are unlikely to reach the temperature required to kill bacteria, scabies mites and lice.

Mobile laundromats

In some larger centres and regional facilities, mobile laundromat facilities are provided with a focus on improving access to hygiene facilities for homeless populations. The largest provider of these service is Orange Sky, providing 17 mobile laundry vans to 117 locations nationwide.⁴⁷⁹ Evaluation of health impacts was not identified.

Ironing

There is some indication from an international study that wearing ironed clothes reduces scabies burden.⁴⁸⁰ This could reflect killing of scabies mites at very high temperatures but is unlikely to be a practical approach at a population level in remote communities.

There is insufficient information to evaluate the effect of any of these other strategies.

Box 9: Legislation to improve access to housing maintenance by allowing community members to make minor repairs

The Australian Building and Construction Commission oversees the qualifications required to undertake construction and maintenance tasks. For plumbing needs, this is legislated through the Plumbers Licensing Act, which requires that only licenced plumbers undertake plumbing tasks. However, a lack of trained plumbers and services means this requirement can cause delays to household repairs in remote Aboriginal and Torres Strait Islander communities. This can exacerbate the negative health consequences of household maintenance issues.⁴⁸¹

Various mechanisms to improve access to plumbing maintenance have been explored – including introduction of a restricted permit for people with training but without a full plumbing licence through a COAG-led revision of the National Occupational Licensing System.⁴⁸¹ This national reform was abandoned in December 2013 and Western Australia acted to introduce jurisdictional provision for a limited licence for non-plumbers to undertake basic repair works.⁴⁸¹

After a period of consultation, legislative changes were made to allow Environmental Health Workers to undertake plumbing emergency repairs.^{482,483} While this decision was not universally supported, it was acknowledged that changes were required to maintain the integrity of remote water sources, prevent ill-health caused by poorly functioning plumbing, and see to prompt repairs of relatively simple issues.⁴⁸³

The desire for community members to be trained and able to provide basic household maintenance is widely identified as a priority in other jurisdictions.⁴⁸⁴ In the Northern Territory, Community Housing Officers and Housing Maintenance Officers provide some ‘handyman’ services when a qualified tradesperson is not required.^{469,485}

HLP2 – Summary and recommendations

- Increasing access to washing facilities for clothes and bedding is likely to be beneficial in reducing Strep A skin infections.
- Washing machines need to reach water temperature thresholds in order to reliably kill bacteria, scabies mites and lice.
- There is no clear evidence supporting household washing machine ownership or shared laundry facilities. Regular, active maintenance of washing machines appears to be critical for longevity of machines for both approaches. In the case of household washing machines, education must be provided to household members around appropriate use and maintenance.
- Developing, enforcing and maintaining building standards which support washing of clothes and bedding should be prioritised at a jurisdictional level.
- Wash-free approaches to killing scabies mites are safe and effective and may provide families with an alternative approach until equitable access to washing facilities is achieved.
- Exploring options to increase the training and employment of local community members in housing maintenance. For example, contracting ACCHSs to manage housing, including housing maintenance; or remote apprenticeship programs for residents.

Case study: Warrant of fitness for houses in Aotearoa (New Zealand)

Many families in New Zealand are forced into poor-quality housing when their income is compromised or they experience discrimination.⁴⁸⁶ Low-income families often live in unsound and unsafe homes, and consequently experience adverse health outcomes.^{487,488} Children are particularly vulnerable to these poor housing conditions; cold and damp homes heighten the spread of respiratory and diarrhoeal diseases and are likely to increase the risk of developing other conditions.^{489,490}

In 2012, the *Children’s Commissioner’s Advisory Group Report on Solutions to Child Poverty* was released, calling for a Warrant of Fitness (WoF) to reduce the negative impact that inadequately insulated housing was having on the health of children in low-income families.⁴⁹¹ In New Zealand, cars undergo a regular, often annual, WoF check as a condition of vehicle registration. It was recommended that the concept of a WoF be applied to rental houses as a way of assessing the health risks associated with housing in low socioeconomic circumstances. This ‘Rental WoF’ has evolved from a research initiative to a set of standards increasingly enshrined in legislation.

Housing guidelines and legislation requiring homes to be in a reasonable state of repair, ‘free from dampness’ and unlikely to cause injury or death had existed in New Zealand for many years. However, inconsistencies made these difficult to enforce.⁴⁹

Progressive efforts to develop a ‘Rental WoF’ evolved over a number of years.

- In 2013, a model identifying 29 criteria for evidence-based ways to improve the health and safety of occupants was conceived under the categories of ‘insulated and dry’, ‘safe and secure’, and ‘essential amenities’. This formed a benchmark by which a house is deemed habitable and fit for use.⁴⁹³

- In 2014, the Housing Corporation trialled the WoF on 400 properties. Surveys took 45–65 minutes to complete, with an additional 20 minutes required to upload the necessary data to Housing New Zealand, at a cost of approximately \$110–\$150 per home.⁴⁹⁴
 - Of those surveyed, the average property passed 95% of the WOF criteria, with 69% of homes having five or fewer non-compliant criteria.⁴⁹⁴
 - An average expenditure of \$576 was required to address repairs to each property to be compliant at an estimated cost of over \$34.5 million nationwide.⁴⁹⁴ The trial was deemed feasible, at a reasonable cost, and with beneficial results for the health outcomes of the tenant. Further trials with five city councils were undertaken by the University of Otago with a smaller set of criteria based upon international research.^{495,496}
 - Additional research has since occurred nationwide, with most success noted in Wellington where the city council has implemented a voluntary scheme since 2017.⁴⁹⁷

While the WoF model was not implemented in its entirety by the New Zealand Government, the *Healthy Homes Standard* under the *Healthy Homes Guarantee Act (HHGA)* was adopted with a primary focus on addressing a lack of heating, and dampness within homes.⁴⁹⁸ It reflects the WoF but further work is under way to evaluate criteria for health housing. Following the pilot, in 2018 the HHGA was passed, adopting almost all the criteria from the WoF. It came into effect in 2019.

This process is broadly similar to efforts to develop and enforce housing standards for remote Aboriginal and Torres Strait Islander communities in Australia. The Healthy Living Practice framework in Australia has existed for decades and provides a foundation for this work. A renewed effort to determine building and construction standards which allow people to support these Healthy Living Practices could mirror the transition from research to national legislation in New Zealand.

Healthy Living Practice 3 – Removing wastewater safely

Baseline situation

Sanitation to remove wastewater includes drainage from the bathroom, kitchen and laundry. Access to safe wastewater removal is poor in many remote Aboriginal and Torres Strait Islander communities. A 2001 study found that 39% of surveyed remote homes did not have the shower or toilet drainage necessary to adequately remove wastewater.⁴³⁸

Evidence of association with Strep A, ARF and RHD risk

The evidence linking wastewater disposal with Strep A infections is weak. There is no existing evidence that Strep A is transmitted through contaminated water or human faecal matter.⁴⁰ However, poor bathroom drainage may make people reluctant to use showers or taps due to flooding. Therefore, capacity to remove wastewater safely may have an indirect effect on other healthy living practices.

One study in remote Northern Territory found houses without functional facilities for removing wastewater had increased rates of skin sores.³⁵¹ However, this was strongly associated with household crowding and may represent a cluster of other risks rather than indicating wastewater disposal is a direct independent risk factor for Strep A transmission and skin infections.

HLP3 – Summary and recommendations

- Adequate housing is a human right and facilities for removing wastewater are fundamental to fulfilling this right. It is not clear that increasing safe wastewater removal will have a direct impact on Strep A infection but is important for preventing a range of other infectious diseases.

Box 10: Housing as a human right

The right to housing is enshrined in a number of international instruments, including Article 25 of the *Universal Declaration of Human Rights*.²⁴¹ This is further defined in the *International Covenant on Economic, Social and Cultural Rights* (ICESCR), which identifies ‘adequate housing’ as a human right (article 11).⁴⁹⁹ Australia is bound by the ICESCR, albeit not through the force of domestic law. The Aboriginal and Torres Strait Islander Social Justice Commissioner has particular functions to protect the human rights of Aboriginal and Torres Strait Islander people, including in housing.²⁴² However, opportunities to enforce this right to housing for Aboriginal and Torres Strait Islander people are rare.

In 2019, residents of Santa Teresa community won a case against the Northern Territory Government in the Northern Territory Civil and Administrative Tribunal for failing to provide repairs and maintenance to houses.⁵⁰⁰ The legal obligations of the NT Government were based on tenancy agreements rather than human rights. However, the precedent of the Santa Teresa case may provide a new mechanism for enforcing agreements which mechanise rights.

Healthy Living Practice 4 – Improving nutrition, the ability to store, prepare and cook food

Baseline situation

Access to household facilities to safely store, prepare and cook food is varied in remote Aboriginal and Torres Strait Islander communities.

Contemporary Healthhabitat survey data suggest that 21% of houses have no refrigerator or freezer for storing food.⁵⁰¹ Many households have poorly functioning refrigerator/freezers with variable temperatures which may be costly to run.⁵⁰¹ Similarly, 37% of houses do not have a fully functional cooktop and 30% have no functional oven.⁵⁰¹ Access to sufficient power for running electrical appliances may also be a barrier as outlined in Box 8. These physical infrastructure/equipment barriers contribute to food hygiene risks and poor nutrition.

Evidence of association with Strep A, ARF and RHD risk

Food safety

Foodborne outbreaks of Strep A sore throat can occur, usually associated with moist foods which have been stored at room temperature.^{502,503} Strep A infections transmitted through food appear to cause particularly severe sore throat symptoms and have a high attack rate.⁵⁰³ However, these events are relatively rare, quite severe and have not been reported among Aboriginal and Torres Strait Islander Australia communities. Foodborne transmission of Strep A is not considered a major driver of burden of disease in remote settings.

Nutrition

It is not clear whether poor nutrition – in general or in specific micronutrients – may contribute to the risk of Strep A infection. In theory, poor nutrition may be associated with reduced immunity, which could predispose people to infection. In a systematic review of risk factors for ARF and RHD, 15 studies relating to nutrition were identified.²⁹ All studies were low quality and used simple measures such as low body weight or body mass index. Only four studies identified a significant relationship between poor nutrition and an increased risk of ARF or RHD.

Some studies in New Zealand have suggested an association between sugar-sweetened beverage consumption and ARF risk.^{361,504,505} One mechanism for this could be an increase in dental caries associated with sugar-sweetened beverages, which may increase susceptibility to Strep A infection of the mouth and throat.

The effect of nutrition on the risk of scabies infestation is also unclear. Impaired nutrition may be a risk factor for developing crusted scabies.³⁶²

HLP4 – Summary and recommendations

- Transmission of Strep A sore throat is possible through contaminated food. However, this appears to be rare and is not the major contributor to Strep A infections for Aboriginal and Torres Strait Islander people in Australia.
- It is possible that improving nutrition may reduce the risk of Strep A infection or ARF. The mechanism for this is poorly understood. Mechanisms may include improved immunity or improved dental health. Research to better understand the role of nutrition in the risk of skin sores and scabies infestation is needed.
- Improving nutrition has a direct impact on many other causes of ill health for Aboriginal and Torres Strait Islander people. Therefore, it is reasonable to continue efforts to improve nutrition at a household level and consider strategies to evaluate the impact on Strep A infection, ARF and RHD.

Healthy Living Practice 5 – Reducing the negative impacts of overcrowding

Baseline situation

Forty-one percent of Aboriginal and Torres Strait Islander people in remote communities live in crowded houses.¹⁶³ Living in a crowded house may be associated with some health risks,²⁸ including an increased likelihood of Strep A infections, with evidence suggesting an increased risk of between 1.7 and 2.8 fold.²⁹ Reducing household crowding is frequently identified as a major priority by Aboriginal and Torres Strait Islander people in remote communities.^{248,506}

Quantifying how much household crowding increases the risk of Strep A infection is complex. Definitions of household crowding are variable, in Australia and in international studies. The terminology, metrics and meaning of household crowding in Aboriginal and Torres Strait Islander communities are all areas of lived experience, academic study and policy debate.³¹ The Canadian National Occupancy Standard is the most widely used metric for household crowding, outlined in Box 11.³⁰

Box 11: Definitions of household crowding in Aboriginal and Torres Strait Islander communities

The Canadian National Occupancy Standard (CNOS) assesses the bedroom requirements of a household based on the following criteria⁵⁰⁷:

- There should be no more than two persons per bedroom;
- Children less than five years of age of different sexes may reasonably share a bedroom;
- Children five years of age or older of opposite sex should have separate bedrooms;
- Children less than 18 years of age and of the same sex may reasonably share a bedroom; and
- Single household members 18 years or older should have a separate bedroom, as should parents or couples.

CNOS is used by AIHW and the National Aboriginal and Torres Strait Islander Social Survey. However, CNOS has significant limitations in the Aboriginal and Torres Strait Islander context and does not account well for extended families living together. Population growth, movement of people and visitors all contribute to overcrowding according to CNOS.

The risk of Strep A infections, ARF and RHD is likely to depend on a range of other factors (including population mixing patterns, health hardware and building type) which are also associated with household crowding. These interrelated associations make it difficult to separate the effect of household crowding from other risk factors. Similarly, family composition, number of siblings and population mixing through day-care attendance may also influence the risk of Strep A, ARF and RHD.⁵⁰⁸

Evidence of association between overcrowding and Strep A, ARF and RHD risk

The most robust evidence exploring household crowding and Strep A, ARF and RHD comes from a 2018 systematic review of worldwide studies.²⁹ Fifty studies examined the association between crowding and Strep A infections, ARF and RHD. Variable measures of crowding were used in included papers and variable definitions of disease endpoints. Of the 14 studies exploring a relationship between crowding and Strep A infection, 57% found a positive association, suggesting it plausible that overcrowding increases the risk of Strep A transmission. A similar proportion of studies found a positive association between crowding and ARF and crowding and RHD. The positive association persisted in seven of the 11 studies which accounted for independent variables (such as household income). Overall, the systematic review concluded there is a causal relationship between household crowding and Strep A infection, ARF and RHD. Living in a crowded house approximately doubled the residents' risk of Strep A infection, ARF, or RHD.²⁹

A number of studies support this association between crowding and Strep A risk in Australia and New Zealand:

- In a mid-2000s study of a remote Aboriginal community in the Northern Territory, the risk of skin sores increased with the number of children per bedroom.⁴⁸
- In the Top End of the Northern Territory, there was a correlation between household crowding and the risk of skin sores.⁵⁰⁹
- In the NT, children living in households with more adults are more likely to have skin sores than other children.⁵¹⁰
- Across Australia, 69% of children presenting with ARF lived in overcrowded houses (more than two people per bedroom), mainly in remote locations.²¹⁹
- In an Auckland case series, average household size for people living with ARF was 5.6 people, above the national average of 3.0.⁵¹¹
- In a rigorous contemporary New Zealand case-control study, household crowding was identified as a risk for ARF on multivariate analysis accounting for a range of potential confounding factors. This association was irrespective of how crowding was measured, including: occupancy (people per house), density (people per room), CNOS and self-assessed household crowding.³⁶¹

However, the association between household crowding and Strep A infection, ARF and RHD has not been demonstrated in all Australian studies.

- In a non-Indigenous urban population in Australia, household crowding, number of bedrooms and number of people in the house was not associated with risk of Strep A sore throat.⁷¹
- In the young urban Aboriginal and Torres Strait Islander population in Far North Queensland with skin sores, there was not a statistically significant association between household crowding and the probability of isolating Strep A from the skin sore.⁵¹²

Overall, a relationship between household crowding and Strep A infection risk is biologically plausible and largely supported by contemporary observational studies in focus populations. The magnitude of this association and other modifying factors is unclear with existing Australian data.

Evidence for different strategies to achieve this Healthy Living Practice

Build new housing stock to reduce household crowding

The health effects of building new housing in remote Aboriginal and Torres Strait Islander communities has been evaluated in a small number of studies.

Housing Improvement and Child Health Study

New houses were built in 10 Northern Territory communities between 2004 and 2005, with an average of 11 new houses per community (range: 7–15).⁵¹³ No concurrent renovation or hygiene programs were conducted. The construction of new houses did not reduce household crowding (defined as the mean number of people per bedroom in the house on the night before the survey). Reducing the number of people in each bedroom by two or more did not statistically reduce the risk of skin infections.³⁴⁷ It was suggested that a much larger increase in investment for housing, environmental health and health promotion may be needed to demonstrate impact.⁵¹³

Although sufficient numbers of new houses in communities could dramatically impact overcrowding, new houses, in isolation, do not guarantee this outcome.⁵¹⁴ Perversely, families may relocate from houses which are not necessarily crowded, but do not have functional facilities, to live in newer accommodation with better resources. For example, a number of families in houses without functioning showers or washing machines may move into a newly constructed house with functional amenities. In this way new houses may exacerbate crowding unless new construction is coupled with repair and maintenance of existing houses.⁵¹⁴ Population increase can also offset benefits of construction of new houses.⁵¹⁵

Summary: Reduce household overcrowding by building new houses		
Domain	Summary	Rating
Evidence	Australian and international data indicates that reducing household crowding is likely to reduce Strep A transmission, ARF and RHD.	Medium
Benefits	Building new houses can reduce exposure to crowded households if it is part of a comprehensive package of household infrastructure management and includes environmental health promotion activities.	Medium
Risks	Building new housing can exacerbate household crowding if not coupled with repair and maintenance programs of existing houses.	Medium
Acceptability	Action to address household crowding is consistently identified as a priority by Aboriginal and Torres Strait Islander peoples and peak bodies. ⁵⁰⁶	High
Feasibility	The continued challenges in building sufficient suitable housing in remote Aboriginal and Torres Strait Island communities indicate that feasibility is an ongoing challenge. There has been progress in certain jurisdictions, including increased Aboriginal involvement in the process (i.e. the NT and Federal governments including the four land councils on all relevant steering committees). ^{179,180}	Medium
Costs	<p>By the most conservative estimates, at least 5,550 new dwellings are required in remote areas to reduce household crowding by 20–30% by 2028.¹⁷⁶ This is a substantial underestimate because:</p> <ul style="list-style-type: none"> • It accounts only for households with more than three bedrooms required and does not account for households needing one or two more bedrooms. • It is based on 2011 census data and requires an update from the 2016 census data and population growth of the Aboriginal and Torres Strait Islander population. • It only accounts for Aboriginal and Torres Strait Islander communities defined by the Australian Bureau of Statistics as a remote location. Therefore, communities considered suburbs of larger townships are excluded. It also excludes small communities, homelands and outstations. • Crowding is defined according to the CNOS which does not reflect the reality of life in remote Aboriginal and Torres Strait Islander communities as discussed in Box 11. <p>Based on 2017 costs, the construction of necessary new houses is estimated to cost at least \$2.7 billion.¹⁷⁶</p>	High
Timeline	The most appropriate new houses are built in consultation with the community and add additional value by training/employing local tradespeople. The timeline to achieve these benefits can be long.	Long
Positive externalities	Constructing new houses has a range of health, social and economic benefits. ⁵¹⁶	High

Summary: Reduce household overcrowding by building new houses		
Domain	Summary	Rating
Equity	Increasing access to new housing stock, in the context of severe shortages, is equity enhancing.	High
Recommendations	New housing stock is essential but must be part of a comprehensive housing management program (spanning health hardware, hygiene promotion, training and skills acquisition, and enabling community environment) ⁵¹³ to be effective in reducing the negative effects of overcrowding and influencing health outcomes.	

Modify existing housing to reduce overcrowding

In addition to the need for new houses, improving the design of existing housing stock to reduce the functional impact of overcrowding may be beneficial.⁵¹⁴ Facilitating increased physical space between people, particularly for sleeping, may reduce the close physical contact which is associated with Strep A and scabies transmission.^{517,518}

A variety of programs and approaches to increase access to functional living space have been attempted, including addition of more bedrooms, more verandas and more functional yard space. Housing with enclosed functional yard space has been identified as a preference in a number of communities.⁵¹⁹ No evaluation of the health impact of expanding functional space was identified on literature review.

Room to Breathe

Room to Breathe is a program running in the Northern Territory since 2017, to build additional living spaces onto existing houses in remote communities.⁵²⁰ The program adds new rooms, verandas and extensions to reduce household overcrowding and increase functional use of space, at a cost of \$200 million over 10 years.⁵²⁰ The 'Early works' schedule began in 22 communities in 2016.⁵²¹ By October 2017, 45 homes in 10 communities had been involved, creating 26 bedrooms and 22 additional living spaces.⁵²² Concerns about the implementation of Room to Breathe included poorly designed extensions which were not considered fit for purpose.⁵²¹

Furnishing the yard

Some Aboriginal and Torres Strait Islander people sleep outside in yards – sometimes in tents or caravans.³⁰ This may be preferable to sleeping inside overcrowded houses in some communities.⁵²³ Camping outside during cultural events is common in some communities. Healthhabitat advocates for 'furnishing the yard' so that outside spaces can function as additional rooms as required and reduce functional overcrowding, and recognise different cultural utility of buildings.⁵²³ This may include fencing, taps, planting, yard kitchen and pit toilets.^{30,514}

'[And] come for rodeo. Backyard gets full – they bring swags. Bring kangaroo and bush tucker. Eat anyone's tucker. Chuck in [for rent] some time... Saw 40 in backyard. Some people sleep inside with babies...'

Aboriginal person interviewed in Memmott, 2012.³⁰

Summary: Modify existing housing to reduce overcrowding		
Evidence	Increasing space is a biologically plausible approach to reducing Strep A transmission. There is a lack of formal evaluation of this particular strategy. However, overall evidence suggests that reducing household crowding is likely to reduce Strep A transmission, ARF and RHD.	
Comments	Unable to evaluate. Unlikely to be harmful to health.	

Box 12: Behaviour adaptations by Aboriginal and Torres Strait Islander people to reduce the spread of infectious disease

Illustrative lessons about the acceptability of behaviour change and potential strategies to reduce infectious disease transmission come from community consultation in the context of pandemic planning. In particular, a participatory action research workshop involving participants from a range of remote and urban communities was held in the context of H1N1 (swine flu) pandemic preparedness.⁵²⁴ Although community concern about H1N1 was particularly high and may have influenced responses, a number of illustrative themes emerged including: keeping families safe, our families our ways, and the realities of big families, small houses and inadequate infrastructure.⁵²⁴

Culturally relevant ways of adapting behaviour change to reduce transmission risk were proposed – potentially including early medical care and people keeping further physically apart than usual.⁵²⁴ Suggestions to share these messages via grandmothers in the setting of a potential pandemic, themed around ‘keeping families safe’ indicated that culturally adapted messaging may be possible. Other strategies – including tissues, tissue disposal facilities, masks and hand gel at community gatherings – may offer practical examples of disease control relevant to Strep A spread.^{524,525} This idea of facilitating cultural practices (funerals and celebrations) by making them safer could include changes in hygiene practices. For example, focus groups suggested that people who were unwell could stand back from other people at gatherings. This would only be acceptable if it was framed in advance as respectful behaviour by Elders with the support of health workers.⁵²⁵

Behaviour change to reduce the risks of crowding – reducing bed-sharing

Given the time involved in building new houses and maintaining health hygiene infrastructure, families seek advice, now, about how to reduce the risks associated with household overcrowding. This may include behavioural adaptations to minimise the impact of household crowding.

Bed-sharing and beds located close to each other are associated with an increased risk of Strep A transmission and subsequent ARF.^{517,518} In a New Zealand study, 49% of children with ARF shared a bed with other people; conversely only 19% of children who did not have ARF shared a bed with other people.⁵¹⁸ However, the association between bed-sharing and ARF in New Zealand does not appear to be significant on subsequent multivariate analysis in a case control study.³⁶¹

Theoretically, behavioural adaptations could change Strep A infection risk by reducing the amount of time that people are exposed to large aerosolised droplets from other people. Changing sleeping behaviours may be one way of achieving this, given a considerable amount of time is spent in bed.

There is some evidence that Strep A spread is most likely in the area around the head and face of people with Strep A infection: historic studies show that Strep A can be found on fabric sheets in higher concentrations near the head of the bed.⁵²⁶ Military barracks are generally arranged to minimise this potential route of transmission by maximising the distance between the faces of sleeping people through head-to-toe sleeping.⁵²⁷ In New Zealand, families were encouraged to sleep ‘head-to-toe’ to reduce people breathing and/or coughing on each other at night time to reduce ARF. Similarly, New South Wales recommendations currently include advice that ‘if possible, children with acute rheumatic fever should have their own beds and bedding’ and that ‘if children share a bed with someone, ‘top and tail’ them to prevent the spread of germs’.⁵²⁸

Biologically plausible approaches to reducing transmission of Strep A while sleeping could include having a ‘safe sleeping zone’ around the nose and mouth, avoiding bed-sharing, sleeping head-to-toe, or sleeping further apart. The specifications for this advice are unknown, including safe sleeping distances. Further research co-designed with communities is needed to identify potential cultural adaptations and acceptability and to define biologic plausibility.

Summary: Develop and encourage safe sleeping messages to reduce Strep A transmission		
Domain	Summary	Rating
Evidence	No evidence of effectiveness of this approach was identified. There is a theoretical basis to identify behaviours which are less likely to transmit Strep A bacteria while sleeping.	Unknown
Benefits	Unable to determine.	Unknown
Risks	Suggesting behaviour changes to reduce risk could stigmatise people who already have Strep A infection, ARF or RHD. Recommendations may also cause stress in households without sufficient space or resourcing for safe sleeping practices and may have unintended harms. An increasing list of key health promotion messages for Aboriginal and Torres Strait Islander communities may become confusing or counterproductive. ^{155,529}	Medium
Acceptability	Acceptability of this approach is unknown. Well-presented behaviour change recommendations based on solid scientific evidence appear to be acceptable, for example in smoking cessation programs. ⁵³⁰ Behaviour changes based on more speculative evidence may be acceptable if co-designed, for example in influenza pandemic planning outlined in Box 12.	Unknown
Feasibility	This concept could be expanded to tie in with other health promotion messages for safe sleeping of children, including recommendations about smoke-free safe sleeping spaces for infants to reduce the risk of sudden infant death. However, feasibility ties in with acceptability to communities, which is unknown.	Unknown
Costs	Co-design and sharing of behaviour change messages can be resource- intensive.	Medium
Timeline	Development and co-design of messaging takes time.	Medium
Positive externalities	Behaviour changes to reduce respiratory transmission of Strep A may also reduce transmission of other respiratory pathogens. Sharing beds may strengthen interpersonal relationships.	Medium
Equity	The equity effects of health promotion to reduce bed-sharing by Aboriginal and Torres Strait Islander people are unknown.	Unknown
Recommendations	Further evaluation is required.	

Behaviour change to reduce the risks of household crowding – respiratory hygiene to reduce Strep A throat infections

Transmission of respiratory droplets can be reduced by changes in respiratory hygiene behaviour. For example, when people cover their mouth when sneezing and coughing, Strep A does not spread as far.⁵²⁷ Minimising contact with nasal discharge – which may contain Strep A bacteria – may also reduce transmission.⁵³¹

Therefore, a health promotion campaign to support respiratory hygiene (covered coughing/sneezing, use and disposal of tissues for nasal secretions and clean faces) may help reduce respiratory transmission of Strep A. However, most of the evidence for respiratory hygiene measures comes from attempts to reduce viral pathogen outbreaks. The effect of respiratory hygiene on Strep A transmission is unknown.⁵³² Advice to sneeze/cough into arms, sleeves or elbows to avoid droplet contamination of hands does not appear to be effective.⁵³³

Some respiratory hygiene messages aligned with the key messages for other diseases, including trachoma where the evidence base for face washing is relatively more developed.⁵³⁴ Respiratory hygiene messages are also an element of the Breathe Blow Cough (BBC) program delivered to school children.³⁵² It may be possible to align these health promotion goals into comprehensive hygiene messaging which aim to reduce a range of bacterial and viral diseases.

Summary: Behaviour change to reduce the risk of household crowding – respiratory hygiene		
Domain	Summary	Rating
Evidence	A small number of studies have explored the effect of respiratory hygiene on droplet transmission. The specific effect on Strep A transmission has not been described in laboratory or community settings.	Low
Benefits	Improving respiratory hygiene could theoretically reduce Strep A transmission based on knowledge of disease transmission through large respiratory droplets.	Unknown
Risks	The risks of recommending respiratory hygiene behaviours are relatively low. Advice could be stigmatising if not appropriately developed and delivered. Advice which requires resources (including the use of tissues, hand gel or functional handwashing facilities) may be difficult for people to implement.	Low
Acceptability	Some respiratory hygiene measures were reported as acceptable to Aboriginal and Torres Strait Islander people in the setting of an infectious disease outbreak. ⁵²⁴	Medium
Feasibility	Embedding respiratory hygiene messages in existing health promotion campaigns about handwashing and healthy living is likely to be feasible.	Medium
Costs	Health promotion materials can be relatively affordable, though co-design and translation into local languages require time and investment.	Low
Timeline	Effective health promotion materials must be co-designed with appropriate messages, metaphors and language. This process takes time.	Medium
Positive externalities	Improved respiratory hygiene behaviours would contribute to the reduction of other diseases such as trachoma and influenza.	High
Equity	Respiratory hygiene behaviours are commonly reinforced in childcare and education settings outside of remote Aboriginal and Torres Strait Islander communities. ⁵³⁵ Providing the same health-promoting messages and support in remote communities is equity enhancing. ⁵³⁵	High
Recommendations	<ul style="list-style-type: none"> The efficacy of respiratory hygiene measures to reduce Strep A transmission is unknown. Pragmatic recommendations about nose-blowing and covering the mouth and nose during coughing and sneezing can be reasonably endorsed based on knowledge of disease transmission. Extensive health promotion campaigns based on these messages are probably premature pending further research into efficacy and acceptability. 	

Mattress elevation or replacement

Aboriginal and Torres Strait Islander people in remote communities commonly sleep on the ground or on mattresses on the floor, rather than on elevated beds.^{536,537} This has raised concerns about contamination of mattresses by dogs, vermin and mould, and limited access for ventilation and cleaning under mattresses if placed on the floor^{537,538} – although the introduction of raised beds for sleeping is a cultural norm without strong evidence of any biological benefit.⁵³⁹ None of the concerns about sleeping on floors or mattresses have been clearly described or quantified. Pilot programs to elevate people and/or mattresses off the floor while sleeping (using hammocks and beds) have been proposed.⁵³⁸ Donations of used mattresses have also been explored.⁵³⁷ No evaluation of these approach was identified during literature review.

Summary: Mattresses off the floor

Evidence	No evidence of the effect of sleeping on the floor on Strep A, ARF or RHD risk was identified.
Comments	No recommendations can be made. Any programs involving bedding elevation or bedding provision should be rigorously evaluated to address this knowledge gap.

Priority housing allocations

Most jurisdictions have capacity for people to apply for priority housing on the basis of family violence, social or medical problems.^{540,541} People with Strep A-associated illness, or at high risk of Strep A-associated illness, may be eligible to be considered for priority housing. In practice, the huge demand for priority housing – including from people with life-limiting medical conditions – generally makes this impossible.

Improve visitor and surge accommodation

Planning and facilities for visitors may help reduce household crowding by providing alternative accommodation at a community level. Supporting tenants to redirect unwanted visitors or providing short-stay accommodation may be possible in some settings.⁵⁴²

Box 13: Governance of housing

Aboriginal and Torres Strait Islander representatives and peak bodies consistently focus on the governance of housing issues. The 2018 Northern Territory Aboriginal Housing Forum statement was entitled 'Good housing starts with community control'.⁴⁰³ The NT Government has also committed to adopting a community housing approach, controlled and delivered by the Aboriginal and Torres Strait Islander community-controlled housing sector.⁵⁴³

Aboriginal and Torres Strait Islander organisations highlight the need to prioritise governance arrangements for community housing approaches, integrated management, community engagement and financial transparency. The implementation details about new houses, repairs, renovation and cyclical maintenance are secondary to establishing good systems of governance.⁴⁸⁴

This focus on governance arrangements is mirrored in the results of the review of the National Partnership Agreement on Remote Housing which made 12 major recommendations¹⁷⁶:

1. A recurrent program must be funded to maintain existing houses, preserve functionality and increase the life of housing assets.
2. Investment for an additional 5,500 houses by 2028 is needed to continue efforts on *Closing the Gap* on Indigenous Disadvantage.
3. The costs of a remote Aboriginal and Torres Strait Islander housing program should be shared 50:50 between the Australian Government and the jurisdictions.
4. Establish a regional governance structure to facilitate better administration of the program.
5. A higher level of transparency is required: a sound performance framework and information processes that are relevant to individuals and communities, and derivative of the information that is needed for regional governance of the program.
6. Best-practice fora should be established to share information across the Commonwealth, jurisdictions, regional governance bodies and service providers.
7. A minimum five-year rolling plan for the program should be established.
8. Regional sample surveys (using the survey-and-fix methodology of the *Fixing Houses for Better Health* program) must form a core part of the regional governance and monitoring strategy.
9. Details about certification of properties (at all stages of building, and for life after acceptance and tenancing) should be reported to the governance structure to ensure construction in remote communities is compliant with the appropriate building and certification standards, and sub-standard builders are penalised.
10. The regional governance bodies should work with local employers to plan how to develop the local workforce and create more local employment.
11. Comprehensive planning across governments, involving local communities, is essential for the next remote Aboriginal and Torres Strait Islander housing national program.

12. Tenancy education programs should be implemented. Outreach services for tenancy tribunals to improve access in remote communities should be funded.¹⁷

At the national level, a funded strategy to address housing infrastructure and health outcomes is desperately needed.¹⁵⁴ Furthermore, a recent meeting of the Joint Council on Closing the Gap resulted in a specific commitment to build the 'formal Aboriginal and Torres Strait Islander community-controlled services sector to deliver Closing the Gap services and programs in agreed priority areas', indicating continued commitment to the above review.¹⁹⁷

HLP5 – Summary and recommendations

- Reducing household crowding is consistently identified as one of the major health priorities for Aboriginal and Torres Strait Islander peoples and peak bodies.
- Of all the environmental risk factors for Strep A infection, ARF and RHD, household crowding has the strongest evidence of association.²⁹
- Reducing household crowding requires a comprehensive approach under the leadership of Aboriginal and Torres Strait Islander people and includes:
 - Aboriginal and Torres Strait Islander control of decision-making and resources;
 - Building sufficient new houses which are fit for purpose;
 - Repair, refurbishment and expansion of new houses; and
 - Comprehensive housing management programs.
- Behaviour change strategies to minimise the health risk of household crowding may be possible in the interim and as part of long-term strategies for sustained health improvements. This may include changes in bed-sharing and respiratory hygiene. Evidence of the effectiveness of these strategies is needed before they are widely recommended.

Case study: Murdi Paaki Healthy Housing Worker Program

The Murdi Paaki Healthy Housing Worker Program was a pilot during the early 2000s initiated and managed by the Murdi Paaki Regional Housing Corporation (MPRHC) in New South Wales.⁵⁴⁴ MPRHC owns and oversees about 600 homes within the region.⁵⁴⁵

The Murdi Paaki program offered training to Aboriginal people to develop their basic environmental health, maintenance and construction skills, enabling quick and efficient carpentry, plumbing and electrical repairs to be carried out on corporation homes.⁵⁴⁵ Delivered by Batchelor College, the training took place over two years with an overall program aim of minimising housing and health hardware deterioration and lessening the effects of housing-induced illness and injury.⁵⁴⁶

The Murdi Paaki program addressed the low rates of skilled tradespeople in rural and remote communities. Lack of access meant that sewerage, ventilation, hot water and plumbing problems often went unrepaired for extended periods of time, negatively impacting household health. There is a known link between 'Healthy Living Practices'⁵⁴⁷ upon which the Murdi Paaki program was based, and child health outcomes, with specific reference to skin disease.³⁵¹

By training Aboriginal people to repair the problems within their own communities,^{544,546} capacity is developed to enable the continuation of a sustainable and efficient maintenance program relatively independent of external influence.⁵⁴⁶ Local employment, individual self-esteem and labour competitiveness are enhanced, alongside improved living conditions and social capital.⁵⁴⁴

Trainees worked alongside qualified environmental health staff and tradespeople during their training to identify and rectify faults, guided by a standardised survey tool that systematically assessed criteria within each household.⁵⁴⁶ Resources and equipment, including personal protective items, were provided.⁵⁴⁶

Several outcomes were identified following the implementation of this program. Improved maintenance and functionality of housing was achieved as well as quicker responses to required repairs with the inclusion of trainees.^{544,545}

Employment prospects of trainees also improved. While the provision of work through Murdi Paaki is dependent upon need and therefore not guaranteed, individuals garnered skills and capacity to carry out work on their own accord and are qualified to complete jobs up to \$10,000 in value.

Employees also noted increased self-confidence and a newfound place within the community following Murdi Paaki involvement.⁵⁴⁶ Finally, positive organisational and community outcomes were acknowledged. Improved management and administration, improved Corporation relationship with tenants, and reduced maintenance costs were associated with having a Murdi Paaki employee on the ground, attending to minor repairs before they became larger issues.^{544,545} Community members saw value in having an Aboriginal worker working within the local community, which was reflected in improved living conditions.^{544,545}

The *Healthy Housing Worker* program has a number of replicable features, including leadership, on-the-ground coordination and local support, relationship and trust, capacity building within the community, and funding and support.⁵⁴⁴ The program succeeded in improving ownership of homes, reducing rates of disrepair, and beneficially impacting upon community health. Many of the lessons learned from this pilot informed subsequent NSW Housing for Health programs, ongoing at time of writing.^{343,548}

While the Murdi Paaki and similar programs offer benefits for the community, employees and residents, they must be conducted well with adequate remuneration of employees and provide sustainable work prospects for benefits to be achieved.

Healthy Living Practice 6 – Reducing the negative effects of animals, insects and vermin

Baseline situation

Animals and insects are part of human communities and ecosystems and have a range of effects on health outcomes. Some of these are outlined below.

Dogs

Dogs are an important part of almost all human communities.⁵⁴⁹ In some Aboriginal and Torres Strait Islander communities, dogs are recognised as providing protection, companionship and having cultural meaning.⁵⁵⁰

Research conducted in 2006 counted about 280 dogs among an Aboriginal community of 900 people; equivalent to three dogs per household.⁵⁴⁹ An additional study approximated between 300 and 400 dogs across 96 houses (800–1000 people) but this was accepted as an underestimate.⁵⁵¹ More recent research suggests dog ownership in Northern Territory communities is 6.3 times higher per household compared with the rest of Australia.⁵⁵²

Insects

Climate conditions mean that some remote communities are susceptible to insect-associated disease, particularly mosquito borne-viruses in the wet season or at endemic levels throughout the year.⁵⁵³ Mosquito management programs and initiatives are challenging in remote communities where there may be large wetlands, areas of still water, or low population density. Community and individual-based strategies to control mosquitoes and encourage people to wear repellent and long-sleeved clothes are commonly used.⁵⁵⁴ Outdoor fires may be used as a form of mosquito repellent in lieu of sprays.⁵⁵⁵ In at least one example, awareness about how to avoid mosquito bites has been high in response to disease outbreaks.⁵⁵⁶

Vermin

Vermin and pests can include mice, rats, snakes and birds.⁵⁵⁷ In one Northern Territory study, Aboriginal carers reported more skin sores and scabies infection among children in households with pests and vermin.⁵¹⁰ The nature of any association between vermin and skin sores is unclear; it is possible that households reporting vermin are also exposed to a range of other risk factors for Strep A transmission.

Evidence of association with Strep A infection, ARF and RHD

Dogs

Strep A infections only occur in humans. There is no evidence that Strep A can be transmitted between animals and humans.^{40,558} A study in a remote Queensland Aboriginal community found that Strep A was not present among dogs.⁵⁵⁹ A study in the United States tested 230 domestic cats and dogs and identified no Strep A.⁵⁶⁰ Other species of Strep bacteria have been identified in animals, meaning that there may be some potential for transfer of bacterial genetic material.^{558,560} There is no evidence that scabies mites which infest dogs reproduce on humans.^{53,561} However, dog scabies may cause a short-term infestation and itch in humans which may lead to skin damage and therefore increased susceptibility to Strep A infection.⁵⁶²

In New Zealand, 1–9% of children admitted to hospital with serious skin infections describe a preceding animal-related injury.⁵⁶³ A third of these skin infections were associated with Strep A, perhaps indicating that animal injuries provide an important mechanism for skin damage and subsequent infection.⁵⁶³

Insects

Biting insects

Insect bites cause localised skin itch which can lead to scratching and skin damage, creating small wounds which may become infected, often with Strep A. In New Zealand, 20–35% of children admitted to hospital with serious skin infections describe a preceding insect bite or sting.⁵⁶³ One-third of these skin infections were associated with Strep A.⁵⁶³ Similarly, studies from England show that increased reports of mosquito bites are followed some weeks later by a spike in reported skin sores.⁵⁶⁴

Non-biting insects

There is no clear evidence for the role of non-biting insects in Strep A transmission. In historic studies in Trinidad, Strep A bacteria was isolated from the Hippelates fly after contact with infected skin lesions of school children.⁵⁶⁵ Some laboratory studies suggest that house flies may be able to digest and then excrete live Strep A bacteria.⁵⁶⁶ No other insect-associated spread has been reported. In particular, there is no evidence for bedbugs as vectors for transmitting Strep A infection.⁵⁶⁷ Their role in itch and skin trauma has not been investigated.

Overall, animals, insects and vermin may contribute to an increased risk of skin damage and subsequent Strep A infection in remote Aboriginal and Torres Strait Islander communities but are unlikely to be the major driver of disease burden. Strategies to reduce these risks could be incorporated in a comprehensive Strep A reduction program at community level.

Evidence for different strategies to reduce the negative effects of animals, insects and vermin

Animal management programs

A range of animal management programs operate in remote Aboriginal and Torres Strait Islander communities, generally focused on improving both animal and human health.⁵⁶² Mechanisms for improved human health may include education about hygiene and handwashing after contact with dogs, and reducing bed-sharing with dogs. Benefits include reduced injuries from dog attacks, improved community and workplace safety, less sleep disturbance from barking and fighting dogs, and improved self-esteem and empowerment through enhanced dog wellbeing.²⁵⁰ Some of these programs have been evaluated.

The Australian Government-funded Dog Health Program is operated by the Nganampa Health Council and delivers a canine health program in Anangu Pitjantjatjara Yankunytjatjara (APY) Lands. It has operated for 20 years, primarily under the leadership of a single vet.⁵⁶⁸ Since inception, the program has expanded from South Australia to Western Australia and the Northern Territory.⁵⁶⁹ Between 2003 and 2013, 18,000 doses of parasitic control agent and more than 3,000 doses of anti-fertility drug were administered.⁵⁷⁰ This program assists in reducing the transmission of infectious diseases such as skin, diarrhoeal and parasitic infections from dogs to humans, while limiting the effects of poor health on dogs.⁵⁶⁹ Anecdotal evidence of improved safety due to the breeding of smaller, less aggressive dogs has also been observed.⁵⁶⁸

Animal Management Work Program Evaluation

The Animal Management in Rural and Remote Indigenous Communities (AMRRIC) is funded by the Federal Department of Social Services to implement animal health and management programs in Aboriginal and Torres Strait Islander communities in the Northern Territory and elsewhere. Between 2010 and 2014, the program worked with three regional councils to train and employ Aboriginal Management Workers (AMWs) to undertake animal health and control activities in remote communities.⁵⁷¹ The creation of this program was a response to the reports of poor health of many animals in rural and remote Northern Territory, including that of companion animals who frequently shared household space and were in regular contact with people.⁵⁷¹

Across the course of the program, 48 community members were trained and employed as AMWs, with 10 maintaining employment at the cessation of funding in 2014.⁵⁷¹ An evaluation identified positive outcomes: engaging community members on animal health and management issues, heightening awareness of dog ownership responsibilities, increasing cross-cultural awareness in the delivery of services, encouraging the community to take up offered population control and treatment services, and improving dog management and human hygiene practices.⁵⁷¹

Summary: Animal management programs		
Domain	Summary	Rating
Evidence	There is no evidence that Strep A or the human scabies mites can spread from dogs to humans. Bites or scratches from dogs may become infected with Strep A.	Low
Benefits	A reduction in community burden of skin infections was anecdotally reported following a dog control program in a central Northern Territory community. ⁵⁷¹ However, high-quality studies demonstrating changes in skin sore burden have not been conducted.	Medium
Risks	Some historical approaches to animal health, including culling, are punitive and unsustainable. ⁵⁷²	Medium
Acceptability	Well-conducted animal health programs appear to be welcomed in a number of remote Aboriginal and Torres Strait Islander communities. ⁵⁷¹	High
Feasibility	A number of animal health programs have demonstrated sustainability over a number of years.	High
Costs	Co-design and delivery of animal health programs require investment in consultation resources. Ongoing staffing costs for employment are likely but may provide an important employment opportunity for people living in remote Aboriginal and Torres Strait Islander communities.	Medium
Timeline	Co-design and delivery of animal health programs require time.	Medium
Positive externalities	Considerable benefits to human and dog health are possible.	High
Equity	Programs which provide veterinary services to remote Aboriginal and Torres Strait Islander communities which would be routinely available in other settings builds equity. Given the importance of dogs in some Aboriginal and Torres Strait Islander communities, dog management programs may be equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> There is limited evidence of direct impact of animal management programs on Strep A infections but many positive externalities. Evaluation of the impact of animal management programs on health outcomes would be useful for further priority setting. 	

Increase access to household insect screens

Guidelines for reducing mosquito, midge and other insect bites in remote communities include the use of appropriate clothing, mosquito nets and household window screens.^{573,574} Recommendations developed for a remote Northern Territory community with a high mosquito burden suggest that *'the best method of avoiding attack at night is to stay inside insect-screened houses'* and that *'screens should be of the correct mesh, fit tightly and be in good repair'*.⁵⁷⁵

However, access to functioning window screening is limited in remote Aboriginal and Torres Strait Islander communities. In response to a 1996 beetle infestation in a Northern Territory homeland community, only one of four houses was noted to have intact flyscreens.⁵⁵⁶ A 2008 environmental health report in one community highlighted that flyscreens were in frequent disrepair and no barrier to insects.⁵⁷⁶ Housing for Health data indicates only 12% of houses have more than 80% of external openings fully screened.⁵⁷⁷

Household insect screens could also be expected to reduce the risk of other insect-borne illnesses, including mosquito-borne viruses and trachoma transmitted by flies.⁵⁷⁷

No Australian programs to increase access to household insect screens were identified or evaluated but they have been shown to be effective in preventing mosquito bites in malaria-endemic regions.⁵⁷⁸

Summary: Increase access to household window screens	
Evidence	None identified on literature review.
Comments	Unable to make a recommendation regarding household window screening for reducing Strep A infections.

Health promotion to reduce insect bites

Fight the Bite

The 'Fight the Bite' campaign is an initiative of the Western Australian Department of Health focused on preventing mosquito-borne illnesses.⁵⁷³ A population survey to assess knowledge, attitudes and practices about mosquitoes and bites was conducted in 2014 among 2,500 people.⁵⁷⁹ Survey results identified that incorrect beliefs about mosquito-borne diseases were widespread, as well as incorrect awareness of risk in regions, including the north of WA where such diseases are abundant.⁵⁷⁹

Entomologists engaged with media specialists within the Department of Health to design a communication strategy aimed at raising awareness of the threat of mosquito-borne diseases in WA.⁵⁸⁰ The campaign included posters, brochures, Facebook infographics, and screen and radio advertisements.⁵⁷³

Tailored materials were also produced for Aboriginal communities since they had different methods of exposure and risk when compared to more urban regions.⁵⁷³ After two years of program delivery, 8.2% of 2,500 survey participants recalled the program.⁵⁸⁰ At a population level this represented 1.7% of people recalling key messages and 1.2% of people changing their behaviour based on these messages.⁵⁸⁰

The influences of local government and social media were greater in northern regions of the State where many remote communities are located.⁵⁸⁰ Insect repellent use was also observed at much higher rates within the Kimberley.⁵⁸⁰

The results of the evaluation indicated heightened awareness and preventative behaviour, considering what was described by the evaluators as a modest budget and resource output.⁵⁸⁰

Summary: Health promotion to reduce insect bites		
Domain	Summary	Rating
Evidence	There is some evidence that health promotion campaigns have a limited effect in increasing knowledge and attitudes and improving behaviour to prevent mosquito and other insect bites.	Medium
Benefits	Reducing the rate of insect bites lessens chances of exposure to vector-borne diseases such as Ross River Virus. Furthermore, infected insect bites are reduced.	High
Risks	In some communities, the preventative measures encouraged, such as bed nets or insect repellent, may be unavailable or unaffordable. This risks people being encouraged to undertake health-protecting behaviours without capacity to do so, a potentially stressful situation.	Medium
Acceptability	Many health promotion campaigns are designed for delivery by an Environmental Health Worker often known to the community, increasing acceptability.	High
Feasibility	Engagement and education can occur relatively easy through the provision of posters, brochures, ads on social media or television/radio, or face-to-face opportunities during service engagement.	High
Costs	Health promotion materials can be relatively affordable, though co-design and translation into local languages requires time and investment.	Low
Timeline	Health promotion activities can commence within a relatively short time period and be continued over an extended period with limited oversight.	Short
Positive externalities	Reducing insect bites reduces the risk of insect-borne diseases. ⁵⁸¹	High
Equity	Health promotion campaigns to reduce insect bites are common in Australia. Appropriate co-designed health promotion messages should also be delivered in remote communities where rates of mosquitoes are often higher than more populous regions.	High
Recommendations	<ul style="list-style-type: none"> Health promotion to reduce insect bites will have limited direct impact on Strep A infections and should not be pursued as a stand-alone disease control strategy. However, reducing insect bites is associated with positive externalities and may be part of a comprehensive program. 	

HLP6 – Summary and recommendations

- There is no evidence of direct transmission of Strep A bacteria from animals or insects to humans.
- Exposure to animals, insects and other vermin increases risk of skin damage which can then become infected by Strep A. Therefore, exposure to animals and insects indirectly increases the risk of ARF and RHD.
- Reducing skin damage in people exposed to animals, insects and vermin may help reduce the incidence of Strep A skin infections.
- Minimising skin damage from insect bites is likely to be most effective when household infrastructure (screens) is coupled with environmental control efforts (reducing stagnant water and killing adult mosquitoes) and health promotion messages about avoiding bites.
- Animal health programs are also likely to contribute to reduced skin damage.

Healthy Living Practice 7 – Reducing the health impacts of dust

Baseline situation

Many remote Aboriginal and Torres Strait Islander communities are exposed to dusty conditions associated with a dry climate and few dust-suppression strategies.⁵⁸²

Evidence of association with Strep A, ARF and RHD

Strep A is not transmitted through environmental dust outside of houses. Inside houses, dust may be contaminated by Strep A bacteria but it is not clear whether dried Strep A in dust can cause infection;^{583,584} neither is it clear whether skin or mucous membrane irritation from dust exposure may occur. In general, dust is not likely to be a major driver of Strep A skin or throat infection.

HLP7 – Summary and recommendations

- Control of environmental dust is likely to have a range of benefits for lung health but is not likely to reduce the burden of Strep A infections, ARF or RHD.

Healthy Living Practice 8 – Controlling the temperature of the living environment

Baseline situations

Some Aboriginal and Torres Strait Islander communities are exposed to extremes of temperature. *Housing for Health* data indicates that 35% of 7,714 houses across Australia had outside shaded air temperatures above 30°C on the day of survey.⁵⁸⁵

Evidence of association with Strep A, ARF and RHD

Temperature and climate conditions may have a range of indirect impacts on the risk of Strep A infection, ARF and RHD including:

Changing risk of skin sores in different climate conditions

Some international studies indicate that skin sore burden tend to increase in warm, wet seasons.⁴⁸⁰ In Australia, there is a general belief that skin sores are more common during the hot, tropical temperatures experienced in northern wet seasons. However, empirical evidence for this belief is limited. A study of skin sores epidemiology in three remote Top End communities (2003–2005) unexpectedly found a higher burden of skin sores in the cooler dry season.⁴⁸ In a subsequent review of multiple datasets from the large East Arnhem Healthy Skin Project, only slight seasonal variation of skin sore prevalence was demonstrated, although variations were not statistically significant.⁵⁸⁶ Contemporary disease modelling does not indicate any variation in the age of first skin infection or scabies for Aboriginal children in remote communities depending on birth season.⁷⁰

Contrastingly, in a Western Australian study, more remote-living Aboriginal children were admitted to hospital for skin infections (including scabies, abscesses and cellulitis) during the wet season.⁶⁹ This difference may represent increased survival of Strep A in warm, wet conditions and increased scabies transmission.⁶⁹

Overall, the effect of climate and temperature on Strep A and scabies risk in remote settings in Australia is unclear.

Changing risk of sore throat in different climate conditions

Sore throat incidence displays seasonal trends in some studies – most common in cool climates when lower winter temperatures may increase household contacts.⁴⁷ This seasonality has not been clearly demonstrated in Australia, though there is little longitudinal data on sore throat in Aboriginal and Torres Strait Islander communities.⁵⁰⁹

Seasonal increases in mosquito bites

Mosquito populations, bites and mosquito-borne diseases also vary according to temperature, rainfall and other climate factors.⁵⁸⁷ Strategies to reduce skin damage from biting insects are addressed in HLP6.

Functional household crowding in cold weather

In cold climates, families who are unable to afford heating may live and sleep closely together in confined spaces to preserve warmth. These close-contact conditions can increase transmission of Strep A infections. Therefore, inability to control household temperature is likely to increase the risk of Strep A infections, ARF and RHD.

Overall, temperature and climate are likely to have an effect on the risk of Strep A infection. However, the direction and magnitude of this association in remote Aboriginal and Torres Strait Islander communities in Australia is not clear. It is not possible to make recommendations about household temperature or climate control as a Strep A reduction strategy.

HLP8 – Summary and recommendations

- Temperature control has important health benefits for Aboriginal and Torres Strait Islander people in remote communities but is unlikely to have a major impact on the risk of Strep A infections.

Healthy Living Practice 9 – Reducing minor trauma

Baseline situation

Aboriginal and Torres Strait Islander people may live in houses which are crowded, poorly maintained and with a high burden of rubbish and debris.³³⁹ This may increase the risk of minor skin damage from cuts and abrasions. Skin which is damaged is more susceptible to Strep A infection.

Evidence for association with Strep A, ARF and RHD

In New Zealand, 10–15% of children admitted to hospital with serious skin infections describe a preceding accident or fall, or other reported skin damage prior to infection.⁵⁶³ A third of these skin infections were associated with Strep A.⁵⁶³

Evidence for different strategies to reduce minor trauma

House and yard tidy days

Several initiatives support households to clean up their homes and yards to benefit their health. In some areas, environmental health workers are encouraged to regularly promote community and yard clean-ups as part of their responsibilities each year. This can reduce build-up of stagnant water and limit the attraction of vermin.⁵⁸⁸ In cyclone-prone regions, the regular removal of large debris from yards is prioritised to avoid these becoming projectiles during significant winds.⁵⁸⁸ Clean-ups can be encouraged at regular community meetings with additional collection supplies arranged if required.⁵⁸⁸

Achieving a tidy yard may be difficult.⁵⁸⁹ Some families with a large number of visitors may not be able to secure cooperation of visitors or tenants in house and yard tidying. Other people may be physically unable to undertake the actions needed to achieve a tidy yard, such as removing large objects or accessing tools or trailers to complete the work.⁵⁸⁹

Keep Australia Beautiful

In Western Australia, Keep Australia Beautiful (KAB) highlights the negative impact of packaging and non-traditional products in remote communities, which contribute to high levels of litter and rubbish.⁵⁹⁰ Interested communities can be provided with resources to conduct their own clean-up, be provided with support from KAB or local rangers versed in the program, or work towards entering the Tidy Towns Sustainable Communities Awards.⁵⁹⁰ Resources designed for remote communities also guide residents through the steps necessary to reduce litter by about 20% per year.⁵⁹⁰

The Northern Territory KAB program uses membership-acquired funding to operate the Litter Prevention Authority, support the Tidy Towns initiative, and fund school programs.⁵⁹¹ Memberships are available personally, or for schools, businesses or councils.⁵⁹¹ The organisation has a specific emphasis on litter reduction and waste management in remote communities.⁵⁹¹

Summary: House and yard tidy days	
Evidence	No evidence for health impacts of yard tidy days or initiatives were identified.
Comments	Unable to make a recommendation.

Homemaker programs

A range of homemaker, home management and family support programs have been developed in Australia. Many of these programs focus on keeping the inside of houses clean and tidy, alongside other health promotion messages.⁵⁹²

Family centres and homemaker programs in Anangu Pitjantjatjara Yankunytjatjara Lands

Homemaker programs, delivered from family centres, were first funded in the APY Lands in 2004 and have had a number of subsequent iterations and funding rounds. The programs involved training Anangu women as Family Support Workers and providing advice and support for home hygiene and parenting.⁵⁹³

No evaluation of the health impact of these programs has been identified.

Summary: Homemaker programs	
Evidence	No evidence for health impacts of homemaker programs or initiatives was identified.
Comments	Unable to make a recommendation.

HLP9 – Summary and recommendations

- In theory, reducing minor skin trauma may reduce the burden of Strep A skin infections.
- Programs which reduce house and yard debris may help reduce minor skin trauma, but no health evaluation has demonstrated this in practice.

Summary of strategies to increase Healthy Living Practices

Chapter 4b outlines different approaches to increase access to Healthy Living Practices (HLPs) for Aboriginal and Torres Strait Islander peoples to reduce the development of Strep A skin and throat infections which can lead to ARF and RHD. Potential approaches are summarised in a standardised framework.

	Evidence	Benefits	Risk	Accept-ability	Feasibility	Costs	Timeline	Positive externalities	Equity	Recommendations	Overall Evidence & Priority
Healthy Living Practice 1 – Washing people											
Health promotion to increase washing	Medium	Low	Medium	Low	Medium	Medium	Medium	High	Medium	Valuable if part of a comprehensive program, co-developed and in local language.	High
Improve access to soap and other health hygiene consumables	Low	Unknown	Medium	Medium	High	Low	Short	High	Medium	Unlikely to be independently effective but may support other HLP1 approaches.	
Develop and enforce building and environmental health standards for remote community housing	Insufficient evidence to evaluate impact on Strep A infection but a widely agreed, rights-based priority which does not require further evaluation.										
Increase access to swimming pools or water parks	Medium	Medium	Medium	Medium	Medium	High	Long	High	High	Likely to be valuable in certain circumstances and conditions.	
Increase access to ablution blocks or shower facilities	Insufficient evidence identified to be able to assess the potential risks and benefits of ablution blocks or shower facilities.										
Strengthen school infrastructure, policies and procedures about handwashing	Insufficient evidence to evaluate but recommendation can be made on the base of rights and legal obligations.										
Healthy Living Practice 2 – Washing clothes and bedding											
Increase access to household washing machine	Low	Unknown	Unknown	Unknown	Medium	Medium	Short	Medium	Medium	Likely to be beneficial but with some risks and ongoing costs.	High
Increase access to community laundromats	Low	Unknown	Low	High	High	Medium	Medium	High	Medium	Limited evidence for evaluation but likely to be beneficial and with possibility of positive externalities.	
Build or repair houses which support washing of clothes and bedding	Houses with adequate plumbing and infrastructure for washing clothes and bedding are likely to increase HLP2 and therefore plausible to lead to reduced skin damage, Strep A infection, ARF and RHD.										
Improve maintenance of household health hardware for washing clothes and bedding	A wide range of strategies to improve remote housing maintenance have been identified. It is not possible to individually evaluate the health effects of these.										
Alternatives to washing clothes and bedding	Medium	High	Low	Unknown	High	Medium	Short	Medium	Low	Wash-free approaches are possible to kill scabies but do not provide all the benefits of washing clothes.	

	Evidence	Benefits	Risk	Acceptability	Feasibility	Costs	Timeline	Positive externalities	Equity	Recommendations	Overall Evidence & Priority
											Low
											Low
											Low
											High
											High
											Medium
											Medium
											Low
											Low
											Medium

Synthesis of environmental and social determinant of health recommendations

Evidence about the effectiveness of strategies to reduce the address the environmental risks of Strep A infections in remote Aboriginal and Torres Strait Islander communities is limited. Although research could help provide more focused technical answers, it is possible to identify actions most likely to effectively reduce the burden of Strep A infection, ARF and RHD from existing information. These actions are summarised below for the highest-impact Healthy Living Practices.

Structural recommendations

- Ensure Aboriginal and Torres Strait Islander leadership in addressing social, cultural and economic determinants of health by:
 - Establishing governance systems which enshrine the decision-making role of Aboriginal and Torres Strait Islander peoples.
 - Acting on the social, economic and cultural priorities determined by Aboriginal and Torres Strait Island peak bodies.
 - Adopting a community housing approach, controlled and delivered by the Aboriginal and Torres Strait Islander community-controlled housing sector.

National recommendations

- The Australian Government, to address all HLPs, should:
 - Develop, cost and implement a National Aboriginal and Torres Strait Islander Housing and Community Environmental Health Strategy.^{154,470} This would address:
 - Increasing housing stock to substantially reduce overcrowding.
 - Improving housing maintenance.
 - Ensuring adequate power and water supply.
 - Update and enforce adherence to the National Indigenous Housing Guide.
 - Identify a package of conditions associated with similar risk factors (provisionally trachoma, otitis media, Strep A infections and respiratory infections) which could all benefit from similar disease-control strategies.
 - Fund community-led action to address these diseases and measure endpoints collectively.

State and Territory recommendations

- All HLPs
 - Ensure Aboriginal and Torres Strait Islander governance of housing construction, management and maintenance processes through their own institutions and organisations.
 - Support employment of Environmental Health Practitioners and provide legal frameworks for their scope of training and employment.
 - Enable regulatory frameworks which enable people living in remote communities to undertake a defined scope of housing maintenance and repairs.
 - Provide clarity about the relationship between education services and health services, including the role of schools and school staff in health-promoting behaviors, health promotion and provision of clinical services.

Community and council level recommendations

- All HLPs
 - Consider use of tools to guide local priority-setting such as the Health Community Assessment Tool.^{594,595}
 - Support community governance of housing construction and maintenance processes.
 - Support the employment of Environmental Health Practitioners.
- HLP1 – Washing hands and bodies
 - Ensure schools have infrastructure, policies, training and time to support handwashing.
 - Explore need for community facilities to increase washing, potentially including an ablution block, water park or swimming pool.
- HLP2 – Washing clothes and bedding
 - Communities, councils and retailers can provide support for household washing machines. This may include selling a small range of quality machines, stocking spare parts, and arranging access to washing machine repairs and maintenance.
 - Explore the need for community laundromats or mobile laundries.
- HLP5 – Reducing the negative effects of household crowding
 - Support and advocate for programs which repair existing houses, expand available space and plan for new housing construction, preferably managed through Aboriginal-controlled housing organisations.
- HLP6 – Reducing the harmful effects of animals and insects
 - Explore the need for animal management programs.
 - Explore the need for mosquito control programs.

Household level recommendations

- HLP1 – Washing hands and bodies
 - Support households to increase hand and body washing through health promotion campaigns which reflect an ecological model of health promotion, through improvements in infrastructure, increased access to washing consumables, and culturally relevant health promotion messages.
 - Provide information about when and how to report the need for household repairs to improve maintenance of plumbing and health hardware systems.
- HLP2 – Washing clothes and bedding
 - Provide information about the benefits of washing clothes and bedding and the temperatures needed to kill scabies mites.
 - Provide information about considerations for buying and maintaining household washing machines and alternative services including laundromats.
 - Provide information about wash-free techniques to kill scabies mites.
 - Provide information about when and how to report the need for household repairs to improve maintenance of plumbing and health hardware systems.
- HLP5 – Reducing the negative effects of household crowding
 - No household-level adaptation to minimise transmission of Strep A in overcrowded houses has been demonstrated to be effective. Although changes in bed-sharing, respiratory hygiene, and increasing outdoor space may be beneficial, there is insufficient evidence to ask people to change living behaviors. This warrants further investigation to understand feasible options for reducing the negative effects of household crowding.
- HLP6 – Reducing the harmful effects of animals and insects
 - Provide information about strategies to reduce the health risks of contact with dogs and insect bites.
- HLP9 – Reducing minor trauma
 - Support engagement in tidy house and yard events.

4 STRATEGIES TO END RHD

4c PRIMARY PREVENTION OF ARF

An overview of opportunities to improve the assessment and treatment of Strep A infections



Introduction

World Health Organization guidelines on rheumatic heart disease (RHD) control define primary prevention as ‘antibiotic therapy of group A streptococcal upper respiratory tract infections to prevent an initial attack of acute rheumatic fever’.²¹³ Antibiotic treatment of Strep A throat infections can significantly reduce the risk of developing acute rheumatic fever (ARF). Treatment with oral penicillin can reduce the attack rate of ARF following Strep A by about 70%. Risk reduction can also be up to 80% with a single intramuscular injection of benzathine benzylpenicillin (BPG).⁵⁹⁶ Therefore, if symptomatic Strep A infections can be diagnosed and treated with an appropriate antibiotic as soon as possible after onset, many episodes of ARF are preventable.⁵⁹⁶⁻⁵⁹⁸

More contemporary international definitions have expanded the scope to include attention to both diagnosis and treatment of Strep A infections, for example: ‘Primary prevention strategies focus on the early diagnosis and timely treatment of GAS pharyngitis (Strep A, sore throat) with antibiotics to prevent the autoimmune consequences resulting from the infection in susceptible individuals.’⁵⁹⁹

In Australia, the definition of primary prevention extends to treatment of Strep A infections of the skin, as well as Strep A infections of the throat. This is based on strong circumstantial evidence of a causal association between skin infections and ARF in Australia and New Zealand. The evidence for Strep A skin infections causing ARF is summarised in Box 2 of Chapter 1. Therefore, in Australia, primary prevention can reasonably be described as the ‘assessment of skin and throat infections and treatment with appropriate antibiotics to prevent ARF in people at high risk of the disease’.

There are also opportunities to reduce the risk of Strep A infection (pre-primary prevention) and strategies which reduce the risk of Strep A transmission once infection has already occurred (post-primary prevention). This is described in Figure 29.

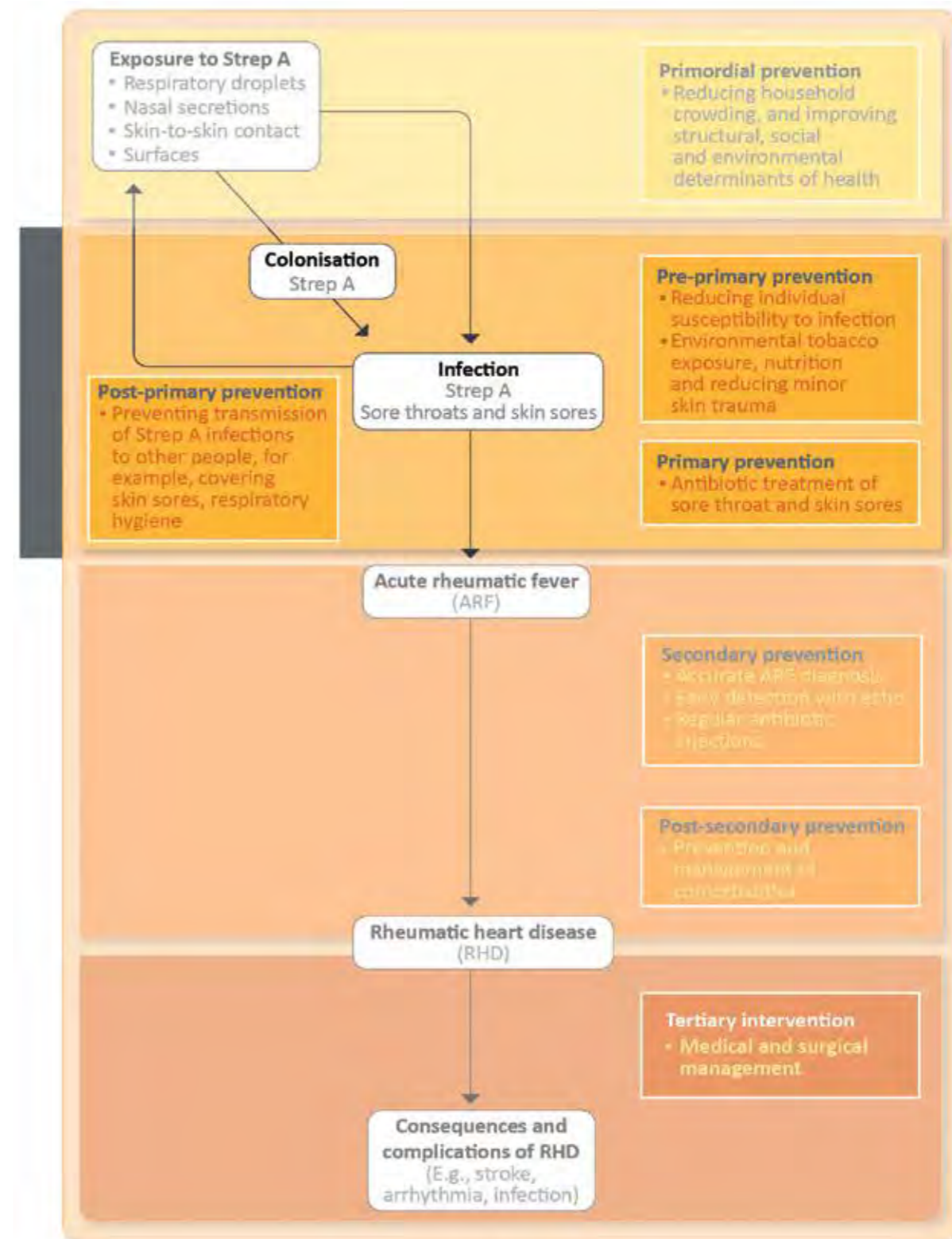


Figure 29: The role of primary prevention in the causal pathway of Strep A infection.

Pre-primary prevention

Pre-primary prevention refers to strategies to reduce the risk of Strep A infection for individual who are at higher risk than others. This individual focus distinguishes pre-primary prevention from population-level strategies related to housing and hygiene. Examples of potential pre-primary strategies are outlined below.

First aid for minor injuries and insect bites to prevent Strep A skin infections

Baseline situation

Any damage to the skin increases the risk of secondary infection with Strep A causing skin sores. Appropriate and timely first aid for minor skin injuries and insect bites may reduce this risk, potentially by allowing the skin breach to heal before exposure to Strep A results in skin sores. There is little information about whether first-aid measures are already widely used by carers of Aboriginal and Torres Strait Islander children in remote contexts. There are some anecdotal reports of traditional medicine use and some qualitative comments from the Pilbara suggest that antiseptic washing does occur.⁶⁰⁰

'I treat the kids with Dettol and dress the sores.'

Aboriginal carer, quoted in Hendrickx, 2017.³⁴

In one small, all-age study in mainstream primary-care settings in Queensland, 20% of people with skin infections had used topical antiseptics or ointments before attending a GP clinic.⁶⁰¹ Topical preparations included salt baths, pawpaw ointment, magnoplasm and aloe vera.

Evidence for strategies to achieve pre-primary prevention

Probiotics to reduce the risk of Strep A throat infections

The Strep A bacteria can live in the back of the nose and mouth without causing active infection. This is called carriage, discussed in Box 1 in Chapter 1. Many other bacteria live in the mouth and it may be possible to replace Strep A (which can cause infections) with other bacteria which do not cause infection. A commercially available product, BLIS K12™, has been developed to pursue this goal by increasing the presence of a non-pathological bacterium, *Streptococcus salivarius* which produces a 'bacteriocin' (a natural antibiotic) that inhibits growth of Strep A.

Streptococcus salivarius K12

Streptococcus salivarius K12 is a probiotic lozenge used in the mouth, which might inhibit growth of the pathogen Strep A.^{602,603} An Italian study investigating this hypothesis enrolled 82 children, including 65 with and 17 without a recent diagnosis of recurrent Strep A throat infections.⁶⁰³ Of those with recent Strep A infection, 45 were treated daily for 90 days with an oral slow-release tablet containing colony-forming units of *S. salivarius* K12.⁶⁰³ There appeared to be a 90% reduction in Strep A throat infection among those treated, as well as a 40% reduction in acute otitis media compared to the untreated control group.⁶⁰³ The medication was assessed as being highly tolerable, with no reported side effects.⁶⁰³

A New Zealand quasi-randomised study of 1,314 children investigated K12 versus placebo lozenges, observing daily treatment in the school week, during school time, for one school year.⁶⁰⁴ In children receiving K12 (n= 584), 7.8% had a throat swab positive for Strep A versus 8.8% who received the placebo (n=553).⁶⁰⁴ This difference was not statistically significant.⁶⁰⁴ The authors concluded there was insufficient evidence to support the routine use of *S. salivarius* K12 for Strep A infection prevention.⁶⁰⁴ However, others have commented on methodological issues in this study, including frequency and efficacy of K12 administration, diagnostic discrepancies, and low carriage of Strep A infection in the population at the time of exposure.⁶⁰⁵

A systematic review analysing four articles with a total of 1,846 participants concluded that K12 is safe and well tolerated, but called for further intervention studies to examine its role as a prophylactic therapy.⁶⁰⁶ The review also found that K12 was not likely to be effective if given in conjunction with antibiotics.⁶⁰⁶

Summary: Probiotics to reduce the risk of Strep A throat infection		
Domain	Summary	Rating
Evidence	Systematic review evidence does not currently support use of commercially available probiotics to reduce Strep A throat infections. ⁶⁰⁶ Effectiveness of a school-based probiotic lozenge program in remote Aboriginal and Torres Strait Islander communities may be lower than international settings because of high rates of antibiotic use, variable school attendance, and apparently low rates of Strep A sore throat. ^{48,586}	Low
Benefits	Real-world benefits of probiotic use have not been identified.	Low
Risks	No biological risks from the use of probiotic preparations have been identified. There may be opportunity costs in focusing on probiotics over more promising alternatives.	Medium
Acceptability	Studies from New Zealand suggest the use of probiotic lozenges is acceptable in Māori and Pacific communities at high risk of ARF. ⁶⁰⁷	Medium
Feasibility	Feasibility of probiotic lozenge administration at schools in remote Aboriginal and Torres Strait Islander communities is unknown.	Unknown
Costs	30 BLIS Probiotic Immune Defence lozenges cost \$24.99 AUD in mid-2019. ⁶⁰⁸ However, programmatic implementation costs for a school-based program are unknown. ⁶⁰⁸	Unknown
Timeline	The timeline for introduction of a probiotic lozenge administration program is unknown.	Unknown
Positive externalities	If effective, probiotic lozenges may also reduce the incidence of acute otitis media.	Medium
Equity	The equity impact of a school-based probiotic lozenge program is unknown.	Unknown
Recommendations	<ul style="list-style-type: none"> There is insufficient evidence to support use of probiotics to prevent Strep A throat infections in Aboriginal and Torres Strait Islander children in Australia. Research to explore prophylactic options may be warranted if the burden of Strep A throat infections is demonstrated to be high in epidemiologic studies. 	

Hygiene measures

Washing minor wounds with water and covering them before they are infected may reduce exposure to Strep A. Other simple hygiene advice, including washing hands with soap and water and keeping fingernails short to reduce scratching of bites, may also be beneficial.⁶⁰⁹ In New Zealand, this has been incorporated into public health promotion messages.⁶¹⁰

Topical antiseptics

Antiseptics are substances which inhibit the growth of bacteria. Using simple topical antiseptics (for example: chlorhexidine, rubbing alcohol, triclosan, or iodine) to clean wounds may reduce infection. Only a small number of historic randomised controlled studies have explored the use of topical antiseptics for preventing wound infection following minor injury.⁶¹¹ This evidence base is insufficient to make clinical practice recommendations.⁶¹¹ However, anecdotally, antiseptic use on wounds is common in many Australian households. A study comparing topical antiseptic and antibiotic treatment (not prevention) of skin sores with 'clean and cover' is under way in New Zealand, the results of which could inform recommendations in the coming years.⁶¹²

Other topical agents in common use in Australia include tea tree oil (with proven antiseptic properties⁶¹³) and pawpaw ointment (unproven antiseptic properties). High-quality studies are needed to better understand the potential risks and benefits of these agents.⁶¹³

Honey

Honey has an antibacterial effect, due to its compositional properties, low water activity and pH, presence of hydrogen peroxide when diluted with water, and inclusion of additional compounds in some variants.⁶¹⁴ While medical grade sterilised honey is marketed as a topical treatment for burns,⁶¹⁵ the Therapeutic Goods Administration acknowledges it as a complementary therapy only,⁶¹⁴ and therefore it is not widely utilised. Furthermore, a systematic review of the known literature failed to reach an evidence-based conclusion regarding the use of honey for topical wound treatment, citing low quality research and differences in studied populations.⁶¹⁶ However, honey is regularly used as a form of bush medicine by Aboriginal and Torres Strait Islander people, who refer to it as ‘sugar bag’,^{617,618} and therefore a literature review is currently under way to better understand the evidence for, and effectiveness of, honey for skin sores.⁶¹⁹

Topical antibiotics

Topical antibiotics are ointments or creams which kill bacteria when rubbed on the surface of the skin, and include mupirocin and fusidic acid.⁶¹¹ Fusidic acid is active against Strep A bacteria and against *Staphylococcus aureus*, a common co-infection in skin sores.⁶²⁰ Increasing antibiotic resistance of *S. aureus* against fusidic acid in New Zealand has been attributed to widespread use for skin sore management.⁶²¹ Similarly, mupirocin resistance emerged rapidly in Aboriginal communities when it was widely used to treat skin sores.^{622,623} The risks of this resistance mean that use of topical antibiotics is not recommended for management of skin wounds or skin sores in Aboriginal and Torres Strait Islander communities in Australia.⁵³

Summary: First aid for minor injuries and insect bites		
Domain	Summary	Rating
Evidence	Applicable real-world evidence about the role of first aid and topical treatments for prevention of infection following minor skin damage is lacking. A study of skin sore treatment is under way in New Zealand which may provide relevant information about infection prevention. ⁶¹²	Unknown
Benefits	The benefits of a first-aid approach to minor wound care are unknown.	Unknown
Risks	Topical antiseptic and antibiotic use risks development of bacterial resistance, particularly if use was widespread as a prophylactic ‘pre-primary’ first approach to treating all minor wounds.	Unknown
Acceptability	One qualitative study suggests that providing more health information and first-aid advice would be welcomed by Aboriginal people in the Pilbara. ³⁴	Unknown
Feasibility	Feasibility of implementing first-aid recommendations, particularly covering wounds, is unknown. Out-of-pocket costs for simple wound dressings in remote communities may be high and access to clean running water for washing wounds may be limited by health hardware issues.	Unknown
Costs	Simple first aid may be associated with some out-of-pocket costs for families and this may be prohibitive. Health system costs to share information and potentially resources about first aid are likely to be relatively low.	Unknown
Timeline	Advice about simple first-aid measures could be incorporated relatively rapidly but substantive changes to clinical guidelines may take some time to implement.	Unknown
Positive externalities	Using first aid to reduce the risk of skin sores would reduce the need for subsequent antibiotic use, providing an important avenue for antibiotic stewardship, empowerment, self-management and, potentially, prevention of downstream complications.	High

Summary: First aid for minor injuries and insect bites		
Domain	Summary	Rating
Equity	Facilities for minor first aid (sufficient running water and simple wound dressings) are widely available in Australia. Ensuring similar facilities are accessible to Aboriginal and Torres Strait Islander people in both homes and public areas is equitable.	High
Recommendations	<ul style="list-style-type: none"> The use of topical antibiotics on skin sores is not recommended given well founded concerns about the development of antibiotic resistance. The effect of simple first-aid measures is currently unknown and cannot be recommended. Research into potential pre-primary prevention for skin sores in Australia may identify options for self-management of skin wounds by families and communities. 	

Treat scabies infections

Scabies infestation causes damage to the skin following scratching and is associated with an increased risk of skin sores. Therefore, treatment of scabies to prevent skin damage is likely to prevent skin sores in populations where scabies is common. *The National Healthy Skin Guideline for the Prevention, Treatment and Public Health Control of Impetigo, Scabies, Crusted Scabies and Tinea in Indigenous Populations and Communities in Australia* was published in 2018 and is supported by a detailed meta-analysis of treatment recommendations.^{53,360}

Recommendations for treating scabies infections in individuals are clear:

- Topical permethrin 5% recommended as first-line treatment in Australia for all age groups (Grade 1A).
- Oral ivermectin recommended if topical treatments have failed and with a medical consultation with a repeat dose in one week (Grade 1A).
- Second-line recommendations for pregnant and breastfeeding women, and children under five years of age or less than 15 kg are also provided.⁵³

At a community/population level, it is possible to reduce the burden of scabies infection through mass drug administration (MDA), screening and treating community members, and comprehensive skin health outreach programs.^{53,360,624}

All methods mentioned do have differential benefits, costs, feasibility, risks and evidence, which will not be explored in depth in this report to limit simplifying a health issue that warrants direct attention, research and evidence-based recommendations.

Other strategies

Gargling to reduce the risk of throat infections

Prophylactic gargling of antiseptic agents may reduce the risk of sore throat, potentially by altering bacteria in the mouth. A small number of studies have explored this possibility, with some evidence of reduced frequency of throat and respiratory infection with regular use of gargles.^{625,626} However, quality of evidence is low, and the effect of regular gargle use needs to be further investigated by research projects before any conclusions and recommendations could be drawn.

Primary prevention

Methods

The structure and approach to this review was based on three foundational data sources:

- **Focus group** – A focus group of END RHD CRE investigators and collaborators was held to scope potential primary prevention strategies. Nine people participated in the primary prevention focus group. They self-identified their primary role as researcher (6), clinician (2), and employed in RHD prevention (1). Seven participants worked primarily in Australia, one in New Zealand and one in another international setting. There were no Aboriginal or Torres Strait Islander participants.
- **Literature review** – A PubMed search focusing on strategies for ARF prevention in Australia was used to identify relevant articles and provide a foundation for further narrative review.
- **Grey literature review** – Reports, evaluations and operational guidelines related to ARF and RHD published in Australia and New Zealand in the past decade were identified through online searches, bibliographic searching, and personal archives of collaborators. Thirty documents were identified and reviewed; detailed results are in preparation for peer-reviewed publication.⁶²⁷

Preliminary review of these three sources revealed access to healthcare (broadly defined) as the unifying issue that needs to be addressed to improve primary prevention. The established Levesque et al.⁶²⁸ model of access to healthcare was used to structure feedback⁶²⁸ (Figure 30). This model has been reviewed with relevance to primary healthcare-access of Aboriginal and Torres Strait Islander people allowing for some cultural adaptations.⁶²⁹

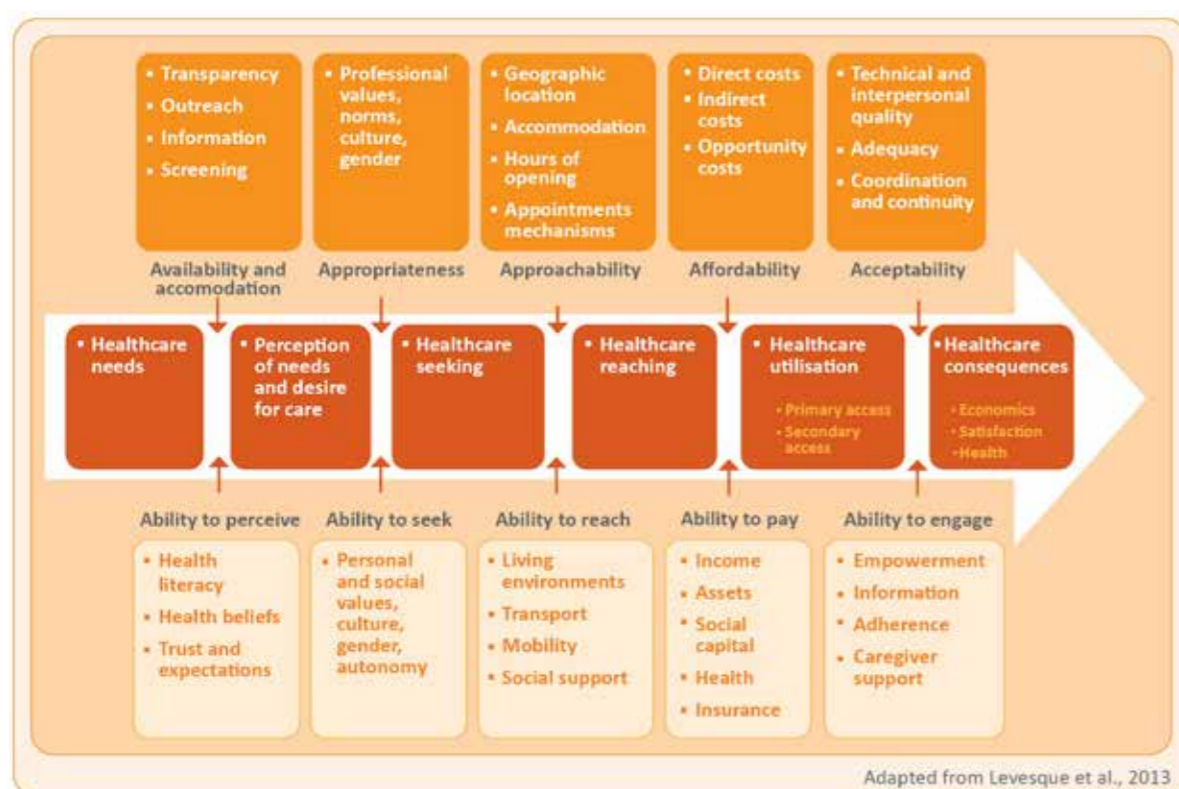


Figure 30: Levesque et al. model of access of healthcare.⁶²⁸

Supply-side strategies to improve primary prevention

Availability and accommodation

(Geographic location, hours of opening, appointment mechanisms)

Baseline situation

In most remote Aboriginal and Torres Strait Islander communities, assessment and treatment of skin sores and sore throats is delivered by primary healthcare clinics. Nationally between 2017 and 2019, 198 organisations provided health services to Aboriginal and Torres Strait Islander peoples with funding through the Indigenous Australians' Health Program (IAHP). Seventy-one percent of these were Aboriginal Community Controlled Health Services, 24% government-run primary-care clinics, and a small number of other providers. These IAHP-funded services provide the bulk of primary medical care in geographic locations with the highest burden of ARF and RHD. Resourcing of culturally appropriate primary healthcare and recruitment and retention of Aboriginal and Torres Strait Islander workers have been addressed in Chapter 4a. Additional barriers to the availability of primary care include:

Lengthy waiting times

Waiting times to access primary-care services can be a significant barrier to accessing healthcare facilities for Aboriginal and Torres Strait Islander people. From 2012 to 2013, 22% of Aboriginal and Torres Strait Islander people who did not seek medical care when they needed to identified that the barrier was 'waiting too long or the service not available at the time required'.⁶³⁰

Waiting times for people to be seen for sore throat and skin sore assessments can be long – particularly in overstretched primary-care services where acutely unwell patients will be triaged and seen first. Waiting times may be a barrier for families who have multiple children and recurrent skin sore and sore throat presentations. Long waits also undermine key messages about prioritising/validating clinic attendance for these conditions.

'You can wait an hour and a half, two hours here.'

Aboriginal carer discussing barriers to treating skins sores, quoted in Hendrickx, 2017.⁶⁰⁰

Limited after-hours services

Some remote primary-care clinics provide after-hours services. For MBS purposes, 'after-hours' care refers to services outside of 8am–6pm weekdays or 8am–12pm Saturdays.⁶³¹ Aboriginal and Torres Strait Islander people have less access to out-of-hours services than non-Indigenous people. The disparity is greatest in remote locations, particularly in the Northern Territory.⁶³¹ In remote community locations where after-hours services are provided, usually only serious medical emergencies are covered.

There are no data in Australia about when families present with skin sores or sore throats, or when they would like to. Data from New Zealand, where attempts have been made to increase health-seeking behaviour for sore throat, indicate that 80% of presentations to the emergency department for Strep A throat infections were 'after hours' or on weekends.⁶³² In Australia, a case-series of people presenting with sore throat to an Emergency Department in Mt Isa suggests that people do access hospitals for sore throats, and some of these presentations are likely to be outside of usual hours.⁶³³

Families of children with sore throats and skin sores may not be able to attend primary-care clinics within regular hours – particularly when children have school commitments and caregivers may be working, studying or awaiting transport. Therefore, limited out-of-hours services may be a barrier to assessment and treatment of skin sores and sore throats. Options to address these barriers are outlined below

Evidence for different strategies to improve availability and accommodation

Expand the range of places and times that people can have skin sores and sore throats treated

There have been no successful attempts in Australia to expand the range of places and times that people can have skin sores and sore throats treated. Therefore, data have been drawn from international programs.

Drop-in sore throat clinics – New Zealand

The New Zealand Government implemented sore throat clinics (also known as rapid response clinics) from 2014 as part of their Rheumatic Fever Prevention Program.⁶³⁴ Māori and Pacific Islander people and those living in low socioeconomic areas aged 4–19 years were eligible to attend these dedicated sore throat clinics. More than 300 clinics were based in general practices, after-hours centres, pharmacies and pathology laboratories across 11 district health boards.⁶³⁴ These drop-in clinics were intended to augment school-based sore throat programs (which did not reach all priority populations and did not function during school holidays) and usual primary-care services (which sometimes incurred an out-of-pocket cost or required an appointment).⁶³⁴

At the clinics, young people were offered a throat swab to detect Strep A and were telephoned if the results were positive.⁶³⁴ Often children were provided with antibiotics at the time of swabbing, and subsequently told to either continue or cease the course depending upon the results.⁶³⁴ In other instances, prescriptions were arranged with the local pharmacy that could be filled if the swabs were positive.⁶³⁴

Formative evaluation of the sore throat clinics was undertaken in 2015, including interviews with parents and caregivers.⁶³⁴ Interviews revealed that awareness of the clinics was poor and people did not realise they were free, however they were valued as being socially sensitive and culturally appropriate.⁶³⁴ Pharmacy-based services were most well-known and viewed as more convenient.⁶³⁴ Parents and young people felt positive about services provided by nurses at general practices, relative to consultations by general practice doctors, which were perceived as rushed.⁶³⁴

Recommendations from the evaluation included greater promotion of the sore throat clinics, continuing the free nature of the service, maintaining long opening hours to accommodate working families, sustaining cultural appropriateness and continuing to keep wait times short.⁶³⁴

Pharmacy-based sore throat assessment and treatment – United Kingdom and internationally

Sore throat assessment and treatment in pharmacies, guided by rapid antigen detection tests (RADT), have been piloted internationally, mainly in high-income settings.^{635,636} Data from the UK are still to be evaluated. Point-of-care testing for Strep A throat infections in 300 pharmacies in New Zealand was announced in mid-2019, focusing on adults at low risk of ARF.⁶³⁷ The results of this initiative may guide development of recommendations for Australia.

Summary: Expand the range of places and times that people can have sore throat and skin sore assessments/treatment		
Domain	Summary	Rating
Evidence	In New Zealand, provision of free sore throat assessment at more than 300 novel locations for children at high risk of ARF increased access to throat swabs. It is not clear whether this service led to a reduction in subsequent ARF. ⁶³⁴	Medium
Benefits	Reducing the barriers to access may improve service utilisation by Aboriginal and Torres Strait Islander people.	Medium
Risks	Disease-specific clinics or services risk fragmentation of primary-care services. Quality of care may be difficult to maintain.	High
Acceptability	Providing services in more locations at more times is likely to be acceptable for patients, though this has not been demonstrated.	Unknown
Feasibility	In remote communities with the highest burden of ARF, there are few service providers and it is unlikely that decentralising from the clinic is feasible.	Unknown
Costs	The potential cost of these novel models of care in Australia are unknown but are likely to be high in small, remote locations. Additionally, services would need to be free at point of care to be comparable with existing services. There is no current mechanism for public funding of point of care testing for Strep A.	Unknown

Summary: Expand the range of places and times that people can have sore throat and skin sore assessments/treatment		
Domain	Summary	Rating
Timeline	The timeline for developing and implementing these novel models of care in Australia is unknown.	Unknown
Positive externalities	No positive externalities were identified.	Low
Equity	Urban and non-Indigenous Australians also largely received services through primary-care providers, although they may have a greater choice of services.	Unknown
Recommendations	<p>The New Zealand model of offering sore throat-specific clinical services is unlikely to be applicable to remote Aboriginal and Torres Strait Islander communities in Australia because:</p> <ul style="list-style-type: none"> • The model relies on throat swabs to be taken to identify Strep A infection and subsequent treatment advice provided. This is at odds with current recommendations for all children at high risk of ARF to have sore throats treated with antibiotic therapy. Timeliness to get a result from a culture for Strep A remains a barrier, meaning an algorithmic approach to treatment is needed. Potential use of point-of-care testing for sore throat may be explored in the future but there is no current basis for recommendations. • The number of service providers in remote communities is small and few services have extended opening hours which would improve access. • Disease-specific care risks fragmentation of comprehensive primary care which has the potential for greatest long-term impact in Aboriginal and Torres Strait Islander health. <p>Dedicated sore throat or skin sore clinics should not be implemented in Australia based on current evidence and the experience of New Zealand.</p>	

Provide assessment and treatment of skin sores and sore throats in schools

Schools are often identified as a location where acute and preventative medical care for Aboriginal and Torres Strait Islander children could be delivered.^{375,638} The peak burden of skin sores and sore throats among school-aged children makes schools a potential hub for assessing and treating Strep A infections.^{471,600}

Primary-care providers who completed a 2019 survey of priorities to primary prevention identified providing assessment and treatment of skin sores, and potentially sore throats, in schools as a high priority. Service delivery models suggested in qualitative comments included sending a school nurse from the clinic to provide school service, providing a clinic at school drop-off and pick-up time, or training/supporting school staff to deliver medical care.⁶²⁷ However, a qualitative exploration of attitudes to skin sores in the Pilbara found teachers and early childhood educators did not believe that children would easily bring skin sores to their attention or seek medical care.³⁴

Some health service delivery programs have historically been offered in schools in remote communities. For example, a program in the 1970s involved treatment and prevention of ear disease in the classroom, including tissue spearing of ears performed by Aboriginal Health Workers while children attended school.⁶³⁹ A decrease in active ear disease was observed between the first and second surveys, however it was unable to be determined if this was directly associated to the program offered.⁶³⁹

Although there are a number of screening programs in schools, there are few sustained, large-scale models of health service delivery embedded in education settings. Schools are not necessarily equipped, willing or resourced to integrate well with health services. Differences between the school and health service in language, approaches and priorities can be barriers to school-based services. Legislative and liability requirements for education and health staff are not clear. Other barriers include lack of standardised position descriptions and clear role scope for School Nurses.⁶⁴⁰ National School Nursing Professional Practice Standards have been developed but widespread implementation of school health service delivery is still underdeveloped.⁶⁴¹ Another limitation of this approach is that families are not aware of what has been provided in terms of healthcare when it is delivered at school.

‘. they teach us a lot about their lingo and so that when we are delivering things to teachers, it’s not coming from a health perspective, it’s coming from an education perspective and making sure that the language that we use is familiar.

They use things, like, I would say, ‘Adjustments,’ and they would say, ‘Differentiated instruction’. And yeah, we would say, ‘Acoustic environments,’ they would say, ‘In-classroom listening.’”

Stakeholder in the Deadly Kids, Deadly Communities program addressing otitis media. Quoted in Duhram et al., 2018.⁶⁴²

School health services

In Western Australia, school health services are jointly provided by the Department of Health and the Department of Education.⁶⁴³ In 2016, this included 77,000 services in primary schools and 80,000 services in high schools requiring the recruitment of 160 new child and school health nurses.⁶⁴⁴ The role of WA School Health Services in providing first aid for minor wounds and management of skin sores and sore throats is unclear.^{643,644}

Summary: Provide assessment and treatment of skin sores and sore throats in schools		
Domain	Summary	Rating
Evidence	No evidence of the effectiveness of assessment and treatment of sore throats and skin sores in Australian schools was identified on literature review. There are examples throughout remote Australia where health services are delivered at the school, e.g. dental, hearing assessments, immunisation, trachoma screening.	Unknown
Benefits	Theoretical benefits of school-based service provision include increased access to assessment and treatment, reduced delays to treatment, and increased convenience.	Medium
Risks	Healthcare provision in the school setting could fragment comprehensive primary care unless carefully developed and integrated. It also risks reducing the time available for education in remote communities, which may have other consequences. Families may also be unaware of what healthcare has been provided when it is delivered at school.	Medium
Acceptability	Acceptability of school-based health services for remote Aboriginal and Torres Strait Islander communities is not well established. However, the SToP trial conducting skin sore assessment and treatment was approved and is currently under way in remote WA schools. ⁶²⁴	Unknown
Feasibility	Delivery of school-based healthcare services faces a number of challenges: <ul style="list-style-type: none"> • Crowded curricula with little classroom time for addressing or responding to health needs. • Practicalities of arranging parental consent for medical care of children. • Relationships with local clinics. • Comfort of teachers and nurses identifying health needs or providing healthcare in educational settings.³⁴ • Perceptions about responsibilities of families and young people for their own health outcomes.³⁴ 	Medium
Costs	Implementing disease-specific sore throat or skin sore clinics is likely to be prohibitively expensive. These costs could be reduced if enhanced approaches to sore throat care were incorporated into a broad school health approach.	High
Timeline	The timeline for developing and implementing novel school-based models of care is unknown.	Unknown
Positive externalities	Not identified.	Unknown

Summary: Provide assessment and treatment of skin sores and sore throats in schools		
Domain	Summary	Rating
Equity	Making schools a hub for provision of health services may risk excluding young people with poor school attendance who may be at greatest risk of Strep A infections. School attendance for Aboriginal and Torres Strait Islander young people in very remote communities in Semester 1, 2017 was less than 70%. ⁶⁴⁵	Medium
Recommendations	<ul style="list-style-type: none"> • Appropriately developed and delivered school-based health services which are endorsed by the community and supported by local primary-care services may have a role in improving treatment and assessment of skin sores and sore throats and other health conditions which present in school-aged children. • Clinics, communities and jurisdictions should explore opportunities to provide healthcare or referral services from schools. Potential service delivery models include: <ul style="list-style-type: none"> - Referral from school teachers to the clinic; - Embedding nurses in schools; and - Training other staff in schools to provide first aid and healthcare services. 	

Use technology to increase assessment and treatment of skin sores and sore throats

A range of technology and telehealth models may improve accessibility to primary prevention in remote Aboriginal and Torres Strait Islander communities. In ACCHS settings, there is some evidence that telehealth may facilitate delivery of culturally appropriate healthcare.⁶⁴⁶ These can be loosely classified based on where information is transmitted from and to:

From community members to primary care

Some stakeholders suggest that facilities for community members (parents, school teachers, lay community workers or others) to send photos of skin sores to primary-care clinics may helpfully reduce barriers to primary-care access. For example, in New Zealand, the ‘MaiHealth App’ has been developed to address shortages of GPs.⁶⁴⁷ In the town of Patea, trained healthcare workers use an app and iPad to collect clinical information, which is then sent to a telehealth team.⁶⁴⁷ A diagnosis is checked by a GP and a prescription arranged with the local pharmacy, and further referral to higher-level services can also be arranged if needed.⁶⁴⁷ ‘Minor’ illnesses, including skin sores and sore throats, are assessed in this manner, with the local hospital undertaking tests for more serious conditions.⁶⁴⁷ Evaluation of the MaiHealth App is yet to be undertaken.⁶⁴⁷

A similar process seems to have been used in a skin health project for a Tuvaluan Pacific Island community project in West Auckland, New Zealand, described by the clinical lead as: ‘We set up a system where community workers would take a photo of a boil and text it to me and I’d prescribe the treatment on the spot.’⁶⁴⁸

From primary-care staff to primary-care staff

Alternatively, transmission of clinical photographs between primary healthcare staff may facilitate or improve quality of outreach care delivery. For example, Aboriginal and Torres Strait Islander Health Practitioners, Health Workers or school nurses may be able to transmit images to GPs and receive advice about management without patients needing to attend the clinic. This kind of approach has been used by Laynhapuy Health Services in East Arnhem Land to support care provision in three remote homelands communities staffed by Aboriginal and Torres Strait Islander Health Practitioners, with weekly nursing visits and periodic medical staff visits.⁶⁴⁹ Funding models to support telehealth services are required to upscale this approach.³⁰²

From primary care to tertiary care

Communication between primary-care services and specialist tertiary providers is an increasing focus in telehealth. However, tertiary input for primary prevention in sore throat and skin sore management is unlikely to be necessary. More complex skin conditions, including crusted scabies, may warrant specialist review. The role of telehealth in management of ARF and RHD is discussed in more detail in *Use technology to increase assessment and treatment of skin sores and sore throats*. Box 14 describes technical issues in telehealth for skin sores and sore throats.

Box 14: Technical issues in telehealth for skin sores and sore throats**Sore throats**

Internationally, the use of telehealth for sore throat assessment has had mixed results. In a United States study of 62 patients, there was poor agreement between telehealth and in-person providers on redness of throat and tonsillar size.⁶⁵⁰ The absence of a physical exam was highlighted as the primary barrier to success.⁶⁵⁰

Skin sores

Workforce shortages and geographic barriers have prompted considerable interest in improving telehealth for skin conditions in Australia.⁶⁵¹ In particular, the Australasian College of Dermatology has actively explored opportunities to use 'store and forward' approaches for photographs to be taken and shared with skin specialists.⁶⁵¹

A system for taking standardised digital photographs of skin sores in the Australian setting has been developed.⁶⁵² Although this has only been used for research purposes to date, adaptation of a simplified protocol for clinical use may be possible. Potentially this could allow healthcare workers in remote settings to send photos of skin sores to clinicians for advice on management. Informal systems for sharing clinical images are already common and formalising these may provide a mechanism to improve quality of care delivery.

Summary: Use of telehealth to support assessment and treatment of skin sores and sore throats		
Domain	Summary	Rating
Evidence	There is some evidence that telehealth facilities can improve healthcare for remote-living Aboriginal and Torres Strait Islander people. The specific application of this approach to skin sores and sore throats is not yet clear.	Unknown
Benefits	Theoretical benefits of telehealth include services which are delivered more promptly, with fewer barriers to access and reduced need for travel.	Unknown
Risks	The risks of telehealth delivery are likely to depend on the protocols used and the systems in place to ensure appropriate antibiotic use and clinical management. They rely on documentation of treatment decisions in the clinical record, access to the platform, and who controls the platform being used.	Unknown
Acceptability	There is no specific information about photograph acceptability for Aboriginal and Torres Strait Islander people in routine clinical care. ⁶⁵³ However, taking and sharing other kinds of clinical photographs has been acceptable in research studies. For example, a screening study of Aboriginal and Torres Strait Islander children in North Queensland used clinical photographs of eardrums, and these were considered acceptable. ⁶⁵⁴ A study using skin photographs in remote Aboriginal communities in the Northern Territory also appeared to be acceptable on the basis of high retention in the study. ⁶²⁰	Medium
Feasibility	Feasibility of telehealth mechanisms is likely to vary significantly by system and setting.	Unknown
Costs	Telehealth costs in remote communities vary significantly based on the cost of satellite and videoconferencing infrastructure. ⁶⁴⁹ Cost savings through reduced travel costs may be possible.	Unknown
Timeline	Timelines to set up telehealth systems depend on setting, scale and location. Discrete programs within individual services may be possible within months to years of preparation and planning. ⁶⁵⁵	Unknown
Positive externalities	The benefits of high-quality telehealth systems would extend far beyond treating just skin sores and sore throat.	High

Summary: Use of telehealth to support assessment and treatment of skin sores and sore throats		
Domain	Summary	Rating
Equity	Telehealth services may improve access to care for communities who would otherwise be under-served and are therefore likely to be equity enhancing.	High
Recommendations	National stakeholders for RHD in Australia should: <ul style="list-style-type: none"> • Explore opportunities to increase the use of telehealth for primary prevention. This could include a scoping survey of systems already in use and review of relevant MBS item numbers. • Research initiatives to evaluate implementation of telehealth services for sore throats and skin sores should be commissioned. 	

Flexible primary-care hours and appointment services

Flexible appointment arrangements are a hallmark of culturally appropriate primary-care services for Aboriginal and Torres Strait Islander people.^{629,656} Flexibility may be achieved through a mix of 'walk-in' capacity, appointment streams, and services provided by Aboriginal and Torres Strait Islander Health Practitioners and nurses.⁶⁵⁶ In combination, these approaches may reduce waiting times and improve access to service.

Various process mechanisms may be needed to facilitate this approach. For example:

- In New Zealand, efforts to reduce waiting times in primary-care services included use of standing orders to allow nurses to provide antibiotics without people needing to see a GP (see description of standing orders below).
- Dedicated appointment streams for children attending primary-care clinics for routine health checks, skin checks or immunisations which are not delayed by acute medical needs.

'Our service has an 'open door policy', as we respond to clients without them making an appointment to see a health worker ... The clients come to us when they need to have their health needs met.'

Staff member, Aboriginal Health Team, quoted in Freeman et al., 2014.⁶⁵⁶

Make it possible for more people to prescribe, dispense and supply antibiotics for primary prevention

In the New Zealand school-based sore throat model, a Manual of Operation Standing Orders was developed. Local arrangements allowed for standing orders to be delegated from a medical practitioner to a registered nurse to supply and administer some prescription medications according to the programmatic guidelines.⁶⁵⁷ An evaluation of antibiotic dispensing practices within this program was conducted on 2014 data. The entire 2014 program covered 23,588 enrolled school children (5–12 years) and treatment of 12,127 sore throats and 13,348 skin sores. Evaluation assessed about 60% of these children, collecting prescriptions from 10 participating pharmacies. Analysis of dispensed antibiotics suggested high adherence to operating guidelines.⁶⁵⁷

Standing orders – a mechanism developed in New Zealand – are written instructions by a medical practitioner which allow a person or class of people who do not have prescribing rights to administer and/or supply specified medication. This is a deliberate attempt to address primary-care workforce shortages and has some parallels with patient group directions used in the United Kingdom.⁶⁵⁸ Standing Orders are used in primary care for practice nurses to provide medication (commonly for constipation, skin infections, pain, urinary tract infections or sore throats) or for pharmacists to be able to monitor and adjust warfarin doses. Qualitative evaluation with stakeholders in New Zealand found that, although there is some confusion about what standing orders are and what they are intended to do, they have generally expanded access to medications and provided a mechanism to extend the scope of practice of health staff.⁶⁵⁸ Standing orders also facilitated sore throat checks by nurses in primary care, anecdotally reducing waiting times.⁶⁵⁹

There is a long history of formal and informal dispensing practices in Australia, particularly to allow for medication to be given by Aboriginal and Torres Strait Islander Health Practitioners in remote locations. Remote area nurses are covered to prescribe, dispense and supply only in certain areas of Australia. For example:

- In the Northern Territory, *Section 250 of the NT Medicines, Poisons and Therapeutic Goods Act* enables a nurse, midwife or Aboriginal and Torres Strait Islander Health Practitioner to supply or administer a schedule 4 or 8 substance within a remote primary healthcare setting according to CARPA protocols.⁶⁶⁰
- In Queensland, the *Health (Drugs and Poisons) Regulation 1996* allows for Aboriginal and Torres Strait Island Health Practitioners to dispense from a list of medications defined by the drug therapy protocol, including antibiotics used for primary prevention.⁶⁶¹
- In Western Australia, Aboriginal and Torres Strait Island Health Practitioners and workers are regulated under the *Medicines and Poisons Regulations 2016* to possess, administer and supply prescription (Schedule 4) medications which have been prescribed by a doctor.⁶⁶² Structured Administration and Supply Arrangements⁶⁶³ also provide authorisation for any health practitioner to administer or supply a medicine to any patient meeting specified circumstances.
- In South Australia, prescription by non-medical healthcare professionals is governed by the *Health Practitioner Regulation National Law (South Australia) Act 2010* and the *Controlled Substances Act 1984*. This includes Aboriginal and Torres Strait Islander Health Workers if relevant training has been undertaken.⁶⁶⁴ A Model Standing Drug Order (SDO) for benzathine benzylpenicillin was developed in 2018 by the South Australian RHD Control Program as a template for use by health services to support nurse-initiated benzathine benzylpenicillin administration.⁶⁶⁵
- In New South Wales, registered nurses are authorised under the *Poisons and Therapeutic Goods Regulation 2008* to supply emergency medications other than schedule 8 medications to those outpatients attending a rural or remote hospital when the pharmacy service is unavailable, and an authorised prescriber is not present in the facility, under a myriad of conditions.⁶⁶⁶

Increasing access to Aboriginal and Torres Strait Islander Health Workers and Health Practitioners who can provide medication for primary prevention requires an increase in workforce numbers (addressed in Chapter 4a) and increasing capacity for medication supply through training, systems and legislative clarity.

Summary: Increase the number of people able to prescribe, dispense and supply antibiotic medication for primary prevention		
Domain	Summary	Rating
Evidence	There is some evidence from New Zealand that increasing the number of people who can provide primary prophylaxis increases access to treatment for sore throats.	Medium
Benefits	A range of dispensing arrangements for Aboriginal and Torres Strait Islander people in remote communities already exist in Australia. Streamlining these could be reasonably expected to increase access to sore throat and skin sore treatment.	Medium
Risks	Increasing access to antibiotics may increase the risk of inappropriate dispensing with subsequent negative impacts on antimicrobial resistance. Studies from New Zealand suggest this risk can be mitigated with strong clinical guidelines and procedures. Dispensing of medication from remote clinics is currently governed by s100 provisions but is not captured by PBS data, making it difficult to track antibiotic use in remote settings. ⁶⁶⁷	Medium
Acceptability	The experiences of protocol-based dispensing through CARPA in the Northern Territory suggest this approach is acceptable for Aboriginal and Torres Strait Islander people.	High
Feasibility	Legislative changes, procedural clarification, training, and quality improvement mechanisms would all be required to scale up increased dispensing. The experiences across northern Australia suggest this is possible.	Medium

Summary: Increase the number of people able to prescribe, dispense and supply antibiotic medication for primary prevention		
Domain	Summary	Rating
Costs	Training and quality improvement process costs would be ongoing to ensure safe dispensing. Cost savings may be possible through task sharing/shifting from GPs to registered nurses and Aboriginal and Torres Strait Islander Health Practitioners and increased access to timely treatment leading to a reduction in ARF incidence.	Medium
Timeline	Planning and implementing systems for increased dispensing would likely take a period of some years.	Long
Positive externalities	Increasing dispensing capacity for health staff in remote locations could improve access to a range of medication for different disease endpoints.	High
Equity	Expanding access to people able to dispense medication could help reduce inequalities in medication access for Aboriginal and Torres Strait Islander people. ⁶³¹	High
Recommendations	National stakeholders for RHD in Australia should work with relevant peak bodies and jurisdictions to explore scope for increasing access to medication for primary prevention through broader dispensing opportunities, accompanied by training and investment in the Aboriginal and Torres Strait Islander health workforce.	

Appropriateness

(Technical and interpersonal quality, adequacy, coordination and continuity)

Baseline situation

There has been little evaluation of the knowledge, attitudes and behaviours of remote healthcare staff about assessment and treatment of sore throats and skin sores. Some studies have explored antibiotic prescribing, potentially providing an indication of appropriate care delivery.

Sore throats

A national Australian study reviewed antibiotic prescribing of 856 GP trainees (registrars) in 2,495 clinical encounters for sore throat.⁴⁹ More than nine different kinds of antibiotics were prescribed for this indication, a far broader distribution than would be expected if antibiotic prescribing guidelines were used. Concerningly, the groups most likely to require antibiotic treatment for Strep A infection were least likely to receive it: Aboriginal and Torres Strait Islander people, young people (5–15 years) and those living in areas of greatest socioeconomic disadvantage.⁴⁹ Although only a small number of consultations with Aboriginal and Torres Strait Islander people or from very remote locations were included in the study, the results suggest that, nationally, care for sore throat is not congruent with existing guidelines. This is supported by other antibiotic-prescribing analysis in Australia, suggesting that antibiotics for sore throat are over-prescribed for many patients but not necessarily prescribed for those with greatest potential to benefit.⁵⁰

A more recent retrospective review of 1,554 primary-care consultations for sore throat in inner and outer regional areas found that antibiotics were prescribed for 81% of sore throat episodes.⁶⁶⁸ Ethnicity of participants was not recorded but the study was described as being conducted in a ‘low-risk’ population. High rates of antibiotic prescribing in this population are not indicated.⁶⁶⁸

Skin sores

There are very little data on primary-care management of skin sores. One small, all-age study from 2005 to 2007 in mainstream Queensland clinics found that 83% of people received an oral antibiotic prescription.⁶⁰¹ These prescriptions did not always reflect antibiotic-prescribing guidelines. Guidelines to keep skin sores covered and avoid work or school attendance appear to be poorly implemented.⁶⁰¹

Overall, guideline-based care delivery for sore throats and skin sores is likely to be variable. Awareness of the link between Strep A skin and throat infections and ARF and RHD is also anecdotally low. This contributes to an evidence–practice gap and the delivery of health services which are not guideline based.

An array of structural and health systems factors contributes to the evidence–practice gap for sore throats and skin sores:

- Most healthcare providers train in settings where RHD is rare and the conditions which precede RHD are unfamiliar to many. Additionally, the remote primary-care workforce is transient; half of nurses stay in each clinic only four months, and 80% have left by 12 months.²⁵³ Therefore retention of context-specific knowledge is likely to be limited.
- Antibiotics are not recommended for the treatment of sore throat among people at low risk of ARF. Resources and training in much of Australia, particularly in non-Indigenous urban settings, are intended to reduce inappropriate antibiotic use for sore throats in primary care.⁶⁶⁹ Practitioners who subsequently move to work in areas with people at high risk of ARF – including short-term remote locums – are not required to have context-specific training. This can lead to confusion about different clinical practices for different at-risk groups.
- Skin sores can be normalised in some high-burden settings, creating an inertia to treatment.^{34,68}

Structural issues impacting provision of primary care are addressed as part of a wider discussion in Chapter 4a.

Evidence for different strategies to improve appropriateness

Improve use of clinical guidelines for assessment and treatment of skin sores and sore throat

Developing and implementing evidence-based clinical guidelines can improve the quality, consistency and safety of care delivered.^{670,671} There has been relatively less research or policy attention to the understanding of how guidelines can best be updated, adapted and evaluated. A range of guideline resources relate to primary prevention of ARF in Australia:

Skin sore guidelines

A wide range of guidelines, protocols and clinical recommendations for managing skin infections in Aboriginal and Torres Strait Islander peoples have been developed in Australia.^{291,672,673} In 2018, the *National Healthy Skin Guideline* for the management of skin infections in Aboriginal and Torres Strait Islander communities was published in order to provide a standardised approach.⁵³

Sore throat guidelines

In 2019, seven different guidelines for managing sore throat were identified in Australia.⁶⁷⁴ New approaches to diagnosis and management continue to be suggested.⁶⁶⁸ Each of these had slightly different recommendations and a different approach to identifying people at high risk of ARF who require antibiotic treatment for primary prevention.⁶⁷⁴

Consolidated clinical guidelines

Several consolidated clinical guidelines provide clinical management information for a range of conditions. The most widely used of these in remote Aboriginal and Torres Strait Islander primary care is the CARPA Standard Treatment Manual developed for use in the Northern Territory.²⁹¹ The independent review of the RFS in 2017 identified a need for ‘*continual monitoring of primary-care clinician awareness and use of the Australian ARF and RHD Guideline and others including the Central Australian Rural Practitioners Association Inc (CARPA) manual with respect to primary prevention related to GAS infections and secondary prophylaxis*’.⁶ Research to understand barriers and enablers of clinician use of CARPA highlights the importance of organisational culture and norm-setting in maintaining high-level fidelity to guideline use.⁶⁷⁵ In the Kimberley Region of Western Australia the Kimberley Aboriginal Health Planning forum has region-specific guidelines that have been in use since 2005 and address clinical needs that are prioritised by clinicians in this region.⁶⁷⁶

Nationally, electronic Therapeutic Guidelines (eTG) are widely used.⁶⁷⁷ A newer initiative to develop localised online HealthPathways to guide referral and management in different geographic locations is also under way in Australia.⁶⁷⁸

Those participating in the Delphi survey did not identify improvements in clinical guidelines as a priority for improving primary prevention.⁶²⁷ Participant comments suggested that access to guidelines is sufficient and that human, time and financial resources to implement this guideline-based care are more likely to have an impact. Conversely, qualitative consultation with healthcare providers in the Pilbara suggested that there were no pictorial guidelines in clinics readily available to assist in the diagnosis of skin sores.³⁴ These views indicate that a system is needed to ensure guidelines are current and widely disseminated.

The National Healthy Skin Guideline 2018 now includes a flip chart with visual prompts for the recognition and treatment of skin infections.⁵³ The Guideline now includes four components: evidence review supported by a published systematic review,³⁶⁰ flip chart, quiz for training of healthcare workers, and a community careworker training resource.

Opportunities to improve use of clinical guidelines and uptake

Improve alignment and accessibility of clinical guidelines for primary prevention of ARF

Changes in evidence, antimicrobial-resistance protocols and new therapies necessitate periodic guideline updates. Guidelines may also be developed by different groups for different settings and end-users. Over time, different versions of clinical guidelines accumulate and can cause confusion.⁶⁷⁹ A move to electronic guidelines which can be regularly and readily updated is improving this situation. For example, eTG is moving to a system of rolling online updates.⁶⁸⁰ However, an active process to manage and align guidelines across jurisdictions and education providers is likely to be needed – particularly for sore throat since clinical guidelines for a relatively small number of people at high risk of ARF differ substantially from population-level guidelines.

Technology may improve access to guidelines and guideline-based care, particularly if guidelines can be made more accessible through phone or mobile apps. Dissemination of knowledge about all of these resources and guidelines is important to guide clinical care.

Summary: Improve use of clinical guidelines for assessment and treatment of sore throat and skin sores

Domain	Summary	Rating
Evidence	Several clinical guidelines relevant to skin sores and sore throats exist in Australia. There is some evidence from non-Indigenous settings that guidelines are not widely adhered to. ^{49,50,668} No studies have explored how to increase use of evidence-based guidelines for assessment and treatment of skin sores and sore throats in communities at high risk of ARF.	Medium
Benefits	Use of evidence-based clinical guidelines can improve quality, consistency and safety of care. ^{670,671}	High
Risks	No risks to increasing the use of clinical guidelines were identified.	Low
Acceptability	Acceptability of well-developed clinical guidelines by end-users is high, particularly for the consolidated CARPA manual. ^{675,681}	High
Feasibility	The CARPA manual and other resources are widely used in Aboriginal and Torres Strait Islander primary care, demonstrating feasibility.	High
Costs	The costs of developing, maintaining and disseminating clinical guidelines are substantial. ⁶⁷⁷ These costs may be offset by improved quality and consistency of care delivery.	Medium
Timeline	A rolling process for reviewing, updating, consolidating and refreshing clinical guidelines is needed.	Ongoing
Positive externalities	Increasing routine use of evidence-based clinical guidelines is likely to increase quality of care delivery. In particular, use of clinical guidelines can increase appropriate antibiotic use and reduce the risk of developing antimicrobial resistance. ⁶⁶⁷	High

Summary: Improve use of clinical guidelines for assessment and treatment of sore throat and skin sores		
Domain	Summary	Rating
Equity	Evidence-based clinical guidelines which provide clear advice for addressing the clinical needs of Aboriginal and Torres Strait Islander people provide an important opportunity for enhancing health equity.	Medium
Recommendations	<p>National stakeholders for RHD in Australia should have remit and resourcing to:</p> <ul style="list-style-type: none"> Review and disseminate guidelines on assessment and management of sore throat and skin sores, and related conditions including scabies infestation. Focus on a standardised risk-stratified approach to assessment and treatment of sore throats. Support jurisdictional activities to increase guideline use and uptake. Align existing guidelines with emerging approaches such as HealthPathways. Consider opportunities to disseminate guidelines through teaching resources and mobile phone applications. <p>Further evaluation of how guidelines are used and how fidelity can be increased is warranted. This may include development of clinical audit capacity as outlined in <i>Develop audit tools to support appropriate primary prevention of ARF</i>.</p>	

Train healthcare workers to confidently assess and treat skin sores and sore throats

There is little research about the education and training needs and priorities for the remote health workforce for skin sores and sore throats.

Considerable clinical care is provided by Aboriginal and Torres Strait Islander Health Practitioners (ATSIHPs) in remote communities. Increasing the support for ATSIHPs, and potentially for lay community workers, may be a form of ‘task shifting’ which can increase access to assessment and treatment of skin infections and sore throats. A cross-sectional survey of ATSIHPs in Western Australia and the Northern Territory found that while 92% had access to a GP to assist with the management of skin conditions, only 15% had access to a dermatologist. Two-thirds of ATSIHPs indicated they lacked confidence in treating and managing the skin infections they see in practice.⁶⁸² The majority expressed an interest in further training.⁶⁸²

Similarly, in the Pilbara region of Western Australia, healthcare staff considered diagnosis of specific skin infections to be challenging.³⁴ Incorrect assessment of skin sore severity and stage of healing has been described.³⁴

Strategies to improve health worker knowledge of skin sores and/or sore throats

Training courses

A small number of ad hoc training events related to skin health have been held or are planned, including Skin Health Symposia (focusing on scabies and crusted scabies) by One Disease, and a Wound Management Program to be run by the Australian Society of Plastic Surgeons in remote Northern Territory locations.^{683,684} Evaluation of these programs has not been identified.⁶⁸³⁻⁶⁸⁵

Online training resources

Online training opportunities may increase access to training by reducing the need for clinical staff to leave remote locations.

Taking care of skin: how to recognise and respond to skin health issues of Aboriginal and Torres Strait Islander people

Developed by the Australasian College of Dermatologists in 2018, these online modules cover nine main disease-specific topics, along with teaching on when to refer people to a GP and how to provide education about skin care.⁶⁸⁶ Each module takes 1–2 hours to complete, however there is no Continuing Professional Development accreditation.

National Healthy Skin Guideline Quiz

The National Healthy Skin Guideline quiz was produced in conjunction with the third edition of the Recognising and Treating Skin Infections Flipchart to assist healthcare providers to easily recognise, diagnose and treat common skin infections.⁶⁸⁷ It contains 16 questions prompting visual recognition of skin conditions via photographs.⁶⁸⁷ Evaluation of this new resource has not yet been conducted.

RHDAustralia

RHDAustralia have a number of online training modules but these do not currently include a focus on skin sore or sore throat management.

Video training

Video training of health professionals in remote areas of WA is conducted to increase knowledge and use of the *National Healthy Skin Guideline* resources (personal correspondence, Dr. Asha Bowen, 2019). Videoconference reduces travel expenses and time, while allowing people throughout the state to participate in training.

Written resources

Recognising and Treating Skin Infections: a visual clinical handbook

A complementary document to the *National Healthy Skin Guideline*, the ‘*Recognising and Treating Skin Infections: a visual clinical handbook*’ resource was developed to train health professionals to recognise skin conditions in rural and remote regions across Australia.⁶⁸⁸ The resource includes images of common conditions for easy reference, as well as recommended methods for treatment and prevention.⁶⁸⁸

‘Beating the Bugs’, a community care worker flipchart

An additional resource to complement the *National Healthy Skin Guideline*, ‘Beating the Bugs’ was developed in collaboration with Aboriginal communities and Puntukurnu AMS.⁶⁸⁹ The flipchart was designed to empower families and community care workers to recognise different skin conditions and provide meaningful information about the treatment required.

Summary: Improve health worker knowledge of skin sores and sore throats		
Domain	Summary	Rating
Evidence	A number of education and training resources address the treatment of skin sores and sore throats in populations at high risk of ARF. None of these have been evaluated.	Medium
Benefits	Providing high-quality education resources and training opportunities likely to improve the quality of care delivered in remote primary-care settings.	High
Risks	<ul style="list-style-type: none"> Education and training resources which do not meet the needs of end-users may be counterproductive – for example, if they are too complex or too time consuming. Fragmented training programs may be confusing, particularly if there are multiple providers or training agencies. Courses which require travel away from the community accrue an opportunity cost in reduced clinic capacity to deliver healthcare. 	Medium
Acceptability	Healthcare workers in remote Aboriginal and Torres Strait Islander primary care consistently identify unmet training needs. Various models for meeting these needs are likely to be appropriate and acceptable for different staff and communities.	Medium
Feasibility	Different models of education and training vary in feasibility and are best customised to the setting.	Medium
Costs	Training costs are an ongoing part of primary-care delivery in Aboriginal and Torres Strait Islander primary-care settings. However, the creation of new training materials would introduce further costs.	Medium

Summary: Improve health worker knowledge of skin sores and sore throats		
Domain	Summary	Rating
Timeline	Development of education resources and training materials is an ongoing process. Updating and cross-referencing these contributes to delays.	Ongoing
Positive externalities	Streamlined processes for identifying training needs and responding to these have capacity to increase quality of care delivery for a range of conditions.	High
Equity	Health professionals working in urban settings have access to a wide range of education and training opportunities. Ensuring remote Aboriginal and Torres Strait Islander primary-care colleagues have similar programs is important for enhancing equity of care.	High
Recommendations	<p>National stakeholders for RHD in Australia should:</p> <ul style="list-style-type: none"> Be resourced to review, develop and disseminate education and training materials on primary prevention, written by and for Aboriginal people. Develop feedback mechanisms to improve these resources over time. <p>The jurisdictional programs should be resourced to:</p> <ul style="list-style-type: none"> Adapt national resources to jurisdictional settings and clinical pathways. <p>Clinics should be supported to:</p> <ul style="list-style-type: none"> Address the logistic barriers to staff training, including lack of internet, lack of locum cover for staff training, and limited clinical capacity. 	

Embed decision support in clinical software

Most primary-care software packages have capacity for decision support items to be added. This means that when health practitioners enter clinical notes for a given condition, they will be prompted to record or consider particular clinical details or recommendations. These prompts can provide clinical benefit by 'nudging' providers towards particular approaches and can improve data recording for quality improvement and audit purposes. For example, in the Northern Territory, recommended cardiovascular risk assessment for Aboriginal and Torres Strait Islander people was more likely to occur in clinics using integrated clinical decision support than those without.⁶⁹⁰

There is no evaluation of decision support for skin sores or sore throats in Australia. Internationally, use of a template within clinical software has improved antibiotic-prescribing behaviour for sore throat presentations in the United Kingdom.⁶⁹¹ In Australia, decision support has been used in Aboriginal and Torres Strait Islander communities for other relevant conditions:

Cardiovascular risk assessment decision support

The Treatment of Cardiovascular Risk in Primary Care using Electronic Decision Support (TORPEDO) study was a cluster randomised controlled trial (RCT) which used computerised decision support, audit and feedback tools, and clinical workforce training to investigate barriers to improved CVD risk management and prevention in Australian primary healthcare services.⁶⁹² The project was implemented in 40 general practices and 20 Aboriginal Community Controlled Health Services in NSW and Queensland over 12 months.⁶⁹² Centres were required to use a project-designed software system during consultations with eligible patients (Aboriginal and Torres Strait Islander people aged ≥ 35 years and others aged ≥ 45 years).⁶⁹³ More than 38,000 patients were included in the study, and the intervention was associated with improved overall risk factor measurements.⁶⁹³ TORPEDO demonstrated that a computer-guided intervention including point-of-care decision support, audit and feedback tools, training and support improved cardiovascular risk factor screening.⁶⁹³ The TORPEDO tool is considered a promising instrument in the prevention of cardiovascular disease, with specific applicability for high-risk groups and ACCHSs.⁶⁹³

ARF/RHD clinical review modules developed for Communicare

Communicare is patient information software used by a number of community health services.⁶⁹⁴ The software provides a single source of patient information and a comprehensive electronic health record, of particular benefit for Aboriginal and Torres Strait Islander organisations dealing with complex care needs in rural and remote communities.⁶⁹⁴ Care management plans and clinical review modules have been developed for ARF and RHD for use within Communicare.⁶⁹⁵ This provides capacity to prompt clinical care at the time of entry – for example by adding automatic recalls for secondary prophylaxis or other reviews – and to review care delivery when reports are generated.⁶⁹⁵ The effects of this work have not been evaluated.

Clinical decision-making tools – Top End Health Service

The majority of primary-care services provided through the Northern Territory Government use the electronic Patient Care Information System (PCIS). PCIS has increasing capacity for decision support including addition of a cardiovascular disease (CVD) risk calculator, combined chronic disease care plan and a Chronic Conditions Management Report. These changes have shifted practice: care plan completion increased from 35% (2012) to 61% (2016) after introduction of automated decision support elements.⁶⁹⁶

Decision support was recommended in the Indigenous Eye Health Roadmap and has also been embedded in case management recommendations for crusted scabies.^{697,698}

Summary: Decision support aids for assessment and treatment of sore throats and skin sores		
Domain	Summary	Rating
Evidence	There is reasonable evidence that decision support can improve guideline-based healthcare, including in remote and Aboriginal and Torres Strait Islander populations.	High
Benefits	Increasing guideline-based care could improve the number of Aboriginal and Torres Strait Islander people at high risk of ARF receiving antibiotic treatment for Strep A skin and throat infections.	Medium
Risks	Increasing the number of decision-support modules can reduce effectiveness.	Medium
Acceptability	Decision-support modules can be acceptable for primary-care staff and patients if they are well developed, piloted and supported for implementation. ⁶⁹⁹	Medium
Feasibility	A number of existing modules for different conditions suggest that decision support is feasible in Aboriginal and Torres Strait Islander primary healthcare settings.	High
Costs	Simple decision-support modules (as required for skin sores and sore throat) can be built at relatively low cost. Technical support to install and use the modules can be an ongoing cost.	Low
Timeline	Building and piloting decision-support modules when best-practice guidelines already exist is relatively quick. Implementation and quality assurance activities require ongoing support.	Short
Positive externalities	Increasing routine use of decision support has the potential to deliver high-quality guideline-based primary care for a range of conditions.	Medium
Equity	The need for decision-support software is potentially higher in remote Aboriginal and Torres Strait Islander settings with high staff turnover relative to the more stable workforce in urban settings.	Medium
Recommendations	<p>National stakeholders for RHD in Australia should:</p> <ul style="list-style-type: none"> Support the development of clinical modules for all clinical software packages for skin sores and sore throat treatment. Provide training and support to install and use these modules to primary-care providers. 	

Develop quality improvement mechanism for skin sore and sore throat management

Baseline situation

Continuous quality improvement (CQI) has been enthusiastically adopted as an important component of improving primary-care services for Aboriginal and Torres Strait Islander people.^{700,701} Although the impact of these initiatives on care delivered has been uneven, CQI approaches do show promise.⁷⁰² The National CQI Framework for Aboriginal and Torres Strait Islander Primary Care (2015–2025) provides a mechanism for strengthening the impact of CQI activities.⁷⁰³

There are no established quality indicators in Australia for assessment/treatment of skin sores and sore throats in communities at high risk of ARF. The absence of CQI tools and mechanisms makes it difficult to identify the current standard of care and opportunities for improvement. CQI initiatives in the management of RHD have provided important opportunities to improve the delivery of secondary prophylaxis and care for people living with RHD.^{252,704} A similar approach is warranted in primary prevention to stop new Strep A infections and recurrences of ARF developing.

Develop audit tools to support appropriate primary prevention of ARF

Audit tools may be used to identify how well services are delivering guideline-based care. For example, in New Zealand, a sore throat audit tool was developed, allowing clinics to identify prescribing patterns for sore throat in Māori children and develop strategies to change where required.⁷⁰⁵ Repeat audits provide an opportunity to assess the impact of health worker training and improve training delivery.^{706,707} Globally, a Cochrane review of 140 studies found that audit and feedback generally leads to ‘small but potentially important improvements in professional practice’. Effectiveness is likely to depend on baseline service delivery and the method of feedback provision.⁷⁰⁸

Summary: Develop audit tools to support appropriate primary prevention of ARF		
Domain	Summary	Rating
Evidence	Clinical audit and feedback provide an important pathway for improving clinical care delivery. No audit mechanisms related to management of skin sores or sore throats are under way in Australia.	Medium
Benefits	Clinical audit could improve understanding of the knowledge–practice gap in primary prevention of ARF and contribute to a broader CQI agenda.	Medium
Risks	Clinical audit processes can be time consuming and if not linked to supportive practice feedback may not equate to improved quality of care delivery. Competing demands and clinical service requirements can be barriers to constructive participation in audit processes.	Medium
Acceptability	Acceptability of audit and CQI processes varies substantially by setting and program implementation.	Medium
Feasibility	A large number of audit and feedback mechanisms are in place in Aboriginal and Torres Strait Islander primary care and appear to be feasible.	Medium
Costs	Development and support to implement clinical audit tools requires a moderate amount of resourcing for salaries and training.	Medium
Timeline	Development of audit tools requires an agreed clinical standard of care which probably exists for skin sores but need to be defined for sore throat management. Development of associated audit tools once clinical standards are agreed could occur within months.	Medium
Positive externalities	Strengthening and embedding CQI processes in remote Aboriginal and Torres Strait Islander primary care has capacity to enhance care delivery across a range of disease endpoints.	High

Summary: Develop audit tools to support appropriate primary prevention of ARF		
Domain	Summary	Rating
Equity	Audit activities which focus on conditions such as skin sores and sore throats which disproportionately affect Aboriginal and Torres Strait Islander people are likely to be equity enhancing.	Medium
Recommendations	National stakeholders for RHD in Australia should develop audit tools to monitor care delivery for sore throat and skin sores.	

Develop ‘look back’ mechanisms for people diagnosed with ARF

Diagnosis of ARF provides a sentinel opportunity to ‘look back’ at opportunities for primary prevention. By identifying events where people had signs or symptoms of Strep A infection but did not receive the recommended antibiotic therapy which would reduce the risk of ARF by 80%, it may be possible to identify systemic barriers, provide feedback to clinical staff, and improve future care delivery. In New Zealand, ‘Rheumatic Fever Case Review Meetings’ occur at all major hospitals where people with ARF are admitted.⁶⁵⁹ A review of clinical notes is conducted and feedback to primary-care colleagues is provided by the GP Liaison Team.⁶⁵⁹

A small case series of ‘missed’ ARF diagnoses in Queensland was published in 2007 which identified some systemic problems in diagnosis and opportunities for further education. No similar activities appear to be currently under way in Australia.⁷⁰⁹

Summary: Look back mechanisms case review following ARF diagnosis		
Domain	Summary	Rating
Evidence	There is limited evidence, but it is feasible that case reviews might lead to improved primary prevention of ARF.	Medium
Benefits	Case review of new ARF diagnosis could potentially: <ul style="list-style-type: none"> • Help identify systemic issues in delivering primary prophylaxis or ARF diagnosis. • Identify education needs of primary healthcare staff. • Provide an opportunity for feedback and support to staff or clinics. 	Medium
Risks	Case review meetings could lead to inappropriate or unhelpful criticism of primary-care services if not conducted within an appropriate CQI mechanism, with primary-care representation and awareness of the context of remote primary healthcare provision.	Medium
Acceptability	Acceptability of case review to people with ARF, communities and primary-care providers is unknown.	Unknown
Feasibility	The feasibility of case review meetings is unknown.	Unknown
Costs	Salary support would be needed for staff to collate information ahead of case review meetings and follow-up.	Medium
Timeline	Establishing a case review mechanism would require governance and information-sharing protocols which may take some time to negotiate.	Medium
Positive externalities	Normalising clinical review and feedback could contribute to improve guideline-based care for a range of conditions.	Low

Summary: Look back mechanisms case review following ARF diagnosis		
Domain	Summary	Rating
Equity	Aboriginal and Torres Strait Islander people in remote communities may not have the support or resources to follow up concerns about quality of care-delivery. For example, it is rarely possible for people to seek an independent second opinion on care or change primary-care providers. External mechanisms may be needed in order to achieve equity with non-Indigenous communities in Australia who may have better access to other systems to seek clinical support.	Medium
Recommendations	<ul style="list-style-type: none"> A program to develop a 'look back' review meeting of ARF notifications should be initiated, with a view to scale up to major referral hospitals accounting for the majority of ARF admissions. This clinical review meeting should: <ul style="list-style-type: none"> Be comprised of multidisciplinary stakeholders, potentially including hospital-based clinicians, the RHD register and primary-care representatives; and Have a clear remit to focus on quality improvement. Resourcing to develop terms of reference, and provide administrative support and feedback of review meeting outcomes, is required for this approach to have impact. 	

Improve diagnosis of Strep A infections

Skin

Diagnosis of Strep A skin infections can usually be made clinically on the basis of typical wound appearance. Confirming the diagnosis of Strep A infection by swabbing the wound and microbiology is only indicated if the skin sore is not responding to standard treatment.⁵³

Throat

Clinical diagnosis of Strep A throat infections is difficult. An estimated 60–80% of sore throats are caused by viral infections which do not benefit from antibiotic treatment.^{52,710} A number of different diagnostic approaches can be used to guide clinical management of sore throats. These are outlined in Table 7.

Diagnostic approaches which confirm the presence of Strep A (through microbial culture or point-of-care testing) have the potential to reduce unnecessary antibiotic use. However, these approaches can also cause clinical uncertainty when there is a concurrent, but unrelated, viral throat infection in the setting of Strep A throat carriage. In these cases, children will have a positive throat culture or point-of-care test but are unlikely to benefit from antibiotic therapy because Strep A is not the organism causing symptoms.

Use of point-of-care tests (PoCTS) in Australia is also complicated by varied epidemiology of Strep A carriage and infection. In some Aboriginal and Torres Strait Islander communities, the proportion of people with Strep A culture-positive sore throats is quite low.^{48,509} This reduces the pre-test probability of PoCTS, making the tests less useful in clinical practice. Research to determine the role of PoCTS as an adjunct to primary prevention in Australia is required. If found to be efficacious, further work would be needed on mechanisms to fund their use, because a user-pays approach is unlikely to lead to good uptake in populations at high risk of ARF/RHD.

Table 7: Diagnostic approaches to guide identification and management of Strep A throat infections.

Strategy	Details	Recommendations
Treat all people at high risk of ARF	Guidelines currently in use in high-risk ARF populations in Australia recommend treating all episodes of sore throat in people aged 3–24 years with antibiotics without confirmatory diagnostic testing. ⁷¹¹ This approach maximises prevention of ARF but has some risks. In particular, increasing antibiotic use when it may not be beneficial and causing pain through benzathine benzylpenicillin administration.	Retain as the default approach in high-risk ARF populations until alternative approaches are sufficiently accurate, acceptable and accessible for use.
Clinical decision rules	There have been numerous attempts to develop a clinical scoring system which can reliably differentiate Strep A infection from viral or other causes of sore throat. However, no scoring system has been demonstrated to reliably distinguish Strep A sore throat from non-Strep A sore throat.	Not accurate enough to recommend in clinical practice. Insufficiently sensitive and specific.
Throat swab culture	The best (gold standard) laboratory test for Strep A in the throat is culture of a throat swab. A sterile swab is rubbed across the tonsils and throat of someone with a sore throat. The swab is sent to the laboratory and used to grow bacteria from the back of the throat. Results from throat swab culture take about two days once the swab reaches the laboratory. Transport delays mean that results are often not available in remote communities in a timely manner to guide treatment.	Routine throat swabbing is not recommended in young people at high-risk of ARF.
Point-of-care tests – Rapid Antigen Detection Test (RADT)	<p>Point-of-care tests (PoCTs) produce a result in the clinic without samples needing to be sent away to the laboratory. Rapid antigen detection tests (RADT) work by detecting parts (antigens) of the Strep A bacteria. Results are usually available within 5–15 minutes. Collection of the sample is the same procedure as pharyngeal swabs for culture. The test itself is a small disposable device similar to a pregnancy test.</p> <p>A 2016 Cochrane systematic review found that relative to throat culture, RADT tests in children with sore throat have a sensitivity of 86% and specificity of 95% for detecting the Strep A antigen.⁷¹² This means that the RADTs give a false negative result 14% of the time and children may miss out on antibiotics they would benefit from. RADTs give a false positive result 5% of the time and children may receive antibiotics they do not need. However, the performance of individual RADTs was highly variable by test used and collection technique. Other large reviews have found similar results and a study exploring the utility of RADT PoCT in New Zealand was abandoned due to poor test performance.^{713,714}</p> <p>Only one RADT study has been conducted in Australia, the sample was 248 people presenting to an emergency department with sore throat.⁶³³ However, the RADT results were not compared with bacterial culture so accuracy cannot be assessed.</p>	PoCT RADTs do not offer sufficient sensitivity or specificity to be used in populations at high risk of ARF in Australia.

Strategy	Details	Recommendations
Point-of-care tests – PCR	<p>Newer, gene testing methods based on polymerase chain reaction (PCR) are also emerging. Samples are collected as for a throat swab and then inserted into a cartridge in a desk-top machine connected to a computer, to detect genetic material of Strep A bacteria in samples. Results are produced within 30 minutes.</p> <p>A pilot study of 145 throats swabs using a PCR-based Strep A test at a tertiary hospital in the Northern Territory compared with cultures revealed a sensitivity of 100% and specificity of 79.3%. This means that a PCR result which was negative for Strep A could confidently indicate the absence of the bacteria and antibiotics could be safely withheld. This would allow for more focused use of antibiotics to treat Strep A throat infections.⁷¹⁵ Emerging international pilot studies of PCR PoCT in primary care are also promising.⁷¹⁶</p>	<p>Emerging technology for more accurate point-of-care Strep A testing appears to show promise. Further research is required before recommendations can be made in the primary-care setting and support for scale-up, including funding, would be required if PCR PoCTs were to be widely implemented.</p>

Summary: Improve the diagnosis of Strep A infections		
Domain	Summary	Rating
Evidence	There is no international experience with wide-scale use of Strep A PoCT as part of population-level primary prevention programs for ARF. However, small studies of new PCR PoCT technology show promise and warrant further investigation. ^{715,716}	Medium
Benefits	Improving diagnosis of Strep A throat infections could reduce unnecessary antibiotic use, therefore minimising pain and high rates of antibiotic use.	High
Risks	A focus on improving the diagnosis of Strep A throat infections could consume significant time and resources. However, population impact will be limited if the number of sore throat infections is low relative to skin infections, if people do not attend clinic for assessment, or if recommended treatment is not acceptable. Therefore, improved diagnostic capacity should be considered a potential adjunct to whole-of-health-system strengthening for Strep A infection management.	Medium
Acceptability	A number of different point-of-care tests are already in Aboriginal and Torres Strait Islander settings.	High
Feasibility	Systems for introducing and supporting use of point-of-care technology are already established in Aboriginal and Torres Strait Islander settings under the auspices of QAAMS (Quality Assurance for Aboriginal and Torres Strait Islander Medical Services). ⁷¹⁷	High
Costs	Emerging PCR technology for molecular point-of-care testing is expensive. However, cost savings in improved treatment may be possible and improving rational use of antibiotics could have further economic benefit.	Unknown
Timeline	Scale-up of point-of-care testing can occur reasonably quickly with sufficient impetus and investment, as demonstrated by the rollout of the enhanced response to syphilis in Aboriginal and Torres Strait Islander communities. ⁷¹⁸ This was accompanied by additional funding and workforce in order to mobilise the services.	Medium
Positive externalities	Use of point-of-care testing in Aboriginal and Torres Strait Islander health may provide an avenue for increased health provider awareness about Strep A infections and quality assurance mechanisms.	Medium

Summary: Improve the diagnosis of Strep A infections		
Domain	Summary	Rating
Equity	Strep A point-of-care testing is not required in low-risk populations where the risk of ARF is limited and antibiotics are not warranted. Ensuring that discriminative diagnostic testing is available in Aboriginal and Torres Strait Islander communities would potentially reduce the burden of the current treat-all approach.	Medium
Recommendations	<ul style="list-style-type: none"> Further investigation of PCR-based PoCTs for Strep A in remote Aboriginal and Torres Strait Islander settings. RADT PoCTs should not be used in communities at high risk of ARF. A conservative treat-all approach for communities at high risk of ARF should be retained using appropriate antibiotics. Research to explore improved diagnostic capacity for Strep A should not be prioritised over health system-strengthening initiatives. 	

Ensure availability of essential medicines

Shortages and stockouts of drugs occur in contemporary Australia, particularly in rural and remote settings.⁷¹⁹ Stockouts of first-line antibiotics for primary prevention have occurred on a number of occasions for benzathine benzylpenicillin (Bicillin L-A®. 2006–2008, December 2012–Jan 2013 and March–April 2014) and for trimethoprim-sulfamethoxazole (from September 2018).^{720,721} Second-line medications – such as mupirocin ointment for decolonisation of staph aureus skin infections – have also been affected.

Stockouts and shortages lead to product substitution of less suitable formulations and to crushing adult tablets for children, and are likely to reduce the overall opportunity for effective primary prevention. The effects of these shortages disproportionately burden Aboriginal and Torres Strait Islander people in remote communities where medication supply is already complicated by long distances and logistic complexities.⁷¹⁹

New mechanisms for reporting drug shortages in Australia came into effect in 2019, intended to increase transparency and opportunities for system-level responses.⁷²² These include mandatory reporting of shortages by pharmaceutical companies, compiled in a centralised website. Jurisdictional and local responses for managing stockouts also need to be developed, potentially including rationing and advice on medication use.⁷²²

‘Sometimes the clinic does run out of the liquid medications and then we give injection.’

Healthcare practitioner referring to treatment of skin sores in the Pilbara, quoted in Hendrickx, 2017.⁶⁰⁰

Summary: Ensure availability of essential medicines	
Comment	Stockouts of first- and second-line antibiotics for primary prevention of ARF have occurred over a number of years in Australia. This is likely to have reduced effective primary prevention. New strategies to reduce the impact of medication shortages have been introduced but the impact of these has yet to be demonstrated, particularly for remote Aboriginal and Torres Strait Islander communities.
Recommendations	<p>National stakeholders for RHD in Australia should have capacity to:</p> <ul style="list-style-type: none"> Monitor access to medication required for management of Strep A infections, ARF and RHD and associated conditions. Work with national agencies working to improve medication supply.

Approachability

(Transparency, outreach, information, screening)

Baseline situation

Approachability of services for assessment and treatment of sore throats and skin sores could be increased by outreach or screening activities. Outreach is considered a particularly important component of improving access to primary care for Aboriginal and Torres Strait Islander people.⁶²⁹

Evidence to strategies to improve approachability

Active case finding of skin sores during routine health checks

Aboriginal and Torres Strait Islander children in remote communities generally have a large number of contacts with the primary healthcare system through child health checks, immunisations, and high rates of infections and non-infectious disease. For example, children in five remote Aboriginal communities in the Northern Territory had a median of 23 presentations to the health service in their first 12 months of life.⁷²³⁻⁷²⁵ High rates of health service utilisation have also been documented in an urban Queensland ACCHS setting.⁷²⁶ These clinical encounters – particularly the annual Aboriginal and Torres Strait Islander Peoples Health Assessment (MBS Item Number 715) – may offer opportunities for active identification of skin sores.

Diagnosis of skin problems among children is consistently reported as one of the main outcomes from 715 health checks: 12% of checks in Orange (a small city in regional New South Wales) and in 18% of child health checks of 432 children in urban Queensland.⁷²⁷⁻⁷²⁹ However, normalisation of skin sores by caregivers and health professionals means that under-diagnosis may still occur during health checks.^{34,68}

A number of guidelines for health checks require or recommend a skin health check. For example, the NACCHO/Royal Australian College of General Practitioner (RACGP) *‘National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people’* recommends opportunistic screening for skin sores as part of the annual health assessment for *‘children living in areas with high rates of infectious skin disease (scabies and impetigo)’*.⁷³⁰ ‘Associated notes’ on MBS item number 715 for the Aboriginal and Torres Strait Islander Peoples Health Assessment include guidance that examination should include ‘skin examination, if indicated’ for children under 15 years.⁷³¹

Similar recommendations for skin examination appear in the *Northern Territory Skin Health Guidelines*.⁷³² However, none of these documents contain guidance about what a skin check should entail or how it should be conducted.

The concept of integrating healthy skin checks into routine service delivery mechanisms is supported by recommendations of previous skin health programs. For example, in summarising the outcomes of the East Arnhem Health Skin Project from 2004–2007, final report authors recommended refinement of the program so that *‘Instead of focusing on community-wide mass treatment at annual ‘scabies days’ and subsequent intensive follow-up screening of all children, we focused on 1) ensuring identification and treatment of skin infections among all infants and other children who presented at the clinic and 2) providing follow-up outreach visits to each household where a child had been diagnosed with scabies.’*⁷³³

The Aboriginal and Torres Strait Islander Peoples Health Assessment (MBS Item 715) provides a potential mechanism for skin examination of Aboriginal and Torres Strait Islander people of all ages on an annual basis. Quality of care for other disease-specific elements improves when formally incorporated in Aboriginal and Torres Strait Islander Peoples Health Assessment activities.⁷³⁴

Child Health Check Initiative

The Child Health Check Initiative (CHCI) began in the Northern Territory in 2007 as part of the Northern Territory Emergency Response (NTER, ‘The Intervention’). CHCI was a child health check for all Aboriginal children aged 0–15 years living in the Northern Territory, funded through MBS Item No. 708 (since merged into MBS Item No. 715 in 2010).⁷³⁵ The CHCI was evaluated in 2011, finding that the development of the CHCI approach was negatively disruptive, did not include stakeholders, and was not well integrated with routine service delivery activities, though additional financial resources for primary care were welcome.^{287,735,736}

An estimated 57–65% of eligible Aboriginal young people under 15 years received a CHCI.²⁸⁷ These encounters provide information about how skin health can intersect with active clinic-based surveillance for skin infections. Overall, 30% of children who received a CHCI check between 2009 and 2011 had a skin problem, 20% required medication for a skin disease, and dressings for skin infections were common.²⁸⁷

About 10% of children aged 4–5 years were documented to have skin sores and 8% documented to have scabies on CHCI check (although CHCI prevalence of both conditions was lower than documented in other routine health check data sources).

Service delivery model

‘Lift the Lip’ is a structured screening tool to assess for dental decay in children under five years of age. Primary-care health staff and parents are encouraged to lift the lip of young children and look for white or brown spots on the front of the teeth. In 2007, a structured approach to offering ‘Lift the Lip’ in primary care in South Australia was implemented and incorporated into routine Child and Family Health Service General Health Checks.⁷³⁷ The program has now been adopted in a number of Australian jurisdictions. Northern Territory recommendations embed ‘Lift the Lip’ in Healthy Under 5 Kids child health checks and can be performed by all health workers.⁷³⁸ This could provide a model for defining what a skin check is and simplifying implementation.

‘It’s really hard. Because I mean we have in our annual health checks a skin check, and we have in all our child health checks a skin check, and we have in our chronic disease checks a skin check.’

‘They’re just one of 50 other items that need to occur. And some of these checks, if you did them comprehensively, would take an hour, each. And clients, and like every body-part program wants to add their bit. Eye health wants to do their vision screening, and long vision screening, and they want it to be more and more complex as time goes on...’

PHC Program Director addressing the inclusion of skin health checks in routine health screening, quoted in Crusted Scabies Evaluation, 2018.⁶⁹⁸

Summary: Embed active case finding for skin sores into routine clinical service		
Domain	Summary	Rating
Evidence	Recommendations to include skin examinations in routine clinical examination already exist but are variably implemented in practice.	Medium
Benefits	The benefits of embedding more deliberative skin checks into routine health checks include: <ul style="list-style-type: none"> • Opportunities to leverage off existing campaigns to increase health checks for Aboriginal and Torres Strait Islander people, including the Deadly Choice shirt incentive and the ‘The Didja Know?’ campaign in the Northern Territory.^{739,740} • Strengthening delivery of integrated, comprehensive primary healthcare delivery.⁷²⁹ 	High
Risks	The addition of more elements and more requirements to health checks increases time and complexity to complete them. This may be a disincentive for health staff if requirements are considered too onerous, ⁶⁹⁸ and may discourage patient attendance if the review is time consuming. ⁶⁹⁸	Medium

Summary: Embed active case finding for skin sores into routine clinical service		
Domain	Summary	Rating
Acceptability	Aboriginal and Torres Strait Islander Peoples Health Assessment appears to be broadly acceptable with increasing rates of uptake. ⁷⁴¹	Medium
Feasibility	Adding or strengthening a healthy skin check to routine clinical encounters – particularly Aboriginal and Torres Strait Islander Health Assessment – is likely to be feasible. The concept of a comprehensive health check is already familiar to Aboriginal and Torres Strait Islander peoples and providers and is funded through an appropriate MBS item number.	High
Costs	The marginal cost of adding a more structured healthy skin check to existing routine care is likely to be low.	Low
Timeline	Consultation and development of tools and training materials to help embed healthy skin checks into routine care delivery could be achieved relatively promptly.	Short
Positive externalities	<ul style="list-style-type: none"> Increasing the quantity and quality of Aboriginal and Torres Strait Islander health checks may improve a range of health outcomes for a number of different conditions.⁷²⁹ 	Medium
Equity	<ul style="list-style-type: none"> Aboriginal and Torres Strait Islander health checks are performed at the highest rate in the Northern Territory, where the highest burden of ARF and RHD occurs. Therefore, this is likely to be an equity-enhancing approach which focuses service delivery in the areas of greatest need.⁷⁴¹ 	High
Recommendations	<p>The RHD National Implementation Unit should be resourced to:</p> <ul style="list-style-type: none"> Develop a working definition of a 'healthy skin check' to provide guidance on the setting (privacy and environment) and components (skin areas to be examined or self-reported). Review the inclusion and specifications of healthy skin checks in the NACCHO/RACGP national guide to a preventative health assessment for Aboriginal and Torres Strait Islander people and associated jurisdictional guidelines. Update clinical software templates for Aboriginal and Torres Strait Islander Peoples Health Assessment with more detailed specifications about a healthy skin check and outcomes/recommendations. This should be done in partnership with primary health clinics. 	

Active case finding of skin sores and sore throats in general school-based health checks

Some schools and communities have an established program of general health screening or 'health checks' delivered through school services. Service delivery models for these initiatives vary – some use primary-care clinic staff and Medicare MBS item numbers, others are conducted as informal health promotion activities. Where school-based health checks are already under way, it may be possible to integrate screening for scabies and skin sores into screening protocols. For example, the *Northern Territory Skin Health Guidelines* recommend that skin health checks be conducted as part of school-aged health screening.⁷³²

However, the recommendation that *'in this age group, check hands, arms, legs, feet and waist. Only check the rest of the skin if scabies or sores are noted, or if itching is present on other parts of the body'* illustrates some of the difficulties in providing comprehensive care in school-based settings.⁷³² This includes issues relating to privacy, consent of caregivers, and the need to include clinical findings in clinical record systems.

Apunipima Pilot program

The Apunipima Cape York Health Council investigated whether school health checks improved health outcomes for students screened in remote settings.⁷⁴² In this region, school health checks are undertaken annually based on the Aboriginal and Torres Strait Islander Health Assessment (MBS item 715). The rationale of the health checks is to provide comprehensive primary healthcare, identify ill health, and arrange for appropriate referral, treatment and follow-up. In 2015, there was an evaluation of the health checks provided to 99 students in one high school from grade 7 to grade 11 by four different health service providers.⁷⁴² A lengthy planning phase (106 days for a three-day screening program) was required. Students and health staff were surveyed about acceptability of the program. Ninety-six percent (n=25) of students stated the screening process was acceptable, though half reported boredom and 44% lack of privacy.⁷⁴² Eighty-four percent of staff felt that the collaboration integrated in the health checks improved student health outcomes, specifically with a referral system.⁷⁴² However, while it was accepted that school health assessments provide care to children who otherwise miss out in remote settings, they do not necessarily equate to improved health outcomes.⁷⁴² Enhancing health promotion within schools was recommended.⁷⁴²

Trachoma screening within the Healthy School Aged Kids (HSAK) program

In the Northern Territory, active case finding for trachoma was coordinated by the Centre for Disease Control and embedded into the Healthy School Aged Kids program operated by the Department of Health and Families.⁷⁴³ In most communities, staff based in regional centres (Darwin, Nhulunbuy, Tennant Creek and Alice Springs) supported clinics and schools to undertake school-based trachoma screening with parental consent. Local primary healthcare staff received training on trachoma screening or the screening itself was undertaken by staff overseeing the program.⁷⁴³ In some communities, ACCHS services offered screening through primary-care services instead.

Otitis media screening in New South Wales

In New South Wales, the School Health Program involved otitis media screening for Aboriginal children aged 0–6 between 2004–2008.⁷⁴⁴ However, an evaluation found the program was costly, did not decrease the prevalence of otitis media among Aboriginal and Torres Strait Islander children, and did not address the underlying determinants of disease.⁷⁴⁵ It was recommended that Local Health Districts move from a screening-only approach and focus instead on prevention, treatment and management of ear disease.⁷⁴⁵

Other smaller health check initiatives occur intermittently, including through service providers such as Clontarf and the Stars Foundation.⁷⁴⁶ Health checks are facilitated between local GPs, Aboriginal corporations and schools to enhance access to regular care.⁷⁴⁷

Summary: Inclusion of sore throat and skin sore screening in routine school health checks		
Domain	Summary	Rating
Evidence	There is little evidence about the impact of general health checks provided in the school setting, nor specific evidence about the impact on sore throat or skin sores.	Unknown
Benefits	In theory, offering school health checks which include skin and sore throat assessment may increase detection and treatment of these issues and reduce barriers to access by reducing the need for clinic attendance.	Medium
Risks	Privacy and confidentiality may be more difficult to ensure when providing health checks in school settings relative to clinical environments. ⁷⁴² Parental/carer consent and involvement in school-based health checks may be more difficult than clinic attendance. ⁷⁴²	High
Acceptability	Despite some concerns about privacy most young people reported, in a small pilot study, that school health checks were acceptable. ⁷⁴²	Medium

Summary: Inclusion of sore throat and skin sore screening in routine school health checks		
Domain	Summary	Rating
Feasibility	A variety of models for school-based screening programs exist and continue to expand, indicating that at least some are feasible for schools and providers. Delivery of this approach at scale has not yet been achieved. It should be noted that the NT is moving away from school-based health checks and encouraging clinic-based assessments.	Medium
Costs	In 2019, the 'Associated Notes' for Medicare MBS item number 715 specify that 'A health assessment should not take the form of a health screening service'. ⁷³¹ Other funding mechanisms for providing this service are unclear. ⁷³¹	Unknown
Timeline	Establishing the systems, protocols and funding mechanisms for school-based health checks may take months or years.	Medium
Positive externalities	High-quality, comprehensive health checks with appropriate follow-up have potential to improve quality of care delivery and potentially health outcomes. ⁷²⁹	Medium
Equity	Providing health checks in schools may address inequities in access to health services. However, inequities may increase between young people who attend school and those who do not.	Medium
Recommendations	<ul style="list-style-type: none"> There is no empirical evidence that school-based health checks improve detection or treatment of skin sores or sore throats. However, school-based health checks have some theoretical benefits and may be beneficial in well-designed programs which are carefully implemented with local clinics, well-resourced and evaluated. 	

Active case finding of sore throats in specific school and community programs

Sore throats may be too mild for families to seek treatment or barriers to accessing health services may be prohibitive.⁷⁴⁸ Active case finding to proactively seek out children with sore throat may address this. An historic program among a Navajo Indian community in the United States provides some proof of concept that school-based identification and treatment of Strep A throat infections may reduce the burden of ARF.⁷⁴⁹ There are two relevant examples of this kind of approach in Australasia:

Yarrabah, North Queensland

Yarrabah is an Aboriginal community in Northern Queensland. In 1985, a survey of community members was led by the Yarrabah Community Council and Aboriginal Community Health Team to establish the prevalence of ARF and RHD.⁷⁵⁰ The study used a combination of clinical examination and clinical records to assess the diagnosis. In total, 1,113 people were examined (89% of the estimated population) with 21.6/1000 people having a history of ARF and 13.5/1000 having a history of RHD.⁷⁵⁰

A program of throat swabbing to identify and treat Strep A carriage or infection began. Throat swabs were collected by the Community Health Team from children aged between 4 and 16 three times a year over six years. People with a positive throat swab were treated and contacts had additional swabbing. Over the six years, 4,802 swabs were collected from 1,312 people and 393 swabs were positive for Strep A.⁷⁵⁰

A repeat survey was conducted in 1991 which included 659 people (52% of the estimated population). One case of ARF was diagnosed in the interval period between 1985 and 1991. The authors attributed this apparent reduction in ARF incidence to the throat swabbing and treatment program.⁷⁵⁰ The methodology of the study and evidence for effectiveness of the sore throat program was subsequently challenged.⁷⁵¹

Reported factors supporting program implementation included the importance of community education (including a video made in the community and screened to households), employment of local health workers who provided project updates to the council, and community ownership of the program.⁷⁵⁰

New Zealand School-Based Program

A randomised controlled trial involving 22,000 school children was carried out in South Auckland in New Zealand between 1998 and 2001.⁷⁵² This region had a large Māori and Pacific Island population with high rates of ARF. Schools were randomised to receive a school-based sore throat service or standard treatment through primary care. In the intervention group, community health workers made daily classroom rounds to ask consented children if they had a sore throat. Children with sore throat had a throat swab taken and were treated with a 10-day course of twice-daily oral penicillin, administered under nurse supervision if the result was positive. The endpoint of this study was the incidence of ARF. Results showed a 20–30% relative risk reduction in ARF diagnosis in the intervention group compared to the control group. However, these findings did not reach statistical significance, meaning they could not be attributed to the intervention. A subsequent meta-analysis of school-based studies did find a significant 60% reduction in incidence of ARF conferred by school-based sore throat clinic programs compared to general practice care.⁷⁵³ However, most studies included in this meta-analysis were low-quality observational data.^{754,755} School-based sore throat screening was incorporated in the 2011 New Zealand Rheumatic Fever Prevention Program.

By early 2014, school sore throat screening was under way in 251 schools, covering 53,998 children in high-risk communities for ARF. Each participating region delivered the school program differently, depending on resources and what worked within their populations. Common across all schools was that children who were found to be positive for Strep A on throat swab received free antibiotics without having to fill a prescription. Some schools also included phone calls to remind families to complete the antibiotic course or management of skin infections. About 36% of children at high risk of ARF had access to school sore throat programs in 2014 over 40 weeks of term time.⁷⁵⁶

The design of the New Zealand school-based program meant that many children with very mild symptoms were attending school and having throat swabs. Therefore, the proportion of Strep A positive swabs from schools in 2014 was 9% relative to the 18% of positive Strep A throat swabs when collected from primary-care settings.⁷⁵⁶ This school-based rate approximates the background rate of Strep A throat carriage, implying that sore throats reported by children attending school may have been caused by viral infection rather than Strep A infection.

A formative and an interim evaluation of the school sore throat program were commissioned.^{756,757} Early themes included need for greater consultation, integration and sustainability planning of the program alongside practical issues in service delivery. Evaluation in 2015 concluded that ARF rates were decreasing but that the decline was not statistically significantly greater in places where the school-based sore throat program was active. Therefore, declines could not be causally attributed to the school-based program.

A number of District Health Boards in New Zealand have moved away from the school-based program in order to focus on improving primary care-based services.⁶⁵⁹

Summary: Active case finding of sore throats or Strep A carriage in schools or communities		
Domain	Summary	Rating
Evidence	Evidence about active case finding of sore throat infections comes from a small number of historical international studies, a 1980s program in Far North Queensland, and a very large contemporary program in New Zealand. ^{750,756,756}	High
Benefits	Active case finding of Strep A infections in schools does not appear to substantively or sustainably reduce development of ARF.	Low
Risks	Active case finding of sore throats in schools may invoke shame if children need to self-identify having a sore throat and being at risk of ARF. ⁶⁵⁹ School-based sore throat programs incur opportunity costs in time and cost which could be directed towards more impactful and effective programs.	High

Summary: Active case finding of sore throats or Strep A carriage in schools or communities		
Domain	Summary	Rating
Acceptability	Ongoing school-based active case finding of sore throat is unlikely to be acceptable in remote Aboriginal and Torres Strait Islander communities where sore throat rates are low.	Low
Feasibility	There are major barriers to implementing the New Zealand school sore throat model in Australia: <ul style="list-style-type: none"> The model used in New Zealand relies on diagnosis of symptomatic Strep sore throat using throat swabs for Strep A, an approach which is not recommended in Australia. The class size in remote communities is small relative to New Zealand sites, which would have major impacts on the service delivery model. Aboriginal and Torres Strait Islander children report a relatively low rate of symptomatic sore throat infections.⁵⁰⁹ School attendance in some settings is low⁶⁴⁵ and children who are at highest risk of ARF may be the least likely to attend school. 	Low
Costs	In one District Health Board in New Zealand, the cost of delivering sore throat and skin sore services within schools was \$280 per child per year in 2013–14. ¹¹⁰ Costs and logistics of managing large volumes of swabs are significant. ⁶⁵⁹ Costs in remote and very remote Aboriginal and Torres Strait Islander communities in Australia would be considerably higher. ⁶⁵⁹	High
Timeline	Developing school-based sore throat screening programs in remote Australian settings would be likely to have a long lead time.	Medium
Positive externalities	None identified.	Unknown
Equity	Active case-finding of sore throats in schools may address inequities in access to health services. However, inequities may increase between young people who attend school and those who do not.	Unknown
Recommendations	<ul style="list-style-type: none"> Active case finding of sore throats in schools in remote Aboriginal or Torres Strait Islander communities based on the New Zealand school sore throat model is not recommended. However, schools do provide an important opportunity to engage with young people at highest risk of skin sores and sore throats, and appropriate models to facilitate this should be explored. 	

Active case-finding of skin sores through skin screening and outreach programs

Since the 1990s, a number of research and service delivery projects in Australia have explored the feasibility and impact of skin health initiatives in remote communities. These have generally included efforts to address scabies and skin sores simultaneously. Some have been based on active case-finding, others on a 'treat all' approach to manage scabies infections.

East Arnhem Health Skin Project

Between 2004 and 2007, a research team undertook mass drug administration of topical 5% permethrin in five remote Aboriginal communities in the Northern Territory to reduce the prevalence of scabies and impetigo in the population.^{53,758} Upon receiving a diagnosis of scabies, children aged under 14 and household contacts were provided with permethrin.⁷⁵⁸ Children with pyoderma or impetigo were referred to the clinic for further treatment. Flipchart health promotion materials were developed to increase awareness and understanding of the condition among community members. Impetigo prevalence reduced from 46% at baseline to 32% at three months and 35% at three years. Scabies prevalence was 16% at baseline, 13% at three months and 16% at three-year follow-up.⁷⁵⁸

Operational guidance for these kinds of programs is provided by Northern Territory guidelines which recommend a five-phase approach of planning, community involvement, screening and treatment, maintenance and evaluation.⁷³²

Community Treatment/Clean Up Day

A program for reducing the prevalence of scabies in Wadeye, a large Northern Territory Aboriginal community, was implemented in 2000.⁷⁵⁹ For three months prior to the intervention, healthy skin messaging was reinforced at the clinic by healthcare workers and Aboriginal Elders.⁷⁵⁹ Posters and leaflets designed by local artists were also used.⁷⁵⁹ One week before, intensive education programs were undertaken, including the correct application of treatment cream and home and personal hygiene strategies required to eradicate scabies from the home.⁷⁵⁹ Children were also screened to determine the presence of pyoderma and scabies.⁷⁵⁹ On treatment day, community clean-up teams assisted residents with cleaning their homes, and distributed soap and 5% permethrin cream.⁷⁵⁹ Upon returning an empty permethrin tube, residents were invited to take part in a community barbecue.⁷⁵⁹ Those with moderate scabies were re-treated after a week and children were re-screened after four months.⁷⁵⁹

The prevalence of scabies, infected scabies and non-scabies pyoderma before the intervention was 35%, 12% and 11% respectively.⁷⁵⁹ At six weeks, this had decreased to 3%, 1% and 4% respectively, maintained at four- and seven-month screening points. Low prevalence was maintained at four and seven months.⁷⁵⁹ Community motivation and involvement were noted as critical elements of success.³²⁸

Integrated skin, scabies, trachoma and acute post-streptococcal glomerulonephritis screening

Acute post-streptococcal glomerulonephritis (APSGN), a kidney disease, can occur after Strep A skin infections. Outbreaks occur intermittently in settings with a high burden of Strep A skin infections. Following a localised community outbreak in 2011, the Northern Territory Centre for Disease Control undertook a large-scale interventional program to screen children for skin sores or kidney disease and to provide treatment to prevent further cases of APSGN in a remote community.⁷⁶⁰ Preparation for screening involved a large public health response including television and radio broadcasts delivered in Aboriginal languages, involvement of Elders and family members reiterating the need for screening via letters, and engagement with Aboriginal Health Workers.⁷⁶⁰

Across a five-day period, 540 children aged 12 months to 17 years were screened for signs of kidney disease (facial and peripheral swelling), skin sores and scabies.⁷⁶⁰ Children aged 4–16 were also screened for clean or dirty faces and trachoma.⁷⁶⁰ Where infection was identified, treatment with the appropriate medication was undertaken.⁷⁶⁰ Personal hygiene messages encouraging clean hands and faces were delivered alongside screening.⁷⁶⁰

Only 57% of eligible children in the community were able to be screened during this period.⁷⁶⁰ In total, 219 cases of skin sores, 17 cases of scabies and 19 cases of trachoma were identified and treated.⁷⁶⁰ A further case of APSGN occurred in the days following the community screening in a child who missed being screened.⁷⁶⁰ A reported strength of the program was an incentive for participation – a sought-after toy was provided to children, particularly those who required treatment with an injection of benzathine benzylpenicillin.⁷⁶⁰

This program demonstrates capacity for screening activities to address multiple disease endpoints (skin sores, scabies, kidney disease and trachoma). It is unclear how the context of an outbreak investigation influenced program implementation, acceptability or sustainability.

Minjilang Scabies Project

A scabies control program using 5% permethrin cream was undertaken in the Northern Territory community of Minjilang in the mid-1990s.⁷⁶¹ Community members were initially examined for scabies and skin sores, with treatment cream offered to all those older than two months of age. Seven follow-up visits were made at varying intervals over the ensuing 25 months, during which people were re-examined, and new cases of scabies treated (including household contacts).⁷⁶¹ The prevalence of scabies was reduced from 29% before the program to less than 10% during the entire follow-up period.⁷⁶¹

SToP

The SToP Trial (See, Treat, Prevent skin sores and scabies) began in the Kimberley in 2019.^{762,763} SToP aims to reduce skin sores in school-aged children by 50%. The SToP trial combines surveillance of skin conditions, health promotion, environmental health and an evidence-based treatment package. The trial will run for five years, with preliminary results expected in 2022.^{624,764}

Summary: Skin health outreach programs		
Domain	Summary	Rating
Evidence	There is good evidence that comprehensive outreach-based skin health programs can be effective in reducing the prevalence of scabies and skin sores. ^{53,360}	High
Benefits	<p>Skin health outreach programs have a number of benefits relative to other service delivery models:</p> <ul style="list-style-type: none"> Control of scabies requires treatment of all household contacts. Contacts may be more likely to be identified on home visits than at schools, clinics or community events. Reducing recurrent scabies infection in a community requires identification and treatment of people with crusted scabies. People with crusted scabies may be unwell, stigmatised or unable to seek healthcare.⁷⁶⁵ Therefore outreach to households may offer the best opportunity to identify people with crusted scabies. Home visits provide an opportunity to provide education and practical support about risk reduction strategies (isolating clothes and bedding) and may improve integration with environmental health services where problems with household infrastructure are identified. 	High
Risks	<p>Outreach services to households may be associated with some increased risks:</p> <ul style="list-style-type: none"> Provision of healthcare outside of clinical environments may mean that equipment for managing complications is less likely to be available (for example, management of anaphylaxis following benzathine benzylpenicillin injection). Safety of healthcare workers requires special attention outside the clinical environment, including risks in transport, or from dogs or violence.⁷⁶⁰ Sustainability of outreach programs can be challenging as funding and staffing change can lead to instability in service delivery models. 	Medium
Acceptability	Acceptability of household outreach programs varies. Some initiatives describe significant difficulty in finding private spaces to conduct skin checks and deliver injections. ⁷⁶⁰	Medium
Feasibility	Feasibility of household outreach for skin health programs has been demonstrated in a number of project implementation models. There are certainly costs and disruptions associated with providing this kind of service outside the clinic, but these are likely to be surmountable with good community engagement, planning, and technical support for program delivery.	Medium
Costs	Outreach program costs can be significant but may be balanced by increased case detection and improved treatment. Resourcing for planning and community engagement are critical for success.	Medium
Timeline	Consultation and planning household outreach skin health programs take time. The Northern Territory Healthy Skin Guidelines provide some recommendations about how planning and community engagement can be conducted, recommending a three-month planning period.	Medium
Positive externalities	Well-designed household outreach programs have the potential to strengthen relationships between clinic and community. Other medical conditions or environmental health issues may be identified in addition to skin-related care.	Medium
Equity	Outreach programs may enhance equity by maximising engagement with people least able or least likely to attend the clinic.	Medium

Summary: Skin health outreach programs		
Domain	Summary	Rating
Recommendations	<ul style="list-style-type: none"> Comprehensive healthy skin outreach programs should be included in primary prevention strategies for ARF in settings with a high burden of skin infection. Primary health clinics should be supported by national stakeholders for RHD, to: <ul style="list-style-type: none"> Work with other stakeholders to develop technical guidelines for how these programs are delivered; Support jurisdictions to develop local implementation plans; and Develop data standards and recommendations for evaluation and monitoring. There must be community leadership and primary healthcare resourcing in the implementation of these programs. 	

Affordability

(Direct costs, indirect costs, opportunity costs)

Baseline situation

There is limited information about whether cost is a significant direct barrier to Aboriginal and Torres Strait Islander families seeking medical care for sore throats and skin sores. Costs may include payments for primary healthcare consultations, medications and consumables (dressing skin infections).

Many of the people at highest risk of ARF live in remote communities where medical assessment is free at point of care and medication is also dispensed without cost to the patient through section 100 provisions. However, some regional towns have a range of providers, including private GP services and private pharmacies, where fees may apply.⁶⁰⁰

Qualitative data from the Pilbara suggests that, although cost is generally not a barrier to accessing primary care, some Aboriginal caregivers of children with skin sores drove to a remote community three hours away to access free services through an Aboriginal Medical Service, rather than pay for private care available closer to home.⁶⁰⁰ Out-of-pocket costs at point of care may be a disincentive to seeking care in some circumstances.

Evidence for strategies to increase affordability

Strategies to reduce financial barriers to care

Optimise the Closing the Gap Pharmaceutical Benefits Scheme Co-Payment Measure (CTG)

Aboriginal and Torres Strait Islander people with a chronic disease, or at risk of developing a chronic disease, in non-remote areas have been able to access subsidies for prescription medication since July 2010.⁷⁶⁶ Accessing the CTG subsidies requires people to register at a participating practice or Aboriginal and Torres Strait Islander health service using a registration form. Prescribers must assess patient eligibility and annotate each script with the letters 'CTG' for the subsidy to apply.⁷⁶⁷ Limitations apply for hospital-generated prescriptions.

The CTG measure reduces the out-of-pocket cost from the PBS co-payment to a concessional rate (\$6.50 per item as of January 2019), or to zero cost for people who would usually receive a concessional rate.⁷⁶⁶

Aboriginal and Torres Strait Islander children who need antibiotics to treat sore throats and skin sores should be eligible for CTG PBS subsidies because they fulfil the following eligibility criteria:

- 'Aboriginal and Torres Strait Islander people *of any age* who present with an existing chronic disease *or are at risk of chronic disease* and in the opinion of the prescriber would experience setbacks in the prevention or ongoing management of chronic disease if they did not take the prescribed medicine and are unlikely to adhere to their medicines regimen without assistance through the measure.'⁷⁶⁸
- 'Prescriptions for all of an eligible patient's PBS medicines are covered under the measure whether or not the medicines are being used to treat chronic or acute medical conditions.'⁷⁶⁸

Antibiotic treatment for children using CTG PBS prescriptions appears to be common. In 2012, 'anti-infectives for systemic use among 0–14-year-olds' accounted for 45.3% of CTG PBS scripts for this age group.⁷⁶⁸ Despite clear indication for use, barriers to the use of CTG scripts are widespread: some prescribers are not aware of the provisions, some primary-care services are not eligible to provide CTG-endorsed scripts, and hospital-generated prescriptions are usually not eligible. There are also limitations regarding annotation of scripts for eligible clients. These distinctions often appear arbitrary to Aboriginal and Torres Strait Islander people and to health professionals providing care to these clients.

'Most of the young ones are missing out [on CTG scripts] cos [sic] they go to the hospital.'

Aboriginal community member in a regional location quoted during a KPMG Evaluation of the Indigenous Chronic Disease Package focus group, 2014.⁷⁶⁸

NACCHO and the Pharmacy Guild of Australia reviewed CTG arrangements in 2015 and identified a range of potential improvements.⁷⁶⁹ Many of these are clearly supported in subsequent national reviews, including the Pharmacy Remuneration and Regulation Review and the Indigenous Pharmacy Programs Review.⁷⁷⁰ These include:

- Linking CTG eligibility with a person's Medicare card, or another national identifier, allowing eligible people living in remote locations who usually access s100 medications to automatically receive CTG subsidies when travelling to urban areas;
- Increasing provider awareness of CTG provisions; and
- Including all appropriate hospital prescriptions in the CTG measure.⁷⁶⁹

In the setting of primary prevention, this would potentially allow people presenting to emergency departments with sore throat/skin sores to receive subsidised CTG PBS antibiotic prescriptions.

Summary: Expanding access to CTG PBS provisions		
Domain	Summary	Rating
Evidence	External evaluation of the CTG scheme has substantially increased access to medication for Aboriginal and Torres Strait Islander people. ⁷⁶⁸ Peer-reviewed research supports positive health impact of CTG PBS provisions. ⁷⁷¹	High
Benefits	Expanding access to CTG PBS subsidies would reduce financial barriers to people who need antibiotics to treat sore throats and skin sores and prevent ARF. Improving and streamlining medicines subsidy systems will benefit patient journey and efficiency, and improve health outcomes.	High
Risks	Few risks to expanding CTG PBS subsidies were identified. There is an unknown, but possibly large, systems and regulation cost to the Federal Departments of Health and Human Services. Implementation of new regulations must be smooth for patients, health administrators and practitioners.	Low
Acceptability	CTG subsidies are acceptable to Aboriginal and Torres Strait Islander people, although confusion about eligibility and provider requirements is an ongoing frustration.	Medium
Feasibility	Implementation of CTG subsidies in 2010 was largely positive and provides a foundation for feasible future expansion. ⁷⁶⁸ Recommended changes to allow expansion are largely administrative rather than substantive re-design. ⁷⁷⁰	High
Costs	Expansion of CTG provisions would incur a cost for the Australian Government. It is likely that this would be offset by reduced healthcare and workflow costs. PBS medicines must be shown to be cost-effective, therefore enhanced access will result in cost benefits.	Unknown
Timeline	Enhancements to CTG subsidies is likely to occur in months to years, possibly within the annual Federal Budget cycle.	Medium

Summary: Expanding access to CTG PBS provisions		
Domain	Summary	Rating
Positive externalities	Expanding CTG subsidies would improve access to medication to treat a wide range of other health conditions. It will reduce workflow and systems costs for primary- and tertiary-care providers.	High
Equity	CTG subsidies address the low uptake of prescription medications relative to clinical need of Aboriginal and Torres Strait Islander people.	High
Recommendations	National stakeholders for RHD in Australia should: <ul style="list-style-type: none"> • Work with the Australian Government to support the <i>Indigenous Pharmacy Programs Reform activities</i> related to improving the CTG measure. • In consultation with the Australian Government, in the context of impending reforms, include information about CTG in educational resources for prescribers to increase awareness and uptake of the scheme. 	

Provide medication to treat sore throat and skin sores free at point of care

Optimise Section 100 Remote Area Aboriginal Health Services (RAAHS) PBS provisions for point-of-care access to medication

Section 100 (s100) PBS arrangements facilitate access to PBS medications for Aboriginal and Torres Strait Islander people through supply directly from remote Aboriginal Health Services. Section 100 provisions allow health practitioners to provide medications from their health service at no cost to the client. The s100 measure has extensive use across all States and Territories with remote areas.

Numerous reviews of this program have occurred, including a Senate Enquiry in 2011 and the *Indigenous Pharmacy Programs Review (IPP)* in 2017.⁷⁷² The value of increasing access to PBS medicines for people living in remote areas has been consistently identified. NACCHO and the Pharmacy Guild have recommended strategies to enhance the program that are consistent with the IPP Review, including:^{769,773}

- Allow all clients of remote ACCHSs and Aboriginal and Torres Strait Islander Medical Services to be able to access medications through the s100 measure, regardless of their location.
- Align or connect the s100 scheme with CTG to streamline clients' access to the scheme and to streamline program administration.^{769,773}

Systems recommendations include greater usage of access data to inform evaluation, development of a national committee to oversee PBS access programs in remote regions, greater quality use of medicines activities in remote areas (through the s100 Support Allowance), and review of the inter-government memorandum of understanding.

Summary: Expand Section 100 PBS provisions		
Domain	Summary	Rating
Evidence	Section 100 (s100) PBS arrangements have demonstrably increased access to medication for Aboriginal and Torres Strait Islander people in remote communities.	High
Benefits	S100 PBS allows people in remote communities to access antibiotics from the clinic in order to treat skin sores and sore throats and prevent ARF.	High
Risks	Because of the specificity of benzathine benzylpenicillin use, expanding the range of people and places where these antibiotics can be dispensed is very unlikely to increase the risk of inappropriate antibiotic use.	Low
Acceptability	Numerous Aboriginal and Torres Strait Islander peak bodies, national reviews, research literature and stakeholder organisations have called for enhancements of the s100 scheme and its Support Allowance, demonstrating acceptability of this approach.	High

Summary: Expand Section 100 PBS provisions		
Domain	Summary	Rating
Feasibility	Numerous reviews have explored and recommended feasible opportunities for s100 expansion. ^{769,773} Technical application of non-remote s100 supply have been a challenge of the s100 reforms within the IPP Review.	Medium
Costs	Expansion of s100 provisions would require a small financial investment from the Australian Government for medication provision. However, this would be offset by reduced healthcare costs, including substituted CTG costs and onerous primary-care workflow costs, if people are able to access essential medicines more readily in non-remote areas.	Low
Timeline	Funding and legislative arrangements for expanding the s100 provision are likely to take some years to be agreed and implemented.	Medium
Positive externalities	Enhancement of the s100 measure and Support Allowance would increase access to a range of medications for Aboriginal and Torres Strait Islander people. Data capture related to remote medication supply would be transformational for ACCHSs and researchers' knowledge of remote medicines use.	High
Equity	Improving access to antibiotics which are provided without point-of-care costs for Aboriginal and Torres Strait Islander people in Australia is a proportionate measure to address the disparate rates of Strep A infection and subsequent complications. Unnecessary convolution in the patient journey is actively inhibiting access and quality care for those who need it most.	High
Recommendations	National stakeholders for RHD should work with the Australian Government to ensure that s100 PBS provisions are enhanced according to the IPP review's recommendations; including that s100 applies to all remote ACCHS and AMS clients irrespective of their geographic location, and that quality use of medicines for remote ACCHSs and AHSs must be improved significantly.	

'[in reference to mainstream health service in town E] Back at that clinic they gave me a script to go buy my son his own shot [Bicillin L-A needle] but I shouldn't be buying my own because they should be provided from the hospital because every kid needs them.'

Aboriginal carer, quoted in Hendrickx, 2017.⁶⁰⁰

Provide or subsidise dressings for skin sores

The National Healthy Skin Guideline recommends that open skin sores should be covered with a watertight dressing.⁵³ Keeping skin sores covered may reduce transmission to other people (by reducing discharge of fluid contaminated with Strep A) and may reduce repeated trauma which could delay healing. However, high-quality dressings which remain in place on active young people living in warm, moist, tropical environments are expensive.

Anecdotal evidence suggests that Aboriginal and Torres Strait Islander people rarely purchase dressings from local shops. Dressings are expensive and may not be suitable for larger sores. More commonly, clinics provide a small number of consumable dressings for people to use at home or request that people come in regularly for dressing changes. A study of skin sores in two remote primary healthcare services found that *'over 12 months, the procedures including dressings and cleaning wounds with topical antiseptics recorded represent a considerable drain upon clinic resources, through staffing time requirements and expenditure.'*⁷⁷⁴ These dressings are not funded and represent a cost to the clinic, although the quantum of these costs is unknown. Small studies of complex wound management costs in urban settings suggest that consumables for wound dressings can be high.²⁹²

The Kiri Ora Healthy Skin Project – New Zealand

A New Zealand program to provide free wound dressings for children with skin sores was prompted by a local public health service.⁷⁷⁵ Nurses promoting healthy skin messages, such as keeping sores clean and dry with a waterproof dressing, identified that wound dressings were too expensive to be accessible. The Toi Te Ora health board subsequently funded healthy skin packs for distribution.⁷⁷⁵ These included soap, plasters, wipes, toothbrushes, nail clippers, lice combs and family-friendly health promotion material.⁷⁷⁵ This enabled the dissemination of health messages to be practised with the tools necessary to achieve them.⁷⁷⁵ No evaluation of the program was identified.

Summary: Provide or subsidise dressings for skin sores		
Domain	Summary	Rating
Evidence	There is some low-quality evidence that cost is a barrier to keeping skin sores covered as recommended. Families do not routinely purchase their own skin sore dressings (which are expensive or unavailable) and provision of dressings is a cost to primary-care clinics. Providing funded dressings for skin sores to families may reduce these barriers.	Medium
Benefits	The benefits of keeping skin sores covered are not well researched but may include improved skin sore healing (reducing repeated damage to fragile skin and infection with new bacteria) and to reduce transmission to other people.	Medium
Risks	Provision of subsidised or low-cost consumable health items can be associated with increased wastage or inappropriate use. ⁷⁷⁶ These risks can likely be mitigated by community-led programming.	Low
Acceptability	Acceptability of consumable distribution programs, including for sensitive items such as condoms, appears to be relatively high, though applicability to wound dressings is unknown. ⁷⁷⁶	Unknown
Feasibility	Programs to support distribution of skin sore dressings could be feasibly modelled on existing strategies for distributing condoms. Menstrual hygiene product distribution remains an ongoing challenge. ³⁹⁵	Medium
Costs	Skin sore dressing costs are largely unknown.	Unknown
Timeline	Development of a skin sore dressing program would require consultation, costing and community engagement planning, likely to take months.	Medium
Positive externalities	Strengthening systems for distributing health consumables may also be relevant for other health-promoting products with different disease endpoints.	Medium
Equity	Addressing agreed difficulties in accessing health-promoting products would promote equity.	Medium
Recommendations	National stakeholders for RHD in Australia should explore the evidence, costs and pilot opportunities to improve distribution of dressings for skin sores in conjunction with research partners.	

Acceptability

(Professional values, norms, culture, gender)

There are many structural determinants of health service acceptability for Aboriginal and Torres Strait Islander peoples; spanning governance arrangement, languages used, physical spaces and community ownership.^{15,629,777} These impact all levels of prevention and management of Strep A, ARF and RHD and are therefore addressed in Chapter 4a, a structural review of health systems factors. This section has a narrower focus on treatment acceptability for sore throat and skin sores.

Evidence for strategies to improve acceptability

Improve treatment acceptability – sore throat

In 2019, there were seven sore throat guidelines in Australia.⁶⁷⁴ Each recommended the use of intramuscular injections of benzathine benzylpenicillin (BPG) as first-line therapy for treatment of suspected Strep A sore throat in young people at risk of ARF. Oral antibiotic medications were recommended as second-line therapy.

Both of these products have a number of acceptability and suitability issues:

- BPG injections are painful.³⁴ This pain may be a barrier to accepting recommended treatment for each episode of sore throat. Additionally, it may reduce the willingness of children and families to present for assessment and treatment of sore throat in the future for fear of painful injections.
- Oral medicine is required twice a day for 10 days, which is challenging for adherence.
- Liquid medication for young children has an unpleasant taste.
- Liquid formulations generally require refrigeration, which is not always available in remote community settings.

There is no information on adherence to oral medications for sore throat for Aboriginal and Torres Strait Island young people at risk of ARF. In a New Zealand study of 65 people at risk of ARF prescribed 10 days of oral antibiotic therapy, only 73.8% of people finished the full course of medication. People who stopped taking antibiotics generally said they stopped when their symptoms improved.⁶³² Completing a full course of antibiotics is likely to be lower in Australia in areas at highest risk of ARF, where multiple barriers to medication adherence include language, health literacy, medication storage and dispensing instructions.⁷⁷⁸

‘If you’ve got something wrong with you and you’ve got a packet of 12 tablets that you have to take and if you’re feeling better after one and you don’t like taking tablets anyway and you don’t go to the chemist and find out what this medication is doing for you, you’re going to take one, feel better and say “I don’t need to take the rest.”’

Aboriginal Health Worker respondent quoted in Hamosi et al., 2006.⁷⁷⁸

Summary: Improve acceptability of antibiotics for treatment for sore throat	
Evidence	There is reasonable evidence that the current antibiotic treatment recommendations for sore throat in Aboriginal and Torres Strait Islander young people at risk of ARF are not acceptable. This is likely to reduce treatment adherence and mean that people do not receive the full benefit of primary prophylaxis.
Recommendations	Research to identify more acceptable and equally effective strategies for primary prevention of ARF infection following Strep A throat infection should be pursued.

Improve treatment acceptability – skin sores

There are a range of clinical guidelines on the management of skin sores in Australia.^{53,672,779}

The *National Healthy Skin Guideline*⁵³ recommends one of three equivalent treatment options for skin sores:

1. Cotrimoxazole oral antibiotic twice daily for three days.
2. Cotrimoxazole oral antibiotic once daily for five days.
3. Intramuscular injectable benzathine benzylpenicillin (BPG).

In general, cotrimoxazole has significantly fewer side effects, was well tolerated, and is less painful than injectable BPG.⁶²⁰ Qualitative input from Aboriginal caregivers in the Pilbara suggests that painful BPG injections to treat skin sores may be traumatising for children. Conversely, others reported that they preferred BPG instead of needing to administer courses of oral antibiotics at home. Recent work in the Pilbara has found that mothers and grandmothers prefer to have treatment options discussed with them and to choose the best solution for their child on each occasion, as opposed to observing standard treatment at each occasion.³⁴

There is no information on the acceptability of adjunct primary prevention opportunities such as wound dressings. Anecdotally, there are some reports that people with skin sores dislike bright white bandages, finding them stigmatising relative to darker ‘tubi-grip’ dressings, which look more like supportive sporting equipment. There is some international evidence that the colour and appearance of wound dressings may influence acceptability.⁷⁸⁰

Box 15: Supporting adherence with oral antibiotics

A range of strategies have been suggested to improve completion of recommended courses of antibiotics. Some of these are derived from the New Zealand sore throat program including:

- A sticker chart to mark off the days for antibiotic medication; and
- Incentives on completion of the full antibiotic course.⁷⁵⁷

During evaluation, New Zealand caregivers reported these resources were helpful.⁷⁵⁷ General advice might include clear explanation to continue antibiotics even if symptoms resolve.¹¹⁶

Other options in Aboriginal and Torres Strait Islander settings could include:

- Directly observed therapy or daily dispensing of oral antibiotics from clinic;
- Engaging community health workers to support oral antibiotic delivery; and
- Medication given at schools with appropriate systems and support.

Clinics and communities need to be supported to explore different models of delivering antibiotic medication. Adequate staff time should be allocated, and activities need to be evaluated.

Summary: Improve acceptability of antibiotics for treatment for skin sores

Evidence	There is reasonable evidence that the current antibiotic treatment recommendations for skin sores in Aboriginal and Torres Strait Islander young people at risk of ARF are not acceptable. This is likely to reduce treatment adherence and mean that people do not receive the full benefit of primary prophylaxis.
Recommendations	Research to identify more acceptable and equally effective strategies for primary prevention of ARF infection following Strep A skin infection should be pursued.

Demand-side strategies to improve primary prevention

Ability to perceive health needs

(Health literacy, health beliefs, trust and expectations)

Baseline situation

Community awareness of the risk of Strep A skin and throat infections preceding ARF and RHD is generally poor.^{109,600} Limited community awareness may be a barrier to seeking medical assessment and treatment of throat and skin infections.⁷⁵⁷ For example, across Australia only half of children who recalled having a sore throat prior to ARF diagnosis had sought medical care for the sore throat.²¹⁹ In some places, childhood skin infections can be so common that they may be considered ‘normal’ both by families and healthcare practitioners, and often people do not seek treatment or are not offered it when attending clinic.⁶⁸

‘Having sores and being unwell is commonplace. It’s normal. We have to start with the young ones and say you don’t have to have these sores. We have to change their mindset....it’s the greatest barrier.’

Aboriginal Nurse Practitioner quoted in Thomas et al., 2017.⁴⁷¹

Evidence for strategies to increase ability to perceive health needs

Health promotion campaigns to increase health-seeking behaviour for sore throats and skin sores

Public health promotion campaigns to change health-seeking behaviour were a core element of a strategy to reduce the incidence of ARF in New Zealand.⁷⁸¹

Bay of Plenty Campaign, New Zealand, 2014

The Bay of Plenty District Health Board developed its own ARF prevention plan to achieve the national Better Public Services target of reducing cases by two-thirds by 2017, specifically acknowledging high incidence of ARF in this region.⁷⁸²

An awareness campaign was delivered over four months in 2014, including resources for health professionals and dissemination of messages across print, visual and social media. The focus of the campaign was to increase knowledge of the link between sore throats, ARF and heart damage.⁷⁸² Local champions were also used for a school-based throat swabbing program and on printed resources.⁷⁸² Previous campaigns conducted during 2010 and 2011 had demonstrated an increase in awareness of ARF, from 22% of participants in April 2010 to 58% in September 2011.⁷⁸² The 2014 campaign was targeted specifically to Māori and Pacific parents, families, and caregivers of school-aged children in communities with a high prevalence of ARF.⁷⁸²

The campaign was evaluated using short intercept surveys completed in public places across the region.⁷⁸² Of those who recalled hearing about ARF, the television and knowledge of people/family members with the disease were the most commonly cited sources.⁷⁸² Three-quarters were aware that ARF is caused by a throat infection, while more than 90% knew ARF can damage the heart.⁷⁸² Almost all acknowledged that completing a course of antibiotics is essential for treating a sore throat.⁷⁸²

New Zealand National, 2014

The New Zealand Health Promotion Agency and Ministry of Health developed and oversaw a Rheumatic Fever Awareness Campaign, implemented between May and August 2014, with the intention of *‘increasing awareness among parents and caregivers of at-risk children and young people about the causes and effects of rheumatic fever’*.^{783,784} Using a multitude of resources such as television, radio and print advertisements, online videos, and public posters, the campaign aimed to increase knowledge of the link between sore throats, ARF, potential heart damage and disease impact.⁷⁸⁴

Messaging was relatively simple, and encouraged early intervention and treatment:

- *‘A sore throat can lead to rheumatic fever if it’s left untreated. Rheumatic fever is very serious and causes heart damage.’*
- *‘Every time your child has a sore throat it could be serious. Don’t ignore, take them to a doctor or nurse straight away to get it checked.’*
- *‘We know it is a big ask to get your child checked every time they have a sore throat but it is important. Do it for them.’*⁷⁸⁴

The campaign was evaluated immediately upon its conclusion, with the evaluation results suggesting that 60% of parents took health action as a direct result of the campaign.⁷⁸⁵ Recall of television advertising was high among the target audience, at approximately two-thirds of the sample.⁷⁸⁴ A third of parents also recalled seeing or hearing ARF advertising at healthcare and community centres, suggesting a sound workforce commitment to message dissemination.⁷⁸⁴ Almost all (92%) found the campaign easy to understand, and awareness of the cause of ARF rose from 45% before May to 66% at campaign conclusion.⁷⁸⁴

New Zealand National, 2015

The 2015 campaign built on the original call to action and used a ‘chain of theorised outcomes’ to underpin expected behaviour change, focusing on families with children at the greatest risk of ARF.⁷⁸³ The main objectives were to increase awareness of the association between sore throats and ARF, the necessity of getting sore throats assessed by a health professional and, as a secondary message, the importance of completing the full antibiotic course for children who have Strep A infection.⁷⁸³

The 2015 Rheumatic Fever Awareness Campaign was independently evaluated, concluding that the campaign was efficient given the level of investment and available resources, had excellent relevance and alignment with key messages, was effective in reaching 95% of the target audience, and was easily understood.⁷⁸³ Recommendations included the campaign period being extended and further emphasis placed on antibiotic adherence.

New Zealand campaigns in the years since 2015

The focus on ARF in New Zealand spurred by the campaigns described above has driven innovations across the nation when communicating messages. These have included a wallet card to help empower families to show it to health providers and ask for their child’s throat to be checked, stickers (*‘Got a sore throat? Tell a grown up’*), and adding messages about ARF to on-hold music for hospitals.⁷⁸²

In Auckland areas with a high burden of ARF and RHD, other strategies were developed by the Ministry of Youth Development, including a Rheumatic Fever Ambassadors Program, ‘Clear ya throat’ spoken word stories, and a ‘Dramatic Fever Edutainment Roadshow’. Many of these strategies were co-developed by young people from high-risk communities, and involved competitions to develop mobile phone applications and technology resources to share key messages.⁷⁸⁶ A feature of New Zealand programs was the use of young people living with ARF or RHD in communications material. Using relatable people and stories improved uptake and impact of key messages.⁷⁸²

By 2017, a survey of caregivers conducted alongside an RHD echocardiography screening project found more than 90% had heard of ARF and the majority of people were aware it could be caused by sore throat. More than 80% of participants indicated that children with a sore throat should see a doctor or a nurse straight away.⁷⁸⁷ However, intensive social marketing about ARF and RHD resulted in reports of racism and shame associated with the condition – an unexpected consequence of the campaign.¹¹²

Summary: Health promotion to increase health-seeking behaviour for skin sores and sore throat		
Domain	Summary	Rating
Evidence	Health promotion campaigns internationally have increased awareness of sore throats and skin sores.	Medium
Benefits	Sore throats and skin sores may be considered commonplace. Increasing awareness about potential risks allows for early identification and intervention prior to more serious illness.	High
Risks	Health promotion resources for use in Australia should be carefully co-developed to avoid stigma, shame or blame for families and communities with high rates of ARF. ³⁸²	Medium
Acceptability	Any health promotion campaign must be designed in consultation with the local community to increase acceptability.	Medium
Feasibility	Health promotion can be delivered in a myriad of settings including at the clinic, school or in public places.	High
Costs	Costs for distribution and delivery may be low but resource and time efforts necessary to develop the campaign and invest in the local workforce may be high.	Medium
Timeline	If developing a campaign from inception, including testing and evaluation, the timeline can be long. Adapted campaigns can have a shorter timeline.	Medium
Positive externalities	It is unknown if campaigns will have a positive effect until tried and evaluated. However, evidence suggests medium benefit.	Unknown
Equity	Health promotion ensures equitable distribution of healthcare messages, especially among vulnerable and at-risk populations.	High
Recommendations	Well-developed, culturally meaningful health promotion campaigns which increase awareness of the risks of skin sores and sore throats should be implemented and evaluated locally and jurisdictionally with support from national stakeholders for RHD in Australia.	

Ability to seek healthcare

(Personal and social values, culture, gender, autonomy)

Baseline situation

There are limited published data on the beliefs and attitudes of Aboriginal and Torres Strait Islander people seeking care for skin sores and sore throats. Aboriginal people from the Pilbara region of Western Australia shared their experiences seeking care for skin sores through interviews with eight participants and three focus group discussions.⁶⁰⁰ All participants reflected on beliefs, norms and attitudes as an influence in deciding when and where to seek medical care for skin sores.

Skin sores are both normalised and stigmatised.^{471,600} Qualitative interview with health services, school staff and community members in New South Wales also indicated that stigma and social exclusion were problematic for children with skin sores.⁴⁷¹

Other concerns highlighted by participants in this study included fears that presenting to a clinic with skin sores may result in the Department for Child Protection and Family Support becoming involved with the child.⁶⁰⁰

‘People get shame with the sores. You know they don’t like to show anyone they have them.’

Aboriginal carer quoted in Hendrickx, 2017.⁶⁰⁰

Evidence for strategies to increase ability to seek healthcare

Empower community-level action to address skin and throat infections

Aboriginal and Torres Strait Islander people consistently identify community engagement, consultation and ownership of health activities as a prerequisite to programmatic success.^{322,323} This need is supported by high-quality evaluations across a very wide range of programs over many years in Australia.³²⁴⁻³²⁶

For example, in a synthesis of contributors to success in Aboriginal and Torres Strait Islander health programs, the following characteristics were identified: community control, community participation/ involvement, resourcing, sustainability, partnerships, workforce, evaluation, accountability, and capacity building.³²⁷ The same need for community engagement, ownership and empowerment applies to skin sore and sore throat programs.

Alpurrurulam Healthy Skin Program

From 2009 to 2014, the Northern Territory community of Alpurrurulam conducted a comprehensive skin health program in partnership with Northern Territory Medicare Local using funding from the Commonwealth Preventative Health Initiative.⁷⁸⁸ The initiative spanned a range of strategies to prevent skin sores and treating existing sores, including:

- Baby bathing kits provided for mums with newborns;
- Whole-of-community Healthy Lifestyle Event;
- Purchase of three industrial washing machines to be used in the community laundry;
- Homemaker domestic skills training;
- Production of the Alpurrurulam Healthy Skin DVD and planning for its launch;
- Healthy Skin activities for children aged up to five years, working with the pre-school and Families as First Teachers (FAFT);
- *Our Healthy Skin Story book* produced with the Alpurrurulam school kids; and
- Delivery of skin health and RHD education at Alpurrurulam school.

External evaluation in 2014 suggested an anecdotal belief that collective action with a broad range of community organisation had succeeded in reducing incidence of scabies and skin infection in the three years post-inception. The greatest successes were attributed to changes in hygiene associated with school-based strategies.⁷⁸⁸ Improvements in data management were highlighted, which would yield benefit for future progression.⁷⁸⁸

Tuvaluan skin health program – West Auckland, New Zealand

Skin and soft tissue infections among people aged under 25 years living in the Tuvaluan community in Auckland have reduced by 40% since 2014, driven by community engagement and participation in a ‘Happy Skin’ project.⁷⁸⁹ Following consultation with community, health promotion messages were disseminated via churches and other suggested channels, supported by local leaders. Key messages included practising personal and home hygiene and reporting sores early for treatment.⁷⁸⁹ The success of the program was highlighted as hinging upon community involvement and drive, as well as extensive consultation in the initiation process.⁷⁸⁹

Summary: Empower community-level action to address skin and throat infections		
Domain	Summary	Rating
Evidence	There is some evidence that community-driven programs to address skin sores are effective relatively to externally implemented programs. This is consistent with a large body of evidence about community leadership and empowerment in Aboriginal and Torres Strait Islander health issues. Providing information about the local burden of Strep A infections, ARF and RHD provides an opportunity for communities to identify local priorities for action.	High
Benefits	Increasing community health-seeking to reduce incidence of skin and throat infections would prevent the development of more serious complications.	High
Risks	Communities are the best placed to identify and act on local priorities. Risk associated with community programs are low.	Low
Acceptability	Community-led programs are likely to be more acceptable and more effective than those which are driven by external agencies.	High
Feasibility	Elements of community-led programs can include access to local clinic and burden of disease data, which can be difficult to access.	Medium
Costs	Costs associated with community-led programs vary by program components.	Medium
Timeline	The timeline for communities to consult and develop locally relevant programming varies.	Medium
Positive externalities	Community engagement and resourcing to address priority health issues makes it possible for Aboriginal and Torres Strait Islander people to determine the most effective health-enhancing approaches.	High
Equity	Self-determination to establish and respond to priorities is equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> • Funding should be available for community-level activities to reduce Strep A skin and throat infection. • Local burden of disease data to inform planning and prioritising of these activities should be available to clinics and communities. • Technical support from national and jurisdictional agencies should be provided at the request of clinics and communities and adapted to local settings, with Aboriginal and Torres Strait Islander leadership. 	

Address stigma associated with sore throats and ensure it is acceptable to seek healthcare

Validation of clinic attendances

Primary prevention strategies within the New Zealand Rheumatic Fever Prevention Program included a focus on congratulating and validating people who have decided to seek healthcare.

There is good evidence from New Zealand that healthcare providers changed their approach to assessing and treating sore throats when patients and their families began to ask explicitly for investigation and treatment.¹¹¹ Anecdotally, a similar process occurred in South Africa when people began to insist on receiving antibiotic treatment. Community engagement and empowerment is an important co-factor in addressing health-seeking behaviour.

'People who felt they had been well accommodated at sore throat clinics say reception staff were friendly and they did not have to wait long to be seen by a nurse or doctor.'

'Parents appreciated it when nurses and doctors treated their child's sore throat seriously and commended them for coming in, and encouraged them to come in again if they were concerned.'

'Parents also liked it when nurses and doctors accommodated all their children in one appointment, even if they were not booked in.'

'They also liked it when they did not feel judged by nurses and doctors for their children having sore throats or blamed if they live in sub-standard housing.'

'They also appreciated it when nurses and doctors spent time explaining, in simple terms, the reasons and treatment for sore throats.'

Extract from the Implementation and formative evaluation of the rheumatic fever prevention program, New Zealand; Grigg et al., 2013⁷⁵⁷

Support engagement in sore throat and skin sore services through care navigation

Health or care navigation happens formally or informally when a person is supported to engage with the health service. In general, navigators come from the same community as the person seeking healthcare and can act as an advocate, listener and supporter in medical encounters. A number of studies have explored whether formalising the health navigation role can help improve access for people from particular groups, or with particular illnesses, or in the primary-care setting.⁷⁹⁰

A small pilot study of Indigenous Patient Navigators in a Queensland hospital found some evidence of benefit, improved satisfaction and tangible utility for Aboriginal people living with cancer.⁷⁹¹ In Western Australia, peer support workers have demonstrated value in supporting Aboriginal parents.⁷⁹² In New Zealand, Māori Whānau Support Workers have been an important part of the integrated ARF response. A 2016 review of the ARF response by one District Health Board found that *'use of kaiāwhina (helper, assistant, contributor, counsel, advocate) to access and support high-risk families has worked extremely well and has proved to be a very cost-effective method of service delivery'*.⁷⁹³

Summary: Support engagement in sore throat and skin sore services through care navigation		
Domain	Summary	Rating
Evidence	There is some evidence of benefit for care navigation in primary care for Aboriginal and Torres Strait Islander people. In New Zealand, community care navigators have been important in an ARF prevention program. Application and relevance of this approach to Strep A infections in Australia has not been well explored.	Low
Benefits	The benefits of community navigation or community workers brokering access to health services are unclear but may include de-normalising skin sores or supporting accountability of clinics to communities.	Unknown
Risks	Care navigation and brokerage relationships already exist in a range of kinship and informal community arrangements. Any attempt to support care navigation would need to be conscious of context and be clearly led by Aboriginal and Torres Strait Islander people.	Unknown
Acceptability	Care navigation roles appear to be acceptable in some settings but this is likely to be heavily dependent on community and context.	Medium
Feasibility	Community navigation programs are likely to require considerable training and support. Feasibility of this approach is likely to depend on community and context.	Unknown
Costs	Costs to develop a care navigation program in remote communities are unknown.	Unknown
Timeline	The timeline to develop a care navigation program in remote communities is likely to require months to years of planning and consultation.	Medium

Summary: Support engagement in sore throat and skin sore services through care navigation		
Domain	Summary	Rating
Positive externalities	Increased community capacity to navigate health services would be expected to improve a range of health outcomes across different disease endpoints.	High
Equity	Advocacy and informal care navigation by community and family members is relatively common in non-Indigenous contexts in Australia and supporting this approach in remote Aboriginal and Torres Strait Islander communities is likely to be equity enhancing.	Medium
Recommendations	<ul style="list-style-type: none"> • Scope for care navigation of skin sore and sore throats should be explored and evaluated in Australia. • This approach should connect with the development of culturally appropriate models of self-management for ARF and RHD, described in the Secondary Prevention chapter. 	

Case study – END RHD Communities

END RHD Communities draws on a strong existing evidence base and acknowledges how Aboriginal communities want healthcare and other services to be delivered. Qualitative research from the Northern Territory indicates that Aboriginal people want help navigating health systems, understanding their health (and their family's health), and assistance with initiatives to address the effects of high healthcare staff turnover.⁴⁷¹

The project develops collaborative approaches to these issues through the employment of Aboriginal Community Workers (ACW) who develop partnerships with those living with ARF/RHD and their families, assisting them to navigate and interact effectively with the healthcare system and other service providers throughout different stages of their ARF and RHD journey.

In addition to care navigation, ACWs provide ancillary health promotion, health literacy training, and health/housing roles in a case management arrangement with high-risk families identified as being impacted by ARF or RHD. Weekly household visits are undertaken by ACWs to promote awareness of Strep A infections: their consequences, treatment and transmission prevention strategies. In this manner, the ACWs become champions of the END RHD health promotion messaging.

There are six activity domains in the project which are based on the best available evidence for what works in Aboriginal and Torres Strait Islander health. This is evident in Figure 31.



Figure 31: Domains of END RHD Communities

1. Service Navigation

The ACWs develop a partnership with the client and their families. Through this relationship, ACWs help families to navigate the healthcare system and other service providers throughout their journey.

2. Housing and environmental health support

Housing-related activities are incorporated as a core component of the ACWs' work. They may have a role in documenting housing issues, scoping solutions, and accessing pathways towards repairs and tenancy issues. They may also have a role in direct service delivery in environmental health issues.

3. Health literacy

English is frequently a second, third or fourth language for people in Aboriginal and Torres Strait Islander communities and there is often a linguistic divide which impedes communication and understanding of health issues in clinical settings. ACWs may have a role in addressing these issues by communicating in ways which are more effective and less time-pressured.

4. Health and education service integration

Partnerships may be possible with schools and other education providers in some jurisdictions. There may be scope to explore innovative partnerships, potentially including school-based health services, as part of this work.

5. Health provider education

Continuous professional development using existing, evidence-based RHD Australia online resources is promoted for healthcare providers at the participating communities. Healthcare providers are encouraged to involve and respect the role of ACWs through meetings with the project team.

6. Community awareness and empowerment

Baseline awareness of Strep A infections, ARF and RHD is poor.²²⁹ Childhood skin infections are so common that they may be considered 'normal'; often people do not seek treatment or are not offered it when attending clinic.⁶⁸

Helping to provide information about when to seek help and what kind of clinical assessment to expect is an important part of supporting communities to be actively engaged in healthcare. There is also a need to raise general awareness of ARF and RHD and to ensure there is sustained community support for END RHD activities.

Evaluation of END RHD Communities is under way.

Ability to reach healthcare

(Living environment, transport, mobility)

Baseline situation

There is no data on physical barriers to people reaching medical care specifically for skin sores and sore throats. However, general data suggest that Aboriginal and Torres Strait Islander people face considerable barriers to accessing primary-care services. Lack of transport is a particularly significant barrier: 14% of Aboriginal and Torres Strait Islander people reported delaying access to a doctor because of transport issues in 2012–2013. In an attempt to address this, in 2017–2018, 86.4% of Aboriginal and Torres Strait Islander Health Program- funded primary-care services offered some kind of transport service – though this included transport to other medical services as well as to primary care.⁷⁹⁴

Primary-care providers commonly report on the importance of transport provision and the difficulties in providing care when vehicles or drivers are not available.^{777,795}

Evidence for strategies to improve ability to reach healthcare

Provide transport to primary-care clinics

Anecdotally, clinic drivers play a critical role in encouraging and welcoming people to attend the clinic. However, clinics are generally not funded to provide transport and the costs of maintaining clinic vehicles, drivers and administrative arrangements for collection and drop-off can be considerable.

Ability to pay for healthcare

(Income, assets, social capital)

Supply-side interventions to reduce the out-of-pocket costs for assessment and treatment of skin sores and sore throats are addressed in 'Accessibility' and include increasing coverage of the s100 pharmaceutical scheme and Closing the Gap pharmaceutical scheme. Strategies which increase capacity to pay could include changes to Centrelink payments and the Community Development Program.

Ability to engage in healthcare

(Empowerment, adherence, information)

Baseline situation

Carers of young people with skin sores in the Pilbara generally described their experiences of clinic consultations as 'passive', with little space or time for participation, negotiation and learning. Carers, health staff and other service providers all highlighted a belief about the 'clinic not providing sufficient health education'.⁶⁰⁰ This represents a missed opportunity to provide information and empower people to be actively engaged in self-management of skin sores and sore throats. The ability of a clinic to engage with patients around skin sores must be considered in the context of primary-care resourcing.

Evidence for strategies to increase ability to engage in healthcare

Increase information sharing and education during clinical consultations for skin sores and sore throats

Providing information and health advice for people with a skin infection when they attend for treatment may be an opportune moment to empower and engage families. Visual aids have been identified as an important avenue to increase knowledge sharing in primary-care consultations with Aboriginal and Torres Strait Islander people.⁷⁹⁶ Some resources to facilitate this have been developed.

Beating the Bugs

'Beating the Bugs' is a community care worker flipchart designed to assist families in navigating the health system to achieve better skin care by providing information that is meaningful for them. The flipchart is designed to be fun, friendly and easy-to-use, enabling community members to recognise different skin diseases, learn about methods of treatment, and work to prevent future infection.⁶⁸⁹

Summary: Increase information sharing and education during clinical consultations		
Domain	Summary	Rating
Evidence	There is some evidence that families do not receive enough information about management of skin sores and sore throats during primary-care consultations for these conditions. Resources for improving information exchange have not yet been evaluated.	Medium
Benefits	Providing relevant information about skin sores and sore throats during clinical consultations may increase medication adherence and provide opportunities to prevent future episodes.	Medium
Risks	Providing relevant, culturally appropriate information is already a core function of primary-care consultations.	Low
Acceptability	Studies from the Pilbara suggest there is demand for more information about skin sores from caregivers of children with skin sores.	Medium
Feasibility	Structured approaches to increase information provision for skin sores and sore throats are likely to be feasible based on similar programs for other conditions.	Medium
Costs	Co-design and translation of appropriate information about managing skin sores and sore throats is associated with some cost.	Medium
Timeline	Development and dissemination of resources could occur over a period of months to years. The time required to engage with patients and families with these resources is also significant.	Medium

Summary: Increase information sharing and education during clinical consultations		
Domain	Summary	Rating
Positive externalities	Increasing health information shared with Aboriginal and Torres Strait Islander people is likely to be important for a range of health outcomes.	Medium
Equity	Verbal explanations, handouts and leaflets are commonly provided in primary-care consultations in non-Indigenous settings in Australia. Facilitating similar information sharing for Aboriginal and Torres Strait Islander people is likely to be equity enhancing.	High
Recommendations	Resources for discussing skin sores and sore throats in primary-care settings for Aboriginal and Torres Strait Islander people in Australia should be developed and evaluated.	

Improve integration of traditional medical practices into primary prevention of ARF

A range of traditional 'bush' medicines are used by different Aboriginal and Torres Strait Islander communities to treat skin sores and potentially sore throats.⁶⁰⁰ Use of traditional medicines by Aboriginal and Torres Strait Islander people in remote communities is common, although few frameworks for integrating these practices alongside biomedical primary care currently exist.⁷⁹⁷ Traditional medicines potentially include the use of honey for skin sores.⁶¹⁹ The biomedical efficacy of traditional remedies for skin sores is currently unknown, although a number of research initiatives are under way.⁵³

'The beauty of bush medicine is it makes us feel good, and it feels good using our own ways to make community strong.'

Elder representative of Palyalatju Maparna Health Committee, quoted in Oliver, 2013.⁷⁹⁷

Summary: Increase integration of traditional medical practice into primary prevention of ARF		
Domain	Summary	Rating
Evidence	Biomedical evidence for the efficacy of different kinds of traditional medicines for treating skin sores is unclear.	Unknown
Benefits	In addition to potential biomedical benefits, traditional medicine practice may also increase engagement, empowerment and opportunities for both-ways learnings.	Unknown
Risks	Risks of traditional medicines for skin sores and sore throats are unknown.	Unknown
Acceptability	Acceptability among patients of traditional medicine practices in the setting of primary healthcare appears to be high. ⁷⁹⁷	High
Feasibility	Integration of traditional medicines into biomedical care models may be possible.	Medium
Costs	Costs of different traditional medical practices vary.	Medium
Timeline	Many traditional medical practices are already under way. It may be possible for clinics or clinical guidelines to more formally include traditional medical practices, although the timeline for this is unknown.	Unknown
Positive externalities	Sharing traditional medical practices may increase biomedical knowledge, increase both-ways learning and elevate the cultural knowledge of Aboriginal and Torres Strait Islander people.	High
Equity	Prioritising and retaining traditional medicine practices of Aboriginal and Torres Strait Islander people enhance equity with respect to culture and health.	High
Recommendations	National stakeholders for RHD in Australia or research partners should review evidence for traditional medical practices related to skin sores and sore throats and make recommendations about further research priorities. Opportunities for integration into clinical guidelines should be considered, led by Aboriginal and Torres Strait Islander people.	

Post-primary prevention

Post-primary prevention occurs once someone has a Strep A infection, and focuses on reducing transmission to other people; approaches do not necessarily directly benefit the person who already has a skin sore or sore throat. At a population level, however, strategies to reduce transmission may help protect against recurrent early life Strep A exposures, which appear to drive susceptibility to ARF.⁷⁹⁸

Reduce transmission of established Strep A infections

Minimise Strep A transmission at school

Transmission of Strep A infections is possible within day-care and school settings.⁴⁰ This risk is likely to be highest when children have active infections. Therefore, a range of guidelines on excluding children with Strep A infections from school have been developed (summarised in Appendix Five). These guidelines vary subtly by jurisdiction.

Guidelines to cover skin sores and exclude children from school are variably implemented. In one small Australian study in a general practice setting, 53% of people received advice to keep the lesion covered and only 10% to stay away from school or work.⁶⁰¹ Some teachers informally report dressing skin sores of pupils to reduce transmission at school.³⁴

The biologic evidence base and efficacy of school exclusion policies is not entirely clear.⁵³ The risk of unintended consequences, particularly on education outcomes given frequent skin infections and implications of missing school time, is also unknown.⁵³

'They're quarantined from school if they've got lesions...their learning falls, then they come into the routine of not going to school.'

Aboriginal Community Controlled Health Service Manager quoted in Thomas et al., 2017.⁴⁷¹

Guidelines for the exclusion of children experiencing infectious diseases by jurisdiction can be seen in Appendix Five.

Summary: Minimise Strep A transmission at school		
Domain	Summary	Rating
Evidence	Evidence that excluding children with Strep A throat or skin infections from school reduces transmission is unclear. ⁵³	Unknown
Benefits	The benefits of school exclusion on reducing transmission of Strep A infection are unknown.	Unknown
Risks	In settings with a high burden of Strep A infection, adherence to existing school-exclusion policies may result in a significant loss of educational time. This may be a particular risk in settings with low baseline school attendance. School exclusion may also risk stigmatisation of children and young people, particularly with skin sores.	High
Acceptability	No information on community attitudes to school exclusion for health conditions was identified.	Unknown
Feasibility	The feasibility of excluding children from school attendance on the basis of health conditions in remote communities is unclear. School staff may not be resourced or trained to identify conditions which warrant exclusion or which require children to be picked up by caregivers.	Unknown
Costs	Indirect costs of school-exclusion policies may include the cost of caregivers being unable to attend education or employment activities. ⁷⁹⁹	Medium
Timeline	School-exclusion policies are currently in place.	N/A

Summary: Minimise Strep A transmission at school		
Domain	Summary	Rating
Positive externalities	Requiring children with skin sores to keep them covered may provide a mechanism for education staff to access additional health services, with implications for other illnesses.	Low
Equity	Exclusion from educational opportunities due to a disease of social circumstance is not equitable. Additionally, children at highest risk of skin sores may be those least likely to attend school and exclusion policies may further entrench disengagement with education.	Low
Recommendations	<ul style="list-style-type: none"> Research into the transmission of Strep A infection should be conducted to be better assess the potential benefits of school exclusion. Infrastructure to support safe school attendance should be prioritised, including provision of handwashing facilities and dressings to cover open wounds. 	

Minimise minor wounds and Strep A transmission associated with sports

Skin sores may be spread through injuries and skin-to-skin contact associated with sporting activity.⁸⁰⁰ In remote Aboriginal and Torres Strait Islander communities, sport is an important cultural and health-promoting activity.⁸⁰¹ Sport and recreation programs are supported by the Australian Government and a number of State and Territory governments.^{802,803} Sporting facilities and access to grassed playing surfaces are limited, sometimes leading to high rates of skin injury from gravel grazes or other hazards.

Opportunities to reduce spread of skin sores through sport should be explored. Guidelines for sporting participation with skin infections exist internationally but were not identified in the Australian setting.⁸⁰⁴

Summary: Minimise Strep A transmission during sporting activities		
Domain	Summary	Rating
Evidence	There is some evidence that skin sores can be transmitted through sporting activity. It may be possible to reduce these risks, although no examples of this were identified in practice in Australia.	Medium
Benefits	Reducing skin sore transmission during sports would reduce the need for primary prevention with antibiotics.	High
Risks	Policies which exclude young people with skin sores from sporting activities are likely to be stigmatising and risk reducing physical activity. Pragmatic policies which minimise transmission risk (such as keeping sores covered or washing prior to sports) may be more appropriate.	Medium
Acceptability	Acceptability of programs to minimise Strep A transmission are unknown, however other health messaging (e.g. not sharing water bottles, avoiding contact with blood and body fluids) has been incorporated into some sporting codes.	Unknown
Feasibility	Feasibility of new policies or approaches to sporting programs in remote Aboriginal and Torres Strait Islander communities is unknown.	Unknown
Costs	Costs of new policies or approaches to sporting programs in remote Aboriginal and Torres Strait Islander communities are unknown.	Unknown
Timeline	Development of new policies and procedures about sporting participation could be expected to take months or years.	Medium
Positive externalities	Potential benefits of this approach include normalising skin care and skin hygiene.	High
Equity	Equity effects of policies to reduce Strep A transmission during sport activities are unknown and are likely to depend on implementation.	Unknown

Summary: Minimise Strep A transmission during sporting activities		
Domain	Summary	Rating
Recommendations	National stakeholders for RHD in Australia should: <ul style="list-style-type: none"> Work with relevant stakeholders to develop approaches to reduce Strep A transmission through sports. These could include: <ul style="list-style-type: none"> Providing dressings to ensure open skin sores are covered prior to sporting events. First aid of minor injuries. Encouraging washing of hands before sports activities. 	

Other strategies

Eradication of Strep A throat carriage

Antibiotic treatment to eradicate carriage of Strep A (which is clinically and immunologically undetectable – see Box 1), is not routinely recommended.^{711,805} Research is under way to understand the effect of Strep A carriage and opportunities to reduce transmission risk.

Tonsillectomy

Low-quality evidence suggests that tonsillectomy may reduce recurrent episodes of sore throat.^{806,807} However, it is not clear that recurrent episodes of sore throat in an individual are associated with increased ARF risk. Tonsillectomy is an invasive procedure with some post-operative risk and is unlikely to be a major component of reducing Strep A throat infections in people at risk of ARF.^{806,807}

Skin decolonisation

Decolonisation protocols are recommended to reduce recurrent skin infections and boils caused by *Staphylococcus aureus* bacteria.⁸⁰⁸ Whether this approach could also be useful in reducing Strep A skin infections is unknown and warrants future research.

Summary of strategies to improve primary prevention of ARF and RHD

Chapter 4c outlines different approaches to increase access to primary prevention treatment of Strep A skin and throat infections. Potential approaches are summarised in a standardised framework.

	Evidence	Benefits	Risk	Acceptability	Feasibility	Costs	Timeline	Positive externalities	Equity	Recommendation	Overall Evidence & Priority
Pre-primary prevention											
Probiotics to reduce the risk of Strep A infection	Low	Low	Medium	Medium	Unknown	Unknown	Unknown	Medium	Unknown	Research to explore prophylactic options may be warranted if indicated by a high Strep A burden.	Research
First aid for minor injuries and insect bites	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	High	High	Additional research is required.	Research
Supply-side strategies to improve primary prevention											
Expanding the range of places and times that people can have sore throat and skin sore assessments/treatment	Medium	Medium	High	Unknown	Unknown	Unknown	Unknown	Low	Unknown	Dedicated sore throat or skin sore clinics should not be implemented in Australia but warrant exploration.	Medium
Providing assessment and treatment of sore throats in schools	Unknown	Medium	Medium	Unknown	Medium	High	Unknown	Unknown	Medium	These services may have a role if endorsed by the community and supported by primary care.	Medium
Use of telehealth to support assessment and treatment of skin sores and sore throats	Unknown	Unknown	Unknown	Medium	Unknown	Unknown	Unknown	High	High	Further research is required.	Research
Increasing the number of people able to dispense antibiotic medication for primary prevention	Medium	Medium	Medium	High	Medium	Medium	Long	High	High	Broader dispensing opportunities should be explored.	Medium
Improve use of clinical guidelines for assessment and treatment of sore throat and skin sores	Medium	High	Low	High	High	Medium	Ongoing	High	Medium	Further evaluation of how guidelines are used and how fidelity can be increased is warranted.	High
Provide more training on assessment and treatment of skin sores and sore throats	Medium	High	Medium	Medium	Medium	Medium	Ongoing	High	High	Integrated, primary prevention-focused training approaches are required.	High
Decision support aids for assessment and treatment of sore throats and skin sores	High	Medium	Medium	Medium	High	Low	Short	Medium	Medium	Clinic modules, training and support are required.	High

	Evidence	Benefits	Risk	Acceptability	Feasibility	Costs	Timeline	Positive externalities	Equity	Recommendation	Overall Evidence & Priority
Supply-side strategies to improve primary prevention											
Develop audit tools to support appropriate primary prevention of ARF	Medium	Medium	Medium	Medium	Medium	Medium	Medium	High	Medium	Audit tools should be developed by the RHD National Implementation Unit	Medium
Look back mechanisms case review following ARF diagnosis	Medium	Medium	Medium	Unknown	Unknown	Medium	Medium	Low	Medium	A pilot program to develop a 'look back' review should be initiated.	Medium
Improve the diagnosis of Strep A infections	Medium	High	Medium	High	High	Unknown	Medium	Medium	Medium	Research should not be prioritised over health system-strengthening initiatives.	Medium
Ensure availability of essential medicines	National stakeholders for RHD in Australia should have capacity to monitor access to medication required for management of Strep A infections, ARF and RHD and associated conditions and work with national agencies working to improve medication supply.										
Embed active case-finding for skin sores into routine clinical service	Medium	High	Medium	Medium	High	Low	Short	Medium	High	A working definition of a 'healthy skin check' should be developed.	High
Inclusion of sore throat and skin sore screening in routine school health checks	Unknown	Medium	High	Medium	Medium	Unknown	Medium	Medium	Medium	Further exploration is warranted.	Medium
Active case-finding of sore throats or Strep A carriage in schools or communities	High	Low	High	Low	Low	High	Medium	Unknown	Unknown	Not recommended.	Low
Skin health outreach programs	High	High	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Skin outreach programs should be included in primary prevention strategies of ARF in settings with a high burden of skin infection.	High
Expanding access to CTG PBS provisions	High	High	Low	Medium	High	Unknown	Medium	High	High	Opportunities to expand CTG PBS subsidies should be explored.	High

Overall Evidence & Priority	Recommendation	Equity	Positive externalities	Timeline	Costs	Feasibility	Acceptability	Risk	Benefits	Evidence
Supply-side strategies to improve primary prevention										
High	National stakeholders should work with the Australian Government to enhance S100 provisions	High	High	Medium	Low	Medium	High	Low	High	High
High	Appropriate health promotion campaigns should be implemented and evaluated.	High	Unknown	Medium	Medium	High	Medium	Medium	High	Medium
Research	The evidence, costs and pilot opportunities to improve distribution of dressings for skin sores should be explored.	Medium	Medium	Medium	Unknown	Medium	Unknown	Low	Medium	Medium
Research	Research to identify more acceptable and equally effective strategies for primary prevention of ARF following Strep A throat and skin infections should be pursued.									
Demand-side strategies to improve primary prevention										
High	Appropriate health promotion campaigns should be implemented and evaluated.	High	Unknown	Medium	Medium	High	Medium	Medium	High	Medium
High	Funding should be allocated to community-level activities to reduce Strep A infection.	High	High	Medium	Medium	Medium	High	Low	High	High
Research	Scope for care navigation of skin sores and sore throats should be explored and evaluated in Australia.	Medium	High	Medium	Unknown	Unknown	Medium	Unknown	Unknown	Low
Medium	Resources for discussing skin sores and sore throats in primary-care settings should be developed and evaluated.	High	Medium	Medium	Medium	Medium	Medium	Low	Medium	Medium
Research	The evidence for traditional medical practices related to skin sores and sore throats should be reviewed.	High	High	Unknown	Medium	Medium	High	Unknown	Unknown	Unknown
Post-primary prevention										
Research	Research into the transmission of Strep A infection should be conducted to better assess the potential impact of school exclusion.	Low	Low	N/A	Medium	Unknown	Unknown	High	Unknown	Unknown
Research	Approaches to reduce Strep A transmission through sports should be explored.	Unknown	High	Medium	Unknown	Unknown	Unknown	Medium	High	Medium

Synthesis of primary prevention recommendations

Primary-care clinics and community recommendations

Clinics, communities and jurisdictions should:

- Explore opportunities to provide healthcare or referral services from schools for sore throats and/or skin sores. Potential service delivery models may include:
 - Referral from school teachers to the clinic.
 - Embedding nurses in schools.
 - Training other staff in schools to provide first aid and healthcare services.
- Be supported to address the logistic barriers to staff training, including lack of internet, lack of locum cover for staff training, and limited clinical capacity.
- Retain a conservative treat-all approach for communities at high risk of ARF, using appropriate antibiotics.
- Be supported by the RHD National Implementation Unit to:
 - Work with other stakeholders to develop technical guidelines for how these programs are delivered.
 - Support jurisdictions to develop local implementation plans.
 - Develop data standards and recommendations for evaluation and monitoring.
 - Ensure community leadership and primary healthcare resourcing in the implementation of these programs.
- Work with the Australian Government to ensure that s100 PBS provisions are enhanced according to the IPP reforms recommendations; including that s100 apply to all remote ACCHS and AMS clients irrespective of their geographic location, and that quality use of medicines for remote ACCHSs and AMSs must be improved significantly.
- Develop culturally meaningful health promotion campaigns which increase awareness of the risks of skin sores and sore throats. These should be implemented and evaluated locally and jurisdictionally with support from national stakeholders for RHD in Australia.
- Explore the scope for care navigation of skin sores and sore throats in Australia. This approach should connect with the development of culturally appropriate models of self-management for ARF and RHD, as described in the Secondary Prevention chapter.
- Explore the evidence, costs and pilot opportunities to improve distribution of dressings for skin sores in conjunction with research partners.

State and Territory recommendations

The jurisdictional agencies should be resourced to:

- Adapt national resources to jurisdictional settings and clinical pathways.
- Develop a 'look back' review meeting of ARF notifications, with a view to scale up to major referral hospitals accounting for the majority of ARF admissions. This clinical review meeting should:
 - Be comprised of multidisciplinary stakeholders, potentially including hospital-based clinicians, the RHD register, and primary-care representatives.
 - Have a clear remit to focus on quality improvement.
 - Include resourcing to develop terms of reference and provide administrative support and feedback of review meeting outcomes.
- Monitor access to medication required for management of Strep A infections, ARF, RHD and associated conditions, and work with national agencies working to improve medication supply.
- Advocate in response to localised medication distribution issues, and work with other technical agencies to make clinical recommendations in the setting of medication shortages as required.
- Develop and evaluate resources for discussing skin sores and sore throats in primary-care settings for Aboriginal and Torres Strait Islander people in Australia.
- Prioritise infrastructure to support safe school attendance, including provision of handwashing facilities and dressings to cover open wounds.
- Work with the Australian Government to support the Indigenous Pharmacy Programs Reform activities related to improving the Closing the Gap (CTG) measure.

RHD National Implementation Unit recommendations

The RHD National Implementation Unit together with the Australian Government, should:

- Explore opportunities to increase the use of telehealth for primary prevention. This could include a scoping survey of systems already in use and review of relevant Medicare items.
- Work with relevant peak bodies and jurisdictions to explore scope for increasing access to medication for primary prevention through broader dispensing opportunities, accompanied by training and investment in the Aboriginal and Torres Strait Islander health workforce.
- Have remit and resourcing to:
 - Review and disseminate guidelines on assessment and management of sore throat and skin sores, plus related conditions including scabies infestation.
 - Focus on a standardised risk-stratified approach to assessment and treatment of sore throats.
 - Support jurisdictional activities to increase guideline use and uptake of clinical guidelines for assessment and treatment of sore throat and skin sores.
 - Align existing guidelines with emerging approaches such as HealthPathways.
 - Consider opportunities to disseminate guidelines through teaching resources and mobile phone applications.
- Be resourced to review, develop and disseminate education and training materials on primary prevention, written by and for Aboriginal and Torres Strait Islander people; and develop feedback mechanisms to improve these resources over time.
- Support the development of clinical modules for all clinical software packages for skin sores and sore throat treatment and provide training and support to install and use these modules to primary-care providers.
- Develop audit tools to monitor care delivery for sore throat and skin sores.
- Develop resources for discussing skin sores and sore throats in primary-care settings for Aboriginal and Torres Strait Islander people in Australia, inclusive of evaluation.
- Work with relevant stakeholders to develop approaches to reduce Strep A transmission through sports. These could include:
 - Providing dressings to ensure open skin sores are covered prior to sporting events.
 - First aid of minor injuries.
 - Encouraging washing of hands before sports activities.
- Develop a working definition of a 'healthy skin check' to provide guidance on the setting (privacy and environment) and components (skin areas to be examined or self-reported).
- Review the inclusion and specifications of healthy skin checks in the NACCHO/RACGP National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people, and associated jurisdictional guidelines.
- Update clinical software templates for Aboriginal and Torres Strait Islander Peoples Health Assessment with more detailed specifications about a healthy skin check and outcomes/ recommendations. This should be done in partnership with primary health clinics.
- In the context of impending reforms, include information about CTG in educational resources for prescribers to increase awareness and uptake of the scheme.

Research stakeholder recommendations

- The use of topical antibiotics for minor skin trauma is not recommended given well-founded concerns about antibiotic resistance. Additional research in Australia should be conducted to understand the effect in warmer climates with different microbiological profiles.
- Research to explore prophylactic options to prevent Strep A throat infections in Aboriginal and Torres Strait Islander children in Australia may be warranted if the burden of Strep A throat infections is demonstrated to be high in epidemiologic studies.
- Further research and assessment are warranted to assess the applicability of dedicated sore throat or skin sore clinics in Australia with a consideration of current evidence and the experience of New Zealand.
- Research initiatives to evaluate implementation of telehealth services for sore throats and skin sores should be commissioned.
- Further evaluation of how clinical guidelines for assessment and treatment of sore throats and skin sores are used and how fidelity can be increased is warranted. This may include development of clinical audit capacity.
- Further investigation of PCR-based PoCTs for Strep A in remote Aboriginal and Torres Strait Islander settings is required.
- Research to identify more acceptable and equally effective strategies for primary prevention of ARF infection following Strep A throat infection should be pursued.
- Research into the transmission of Strep A infection should be conducted to better assess the potential benefits of school exclusion.



4 STRATEGIES TO END RHD

4d SECONDARY PREVENTION OF ARF AND RHD

An overview of opportunities to improve prevention and management of ARF and RHD



Chad receives his bicillin injection every 28 days at his local Aboriginal Medical Service, SWAMS

Introduction

Secondary prevention focuses on people who have had acute rheumatic fever (ARF), or who have rheumatic heart disease (RHD) and are at risk of recurrent ARF. The primary focus of secondary prevention in Australia has been delivery of secondary prophylaxis, defined by the World Health Organization (WHO) as *'the continuous administration of specific antibiotics to patients with a previous attack of rheumatic fever, or well-documented rheumatic heart disease. The purpose is to prevent colonization or infection of the upper respiratory tract with group A beta-haemolytic streptococci and the development of recurrent attacks of rheumatic fever.'*²¹³ The spectrum of secondary prevention in the context of Strep A, ARF and RHD progression can be seen in Figure 32.

Delivery of secondary prophylaxis with antibiotics prevents Strep A infections, which in turn prevents recurrent episodes of ARF. Prevention of ARF recurrences is strongly associated with better clinical outcomes.^{809,810} Regular intramuscular injections of benzathine benzylpenicillin (BPG) are generally recommended as the preferred agent for secondary prophylaxis. Regular prophylaxis administration reduces ARF recurrences and appears to reduce overall mortality.^{811,812} Secondary prophylaxis with injectable BPG has been the global standard of care since the drug's development in 1950. Soon after, registers were developed to record the names of people needing secondary prophylaxis in order to support care delivery.⁸¹³

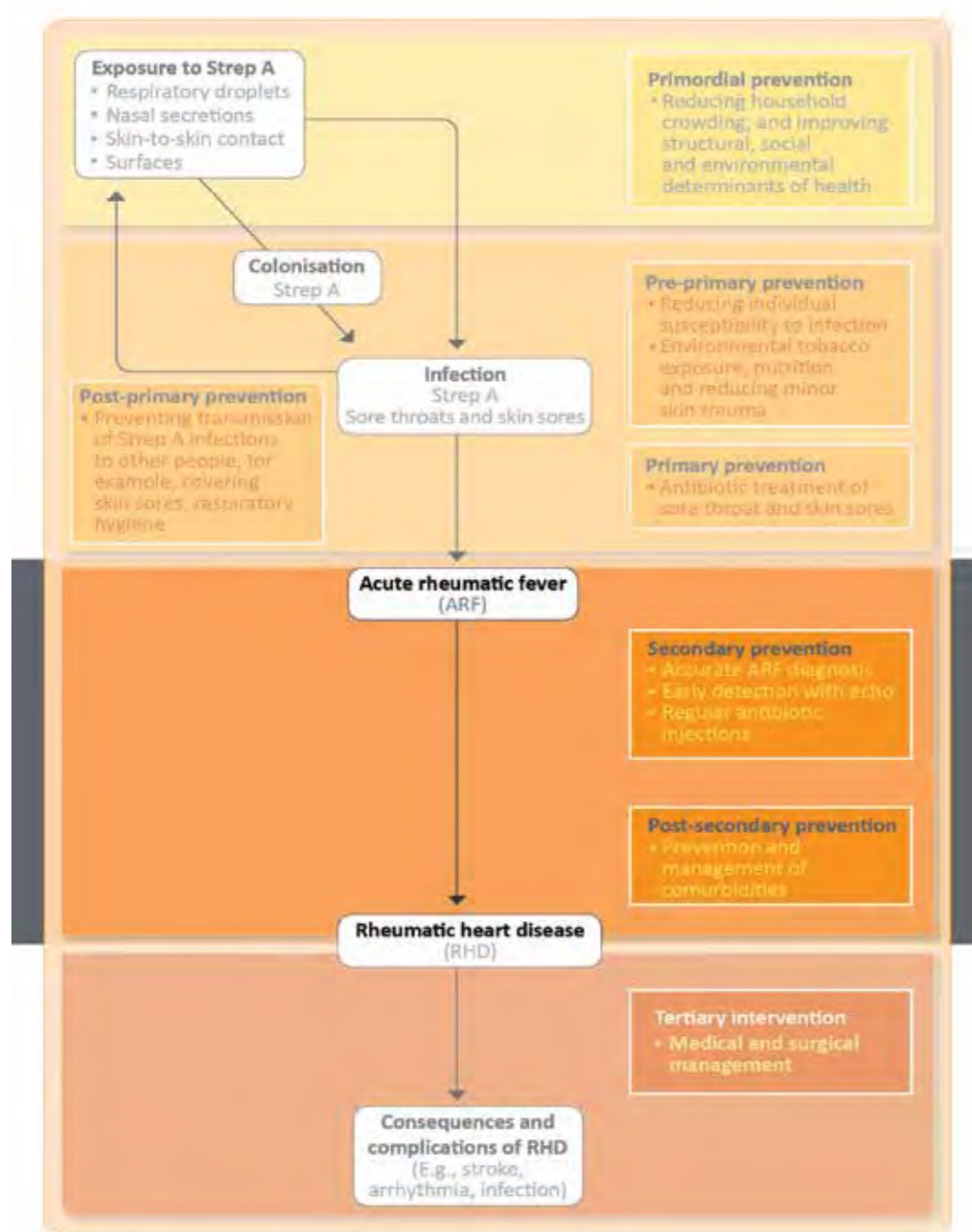


Figure 32: The spectrum of secondary prevention.

This chapter was written prior to the release of the third edition of the *Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease* and therefore does not reflect recommended changes. Please refer to the Guideline for a summary of key changes.⁷¹¹

Methods

Secondary prophylaxis has been a major focus of efforts to address RHD in Australia over the past 20 years. There have been several local high-quality studies and reviews which have provided an evidence base for some, if not all, secondary prevention initiatives. Key recommendations have been drawn from these studies, in conjunction with systematic reviews exploring secondary prophylaxis delivery globally.^{99,814-816} In addition, examples of programs and initiatives illustrative of a type of approach or strategy have been selected to inform recommendations. This is not an exhaustive record of all programs implemented in Australia. Where possible, those which have been evaluated have been prioritised but some initiatives where there is anecdotal evidence of success or acceptance have been included in this review.

ABCD2 study

The ABCD2 study aimed to engage stakeholders in identifying priority evidence–practice gaps and strategies for improvement for ARF/RHD.²⁵² Phase 1 of this study included clinical record audits of 897 people with ARF/RHD in 44 health centres between 2012 and 2014, alongside 22 health service assessments. Results from these audits were presented to primary-care stakeholders and seven priority areas for action were identified²⁵²:

- Increase uptake of planned BPG injections to 80% or more for all clients who are prescribed injections.
- Strengthen activity to follow-up clients who received less than 80% of planned BPG injections within a 12-month period.
- Support health centres to prioritise disease-management planning.
- Improve recording of key information related to delivery of BPG injections, such as planned frequency, current prescriptions and clinic master charts.
- Improve levels of recording ARF diagnoses (including suspected ARF).
- Strengthen efforts to provide interventions for clients who have ARF despite adequate injection delivery.
- Improve the practice and recording of ARF education for all clients.

In Phase 2, clinical record audit data from 2008 to 2014 were collected for 2,581 people across 60 health centres, and 80 systems assessments were conducted. Trends of these data across time were presented to primary-care stakeholders to identify barriers and enablers to deliver care for ARF and RHD. Key themes included²⁵²:

- Staffing and workforce (including adequate staff numbers, retention and administrative staffing support).
- Self-management (including resources to support self-management for people living with ARF/RHD).
- Population health (clinical teams having information about service populations can apply a population health approach).
- Teamwork (systems and processes to support primary-care staff functioning as a team).
- Community capacity, engagement and mobilisation (systems to enhance the expectations of communities for best-practice care; support health literacy; and to support clinics to work in partnership with communities).
- Clinical information systems and communication technology (training and support to use clinical information systems).
- Training and development (systems to support learning within and between organisations).
- Patient-centred care (supporting the needs and aspirations of Aboriginal and Torres Strait Islander peoples and communities).
- Quality improvement (support for primary-care clinics to interpret and respond to improvement data).
- Leadership and management.
- Knowledge (generally considered adequate to deliver best-practice care).
- Focus (support for primary-care staff to deliver best-practice care for ARF/RHD).

The RHD Secondary Prophylaxis (RHDSPP) Trial

The RHDSPP Trial, conducted in the Northern Territory (NT) from 2013 to 2016, explored whether a primary healthcare-based intervention could improve secondary prophylaxis delivery for people with ARF and RHD. The study was a stepped-wedge randomised trial in 10 clinics in the Northern Territory, involving rollout of multi-component interventions with baseline, intensive and maintenance phases. The study was designed to optimise health systems and community resources, aligned with the Chronic Care Model (CCM), and included continuous quality improvement feedback. The intervention comprised sets of 'action plans' developed and implemented by the health centres, including changes to practice around clinical information systems, development of community linkages, decision support, health systems, delivery system design and self-management support. The primary outcome was the proportion of people receiving $\geq 80\%$ of scheduled penicillin injections, compared to baseline rate. Secondary outcomes were 'days at risk' (i.e. number of days late for SP injections), ARF recurrence rates, and impact of the intervention on other clinic activities.^{107,817}

Overall, no significant increase in adherence was achieved through the study. Significant improvement occurred during the maintenance phase of the trial for those patients already receiving $\geq 90\%$ of scheduled injections. Secondary prophylaxis adherence was best among children, who have the highest risk of ARF recurrence. Twelve months may have been insufficient to detect a true effect given the complexity of the intervention. Communities faced staff turnover of up to eight nurses in the 15-month period that the RHDSPP Trial was conducted; this affected implementation of the intervention. More successfully implemented changes in practice involved changing clinic-based systems. Least successfully implemented changes included establishing effective community linkages and providing self-management support. Effectiveness of the intervention was limited by the failure to adequately implement change in all key areas of the CCM.^{107,817}

Review of the Rheumatic Fever Strategy

In 2017, an evaluation was undertaken of the Australian Government's Rheumatic Fever Strategy (RFS) since the commencement of the National Partnership Agreements in 2009.⁶ It included consultation with 72 individuals in 35 organisations; jurisdictional control program and registry staff, State and Territory health department staff, clinicians, Aboriginal and Torres Strait Islander Health Workers, academics, and key stakeholders such as expert advisers and peak non-government organisations.⁶ The review focused on whether the RFS had been implemented as expected, whether expected outcomes were achieved, what improvements could be made, the overall cost, and how sustainable the RFS initiatives were beyond the greater funding period.⁶ Key recommendations were⁶:

- Renew the RFS and National Partnership Agreements (through which the States and Territory are funded under the RFS) for a further four-year period to maintain and build on momentum and to assist in attracting and retaining staff.
- Maintain the existing focus of the RFS on secondary prevention but also consider broadening preventative efforts to include primordial (environmental prevention) and early intervention healthcare measures (primary prevention).
- Streamline the provision of data from jurisdictions to the data collection system (DCS) by considering alternative governance arrangements for the DCS that would overcome existing barriers and delays.
- Participating jurisdictions to increase the automation of patient data capture and reporting, and seek to enable real-time access to clinicians and health services to registry data and patient records.
- Improve education and training for healthcare providers, individuals, families and communities to raise awareness.

Overall, it was found that the RFS had multiple successes, including improved monitoring and surveillance of ARF and RHD, increased awareness of the disease, and improved secondary prophylaxis. However, more work was required to refine and strengthen State-and Territory-based programs, education and training of staff, staff retention, and reporting of registry data.⁶ The review did not consider areas outside the scope of RFS funding and made no substantive suggestions about primary or environmental prevention of Strep A infection or ARF.

Secondary prevention

Early and accurate diagnosis of ARF

Baseline situation

Among all Aboriginal and Torres Strait Islander people with a new RHD diagnosis between 2013 and 2017, about four out of five people did not have a previous ARF episode recorded on the registers.¹⁶⁹ Given the main pathway for developing RHD is following an episode of ARF, this raises a number of possibilities:

ARF symptoms are absent or mild and people do not seek medical care

It is possible that a subset of people with ARF do not feel unwell or are minimally unwell with the condition, and therefore do not seek medical care. Individuals who have carditis as the sole feature of ARF (3–25% of ARF patients)⁸¹⁸ may have fever as the only symptom. Indolent or 'insidious onset' carditis, which lacks overt episodes of discrete ARF, may be under-recognised in Aboriginal and Torres Strait Islander children.⁷⁵ Certainly, many people with RHD do not recall a preceding event consistent with ARF – although symptoms could have been forgotten given the delay of months or years which is possible between ARF and RHD diagnosis. The possibility of ARF which causes no or only minimal symptoms is impossible to define, given that current diagnostic criteria rely on a constellation of clinical symptoms and non-specific blood tests conducted during a symptomatic event.

ARF symptoms are present but people do not seek medical care

Awareness of ARF and RHD is low in many Aboriginal and Torres Strait Islander communities.^{98,101} Access to appropriate medical services may also be limited. In one New South Wales study of young people diagnosed with ARF (n=26, five identifying as Aboriginal or Torres Strait Islander, 10 as Pacific Islander and 11 young people with undisclosed ethnicity), 65% of participants had a delay in accessing medical care (median of 21 days, range 14–16 days).⁸¹⁹ People who have symptoms of ARF may not be aware that they should seek medical assessment, or may face prohibitive barriers to accessing medical care.

Symptoms of ARF are not recognised by the health workforce

It is not uncommon for the arthritis/arthritis of ARF to initially be attributed to an injury from an activity such as playing sport. There is no single diagnostic test for ARF, instead a number of symptoms, signs and non-specific laboratory tests that need to be assessed together to make a diagnosis. In practice, this means that healthcare providers need to have a heightened suspicion of ARF in high-risk populations to initiate the testing required to make a diagnosis. If healthcare providers are not aware of ARF or do not collect relevant clinical information, then the diagnosis may be missed, particularly given that specific symptoms can present randomly. This is also accentuated by high staff turnover and difficulties accessing training in remote areas.²⁵³ Increasing awareness and supporting clinical investigation may be an important opportunity to increase diagnosis.

Delay in making the diagnosis

Even if healthcare staff suspect and investigate for ARF, review by a hospital specialist is often needed to make a definitive diagnosis. Australian guidelines recommend that everyone with suspected ARF be admitted to hospital to make this possible.⁷¹¹ Data on the proportion of people suspected to have ARF who are admitted are not publicly available but it is thought to be less than 100%. Barriers to diagnosis include late presentation with symptoms, inability to perform required tests, or delays with admission to hospital, particularly for people living in remote areas. This means that the critical window for blood tests, electrocardiogram, and echocardiography may be delayed or even missed.

These multifactorial delays in recognising and appropriately referring suspected ARF are well recognised. Diagnostic confusion has been described in a case series of young people in Far North Queensland in the mid-2000s and in a consecutive case series published in the Northern Territory in 2006.^{709,820} Similarly, in a paediatric New South Wales population, three of 26 young people with ARF had delayed referral for diagnosis from emergency medicine or primary care.⁸¹⁹

The diagnosis of ARF is not adequately documented

The complexity of making a diagnosis of ARF contributes to difficulties in the recording of ARF and suspected ARF diagnosis in personal clinical records.²⁵² Additionally, there may be confusion about responsibility for disease notification. Notifiable diseases must be reported to health authorities when they are diagnosed. While most notifiable conditions are notifiable by laboratories, ARF requires a clinical diagnosis. In jurisdictions where ARF is notifiable, notification to the relevant authority is the role of the treating clinician who makes the diagnosis.

In Australia, ARF and RHD have been designated notifiable diseases in several jurisdictions, as outlined in Figure 33. These notifications provide the most contemporaneous information about who has ARF and link directly to the RHD register to provide information about people requiring secondary prophylaxis.

	NT	QLD	WA	SA	NSW	VIC, TAS, ACT
RHD Control Program established	1997 [†]	2009	2009	2010	2015	X
ARF/RHD Register established	1997	2006	2009	2012	2016	X
Confirmed ARF notifiable	1996	1999	2007	2016	2015	X
Probable ARF notifiable	2019	X	2015	2016	2015	X
Possible ARF notifiable	X	X	2015	2016	X	X
Confirmed RHD notifiable	2019	2018	2015	2016	2015 [§]	X
Borderline RHD notifiable	X	2018	2015	2016	X	X

[†] The Top End Control Program was established in Darwin 1997, and expanded in 2000 to include the whole NT.
[§] Notification of RHD only in persons aged less than 35 years.

Figure 33: History of ARF and RHD notification and RHD Control Programs in Australia.⁷¹¹

The completeness of ARF notification across the jurisdictional registers is unknown in Australia. However, concerns about incomplete notification were noted during the Rheumatic Fever Strategy evaluation in 2017, which describes an audit of hospital records in Queensland which identified 600 people with ARF and RHD who had not previously been identified on the RHD register.⁶

Evidence for strategies to increase early and accurate diagnosis of ARF

Increasing health-seeking behaviour for symptoms of ARF through health promotion

Increasing community awareness of ARF could increase the probability that young people with symptoms of ARF (including joint pain, fever and abnormal movements associated with chorea) seek medical assessment. Sharing information about ARF with young people, families and communities, as well as upskilling the remote health workforce (including education and sport and recreation staff), may be beneficial.

Take Heart

The 'Take Heart' initiative created by Moonshine Agency comprises three elements⁸²¹:

- A documentary movie, *Take Heart – The Quest to Rid Australasia of Rheumatic Heart Disease*, and two community-based activities intended to raise awareness of ARF and RHD symptoms.
- Events conducted in Aboriginal and Torres Strait Islander communities at high risk of ARF and RHD, to increase preparedness for taking appropriate action when symptoms are present.
- A social and mass media campaign to raise awareness about ARF and RHD, and provide a support network for those affected by these conditions and those close to them.

Developmental evaluation of this approach in 2017 found the Take Heart short videos and other resources had been well-received and were used regularly.⁸²¹ Strengths included the use of video media, inclusion of children from the Northern Territory, and use of local Aboriginal and Torres Strait Islander languages. Community events were developed iteratively, with greater engagement occurring at events with strong community leadership.⁸²¹ No attempt was made to quantify any changes in health-seeking behaviour during developmental evaluation.

On Track Watch

On Track Watch was a participatory action research project undertaken in a remote Northern Territory Aboriginal community to work towards elimination of RHD using a 'both-ways learning' (reciprocal knowledge co-creation) approach.¹⁰² The intention was to raise community awareness of ARF and RHD and their causation, and to promote preventive strategies and health-seeking behaviours. Aboriginal community researchers devised and delivered activities related to understanding and addressing social determinants of RHD. Findings of the evaluation included the importance of valuing traditional knowledge and ways of learning, such as locally meaningful metaphors to explore unfamiliar concepts; empowerment through critical thinking and community ownership of knowledge about RHD and research; and providing practical guidance in implementing empowering and decolonising principles.¹⁰²

While no examples of increased health seeking for ARF symptoms were evident in this project, changes in local practices relating to health were observed, such as a community researcher taking a child to the clinic for treatment of skin sores who might otherwise not have sought healthcare. The empowering effect of health knowledge was also evident; one community researcher stated: *'I feel very strong now about taking care of djamarkuli (children).'*¹⁰²

END RHD Communities

END RHD Communities is a project currently under way in a number of NT and Australian communities to ensure that individuals and households affected by ARF and/or RHD have access to additional secondary preventive activities beyond penicillin alone.⁸²² The term Secondary Prevention Plus (SP Plus) has been developed to emphasise that more can be done than simply giving benzathine benzylpenicillin injections to these individuals at higher risk of (recurrent) ARF. Key components of the study are for Aboriginal community workers to gain and pass on knowledge about ARF, ARF prevention, and when to seek healthcare; and to help navigate interactions with health services. This includes health promotion to increase health-seeking behaviour for symptoms of ARF; no evaluation is available yet.⁸²²

ARDS Audio Programs

In 2011, a 14-part educational series on ARF and RHD aired on the Yolŋu Radio Service (Northern Territory). The series explained the differences between ARF and RHD, the relationship between the two, how it is acquired, causes, medicines and treatment, and prevention methods. The broadcasts are also available to be downloaded in MP3 audio format and have been recorded in the local Yolŋu Matha language.⁸²³ No evaluation of these resources has been identified.

Champions4Change

RHDAustralia (RHDA) has developed an initiative to support communities living with RHD involving the use of community champions – those with the lived experience who can act as navigators or brokers between individuals and communities and the healthcare systems (Aboriginal and Torres Strait Islander liaison officers/ambassadors).⁸²⁴ The champions enable two-way learning by translating the meaning of health from their perspective into ways that help healthcare workers understand the feelings and experiences of those living with ARF and RHD.⁸²⁴ Through this program, champions assist individuals navigating the healthcare system and provide emotional, social and educational support to those in their own communities.⁸²⁴ In addition, champions are encouraged to design initiatives and projects within their own community, which are then supported by RHDA. The projects are funded by RHDA but led by the champions themselves. For example, one champion based in Katherine, NT, is designing a 'talking poster' for her local clinic, which discusses, in local language, the signs and symptoms of ARF.

Other champions would like to create an ‘information day’ at their local school, to inform students and families of ARF and RHD. A camp is planned for 2020, where champions will be invited to spend two days together discussing new initiatives, sharing projects in their community, attending workshops and sessions, and providing peer support.

Champions are also invited to attend and present at conferences for health professionals, where they’re able to share their stories and discuss challenges faced when navigating the healthcare system. Champions presenting for RHDA regularly receive overwhelmingly positive feedback from attendees.⁸²⁴

Summary: Health promotion to increase health-seeking behaviour for symptoms of ARF		
Domain	Summary	Rating
Evidence	No studies have attempted to measure the effect of health promotion interventions intended to increase health-seeking behaviour for ARF symptoms in Australia. Developmental evaluation from Take Heart suggests that increased awareness may increase health-seeking behaviours.	Medium
Benefits	Increased awareness of ARF and associated changes in health-seeking behaviour could increase the probability of accurate ARF diagnosis and allow for timely initiation of secondary prophylaxis.	High
Risks	Increased awareness may contribute to community concern about possible ARF, particularly given many symptoms are non-specific. If primary-care services are not resourced to respond to increased health-seeking behaviour, or if training is not provided to assess the possibility of ARF, benefits will not be achieved.	Medium
Acceptability	Health promotion programs aiming to increase health-seeking behaviour for ARF must be tailored to the community being targeted, to heighten acceptability among residents. Acceptability among health professionals is unknown.	Medium
Feasibility	Baseline awareness of ARF is low in most settings, and symptoms which are concerning for ARF are quite biomedical. Development of culturally relevant key messages about health-seeking behaviour requires careful co-development with communities.	Medium
Costs	Development of key messages, translation and adaptation to meet the needs of individual communities requires resourcing.	Medium
Timeline	The development of appropriate health promotion materials may take some months.	Medium
Positive externalities	If successful, this approach has potential to be positive and increase self-management of immediate environment, illness and disease.	High
Equity	Equipping individuals and communities with the knowledge necessary to identify their own ill health and seek help is equitable.	High
Recommendations	<ul style="list-style-type: none"> Health promotion strategies to raise community awareness of ARF symptoms and encourage health-seeking behaviour needed to improve diagnosis of ARF. The best approach to increase health-seeking behaviour is not yet clear and a mix of approaches is likely to be needed. Health promotion resources should be developed by communities with support from national and jurisdictional agencies to share key messages about ARF. 	

Increase awareness, training and support for healthcare workers to suspect and diagnose ARF

Increasing awareness of ARF incidence and diagnostic pathways among the health workforce is important to increase detection of ARF. ARF can be complex to diagnose and requires a range of contemporaneous clinical investigations, detailed clinical examination and consideration of potential confounders, including the effectiveness of medications to reduce joint inflammation.^{75,820} A range of training and awareness-raising strategies have been implemented to increase awareness of ARF and knowledge about the diagnostic pathway:

Online training modules and resources

Online training modules have been developed by RHDAustralia to support Aboriginal Health Workers, Aboriginal and Torres Strait Islander Health Practitioners, nurses, midwives and clinicians. They include information about when to consider ARF and how it is diagnosed. Customised content has been developed by some jurisdictions, including an orientation film for new staff in remote settings in Western Australia and a similar resource in South Australia.^{825,826}

RHD Workshops

ARF/RHD workshops have been hosted by jurisdictional control programs with support from RHDAustralia in recent years, as well as independently, reaching many health professionals. RHDAustralia partners with most jurisdictional control programs to deliver workshops on ARF and RHD. The organisation has a suite of modules which can be tailored to the jurisdiction and are available for GPs, nurses, Aboriginal Health Workers, and other allied health professionals. RHDAustralia works with the control programs to determine the location and time of the events, however generally it is encouraged that workshops occur in rural and remote regions to avoid participants having to travel significant distances to cities. In 2018, RHDA delivered nine workshops in two jurisdictions (personal correspondence, Rebecca Slade, 2019).

RHDAustralia diagnosis calculator app

RHDAustralia has developed an electronic application which helps to guide clinicians through case scenarios to identify ARF. A guideline application includes further information to guide investigations, management and notification of ARF.⁸²⁷ The app aligns with RHDAustralia and international clinical guidelines on ARF. Formal evaluation is under way and results are not yet available, although anecdotally it is in widespread use among clinical staff who work in remote Aboriginal and Torres Strait Islander communities. The app has been downloaded nearly 12,000 times since July 2014 (personal correspondence, Rebecca Slade, 2019) and is being translated into Italian and Turkish after requests from clinicians in those countries.

Ensure ARF is embedded into existing clinical guidelines

The 2018 evaluation of the Central Australian Rural Practitioners Association (CARPA) Standard Treatment Manual use in primary care highlighted the importance of having information about ARF diagnosis integrated in a range of clinical resources. This may be particularly important for visiting or short-term medical and nursing staff who are unfamiliar with ARF.

‘One area that I felt really out of my depth was just diagnosing rheumatic fever, and it was just there in the book.’

Participant 13 (GP or GP Registrar), quoted in Jones and Reeve, 2018.⁶⁷⁵

Other resources, including decision support in clinical software, may be an important adjunct to training resources. The role of decision support is discussed in Chapter 4c.

Summary: Increase awareness and training of healthcare workers to suspect and diagnose ARF		
Domain	Summary	Rating
Evidence	There are no formal studies exploring how to improve healthcare worker awareness of ARF. A wide range of approaches have been implemented, although few of these have been evaluated.	Low
Benefits	Increased health workforce awareness of ARF is likely to increase case detection, increasing scope for early diagnosis and early intervention with secondary prophylaxis.	High
Risks	Efforts to increase awareness of ARF could lead to overdiagnosis, specifically with criteria for possible ARF.	Medium
Acceptability	Health workforce education and training meets the expressed needs of health workers and is likely to be broadly acceptable.	High
Feasibility	Development and delivery of training and education resources is feasible.	High
Costs	The cost of developing and delivering training programs varies by setting and format.	Medium
Timeline	Developing training resources from established clinical guidelines can occur relatively promptly.	Short
Positive externalities	The benefits of increased health worker awareness have a direct impact on ARF outcomes.	Low
Equity	Improved awareness of ARF is likely to address inequitable under-recognition and under-treatment and therefore to have an equity-enhancing effect.	High
Recommendations	<ul style="list-style-type: none"> A range of training opportunities and resources are needed to increase health worker awareness of ARF. These should continue to be developed and disseminated by national stakeholders for RHD in Australia. Active review of other clinical guidelines, including CARPA, Therapeutic Guidelines Australia, and other resources used in high-risk communities, should be ongoing to ensure that diagnosis and management of ARF is consistent and in line with national best practice. 	

Improve technical capacity for ARF diagnosis

In addition to elevated inflammatory markers C-reactive protein (CRP) or Erythrocyte sedimentation rate (ESR), two serologic blood tests are used to help to make the diagnosis of ARF by demonstrating recent Strep A infection: ASOT and Anti-DNase B.⁷⁵ A 2019 audit of Strep A serology for people diagnosed with ARF, admitted to hospital, and notified to the RHD register in the Northern Territory demonstrated that blood test ASOT and Anti-DNase B results were available for the vast majority (92%) of people.⁸¹⁸ However, completeness of serology records is likely to be lower for people who were not admitted to hospital or not notified to the RHD register.

Access to these blood tests through public and private laboratory services which are used by most remote primary-care clinics is limited. Low volume of testing means the machines are located in only a small number of centres and that blood samples must be physically transferred interstate for results. This leads to an average turnaround time of about 10 days for ASOT and Anti-DNase B results.⁷⁷ Laboratory services used by most remote primary-care clinics are limited. ASOT (but not Anti-DNase B) has recently become available onsite at the main public tertiary referral hospital laboratory in the Northern Territory.

Research initiatives are under way to develop improved diagnostic approaches for ARF. These may include more accurate laboratory techniques for measuring Strep A serology⁸²⁸ or development of entirely new biomarkers for ARF itself.^{829,830}

Summary: Increase access to Strep A serology blood tests for ARF		
Domain	Summary	Rating
Evidence	Empirical studies to demonstrate that reducing delays in Strep A serology results improves ARF diagnosis are not appropriate. However, ensuring that all necessary information for assessment of the diagnostic Jones Criteria for ARF is available can reasonably be expected to increase diagnostic sensitivity and specificity of diagnosis.	Unknown
Benefits	Improving access to Strep A serology testing and other diagnostic tests required for ARF diagnosis could improve diagnostic accuracy.	Medium
Risks	No risks to increasing access to Strep A serology testing for ARF were identified.	Low
Acceptability	Access to more clinical information is likely to be acceptable to clinicians.	Medium
Feasibility	Feasibility of providing timely Strep A serology results is unknown.	Unknown
Costs	Increasing access to Strep A serology testing implies an increased cost to the health system if more tests are ordered. This cost is likely to be offset by improved diagnosis and management of ARF.	Low
Timeline	Timeline for improving access to Strep A serology results is unknown.	Unknown
Positive externalities	Strep A serology testing is used to help diagnose a number of other conditions (e.g. acute post-streptococcal glomerulonephritis). ⁸³¹ Improving timely access could increase diagnostic precision for other diseases.	Medium
Equity	Improving access to timely Strep A serology results for communities with the highest burden of ARF is likely to be equity enhancing.	Medium
Recommendations	<ul style="list-style-type: none"> More information about access to relevant serology blood test infrastructure in each jurisdiction is needed to identify potential improvement opportunities. Research initiatives to identify more sensitive and specific diagnostic tests for ARF should continue. 	

Improve the utility of ARF notification

ARF is notifiable in five jurisdictions in Australia. Mandatory notification contributes to important epidemiologic information for monitoring the burden of ARF, and provides pathways to trigger outbreak investigations and enrolment on to RHD registers.^{6,832} However, the notification process, data reporting and links to RHD registers vary in each State and Territory, as outlined in Box 16; and the process in some jurisdictions requires manual notification to multiple agencies. This is likely to be a barrier to enrolling people on RHD registers, resulting in missed opportunities for register-based care, discussed further in this chapter in *Health system factors – Registers*. Box 16 and Box 17 describe the jurisdictional processes for ARF and RHD notifications and inclusion on registers.

Box 16: Overview of jurisdictional processes for ARF and RHD notifications and inclusion on registers

- In **New South Wales**, the treating clinician who identifies a person with suspected ARF (all ages) or suspected RHD (in those under 35 years of age) is required to complete a notification form and submit it to the Public Health Unit. The Public Health Unit provides this information to the Local Health District RHD coordinator for follow-up.⁸³³ Informed, 'opt-in' consent is required for people to be included on the register.⁴
- In **South Australia**, ARF and RHD notifications are made to the Communicable Disease Control Branch, via direct phone call or the standard SA notifiable conditions reporting form, within three days of suspecting or confirming a diagnosis.⁶ This Branch is separate

from the SA Rheumatic Heart Disease register.⁸³⁴ Therefore, two separate notifications are required.⁶ RHD register staff attempt to compile clinical details from primary and tertiary care following notification. The 2017 review of the Rheumatic Fever Strategy indicates that assembling this clinical information sometimes requires Freedom of Information requests.⁶ As of March 2019, consent is not required for inclusion on either registers.

- In **Queensland**, both ARF and RHD are notifiable. Notifications are made via a notification form completed by diagnosing clinicians and sent to the Queensland RHD Register and Control Program.⁸³⁵ Patient consent is not required prior to being placed on the state-wide ARF and RHD Register.⁸³⁶ The Register is able to be accessed by clinicians and support staff involved in the care and coordination of patients with ARF and RHD, but they must firstly make a formal application.⁸³⁷
- In the **Northern Territory**, notification of ARF and RHD is mandatory, with a completed form returned to the NT Department of Health Centre for Disease Control.⁶ Inclusion on the ARF and RHD Register does not require consent.⁶ Register data is able to be accessed, on request, by clinicians and support staff involved in the care and coordination of patients with ARF and RHD.
- In **Western Australia**, treating clinicians are required to provide notice when they suspect a patient has, and is currently being treated for, ARF or RHD – including knowledge of previous diagnoses or treatments in another jurisdiction.⁸³⁸ To report, the treating clinician is required to complete an ARF and RHD notification form and provide a copy of each diagnostic test (including an echocardiogram).⁸³⁸ For acute rheumatic fever the acute phase, beginning when the patient is diagnosed with ARF and ending three months later, is also recorded. RHD notifications must also include a copy of each medical specialist's report within 30 days after the medical specialist finalises the report.⁸³⁸ Notifications are provided to the WA RHD Register and Control Program.⁸³⁸ Patients are also required to be informed that it is a statutory requirement for their information to be sent to the Register.⁸³⁸ An individual can request in writing to the Chief Health Officer that there only be limited disclosure of identifying information on the Register about a specific person.⁸³⁹

Simplify the process of ARF notification

It may be possible to simplify notification of ARF at a jurisdictional level by mapping current notification pathways and seeking opportunities to: increase online notification, increase data input from different sources (primary care, laboratory providers and hospital admissions), and to share information between care providers.

Make ARF nationally notifiable

Discussions about the suitability of ARF as a nationally notifiable disease in Australia have been under way for many years.²¹⁴ The process for a condition to become nationally notifiable is established by criteria from the Communicable Diseases Network of Australia (CDNA). National notification of ARF was considered by CDNA in 2010, however this did not progress.⁷⁵ In a 2015 review of ARF against these criteria, ARF and RHD both ranked 23.5/48 points, meeting the threshold for 'national notification to be considered further'.⁸³³ Incorporating ARF into the National Notifiable Diseases Surveillance System would mandate a standardised national approach to notification. This would potentially have a range of benefits: clinicians working across different jurisdictions would all be familiar with a standardised approach to notification and incoming data could be managed.

Summary: Improve the utility of ARF notification		
Domain	Summary	Rating
Evidence	No empirical studies have explored the effect of ARF notification in Australia. However, the steady increase in legislated notification of ARF across Australia provides some indication that notification is desirable or beneficial.	Medium
Benefits	Notification of ARF allows for population-level benefit (by providing epidemiologic information), facilitates outbreak investigation, and can link people to RHD registers. These benefits are likely to be maximised by national-level notification.	High

Summary: Improve the utility of ARF notification		
Domain	Summary	Rating
Risks	The lack of a single diagnostic test for ARF means that case identification and notification must be made by the treating clinician, a process which can be time consuming and an opportunity cost for other clinical activities.	Medium
Acceptability	Options to simplify or streamline notification processes are likely to be acceptable to clinicians. The perspectives of Aboriginal and Torres Strait Islander people on disease notification are unknown.	Unknown
Feasibility	Attempts to simplify notification pathways for ARF at a jurisdictional level are ongoing but are generally constrained by legislative and privacy concerns. Feasibility of national-level notification is unclear.	Unknown
Costs	Any change to notification processes requires education of health staff and development of training resources. This incurs a cost, although costs may be offset by overall gains in health system efficiency.	Medium
Timeline	Procedural change for disease notification generally occurs slowly, over months to years.	Long
Positive externalities	Optimising functionality of ARF notification would be potentially time saving, allowing for activities which improve other disease endpoint outcomes.	Medium
Equity	Improving notification processes is likely to be equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> • Efforts to streamline notification processes for ARF at jurisdictional level should continue. • National stakeholders for RHD in Australia should be resourced to apply to the Communicable Diseases Network Australia for ARF to be considered nationally notifiable. 	

Improve diagnosis of RHD

Baseline situation

The diagnosis of RHD may be made at any stage in the causal pathway of the disease; from subclinical disease detectable on echocardiographic assessment, generally when the diagnosis of ARF is being considered; to advanced valve disease presenting with clinical symptoms. Occasionally, diagnosis is only made at post-mortem examination.

Diagnosis of RHD before heart valve damage becomes severe provides an opportunity to begin secondary prophylaxis. Secondary prophylaxis reduces the risk of heart valve disease progressing to severe RHD and may allow for some improvement (regression) or even complete resolution of mild RHD.⁸⁴⁰

Ideally, secondary prophylaxis is initiated after the first episode of ARF. However, in Australia, 80% of people diagnosed with RHD do not have a register record of a preceding episode of ARF and 19% are diagnosed with severe RHD.¹⁶⁹ Late diagnosis of advanced RHD means people are not able to benefit from disease-altering secondary prophylaxis and may suffer otherwise preventable complications of the disease, such as heart failure, arrhythmia, stroke and premature death.

The opportunity to diagnose RHD before it becomes symptomatic raises the possibility of screening programs to detect RHD in the latent phase before symptoms develop. Suitability of any medical condition for screening asymptomatic people can be assessed using agreed public health criteria, summarised in Table 8.^{841,842}

Table 8: Suitability of early RHD for screening.

Indicator	Reasoning
Evidence of a significant burden of disease	The prevalence of RHD among Aboriginal and Torres Strait Islander people in northern Australia is one of the highest in the world.
Condition must have a latent stage	RHD has an asymptomatic phase when heart valve damage can be detected before symptoms are evident. ²²⁵
The latent stage must be detectable by simple, accessible and sensitive tests	Auscultation with a stethoscope can be used to identify some people with early RHD which is not yet symptomatic. However, auscultation is not sufficiently accurate (sensitive or specific) at detecting asymptomatic RHD for screening. ⁸⁴³ Echocardiography, using ultrasound to examine the heart, is more accurate at detecting asymptomatic RHD and is the most suitable model for screening. ²²⁵ Echocardiography is a non-invasive procedure with painless application of the scanning probe to the chest, although it does require the chest to be partially exposed. ⁸⁴² Echocardiography screening appears to be acceptable in Aboriginal and Torres Strait Islander communities where it has been used. ⁸⁴⁴
The early stage of disease must be treatable with adequate therapy	The natural history of latent RHD is variable. Some early heart valve lesions improve (regress), some remain stable, and other heart valve lesions progress to clinically significant RHD with complications. Many people die if left untreated. ⁸⁴⁵ The risk and rate of this progression is poorly understood but is related to the severity of disease at diagnosis and access to healthcare and cardiac surgery. ⁸⁴⁰ The World Heart Federation (WHF) criteria for echocardiography diagnosis define two categories of latent RHD: borderline RHD and definite RHD. ²²⁵ In general, asymptomatic people with definite RHD on screening echo are at risk of valve disease progression and should receive secondary prophylaxis, depending on age and disease severity. ⁸⁴⁶ However, the role of secondary prophylaxis in borderline disease is unclear, and results from small follow-up studies are variable. ^{840,847,848} A large international randomised trial (GOAL) is currently under way to address these questions. ⁸⁰
Early intervention must improve prognosis	The clinical effect of early diagnosis of RHD through echocardiography screening remains unclear, as the majority of studies were performed in regions of the world with limited access to secondary prophylaxis, cardiac medications and/or cardiac surgery. ⁸⁴⁵

Screening for RHD with ultrasound (by echocardiography)

A number of different research studies have occurred in Australia to understand the role of echo screening for RHD. The largest of these studies was gECHO, conducted from 2008 to 2010 and including approximately 4,000 Aboriginal and Torres Strait Islander children (5–15 years) from 32 remote communities across four regions of northern and central Australia. Participants had echocardiography screening,^{849,850} using portable echo machines and expert echocardiographers. Overall, 4.6 new cases of RHD were detected on echocardiography screening for every 1,000 children screened. Sixty-two children with 'borderline' RHD were detected (15.7/1,000).⁸⁴⁹ The clinical significance of progression of borderline RHD heart valve changes with and without secondary prophylaxis is currently unknown.⁸⁴⁸ Based on this gECHO study, echocardiography screening in high-risk Aboriginal communities in Australia was found to be cost-effective on economic analysis. This was based on assumptions that RHD could be identified two years earlier than it otherwise would have been; that secondary prophylaxis for definite RHD would be started at diagnosis; and that this would result in reduction in disease severity.⁸⁵¹

Other echocardiography screening activities in Australia include SACRHD (2015–2018, South Australia, metropolitan, rural and remote), QLD screening 2018–2020, and screening in the context of ARF and RHD clusters and at the request of small communities.^{58,852,853}

The risks of progression of borderline and early mild definite RHD identified on echocardiography screening, with and without secondary prophylaxis, are currently being explored by the GOAL trial in Uganda.⁸⁰

Internationally, new research has explored training non-expert operators (nurses, community health workers) to undertake echocardiography screening and has considered the role of smaller, more portable echocardiography machines. The results of these studies are promising and may offer a more accessible and cost-effective way to diagnose RHD in resource-poor countries.⁸⁵⁴⁻⁸⁵⁶

The first Australian study using non-expert operators and handheld machines (Pedrino) was conducted in West Arnhem Land in 2018. This study found a very high prevalence of RHD and identified children on echocardiography screening with severe RHD who needed heart surgery.⁸⁵³ A number of organisations and reports have considered the role of echo screening for RHD in Australia in recent years, as evident in Table 9.

Table 9: Organisations and reports considering the role of echo screening for RHD in Australia

Organisation/Report	Key Points
RHD Echocardiography Screening workshop, August 2016 ⁸⁵⁷	A workshop convened by RHD Australia and the END RHD CRE, facilitated by the Deeble Institute for Health Policy Research and the Australian Healthcare and Hospitals Association, was attended by 30 clinical, government, research and primary-care representatives. The workshop acknowledged that, while echocardiographic screening in high-risk communities may be cost-effective, there are other considerations to be considered (including opportunity costs, given that community-level screening is a major and expensive logistical exercise). The workshop concluded there may be a role for echocardiographic screening in some communities, not as a stand-alone activity but as part of a comprehensive RHD control strategy.
Australian Medical Association Report Card on RHD, 2016 ³⁰¹	'Use, but not as stand-alone intervention. It must be coupled with increased resources to improve secondary prophylaxis and ensure health systems can deal with extra cases that will be detected by screening.'
Evaluation of Australia's Rheumatic Fever Strategy, 2017 ⁶	'Key findings: <ul style="list-style-type: none"> • Screening for RHD via echocardiography can identify cases previously undetected. • Studies exploring echocardiography screening have identified several borderline cases with unclear implications and treatment options. • A cardiologist is required to perform accurate screening for RHD via echocardiography. • Screening has obvious benefits in identifying previously undiagnosed cases of RHD. There are currently several issues that need to be resolved before its full utility can be assessed.'
Communicable Diseases Network Australia (CDNA) SoNG for ARF and RHD, 2018 ⁸³²	'The appropriate definition of an ARF outbreak is unclear and may evolve over time, or different definitions may be selected in different States/Territories. Components of an outbreak response may include 'active case finding' – specifically examine at-risk contacts (e.g. aged <21 years, depending on resources) for features of ARF. Cardiac auscultation by an experienced clinician but where possible use of a portable echocardiogram will provide the best sensitivity for diagnosis.'
National Strategic Action Plan for Childhood Heart Disease, 2019 ¹⁴²	'Recommendation 1.2: Develop authoritative national clinical practice guidelines on Childhood Heart Disease for health services and health practitioners throughout Australia: The development of guidelines for echocardiographic screening for RHD is one priority area for consideration.'

Summary: Screening for RHD by echocardiography		
Domain	Summary	Rating
Evidence	Echocardiography can detect RHD before symptoms begin.	Medium
Benefits	Echocardiography screening has benefits for people detected with definite RHD if high-quality secondary prophylaxis is then delivered, as it can lead to regression and even resolution of RHD. There are also benefits for the small proportion of people detected with severe disease by echocardiography screening, who can receive surgery following diagnosis and thereby minimise risk of complications including stroke, heart failure, arrhythmias and death. The potential benefits for those with borderline RHD – a similar number of people as will be diagnosed with definite RHD – are unknown. There are additional population-level benefits from high-quality data on the burden of disease and thereby monitoring disease trends and evaluating other interventions that are designed to reduce the rates of ARF or RHD, e.g. vaccine trials. Moreover, screening activities generally increase community awareness and engagement in RHD control and hence may be a catalyst for better uptake of other ARF, RHD and Strep A control activities.	Medium
Risks	<p><u>Individual risks from echocardiography screening</u></p> <ul style="list-style-type: none"> Echocardiography screening may impact quality of life or create health-related anxiety.^{787,844,858,859} This impact could potentially be mitigated by strategies to improve health literacy, such as peer support groups.⁸⁶⁰ Decisions about whether to give secondary prophylaxis to those with borderline RHD on echocardiography and if so, for how long, have profound implications for the individual, with potential harm from adverse effects of BPG. <p><u>Potential risks to the health system</u></p> <ul style="list-style-type: none"> Opportunity cost of resources devoted to echocardiography screening may reduce capacity to deliver other strategies to prevent new cases of Strep A infection and ARF, or other cost-effective health interventions. The risks may include needs-based funding for cardiology in Australia. Potentially unnecessary secondary prophylaxis in those with borderline RHD or echocardiography is an added burden on the health system. 	Medium
Acceptability	Echocardiography screening appears to be acceptable to Aboriginal and Torres Strait Islander communities in most settings, particularly when it is coupled with community-led action to reduce the burden of Strep A, ARF and RHD.	High
Feasibility	Echocardiography screening using expert operators has been conducted in a number of remote Aboriginal and Torres Strait Islander communities.	Medium
Costs	Echocardiography screening using expert operators in remote Aboriginal and Torres Strait Islander communities is cost effective within certain parameters. ⁸⁵¹	High
Timeline	Development of echocardiography screening programs requires input from communities and a range of stakeholders to be effective. Screening must be coupled with support to delivery secondary prophylaxis.	Medium
Positive externalities	Echocardiography screening activities can engage individuals and communities in wider action to reduce the risk of Strep A infections, ARF and RHD.	High
Equity	Echocardiography screening has the potential to be equity enhancing if it improves delivery of disease-altering secondary prophylaxis for the inequitable burden of RHD.	Medium

Summary: Screening for RHD by echocardiography		
Domain	Summary	Rating
Recommendations	<ul style="list-style-type: none"> Echocardiography screening for RHD may be considered in communities with high rates of ARF and RHD, or in the context of ARF outbreak investigation or follow-up. When echocardiography screening is undertaken, there must be community support and input, and systems and resources available for the provision of education, secondary prophylaxis, and follow-up. Ideally, screening would form part of a comprehensive health response to RHD in communities. The RHD National Implementation Unit should provide advice to communities, government agencies and service providers around criteria and thresholds for screening, funding mechanisms, and technical guidance on implementation of community echocardiographic screening. Further research is required on the role of echocardiography screening in other populations (e.g. pregnant women at high risk of RHD), the use of non-expert operators, and incorporation of screening into routine health checks. Mass population-level echocardiography screening for RHD is not recommended at this time. 	

Improve delivery of secondary prophylaxis

The majority of Aboriginal and Torres Strait Islander people receiving secondary prophylaxis to prevent recurrent ARF have regular injections of the antibiotic benzathine benzylpenicillin (BPG) every 21–28 days. Receiving more than 80% of scheduled injections appears to be protective against recurrent episodes of ARF⁸¹¹ – presumably by protecting against Strep A infections, the subsequent autoimmune response, and progression of heart valve damage to RHD. However, despite investments over many years, delivery of injections remains challenging, with only 36% of people on RHD registers in Australia receiving more than 80% of scheduled injections in 2017, as outlined in Figure 34.⁷⁷

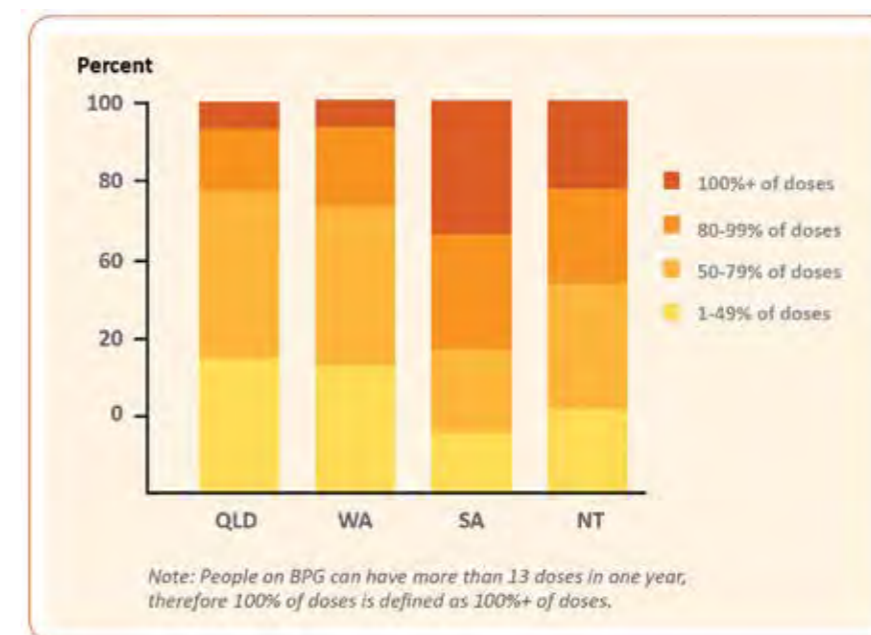


Figure 34: Proportion of scheduled secondary prophylaxis injections delivered for Aboriginal and Torres Strait Islander people in Australia by jurisdiction in 2017.⁷⁷

Some of the difficulties in delivering regular injections for young Aboriginal and Torres Strait Islander people are self-evident, including that the injections are painful, are required too frequently over many years, and are provided by a health system that is under-resourced, with high staff turnover and many competing demands.²⁵³ Characteristics of the medication, condition and context all contribute to low rates of secondary prophylaxis adherence.^{814,815}

The World Health Organization (WHO) has developed a framework for conceptualising adherence to long-term medical therapies, reproduced in Figure 35.⁸⁶¹ This framework provides a useful way of classifying barriers to secondary prophylaxis delivery and identifying how they may be addressed.



Figure 35: Determinants of adherence to long term-therapies.⁸⁶¹

People and culture-related factors

Baseline situation

A range of personal and cultural factors influence adherence to delivery of secondary prophylaxis.

Culture

The overwhelming majority of people receiving secondary prophylaxis against ARF in Australia are Aboriginal and Torres Strait Islander people with a diversity of cultural connections, beliefs and preferences. The experiences of Aboriginal and Torres Strait Islander people during clinical encounters for secondary prophylaxis, and the relationship with health clinic staff and with community have a significant influence on secondary prophylaxis delivery.^{100,105,106} Ensuring that cultural considerations – including opportunities to receive care from Aboriginal and Torres Strait Islander staff, in Aboriginal and Torres Strait Islander languages and according to other personal preferences – are discussed in Chapter 4a.

Ensuring access to culturally outstanding primary-care services is likely to be a major facilitator of chronic disease self-management, particularly secondary prophylaxis delivery for ARF/RHD. These factors are further addressed in the ‘*Culture, Communication, Clinical Interactions: factors for change in chronic disease self-management*’ model developed by Ms Vicki Wade, Senior Cultural Advisor for RHD Australia, reflected in Figure 36. Opportunities to address these domains are explored throughout this chapter, including shared decision-making (including negotiating preferences for pain reduction of secondary prophylaxis delivery), the ongoing need for health promotion resources (including education on ARF and RHD diagnosis and in appropriate Aboriginal and Torres Strait Islander languages), and opportunities for care navigation and cultural supports through peer support and other networks.

Age

Secondary prophylaxis for Aboriginal and Torres Strait Islander people in Australia is delivered most effectively to young children.⁸¹¹ Across the Northern Territory, Queensland, Western Australia and South Australia, register data demonstrate that people aged 15–24 years have lower adherence than people aged less than 15 years, with almost a third in this age group receiving less than half of their prescribed doses.⁷⁷ In early childhood years, secondary prophylaxis is facilitated by parents or caregivers. The lowered rates of adherence in adolescence may be multifactorial – marking the beginning of taking responsibility for their own prophylaxis adherence.¹⁰⁴

Gender

At a population level, males and females have similar levels of secondary prophylaxis adherence. However, more detailed analysis of RHD Register data from the Northern Territory suggests that being female is significantly associated with higher levels of secondary prophylaxis adherence.⁸¹¹ The experiences of women with ARF and RHD may also be influenced by reproductive health considerations.⁹⁸

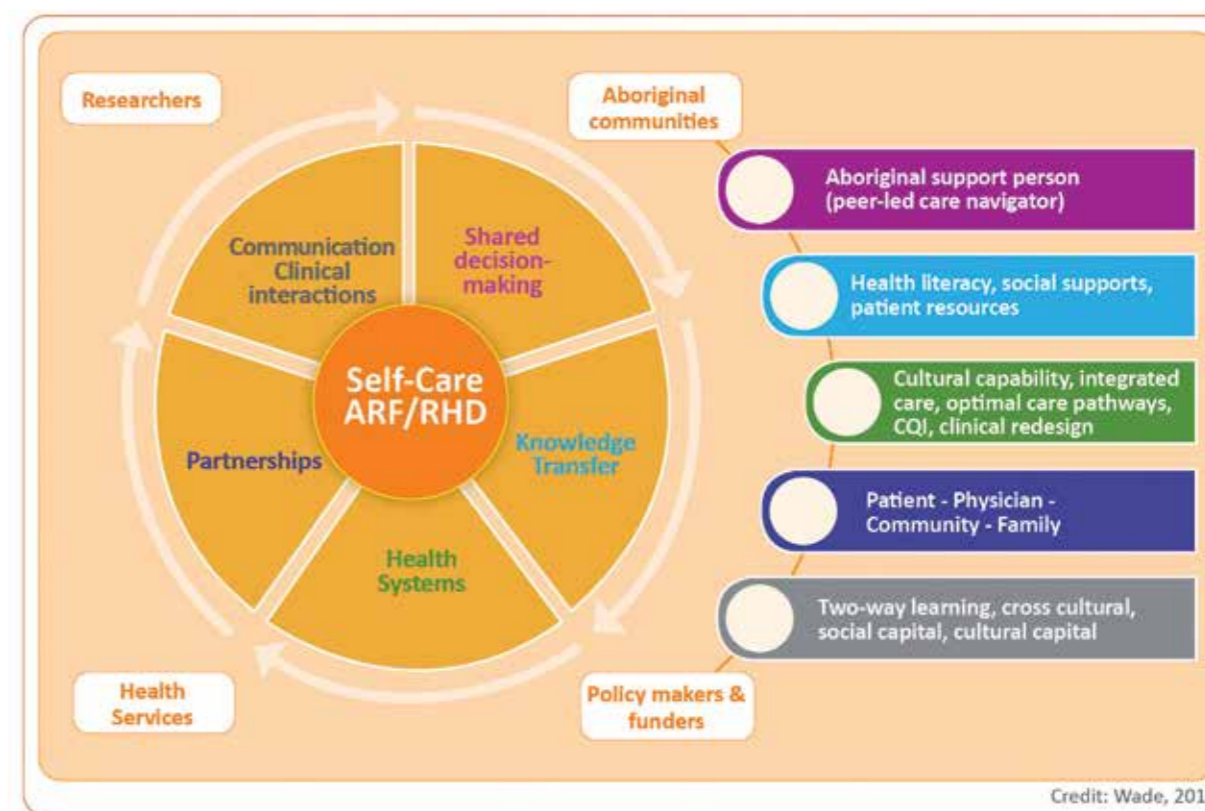


Figure 36: Culture, Communication, Clinical Interactions: factors for change in chronic disease self-management.⁸⁶²

Facilitate peer support for people living with RHD

Being diagnosed with RHD can be a frightening and overwhelming experience, particularly if the diagnosis is made late in the disease when people are experiencing debilitating symptoms or complications from RHD. Many people with RHD are unsure about the cause of disease and its consequences.^{98,863-865}

Support to understand the disease, its treatment and prevention, and other health promotion activities is an important part of helping people living with RHD to manage their disease and contribute to managing their own care.^{98,862} There is some evidence that these benefits occur for young people in Australia living with chronic disease.⁸⁶⁶ Internationally, RHD peer support programs have shown improved overall health-related quality-of-life scores and helped participants ‘*feel less scared about the future*’.^{659,860} A small number of programs have been piloted to explore different kinds of peer support for RHD in Australia.

Champions4Change

Champions4Change involves those living with ARF or RHD assisting with the navigation of the health system, alongside education and disease management.⁸²⁴ Anecdotal evidence suggests the program assists significantly with the uptake and maintenance of secondary prophylaxis protocols, allowing people to act as peers within their communities and providing a mechanism of support for other young people.

Ngukurr needle crew

Clinic staff facilitated young people with RHD to provide ‘mental and emotional support’ to each other while receiving their injections in an informal program in Australia.⁸⁶⁷ *The Needle Crew* involved twelve Ngukurr youths in the remote Northern Territory community providing peer support during their spare time to those overdue for secondary prophylaxis.⁸⁶⁷ With permission from the school and their families, crew members aged between nine and 15 collected students who were scheduled to take their needles, encouraging them to take responsibility for their health.⁸⁶⁷ Peer support has enabled those with ARF and RHD to have an increased understanding of the need for injections while being able to relate to members of the crew, who demonstrate leadership and initiative.⁸⁶⁷

Happy Healthy Heart Kids

An all-female RHD peer support group, self-titled the ‘Happy Healthy Heart Kids’ (3HKids), was trialled at the Menzies School of Health Research in November 2017, involving six people with RHD and their family members (personal correspondence, Dr. Alice Mitchell, 2018). While coming from different communities in Yirrkala and not having met previously, attendees were all members of the same language group. The session ran for 60 minutes and attendees had the opportunity, through an informal format, to ask illness-related questions to the workshop facilitator, who spoke their language; and to participate in craft activities and group discussion and share snacks and drinks. Support group attendees expressed their appreciation for the program and were interested in attending subsequent events. The event organiser identified several reasons for the success of the session, including the location (away from a clinic setting), the opportunity for family members to attend, and the facilitation provided by non-clinic staff.

Danila Dilba Peer Support initiative

A peer support initiative facilitated by Danila Dilba Health Service (DDHS) aimed to address the needs of young people living with RHD and evaluate the potential for a peer support program within the Darwin region.⁸⁶⁸ The genesis for the project emerged through an awareness that living with a chronic disease can be an isolating and challenging task, with encouragement often gained from those sharing the same experience.⁸⁶⁸ Five young people participated in the pilot program, which took place over three sessions. These involved discussions about RHD, support activities such as cooking, games, and opportunities for the young people to connect and discuss their experiences.⁸⁶⁸ While the sample size was small, the project demonstrated a need for an ongoing program in the Darwin region to assist young people navigating living with RHD.

South Australian RHD Camp

Children aged 9–15 and living with RHD in South Australia were invited to a two-day camp hosted by SA Health.⁸⁶⁹ During this period, children took part in educational activities focusing on treatment and general health and hygiene, as well as sporting and outdoor pursuits.⁸⁶⁹ The camp provided young people with an opportunity to connect with those with a shared experience while collectively learning more about RHD.⁸⁶⁹

Take Heart

Developmental evaluation of the Take Heart program in the Northern Territory indicated the program was fostering the development of role models. In particular, young people with ARF and RHD were reported as able to assist their peers navigating a new and unfamiliar health journey.⁸²¹

Summary: Peer support for people affected by ARF and RHD		
Domain	Summary	Rating
Evidence	There is strong evidence that peer support activities can be beneficial for young people living with chronic disease. Although there has been limited formal evaluation of peer support programs for young people with RHD in Aboriginal and Torres Strait Islander communities, they appear to be well regarded and likely to incur similar benefits.	High
Benefits	There are a number of self-reported benefits in improved peer support capacity, including quality of life and confidence in self-management. Improved secondary prophylaxis or clinical outcomes associated with participation in RHD peer support programs have not been demonstrated but are plausible.	High

Summary: Peer support for people affected by ARF and RHD		
Domain	Summary	Rating
Risks	There are several acknowledged risks implicit in peer support programs, including participants making unfavourable assessments of themselves relative to the group, and sharing of behaviours which are counterproductive. ⁸⁶⁶ Additionally, programs which are not culturally appropriate or poorly facilitated can be harmful if incorrect or stigmatising information is shared. Participation in a peer support program also implies that people are comfortable disclosing their history of ARF and RHD. Community and cultural leadership with strong technical support could mitigate these risks.	Medium
Acceptability	Peer support programs appear to be acceptable in a range of small pilot programs.	High
Feasibility	Establishing peer support programs appears to be feasible but maintaining momentum may be challenging, particularly for small programs relying on committed individuals.	Medium
Costs	Simple peer support initiatives are possible with relatively little funding. Larger-scale activities, including those which connect people between remote communities, require transport and potentially staffing costs.	Medium
Timeline	Peer support programs can be developed with some months of planning.	Medium
Positive externalities	Peer support programs which increase health literacy and self-management capacity may support improvements in outcomes for a range of health conditions.	Medium
Equity	Improving access to information and connection with other people living with chronic disease for remote Aboriginal and Torres Strait Islander young people is likely to be equity enhancing.	Medium
Recommendations	<ul style="list-style-type: none"> There is reasonable evidence that peer support programs can improve the lived experience for Aboriginal and Torres Strait Islander young people affected by ARF and RHD. Resourcing to support peer support programs and encourage connections and self-management should be provided, and a range of peer support models iterated by people living with ARF/RHD and communities. Clinical information relevant to peer support programs should be provided to help share high-quality, relevant information. 	

Health system factors – Registers

Baseline situation

RHD registers have been recommended by the World Health Organization to support care delivery for ARF and RHD since the 1950s.^{813,870} This recommendation has been applied in Australia with implementation of RHD registers in five Australian jurisdictions: Northern Territory (established in 1997), Queensland (2006), Western Australia (2009), South Australia (2012) and New South Wales (2016) – summarised in Box 17.

An external evaluation of the *Rheumatic Fever Strategy* in Australia in 2017 found that these registers were effective at increasing support to primary-care clinics that deliver secondary prophylaxis and to people needing secondary prophylaxis and improving national understanding of the burden of RHD.⁶ There is no information in Australia about the clinical benefit for people enrolled in an RHD register relative to people who are not. However, a contemporary study from New Zealand demonstrates that young people on a register-based secondary prophylaxis program received 94% of scheduled injections. This was in contrast to 37% of scheduled injections for a small number of people receiving secondary prophylaxis in unstructured primary care.⁸⁷¹ Interviews with stakeholders suggests that there is a perception of improved clinical care when RHD registers are introduced and function well.⁶

Box 17: Register-based control programs in Australia

ARF and RHD registers in the five Australian jurisdictions are overseen by RHD control programs. RHD registers function with the primary aim to improve the delivery of secondary prophylaxis.^{12,213} The primary aims of RHD control programs are to⁷⁵:

- Identify and register known cases of ARF and RHD;
- Improve uptake of and adherence to secondary prophylaxis;
- Increase awareness of disease diagnosis and management among healthcare providers;
- Improve clinical care and follow-up;
- Support education and health promotion for individuals, families and the community;
- Promote primary prevention aimed at preventing initial ARF episodes; and
- Monitor patient outcomes and improve program strategies through the collection and use of data.⁷⁵

The RHD control programs in the NT, SA, QLD and WA are funded under the Australian Government's Rheumatic Fever Strategy through a National Partnership Agreement. The required outputs under these agreements are the improved detection, monitoring and management of ARF and RHD through: (a) improved clinical care, including improved delivery of and adherence to secondary prophylaxis antibiotics; (b) provision of education and training for healthcare providers, individuals, families and communities; (c) annual collection and provision of agreed data to the Australian Institute of Health and Welfare (AIHW) for national monitoring and reporting of ARF and RHD and measuring of program effectiveness in the detection and management of ARF and RHD; and (d) maintenance of a dedicated state-wide patient register and recall system for ARF and RHD.¹²² The NSW program is funded by the NSW State Government, outside the Rheumatic Fever Strategy, but shares the aims of the other programs.²³⁷

Recommended elements of an RHD control program include but are not limited to⁷⁵:

- Commitment from national, regional and local services.
- Long-term funding and support.
- An advisory committee comprising medical specialists, general practitioners, epidemiologists, nurses, public health practitioners, Aboriginal health service organisations, and community representatives.
- A dedicated coordinating team.
- An electronic patient register that supports patient management.
- Prioritisation of primary and secondary antibiotic prophylaxis delivered within the framework of primary healthcare.
- Planning and advocacy for a stable supply of benzathine benzylpenicillin.
- Development of the ability to find new cases of ARF and RHD.
- Ability to assess and monitor the burden of disease.
- A commitment to partnerships between clinicians and public health.
- Provision of education for health practitioners and health workers.
- Health education for the community and for those with disease and their families.
- Legislation and/or regulations warranting the notification of ARF/RHD which is supported by public health surveillance activities at the State or Territory level.
- A priority system that ensures services are delivered to those at highest risk.
- A mechanism for monitoring delivery of secondary prophylaxis and ongoing care.
- Regular evaluation of all services and activities.⁷⁵

Inaccuracies in register data stemming from manual data entry have been identified in assessments.⁸⁷² Limited resources and large caseloads have been identified as contributors to this issue.⁸⁷² It is also likely that geographic mobility impacts the delivery of secondary prophylaxis. For example, 30% of people receiving secondary prophylaxis moved within New Zealand or overseas over an eight-year period.⁸⁷¹ Similarly, some Aboriginal and Torres Strait Islander Australians move frequently between different regions and jurisdictions. Informal attempts to account for this mobility include a strong working relationship between the Northern Territory and South Australian register-based control programs.

The 2017 evaluation of the *Rheumatic Fever Strategy* recommended that 'It should be a priority for all jurisdictions to collaborate and develop strategies and systems to improve the flow of information between jurisdictional registries and relevant health services. Improvements in this area are likely to flow on to the effectiveness of recall process, reduce manual data entry for registry and health service staff, improve the accuracy of registry data and the efficiency of registry operations.'⁶ There are a number of potential strategies to achieve this goal.

Improve function of RHD registers

Ensure RHD register details are accessible to clinicians at point of care

RHD registers assist in identifying whether an individual person is due for a BPG injection on any given day. This information is critical to clinicians who deliver secondary prophylaxis injections and to people living with ARF/RHD who want to know when their next injection is due. Many people receive BPG injections from different clinics without integrated medical records. Therefore, the RHD register assists in establishing when injections were given and when they are due.

However, access to this information from RHD registers is variable across jurisdictions in Australia. The Rheumatic Fever Strategy evaluation in 2017 noted that in WA, for example, the Department of Health firewall meant Aboriginal Community Controlled Health Organisations were unable to access the register directly due to WA Health security restrictions.

Align jurisdictional register data fields

The five Australian RHD registers have been developed independently and at different points in time, although the register in South Australia is shared with the Northern Territory.²²⁴ The second edition of the Australian Guideline specifies a recommended dataset for ARF/RHD registers. However, collection and interpretation of this data nationally are complicated by under-resourcing of the registers.

Single national register

A single national register to identify people with ARF and RHD and support secondary prophylaxis and ongoing clinical care may be beneficial. A number of reviews have recommended the development of a national register, including the ABCD2 study in 2016.²⁵² The 2017 evaluation of the *Rheumatic Fever Strategy* identified that a lack of being able to share information across State and Territory boundaries was a barrier to continuity of care.⁶ Further work is needed to determine feasibility of a single national register given Australia's varying jurisdictional privacy legislation.

Integration of secondary prophylaxis records with My Health Record

The Australian *My Health Record* was launched in 2018 to provide a secure online summary of personal health information for all Australians. It includes information about shared health summaries, discharge summaries, prescription and medicine-dispensing records, and pathology and diagnostic imaging results.⁸⁷³ Development of the *My Health Record* may provide an opportunity to share clinical information about people receiving secondary prophylaxis who seek care from different services.⁶ Potentially, it may improve recording of when and where people have received BPG injections. However, the real-world usefulness of *My Health Record* for this purpose has not yet been demonstrated.

Summary: Improve the function of RHD registers		
Domain	Summary	Rating
Evidence	There is reasonable international evidence that enrolment in an RHD register improves delivery of secondary prophylaxis. Although this has not been empirically demonstrated in Australia, clinical stakeholders generally report that registers are an important support for care delivery.	Medium
Benefits	The clinical benefits of RHD registers (presumptively, increased delivery of secondary prophylaxis injections and reduced administrative burden in primary-care clinics allowing more time for engagement with people living with RHD) can be maximised if RHD registers have capacity to provide information about secondary prophylaxis due dates at point of care with real-time information.	High

Summary: Improve the function of RHD registers		
Domain	Summary	Rating
Risks	Informed consent and privacy considerations have been addressed in different jurisdictions during RHD register development. It is not clear that the balance between consent and privacy and clinical utility is optimised in all settings. A review of risks and benefits of register-based systems, including people living with ARF/RHD, is warranted.	Unknown
Acceptability	Acceptability of current RHD register systems for clinical staff is variable across Australian jurisdictions. Clinical staff report frustrations with manual data entry and limited access to register information in some settings. ⁶ Little is known about acceptability of RHD register systems for people enrolled on RHD registers.	Unknown
Feasibility	A range of options to improve register function are possible. Feasibility is likely to depend on jurisdictional engagement in register optimisation and resourcing.	Unknown
Costs	Any changes to RHD register function are likely to incur costs on top of already existing outlays.	Medium
Timeline	A complex network of legislation, policies and protocols within and across jurisdictions influences current function of RHD registers. Any changes would require navigating these guidelines, a process which has historically been time consuming.	Long
Positive externalities	Increasing the clinical utility of RHD registers would minimise the administrative burden of delivering secondary prophylaxis in primary care, increasing time available for other primary-care roles including engagement and education.	Medium
Equity	Optimising RHD register function could increase equity of access to care across different jurisdictions.	Medium
Recommendations	<ul style="list-style-type: none"> Optimising the effectiveness of RHD registers is critical to successful delivery of secondary prophylaxis. The RHD National Implementation Unit should be tasked with conducting an updated review of RHD register function, including the perspectives of Aboriginal and Torres Strait Islander people enrolled on RHD registers. Treating clinicians should be consulted and recommendations made to optimise register function jurisdictionally and nationally. 	

Improve recording and reporting of secondary prophylaxis delivery

Documenting secondary prophylaxis delivery is clinically important (to assess whether an individual person living with RHD is at risk of Strep A infection and ARF recurrence from inadequate adherence); provides administrative data to understand how successfully secondary prophylaxis is being delivered to a community or population; and assists research activities.⁸¹⁶

Health system factors – Clinics

Baseline situation

In addition to RHD registers, primary health systems factors can have a substantial impact on secondary prophylaxis delivery.¹⁰⁷ The effect of clinic-level systems was well demonstrated by the RHDSP study in which a range of predominantly clinic-level ‘action items’ were attempted to improve secondary prophylaxis delivery.^{229,874} Although systemic changes were not demonstrated across all participating clinics, increased prophylaxis delivery by at least one high-performing clinic was associated with community-controlled governance, staffing stability, a relatively small number of people living with RHD, and continuous quality improvement processes.²²⁹

The important impact of clinic-level experiences and interactions is intuitive: people receiving regular secondary prophylaxis injections are usually in frequent contact with the health system, amplifying administrative or logistical frustrations of care with each visit. These include lengthy waiting times and limited after-hours services in common with barriers identified for primary prevention.

Evidence for strategies to improve health systems issues in clinics

Clinics – outreach services for secondary prophylaxis delivery

Outreach secondary prophylaxis occurs when benzathine benzylpenicillin injections are delivered outside of clinic – at homes, schools, workplaces or other locations convenient for people. Outreach may improve access to care by reducing logistic barriers to attending clinic, including long waiting times, difficulties in accessing the clinic, being able to seek care during working hours, and fostering relationships with outreach staff. Barriers to outreach programs include health service and clinic-level health and safety protocols and/or resource constraints, meaning staff are unable to make outreach visits.

Currently, outreach secondary prophylaxis is offered on a discretionary basis by some clinics in Australia.⁹⁹ No formal outreach programs have been described nor has there been any published evaluation of the impact of outreach of secondary prophylaxis. However, qualitative data from a number of studies suggest that improving access to outreach options is considered a priority by clinical staff in primary care settings, including a study in the Kimberley region, the large ABCD2 study, and the Northern Territory-based RHDSP study.^{103,107,627} Outreach services were also identified as beneficial by some people living with ARF/RHD.

‘They send me text messages and the nurse comes to see me at home, and if I am at school, she comes to the school and gives the injection.’

Young Aboriginal woman, Read et al., 2018.¹⁰⁷

New Zealand – nurse-based outreach program

To increase the uptake of secondary prophylaxis in New Zealand, community nurse-run clinics are used to conduct outreach. People living with ARF and RHD are placed on a register and parental consent is given for their children to receive BPG every 28 days.⁸⁷⁵ Registered nurses deliver the medication at school, home, work or a clinic, depending on the preference of the individual.⁸⁷⁵ Samoan and Tongan nurses are also employed to provide culturally appropriate care to Pacific Islander children.⁸⁷⁵ When evaluated, compliance rates ranged between 79.9% to 100%.⁸⁷⁵ Those living with ARF and RHD described building rapport with their nurses, who in turn became familiar with the best manner in which to deliver the injection according to personal preference of the individual.¹¹⁴ Delivering the injection in a location convenient to the young person was also seen as beneficial and an enabler of secondary prophylaxis delivery.¹¹⁴

Summary: Outreach services for secondary prophylaxis delivery		
Domain	Summary	Rating
Evidence	Empirical evidence for outreach secondary prophylaxis delivery is unknown in remote Aboriginal and Torres Strait Islander settings in Australia. However, anecdotal reports from people living with ARF/RHD and from primary-care staff suggest that outreach is considered positive when offered on an ad hoc basis. Formal outreach programs in New Zealand have high rates of secondary prophylaxis delivery.	Medium
Benefits	While outreach is positive in terms of treatment delivery, it may not encourage self-management of care.	High
Risks	The safety of healthcare workers may be challenged from risks such as pets, violence and travel. Adverse drug reactions may also occur.	Medium
Acceptability	Evaluation indicates outreach secondary prophylaxis services were highly acceptable for people living with ARF and RHD in New Zealand. ^{114,875} Outreach opportunities seem to be welcome in at least some Aboriginal and Torres Strait Islander settings. ⁸⁷⁶	High

Summary: Outreach services for secondary prophylaxis delivery		
Domain	Summary	Rating
Feasibility	The existence of ad hoc arrangements for secondary prophylaxis in different parts of Australia suggests the approach is feasible. However, safety and consistency of services is unknown. Access to outreach services could be increased and strengthened if agreed clinical protocols were developed.	Medium
Costs	The cost of delivering outreach secondary prophylaxis in remote Aboriginal and Torres Strait Islander communities is unknown but likely to include staff time to leave the clinic and increased use of clinic vehicles. These may be offset by more effective and efficient delivery of secondary prophylaxis with corresponding reduced ARF recurrence.	Unknown
Timeline	Development of protocols and procedures for outreach-based secondary prophylaxis delivery could occur over months or years by exploring current practices and seeking to align with relevant clinical guidelines.	Medium
Positive externalities	Outreach services may also provide an opportunity for staff to address environmental health and provide ongoing education about Strep A, ARF and RHD outside the primary-care setting.	High
Equity	Ensuring access to secondary prophylaxis in a timely manner is highly equitable.	High
Recommendations	<ul style="list-style-type: none"> International evidence and expressed preferences from Australian stakeholders suggest that increasing capacity for outreach secondary prophylaxis is a priority. National stakeholders for RHD in Australia should be resourced to: <ul style="list-style-type: none"> Scope current models of outreach secondary prophylaxis delivery and other relevant outreach programs; Consult with stakeholders to identify regulatory considerations and best practice; Provide guidance about outreach delivery of secondary prophylaxis; and Support evaluation to iterate these outreach-based models of care. Primary-care providers should be resourced to provide outreach secondary prophylaxis services where community demand indicates that this is a priority. Primary-care settings should be resourced to conduct continuous quality-improvement activities to identify opportunities for outreach. Clinics considering outreach secondary prophylaxis delivery should address the safety of healthcare workers (including risks from pets, violence and travel) as well as their capacity to manage adverse drug reactions in the community. 	

Flexible appointment arrangements for secondary prophylaxis delivery

Long wait times and inflexible appointment systems for secondary prophylaxis administration are frequently identified as a barrier to adherence. Increasing flexibility is an important element of providing culturally appropriate primary-care services and may be possible through a mix of different approaches.^{629,656} For example, waiting times are reduced if people attending for BPG injections are prioritised for treatment, such as using a 'fast track' card or other signal.¹⁰⁷ Alternatively, some services provide dedicated injection clinics with appropriate staffing to better support people through the process. In the SP study, one health facility was able to increase access to secondary prophylaxis delivery by providing services over lunchtime.⁸⁷⁶ No formal evaluation of these different approaches has been identified.

'Most of them know [my son]. He went after school ... he didn't get seen until half past three. That's an hour ... He just waited and waited. Bloody file should be there. He goes there every month ... They need to open their eyes more.'

Mother in the Kimberley region reporting on secondary prophylaxis experiences at a hospital, quoted in Mincham, 2003.¹⁰³

Appoint RHD-focused staff within primary-care clinics

The resource and workforce constraints within remote primary-care clinics are addressed in Chapter 4a. These challenges can make it difficult for clinics to manage the administrative and clinical demands of delivering secondary prophylaxis injections.¹⁰⁷ Creating a focused ARF/RHD portfolio for clinic staff may help address this issue and improve secondary prophylaxis delivery in several ways:

- Qualitative studies from across Australia have found that supportive relationships with clinical staff encourage trust and support return attendance.^{103,877} In particular, some people receiving secondary prophylaxis injections report that having a good relationship with the health worker providing injections helps makes the interaction more predictable and less intimidating.^{99,103} Clinics may be able to facilitate these kinds of supportive relationships by nominating a single dedicated healthcare worker responsible for administering secondary prophylaxis injections. Evidence from Australia suggests that this approach can improve adherence.^{123,877,878}
- Administrative management of clinic recall lists for secondary prophylaxis delivery can be time consuming. In a number of jurisdictions, clinics receive a faxed or emailed list of people due for secondary prophylaxis injections from the RHD register.⁶ Clinics commonly need to cross-reference these lists with local recall lists, add recalls for individual people living with ARF/RHD, and communicate with clinic drivers or administration staff about people who need to attend. Without consistent oversight, this process can become fragmented. Appointing a clinic coordinator with responsibility for secondary prophylaxis can streamline planning and strengthen delivery of secondary prophylaxis.

Appointing staff to an ARF/RHD portfolio has been identified as important in several reviews. The ABCD2 study recommended that clinics 'establish a dedicated staff role with responsibility for RHD care' and the SP study identified the importance of a 'well-defined RHD coordinator role' for successful implementation of service delivery improvements throughout the study.^{107,252}

Summary: Appoint RHD-focused staff within primary-care clinics		
Domain	Summary	Rating
Evidence	There is relatively strong evidence that having dedicated staff in primary-care clinics with responsibility for administering and overseeing secondary prophylaxis injections can help improve prophylaxis delivery.	Medium
Benefits	Benefits of a portfolio-based approach to care appear to include more consistent experiences of injection delivery and strengthened administrative capacity.	Medium
Risks	Health staffing turnover in remote Aboriginal and Torres Strait Islander communities is high. In the SP study, the RHD coordinator role moved between individuals in each of the 10 clinics 2–8 times over a 15-month period. ²²⁹ Ensuring training and support for each RHD coordinator in clinics was challenging. ¹⁰⁷ Specialisation of roles within primary-care clinics may confound staffing challenges and potentially undermine a generalist approach in which secondary prophylaxis is 'everyone's business'.	Medium
Acceptability	Appointment of appropriate staff members responsible for injection delivery appears to be acceptable for people receiving secondary prophylaxis injections. Acceptability of a portfolio-based approach for primary-care clinic staff is unknown.	Medium
Feasibility	Appointing primary-care staff to specific responsibilities within remote primary care is relatively common, including chronic disease roles, child health nurses and complex condition coordinators. These roles often reflect differing funding sources, which incurs a reporting and administrative burden for clinics. Flexible funding models for primary care provide the most feasible approach to role allocation within individual clinics.	Medium

Summary: Appoint RHD-focused staff within primary-care clinics		
Domain	Summary	Rating
Costs	Staffing costs for remote primary-care clinics are high and securing dedicated staff time for ARF/RHD activities would require additional resourcing. These costs may be offset by improved efficiency and care delivery.	High
Timeline	Developing a portfolio approach to ARF/RHD management in remote primary care could be developed within weeks to months and could potentially be supported/accelerated by technical support for role descriptions. Resourcing for dedicated staff time is likely to take longer to secure and disperse.	Medium
Positive externalities	Portfolio-based approaches to primary-care service delivery may offer improvements in efficiency and clinic function across a range of clinic areas.	Medium
Equity	The equity effect of dedicated staffing ARF/RHD is unknown.	Unknown
Recommendations	<ul style="list-style-type: none"> There is reasonable evidence that appointing clinic-level staff members with responsibility for delivering and following up secondary prophylaxis is likely to improve prophylaxis delivery. Remote primary-care clinics should be resourced to facilitate designated staff to have responsibility for delivering secondary prophylaxis. Roles and ways of working for this position should be supported by national and jurisdictional agencies. 	

Other strategies

A range of other strategies may be possible to improve delivery of secondary prophylaxis:

Share local innovation and best practice

Reviewing efforts to improve secondary prophylaxis delivery for Aboriginal and Torres Strait Islander people in Australia reveals a long history of local innovation and pilot programs.^{879,880} However, clinics and communities have not always had resourcing or platforms to share these experiences and disseminate best practice. Creating a network of people and communities working to improve secondary prophylaxis delivery may help take some of these initiatives to scale.

Focus on delivering highest-quality secondary prophylaxis at the period of greatest risk

The risk of ARF recurrence and disease progression is highest in the first year after ARF diagnosis.⁸⁷ Therefore, the period following an ARF diagnosis may represent an important biological window when the potential benefit of high-quality secondary prophylaxis delivery is highest. However, current register clinical systems do not distinguish the underlying risk of delayed or missed injections according to clinical priority.⁸⁸¹ Understanding how to allocate resources to maximise clinical impact is likely to require some consideration.

Develop systems to deliver secondary prophylaxis in a range of settings

There is some evidence that delivery of secondary prophylaxis injections outside of 'usual' community primary-care settings is reduced, for example, if people are admitted to hospital, in prison, or away at boarding school.⁸⁷² Establishing systems that facilitate secondary prophylaxis in these settings is essential for achieving high rates of compliance.

Condition-related factors

Baseline situation

One challenge in delivery of secondary prophylaxis is that the people may feel well, and the rationale for needing the injections may not be clear or welcome in the absence of symptoms.^{103,107} A natural extension of this is that Aboriginal and Torres Strait Islander people living with ARF and RHD want more knowledge and communication about their condition.¹⁰³ Interviews conducted during evaluation of END RHD Communities identified that '*clients revealed that they had many questions about their condition and often felt powerless to ask them within the clinic environment*'.¹⁰⁷ Therefore, the condition-specific details of ARF and RHD are likely to be a barrier to secondary prophylaxis delivery. It may be possible to address these barriers through knowledge sharing.

Strategies to address condition-related factors

Address knowledge, attitudes and behaviours about illness and medication

Increase inpatient education on diagnosis

RHD program staff in most jurisdictions currently visit young people diagnosed with ARF when in hospital. In South Australia, the RHD Control program routinely visits children in hospital to provide resources and support materials.⁸²⁶ Increasing inpatient education upon diagnosis allows the individual living with ARF or RHD time to consider questions they may wish to ask staff, as well as opportunities to familiarise themselves with medications, procedures, and consultations regularly required for disease maintenance. Individuals can also be linked in with community peer support programs upon discharge.

Development of education resources

A number of studies have identified strong demand for more educational tools, resources and opportunities for people living with ARF and RHD.¹⁰³ Many resources have been developed to address this need, collated in the RHD Australia resource library. Through existing models, communities with high rates of disease can be encouraged to develop their own resources. Communities can also be supported to disseminate these resources in the most appropriate areas, such as the health centre or school.

Ensure consistent messages from healthcare providers

Consistent messages about the value of secondary prophylaxis should be available for all healthcare staff, communities and people living with ARF and RHD. The goal should be 100% of scheduled injections for every person receiving secondary prophylaxis.⁸⁸² Achieving consistent messaging also requires regular staff training to combat the effects of high staff turnover.

Socioeconomic factors

Baseline situation

Financial cost is an important determinant of adherence with secondary prophylaxis. Internationally, children who had to pay for BPG were much less likely to receive the recommended number of doses each year.⁸⁸³ Most people receiving secondary prophylaxis in remote Aboriginal and Torres Strait Islander communities receive BPG free at point of care through section 100 provisions. The arrangements for remote medication action through s100 are discussed in Chapter 4c on Primary Prevention.

Strategies to address socioeconomic factors

Ensure benzathine benzylpenicillin is free at point of care for people who require secondary prophylaxis

Some Aboriginal and Torres Strait Islander people access secondary prophylaxis outside of remote communities eligible for sS100 medications. This means that some people require a prescription to collect BPG from a pharmacy and take it to a health service (e.g. ACCHS) or GP for administration, creating a barrier to access. As of 2019, the cost for a single 1.2 million IU dose of benzathine benzylpenicillin is \$41.00.⁸⁸⁴ This co-payment is further reduced for those with a concession card and those accessing the Closing the Gap – PBS Co-payment Measure.⁷⁶⁶ Irrespective of a patient medicines co-payment, the non-remote patient's journey is also materially more onerous and complex. A typical scenario may include:

- The patient presents to a prescriber for a consultation and receives a benzathine benzylpenicillin prescription.
- This prescription is taken to a pharmacy and dispensed (or ordered if it is not stocked because it's not an overly common item); the pharmacy may be some distance from the clinic.
- The medicine is dispensed and must be stored in a cool bag and taken straight back to the clinic, or to the patient's home for storage in the fridge.
- The medicine (box of 10 doses) is presented to the clinic for administration but the patient may need to return at a later date when the appropriate practitioner to administer it is available.
- The patient and clinic must consider where the remaining nine doses are stored, noting that sometimes clinics and/or patients may not have adequate fridge space, cold-chain procedures or facilities to store it.

Benzathine benzylpenicillin is listed on the Prescriber Bag with a PBS Note specifying use for syphilis. Expanding this to RHD would address the convoluted process outlined above, and remove the co-payment barrier that exists for some clients.⁷⁶⁶ While research indicates a substantial proportion of BPG provision is likely to occur within s100 sites, it is important that access to secondary prophylaxis remains for those requiring injections when they travel to non-remote areas, or if schooling necessitates a move to a capital city. Individuals should be supported to access these services to ensure no financial barrier is experienced when trying to access essential medication.

Summary: Ensure benzathine benzylpenicillin is free at point of care for people who require secondary prophylaxis

Comments	Benzathine benzylpenicillin should be free at point of care for people who require secondary prophylaxis by changing Prescriber Bag criteria. This will reduce the financial barrier to access and significantly streamline the patient journey and practitioner workflow. Enhancing measures that subsidise prophylaxis medicines (i.e. PBS and s100 schemes) will also further improve the patient journey and reduce financial barriers to access (explored further in Chapter 4c).
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Therapy-related factors

Baseline situation

Secondary prophylaxis with BPG injections implies a number of treatment-related factors which impact on care delivery:

- Injections are indicated every 21 to 28 days to be effective. This is not necessarily an intuitive time frame and requires both people with ARF/RHD and healthcare providers to 'remember' that injections are due.
- Injections are often considered to be painful.

A number of strategies have been proposed and evaluated to address these therapy-related factors.

Strategies to address therapy-related factors

Support people to remember to have injections through memory cues

Remembering to have injections, particularly when they only occur every few weeks, can be challenging, especially when the individual feels well. This may be exacerbated in large families or those with many children with different health issues. Strategies to improve adherence include:

Prophylaxis cards

People living with RHD can be given a card which can be used to record BPG administration dates. The cards may help people living with RHD remember when their next injection is due and can also provide clinicians an indication of whether injections have been missed or given elsewhere. In the Northern Territory, cards developed by Laynhapuy Homelands Aboriginal Corporation have been written in local language and provided to those requiring injections, however there is no evaluation as to the success of this initiative.⁸⁸⁵ Reminder cards are also available in Queensland and hosted on the RHD Australia website.⁸⁸⁶ There is also some international suggestion that providing prophylaxis cards may support self-management of ARF/RHD.⁸¹⁵

Phone reminders

Phone calls or text messages can be a useful reminder for people that injections are due. Some participants in the SP study identified that receiving text messages about secondary prophylaxis injections was helpful.^{229,874} In Samoa, attempts to increase adherence involved staff calling with reminders if patients had not attended the clinic within the designated time period.⁸⁸⁷ Participants in one Australian study wanted to be reminded when injections were due and phone calls and/or messages may be a way of achieving this.¹⁰¹ However, barriers to this include individuals not being able to attain their own phone, lost phones or changing numbers, and staff time.

Calendars

The South Australian RHD Control Program developed a calendar in 2015 which contains messages about ARF and RHD. Centred around the key message 'Don't miss out on the things you love', the calendars are provided to primary-care providers and patients.^{826,888} Evaluation was conducted in 2017 through a survey to Aboriginal primary-care staff and included the following feedback:

- Staff reported having the calendar on their desk was a good prompt to start a conversation with RHD patients.
- All respondents said that it increased their confidence in delivering education about the need for ongoing secondary prophylaxis. Staff liked that the information was on the back of the calendar and they didn't have to remember off the top of their head.
- Respondents stated that patients particularly enjoyed that images were of local people.

Full moon reminders

In 2006, the Central Australia RHD control program launched a novel effort to encourage people with RHD to time BPG injections with the full moon.⁸⁸⁹ A range of strategies including personal calendar cards, full moon posters and radio advertisements were developed. A moderate increase in BPG uptake was demonstrated, with more consistent uptake during the full moon.⁸⁸⁹

Summary: Support people to remember to have injections through memory cues

Domain	Summary	Rating
Evidence	Evidence varies for the efficacy of different reminder systems for secondary prophylaxis injections. However, when considered collectively, reminder systems appear to be associated with increased delivery of secondary prophylaxis compared to no reminder systems. The most appropriate reminder systems are likely to vary by context.	High
Benefits	Optimised reminder systems improve delivery of secondary prophylaxis; they may potentiate self-management capacity and reduce the administrative demands of secondary prophylaxis delivery.	High
Risks	Reminder systems may be intrusive or inappropriate, which could create a barrier to engagement with healthcare providers. Careful co-design of reminder strategies with communities which will be using them may mitigate this risk.	Medium
Acceptability	Acceptability of reminder systems is likely to vary between different modalities. In general, reminder systems appear to be acceptable.	Medium
Feasibility	It is possible to automate some reminder systems (such a text messages) while others may require input from clinic staff.	Medium
Costs	Relatively simple reminder tools may be possible at low cost.	Low
Timeline	Reminder systems can be developed by communities and clinics within weeks to months.	Short
Positive externalities	Reminder systems for secondary prophylaxis may be applied to other medical care delivered at fixed intervals, including weekly administration of new diabetes injections and some weekly antibiotics for chronic lung disease.	Medium
Equity	Reminder systems may overcome systemic barriers to healthcare which would otherwise disadvantage young people living with ARF/RHD, and are therefore equity enhancing.	Medium
Recommendations	<ul style="list-style-type: none"> • National stakeholders for RHD in Australia should be resourced to share examples of successful systems, support evaluation where requested, and develop a suite of opportunities to strengthen prophylaxis reminders. • Communities and clinics should be resourced to develop and deliver locally relevant reminder systems for secondary prophylaxis injections. 	

Support people to remember to have injections through technology

Digital technologies and social media are expanding in use across Australia and the world, including among Aboriginal and Torres Strait Islander youth. Social media has been identified as enabling young people to feel a sense of power and control over their lives while establishing and continuing family and community connections.⁸⁹⁰ Social media and technology have also been explored as enablers of health and wellbeing for those in remote settings.

Take Heart App

The *Take Heart* app, available on iOS- and Android-compatible mobile phones, is designed to assist those who require secondary prophylaxis to stay on track with their injection program.⁸⁹¹ The app is also useful for family, friends, co-workers, health workers and clinic staff caring for or supporting people who require regular injections.⁸⁹¹ It includes several reminder tools and alerts, including daily push reminders in the week before the injection is due, and a calendar function tool.⁸⁹¹ Users can quickly see if they are on or off track for their injections; they can customise the app to suit personal preference and can manage multiple users on one device.⁸⁹¹ Furthermore, the app requires no ongoing network access once downloaded.⁸⁹¹

Evaluation through qualitative interviews sought to determine the extent to which the app is acceptable and implementable.⁸²¹ Positive features included that the app is free, does not require a large amount of memory on the phone, and is simple to use.⁸²¹ The ability for the app to operate without mobile data was also appreciated, especially by those in remote areas who may not have access to regular reception.⁸²¹ Carers also noted the ability to manage multiple children on the same app.⁸²¹ However, app analytics indicated that a significant portion of those who had downloaded the app initially had since uninstalled it, and there were only six active iOS users identified in one month during the evaluation period.⁸²¹ Glitches in the app and inaccuracies in phone notifications were identified as being some of the challenges in sustained usage.⁸²¹

Treatment Tracker App

The Treatment Tracker app developed by RHD Australia is free to download on Android and iOS mobile devices and is designed to both remind and motivate those requiring secondary prophylaxis to receive their injections on time.⁸⁹² Once downloaded, users are prompted to create a profile and avatar and enter their date of last injection. More than one user can be created on the same device if the app is being used by a parent or guardian to manage the secondary prophylaxis of multiple children.⁸⁹² Users are sent notifications leading up to the date of the next injection and reminders if it is missed. Points are amassed each time an injection is received, which can be used to upgrade an avatar with new outfits and accessories.⁸⁹² The app can run without internet connection once downloaded.⁸⁹² It is yet to undergo evaluation, but as of July 2019, had been downloaded 607 times (personal correspondence, Rebecca Slade, 2019).

Summary: Support people to remember to have injections through technology		
Domain	Summary	Rating
Evidence	There is some evidence that mobile phone apps and other technologies can support timely secondary prophylaxis delivery.	Medium
Benefits	Apps may act as a memory cue for people receiving secondary prophylaxis and may facilitate independent self-management.	Medium
Risks	There is the risk of personal information being shared if people share phones or account details. Information about confidentiality and safe technology use could be incorporated into app development or account set-up to mitigate some of this risk.	Medium
Acceptability	When designed in consultation with end-users, acceptability of reminder apps appears to be high.	High
Feasibility	With appropriate resourcing and co-design, app development is achievable.	Medium

Summary: Support people to remember to have injections through technology		
Domain	Summary	Rating
Costs	The development and maintenance of an app requires moderate funding.	Medium
Timeline	App development and consultation with end-users is required.	Medium
Positive externalities	Use of apps and other technology may provide an opportunity to facilitate self-management and delivery of other health-promoting education and behaviours.	High
Equity	Use of mobile phone or technology-based apps could contribute to inequity if they are only available to people who own a mobile phone or have access to phone data.	Medium
Recommendations	<ul style="list-style-type: none"> National stakeholders for RHD in Australia should be resourced to evaluate the use of existing apps in conjunction with research partners, clinic staff and end-users. This information should be used to make future investment decisions about supporting new apps. 	

Minimise pain from secondary prophylaxis injections

Pain from intramuscular injections of BPG is likely to be a barrier to adherence, though individual experience of pain is subjective.^{100,105}

In an Australian study among Aboriginal children receiving BPG injections for treatment of skin sores, 30% of young people had persisting injection site pain at 48 hours. Ten per cent of children required pain relief for injection pain.⁶²⁰ In a New Zealand study, 405 patients (from five years of age to adult) reported a mean pain score of 5.4/10 during administration of Bicillin L-A®(Pfizer).⁸⁹³

‘When I get the injection, it is painful for two to three days. I limp and it sometimes keeps me awake at night. It leaves a lump in buttock that is painful to touch.’

18-year-old woman receiving secondary prophylaxis for seven years, quoted in Mitchell et al., 2018.¹⁰⁵

A range of approaches to reduce injection pain have been trialled. Biomedical approaches include use of direct pressure, vibrating devices, cold packs and adding local anaesthetic to benzathine benzylpenicillin.^{105,893,894} Other strategies include administration by a trusted healthcare provider in a comfortable environment.¹⁰⁵ Administration guidelines have been developed to reduce the pain associated with secondary prophylaxis injections in Australia, although these have not been evaluated.⁸⁹⁵ A range of different approaches to offering and providing pain reduction strategies appear to be in use across Australia, including use of local anaesthetic (Figure 37).¹⁰⁵



Figure 37: The hierarchy of use for secondary prophylaxis pain management.

As described in Chapter 2, lived experience research suggests that variability in using pain minimisation techniques is a concern for people receiving secondary prophylaxis injections. The ideal product characteristics of BPG are a less painful formulation than those currently available, injectable, of a comparable cost and with a long-lasting dose interval.⁸⁹⁶

Summary: Reduce pain from secondary prophylaxis injections		
Domain	Summary	Rating
Evidence	There are a range of biomedical and non-biomedical strategies for reducing the pain of BPG injections with low and moderate evidence of effectiveness.	Medium
Benefits	Efforts to reduce pain are a clinical imperative. Reducing pain of injection delivery may also increase secondary prophylaxis adherence for some people.	High
Risks	Some strategies to reduce the pain of secondary prophylaxis delivery may be associated with clinical risk (for example, the use of local anaesthetic added to benzathine benzylpenicillin). Exploring these risks in more detail and providing practice guidelines would be likely to reduce risks.	Medium
Acceptability	Qualitative research suggests that Aboriginal and Torres Strait Islander people generally want more control and consistency about how secondary prophylaxis injections are delivered and pain minimisation strategies are offered. Efforts to pursue these goals are likely to be acceptable.	High
Feasibility	Ongoing staff education, practice guidelines and research to minimise pain from secondary prophylaxis delivery are all feasible with sufficient resourcing.	High
Costs	Clinical protocols and resources for health staff delivering secondary prophylaxis could be updated and disseminated at relatively low cost. Substantive guideline changes or clinical research to explore novel methods of pain reduction would be associated with higher costs.	Medium

Summary: Reduce pain from secondary prophylaxis injections		
Domain	Summary	Rating
Timeline	Process changes could be implemented within months, substantive clinical practice changes are likely to take years to implement.	Medium
Positive externalities	Process changes which increase consistency of pain reduction strategies for BPG injections may have a flow-on effect to other painful intramuscular injections and procedures.	Medium
Equity	Improving consistency of pain reduction techniques offered for secondary prophylaxis injections would be equity enhancing by reducing current variations in practice.	Medium
Recommendations	<ul style="list-style-type: none"> A range of strategies can reduce the pain of secondary prophylaxis injections and these should be offered routinely before injection delivery. National stakeholders for RHD in Australia should continue to be resourced to review these strategies, develop clinical practice guidelines and disseminate these approaches. 	

Provide incentives for having secondary prophylaxis injections

Providing material incentives has been suggested as an option to increase uptake of secondary prophylaxis.^{252,815,897} A small pilot program to trial the use of incentives has been described in Australia, where those living with ARF and RHD would receive a small prize after three consecutive needles on time.⁸⁹⁸

A New Zealand study investigated whether an incentive program improved secondary prophylaxis uptake over a one-year period.⁸⁹⁹ The incentive was a mobile phone and a \$20 monthly 'top-up' for data and call usage if injections were received.⁸⁹⁹ Among the 77 participants, it was found that injections increased significantly among those who intermittently received SP immediately post-intervention, and then decreased slightly over time.⁸⁹⁹ It was determined that the incentive demonstrated positive impacts for those identified as being partially adherent and facilitated greater lines of communication between patients and clinic staff that enabled more regular reminders to be undertaken.⁸⁹⁹

Summary: Provide incentives for having secondary prophylaxis injections		
Domain	Summary	Rating
Evidence	There is moderate evidence of the use of incentives to increase the uptake of secondary prophylaxis, however it has not been explored in depth in Australia.	Medium
Benefits	Increasing the rate of secondary prophylaxis yields individual benefit and may have wider benefit for the healthcare system if the chances of disease progression are reduced.	Medium
Risks	Incentives could be viewed as paternalistic and coercive. An expectation of incentives could become associated with other medical procedures. Sustainability of inactive programs may be difficult if funding sources change over time and a reduction in secondary prophylaxis delivery could occur if incentive programs were stopped. Further, if not widespread, those receiving SP could move from an incentive program to a non-incentive program, resulting in inconsistencies in service and expectation.	Medium
Acceptability	The acceptability of incentive programs for secondary prophylaxis delivery in Australia is largely unknown and would require careful consultation.	Unknown
Feasibility	The logistics of offering incentives may be challenging, especially in ensuring incentive items were provided to the correct individual.	Medium
Costs	Depending on the type, frequency and delivery of incentives, costs may be high. However, apps like the Treatment Tracker with a built-in incentive system where injections go towards buying things for an avatar can occur at no additional cost.	Medium
Timeline	Establishing an incentive system would require some baseline work and continued management to ensure it is age- as well as culturally and ethically appropriate.	Medium
Positive externalities	If incentives were successful, more regular engagement with health services would be facilitated.	Medium
Equity	While secondary prophylaxis incentives would benefit those living with ARF/RHD, they may be viewed as inequitable by others requiring regular care for other illnesses.	Low
Recommendations	Further research is required to investigate the acceptability, cost, sustainability and feasibility of interventions to increase uptake of secondary prophylaxis.	

Summary of strategies to improve secondary prophylaxis

Chapter 4d outlines different approaches to increase delivery of secondary prophylaxis to prevent recurrent episodes of ARF. Potential approaches are summarised in a standardised framework.

	Evidence	Benefits	Risk	Acceptability	Feasibility	Costs	Timeline	Positive externalities	Equity	Recommendation	Overall Evidence & Priority
Early and accurate diagnosis of ARF											
Health promotion to increase health-seeking behaviour for symptoms of ARF	Medium	High	Medium	Medium	Medium	Medium	Medium	High	High	Health promotion resources should be developed by communities.	High
Increase awareness and training of healthcare workers to suspect and diagnose ARF	Low	High	Medium	High	High	Medium	Short	Low	High	Training opportunities and resources should continue to be developed and disseminated.	High
Increase access to Strep A serology blood tests for ARF	Unknown	Medium	Low	Medium	Unknown	Low	Unknown	Medium	Medium	More research is required.	Research
Improve the utility of ARF notification	Medium	High	Medium	Unknown	Unknown	Medium	Long	Medium	High	Efforts to simplify notification processes for ARF at a jurisdictional level should continue.	High
Improve diagnosis of RHD											
Screening for RHD by echocardiography	Medium	Medium	Medium	High	Medium	High	Medium	High	Medium	Mass population-level echocardiography screening for RHD is not recommended at this time.	Medium
Improve delivery of secondary prophylaxis											
Peer support for people affected by ARF and RHD	High	High	Medium	High	Medium	Medium	Medium	Medium	Medium	Resourcing to support peer support programs and encourage self-management should be provided.	High
Improve the function of RHD registers	Medium	High	Unknown	Unknown	Unknown	Medium	Long	Medium	Medium	Optimising the effectiveness of RHD registers is critical to successful delivery of SP.	High
Outreach services for secondary prophylaxis delivery	Medium	High	Medium	High	Medium	Unknown	Medium	High	High	Increasing capacity for outreach SP is a priority.	High

	Evidence	Benefits	Risk	Acceptability	Feasibility	Costs	Timeline	Positive externalities	Equity	Recommendation	Overall Evidence & Priority
Improve delivery of secondary prophylaxis											
Appoint RHD-focused staff within primary care clinics	Medium	Medium	Medium	Medium	Medium	High	Medium	Medium	Unknown	Remote primary-care clinics should be resourced to facilitate designated staff to have responsibility for delivering SP.	High
Ensure benzathine benzylpenicillin is free at point of care for people who require secondary prophylaxis	Benzathine benzylpenicillin should be free at point of care for people who require secondary prophylaxis by changing Prescriber Bag criteria. This will reduce the financial barrier to access and significantly streamline the patient journey and practitioner workflow.										
Support people to remember to have injections through memory cues	High	High	Medium	Medium	Medium	Low	Short	Medium	Medium	Communities should be resourced to develop and deliver locally relevant reminder systems for SP injection.	High
Support people to remember to have injections through technology	Medium	Medium	Medium	High	Medium	Medium	Medium	High	Medium	Further research is required.	Research
Reduce pain from secondary prophylaxis injections	Medium	High	Medium	High	High	Medium	Medium	Medium	Medium	Strategies to reduce the pain of SP injections should be routinely offered before injection delivery.	High
Provide incentives for having secondary prophylaxis injections	Medium	Medium	Medium	Unknown	Medium	Medium	Medium	Medium	Low	Further research is required.	Low

Synthesis of secondary prevention recommendations

Community level recommendations

- Resourcing to aid peer support programs and encourage connections and self-management should be provided, and a range of peer support models iterated by communities and people living with ARF/RHD.
- Clinical information relevant to peer support programs should be provided to help share high-quality and relevant information.
- Primary-care providers should be resourced to provide outreach secondary prophylaxis services where community demand indicates that this is a priority, and to conduct continuous quality-improvement activities to identify opportunities for outreach.
- Clinics considering outreach secondary prophylaxis delivery should address the safety of healthcare workers (including risks from pets, violence and travel) as well as their capacity to manage adverse drug reactions in the community.
- Remote primary-care clinics should be resourced to facilitate designated staff to have responsibility for delivering secondary prophylaxis.
- Communities and clinics should be resourced to develop and deliver locally relevant reminder systems for secondary prophylaxis injections.
- Echocardiography screening for RHD may be considered in communities with high rates of ARF and RHD, or in the context of ARF outbreak investigation or follow-up. When echocardiography screening is undertaken there must be community support and input, and systems and resources available for the provision of education, secondary prophylaxis and follow-up. Ideally, screening would form part of a comprehensive health response to RHD in select communities. Jurisdictional programs would have a key role in reviewing where screening may be required, based on incidence of ARF identified in the data.

State and Territory recommendations

- Efforts to simplify notification processes for ARF at jurisdictional level should continue.
- Jurisdictional programs should work together with primary-care clinic staff members responsible for secondary prophylaxis delivery.

National recommendations

- Health promotion resources should continue to be developed by national and jurisdictional agencies with communities to raise awareness of ARF symptoms and encourage health-seeking behaviour.
- Training opportunities and resources to increase health worker awareness of ARF symptoms and pathways should continue to be developed and disseminated by national stakeholders for RHD in Australia. Active review of other clinical guidelines – including CARPA, Therapeutic Guidelines Australia and other resources used in high-risk communities – should be ongoing to ensure that diagnosis and management of ARF is consistent and in line with national best practice.

RHD National Implementation Unit recommendations

The RHD National Implementation Unit should be resourced to:

- Conduct an updated review of RHD register function, including the perspectives of Aboriginal and Torres Strait Islander people enrolled on RHD registers. Treating clinicians should be consulted and recommendations made to optimise register function jurisdictionally and nationally. This should occur in acknowledgement that optimising the effectiveness of RHD registers is critical to successful delivery of secondary prophylaxis.
- Scope current models of outreach secondary prophylaxis delivery and other relevant outreach programs, consult with stakeholders to identify regulatory considerations and best practice, provide guidance about outreach delivery of secondary prophylaxis, and support evaluation to iterate outreach-based models of care.
- Work with communities around clinical staff responsible for secondary prophylaxis delivery in conjunction with jurisdictional programs to identify and share successful programs.
- Share examples of successful systems, support evaluation where requested and develop a suite of opportunities to strengthen prophylaxis reminders.
- Evaluate the use of existing mobile apps for secondary prophylaxis reminders in conjunction with research partners, clinic staff and end users.
- Review strategies to reduce pain of secondary prophylaxis injections, develop clinical practice guidelines, and disseminate these approaches.
- Provide advice to communities, government agencies and service providers around criteria and thresholds for screening, funding mechanisms, and technical guidance on implementation of community echocardiographic screening.
- Apply to the Communicable Diseases Network of Australia for ARF to be considered nationally notifiable.

Research stakeholder recommendations

- Research initiatives to identify a more sensitive and specific diagnostic test for ARF should continue.
- Further research is required on the role of echocardiography screening in other populations (e.g. pregnant women at high risk of RHD), the use of non-expert operators, and incorporation of screening into routine health checks.
- Further research is required to investigate the acceptability, cost, sustainability and feasibility of interventions to increase uptake of secondary prophylaxis.

4 STRATEGIES TO END RHD

4e TERTIARY CARE FOR PEOPLE WITH RHD

An overview of opportunities to assist those living with RHD to live life to its full capacity



Photo credit: RHD Australia

Introduction

Tertiary care in the context of rheumatic heart disease (RHD) is focused on people already living with RHD to reduce symptoms, improve quality of life and extend life expectancy. The aims of tertiary care for RHD are to monitor the function of the heart and heart valves, to provide advanced medical and surgical management, and to provide other primary and specialist health services which prevent complications (Figure 38).^{18,75} Optimising clinical outcomes for people living with RHD is a moral imperative in Australia. In people with severe RHD, damage to heart valves can progress such that it significantly impairs the function of the heart. People with severe RHD may require cardiac surgery to repair or replace the cardiac valves.¹⁸ Surgery among young people is not uncommon. In the Northern Territory, 60% of people diagnosed with RHD between the ages of 15–24 years will require heart valve surgery within five years of diagnosis.¹

People living with RHD need care from a range of primary and specialist health providers, making timing and coordination particularly complex. They require reviews by a specialist experienced in RHD management, access to echocardiography to assess valvular and cardiac function, adequate monitoring of anticoagulation therapy in those with atrial fibrillation and/or mechanical prosthetic valves, access to oral healthcare, and timely referral for heart surgery.⁷⁵ In addition, pregnant women with RHD require enhanced care because pregnancy places an increased demand on the heart, even in otherwise well women. These normal changes, including an increase in blood volume and heart rate, a reduction in the resistance of arterial circulation, and increased cardiac output, can worsen pre-existing heart valve issues such as those associated with RHD.⁹⁰⁰

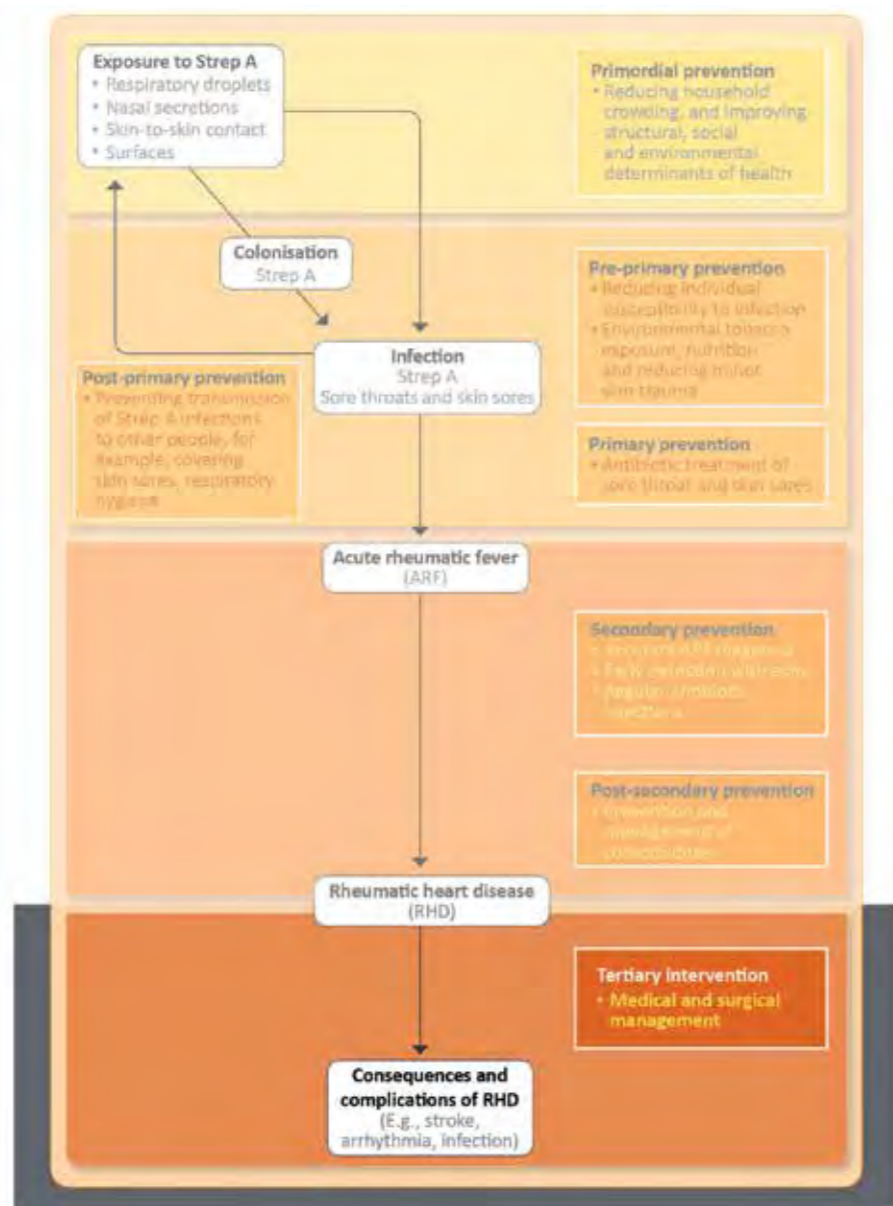


Figure 38: The spectrum of tertiary care.

This chapter addresses a number of the critical priority issues in improving outcomes for Aboriginal and Torres Strait Islander people living with RHD. The focus of the *Endgame Strategy* is preventing new diagnoses of acute rheumatic fever (ARF) and RHD. Tertiary care does not prevent people developing ARF and RHD, therefore the scope of this chapter is constrained to a relatively small number of priorities needed to provide the best possible care for people already living with RHD. Furthermore, this chapter is not an exhaustive discussion of the many areas which need to be addressed to improve Aboriginal and Torres Strait Islander heart health. A detailed overview of these issues is provided in *'Better Cardiac Care measures for Aboriginal and Torres Strait Islander people: first national report 2015'*.¹³⁸

In the absence of an overarching framework for describing tertiary services for people living with RHD, this chapter is structured loosely around an individual patient journey. An approximate framework for this journey is outlined in Figure 39. This framework represents an example clinical trajectory – including the need for routine specialist review, specialised medical management, and surgical planning for people with severe RHD.

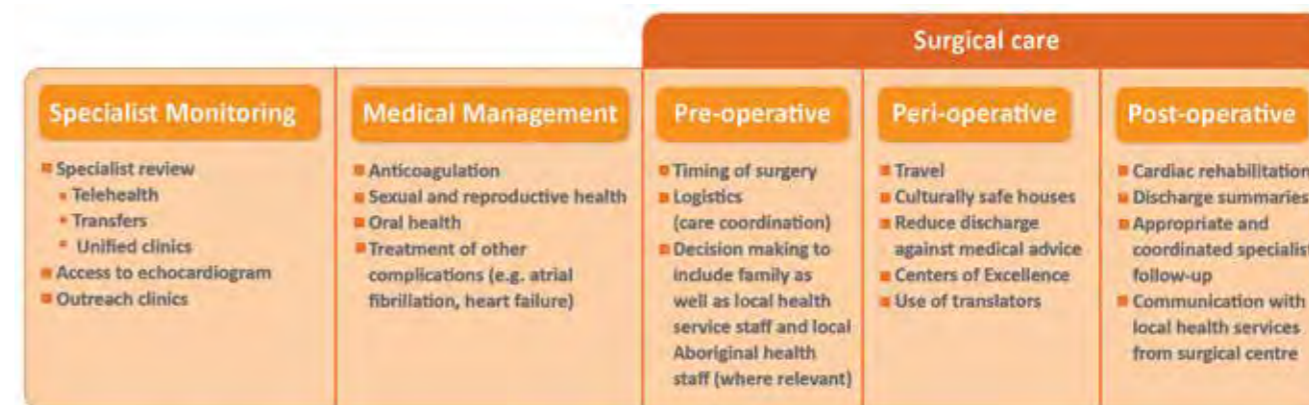


Figure 39: Framework describing the individual patient journey.

The service delivery requirements to achieve high-quality, patient-centred care for Aboriginal and Torres Strait Islander people living with RHD are considerable. Models of service delivery need to be flexible and coordinated through primary healthcare. In order to provide people living with RHD the best opportunity for good health and wellbeing, it is essential to have sufficient resourcing of primary healthcare services, workforce and training. These structural issues are addressed in detail in Chapter 4a.

Methods

A range of existing reports inform thinking about tertiary care for RHD in Australia. A small number of these are specific to RHD but many reflect shared priorities for management of conditions with similar medical management needs (including congenital heart disease and ischaemic heart disease). Key recommendations have been drawn from these documents. In addition, examples of programs and initiatives illustrative of a type of approach or strategy have been selected to inform recommendations. The key data sources include:

Cardiac Society of Australia and New Zealand 2011 Indigenous Cardiovascular Health Conference Priorities identified at the conference held in Alice Springs in 2011 focused around echocardiography, secondary prophylaxis and management of advanced RHD.²²⁶ Further research was advocated for prior to echocardiographic screening for RHD being incorporated into Australian clinical practice.

Secondary prophylaxis was acknowledged as a priority, with a focus on the development and evaluation of primary healthcare-based programs to enhance uptake. National centres of excellence for the surgical management of RHD were considered imperative. Other priorities included early referral for surgical assessment, a national RHD surgical register, and a research strategy for the assessment, intervention and long-term outcome of surgery and other interventions for RHD.²²⁶

National Strategic Action Plan for Childhood Heart Disease 2019

The priorities identified in this strategy around tertiary management for RHD are primarily drawn from the *National Strategic Action Plan for Childhood Heart Disease (CHD) 2019*.¹⁴² This plan was developed by HeartKids on behalf of the Australian Government's Department of Health, in collaboration with clinicians, researchers, patients and carers.

The Plan aims to deliver the following:

- Australian standards of care for CHD, inclusive of neurodevelopmental and mental health standards;
- More specialist CHD health professionals and specialist CHD centres;
- Increased awareness of CHD and improved access to information, support and resources for those impacted by CHD;
- Greater research into evidence to inform early intervention and improved methods of treatment; and
- Monitoring and surveillance of the Action Plan to ensure benefit.¹⁴²

END RHD CRE Focus Group 2018

To inform thinking about RHD, a focus group of END RHD CRE investigators and collaborators was convened in May 2018 to scope potential priorities [HREC RA/4/20/4489].⁹⁰¹ Nine people participated in the tertiary care focus group. They self-identified their primary role as clinician (5), employed in RHD (2), researcher (1) and student (1). Six participants worked primarily in Australia and three in other international settings. There were no Aboriginal or Torres Strait Islander participants. Key themes included:

- The need for culturally appropriate surgical and clinical services and care;
- Improving access to specialist cardiology services Australia-wide;
- Optimising transition of care from paediatric to adult services, including specific adolescent models;
- Care during pregnancy for women with RHD or at high risk of RHD;
- Development of national centres of excellence and standards of care for services providing surgery for RHD; and
- Increasing diagnostic services in rural and remote Australia.

Tertiary care

Specialist review and monitoring of people with RHD

Improve access to specialist assessment and monitoring for people with ARF/RHD

Baseline situation

Aboriginal and Torres Strait Islander people with RHD have a number of ongoing medical needs. In addition to access to culturally appropriate primary-care services, best practice for RHD entails⁷⁵:

- Secondary prophylaxis with antibiotics (addressed in Chapter 4d);
- Monitoring of anticoagulation in people with atrial fibrillation (AF) and/or mechanical prosthetic valves;
- Access to oral healthcare to reduce the risk of endocarditis;
- Access to serial echocardiography to monitor heart and valve function;
- Management of symptoms relating to heart failure, arrhythmias or other complications of RHD;
- Regular access to a specialist physician, paediatrician and/or cardiologist;
- Transition to adult care pathways, including sexual and reproductive health;
- Preconception care for women, including planning interventional therapy; and
- Access to cardiothoracic and interventional cardiology services for those with more severe RHD.

There is some evidence that these specialist medical needs are not being met. Mid-2000s audits of guideline-based care delivery in the Kimberley region of WA and Far North Queensland identified significant service gaps. For example, across both locations only 55% of people with RHD had had specialist review by a paediatrician, physician or cardiologist within the timeframe recommended by clinical guidelines.²²⁷ Similarly, only 60.5% of people had undergone echocardiography review of their heart within the recommended timeframe.²²⁷

A challenge for those living in rural or remote areas is arranging appointments to match fixed transport options, which can run irregularly. In one study, a third of all patients and carers highlighted this as a specific barrier to their care, with a common consequence being that they had to stay in the unfamiliar setting overnight or for days longer than required.⁹⁰² Furthermore, erratic postal schedules meant appointment notices arrived close to the appointment date, further challenging transport arrangements.⁹⁰² The study found that the onus often fell on rural and remote healthcare workers to arrange travel for those with planned admissions or outpatient appointments.⁹⁰²

Access to specialists for Aboriginal and Torres Strait Islander people in remote locations can occur in three main ways: travel of people living with RHD, travel of specialists, and telehealth. All successful models require integrated multidisciplinary care. Variations of these approaches are presented in Figure 40.

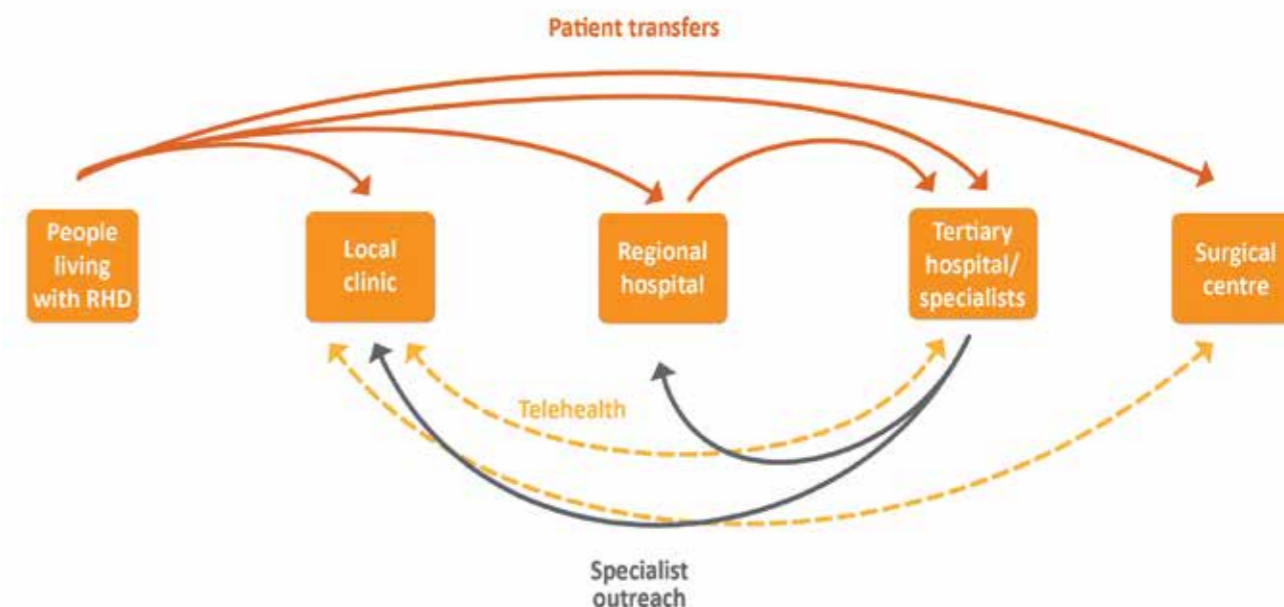


Figure 40: Patient journey in accessing specialist care for RHD

Optimise travel for people living with ARF/RHD to access specialist services

Accessing specialist care for RHD often involves patients travelling long distances, from remote locations to metropolitan centres as well as interstate for specialist cardiac services. It is widely acknowledged that Aboriginal and Torres Strait Islander people needing to travel vast distances for cardiac surgery are confronted with cultural, financial and personal challenges.⁹⁰³ Research indicates this includes a lack of safe roads, poor access to public transport, and unroadworthy vehicles.⁹⁰² Navigating these conditions as well as travelling while unwell is also detrimental to wellbeing.⁹⁰²

Experiences vary with urgency of travel. In one study people who were acutely evacuated for emergency treatment felt relatively well supported compared to people who needed to travel independently but at short notice for specialist services.⁹⁰² However, in both instances staff have reported patients arriving without necessary paperwork, scans, money, clothes or escorts, to the detriment of care.⁹⁰² Rates of 'did not attend' appointments at tertiary centres are also significantly higher for people living in rural and remote locations.⁹⁰⁴

Unfamiliarity with the location, uncertainty about the procedure, and time away from country and family are additional concerns experienced by Aboriginal and Torres Strait Islander people travelling for health reasons.⁹⁰⁵ Many have also experienced a family member going to the city for a procedure and not returning due to further ill health or death, lessening their own confidence in the process.⁹⁰⁵ Lastly, a lack of privacy within the hospital setting and restrictive guidelines on visitors may deter many from accessing tertiary care as needed.⁹⁰⁵

The Patient Assistance Travel Scheme (PATS) provides patients and eligible escorts in rural and remote regions of Australia with the financial assistance required to travel to and stay near specialist medical services while undergoing care.⁹⁰⁶ Each scheme is managed by the respective State or Territory within which the patient resides.⁹⁰⁶ Payments and rates vary between jurisdictions but generally still require the patient and their family to contribute some funds towards travel and accommodation. Subsidies for fuel and lodgings exist but are not intended to cover the full costs of visiting a major town or city for healthcare. Furthermore, payments do not allow for earnings lost by the patient and/or their carer, which are more substantial due to the greater number of days required to travel than for people living in urban areas. Additionally, only a select number of specialist visits are covered by PATS and not all requests are deemed eligible.

Other issues include non-uniform eligibility criteria and travel and accommodation benefits between States and Territories, a lack of availability for allied health and dental services on many schemes, inflexibility with transport options, and a complex application process.⁹⁰⁷

Optimise the Patient Assistance Travel Scheme (PATS)

Several reviews of PATS schemes have been undertaken to achieve consistency between jurisdictions while ensuring a level of fairness for rural and remote patients. Recommendations have included:

- Increasing the amount awarded towards accommodation costs.⁹⁰⁸
- Lowering the threshold that patients must travel before becoming eligible for PATS assistance.
- Allowing automatic approval of an escort and their costs for a child under the age of 18 years.²⁷
- Strengthened support for caregivers with children, including travel provision for all children of breastfeeding mothers.
- Creating a less bureaucratic and more streamlined process that is easier for families to navigate during difficult periods.⁹⁰⁶
- The development of national standards for PATS delivery.⁹⁰⁹
- Greater mechanisms to monitor performance, identify areas for improvement, and review the standards as required.⁹⁰⁹
- Expansion of services to include allied health, dental care and screening services.⁹⁰⁹

A recent WA review found that the funding received did not reflect a realistic proportion of costs incurred out of pocket by patients, so funding needed to be adjusted in line with inflation as well as expanding service eligibility and access.⁹¹⁰

Summary: Optimise PATS		
Domain	Summary	Rating
Evidence	No empirical evidence of access to specialist services for people with and without PATS support was identified. However, a number of reviews have identified that financial support through the PATS program is considered important or essential for facilitating specialist access for people living in rural and remote Australia. A number of reviews have identified opportunities to improve PATS.	High
Benefits	An optimised PATS system, which is easier to navigate and access for people living with RHD, families, primary-care staff and specialist services, could improve access to specialist review, reduce costs associated with inefficiencies, and potentially improve acceptability.	High
Risks	PATS systems in each jurisdiction are complex networks and system redesign may be associated with confusion, disruption or increased costs.	Medium
Acceptability	Improving and streamlining PATS services is an expressed priority for a range of stakeholders, including people living with RHD, community members, primary-care staff, and specialists. ^{906,907,910}	High
Feasibility	Despite a number of reviews over some years to optimise PATS services, change has been slow, reflecting system complexity and costing concerns.	Low

Summary: Optimise PATS		
Domain	Summary	Rating
Costs	Changes to PATS arrangements are potentially costly, although efficiency gains may recoup some of these travel costs.	High
Timeline	Changes to PATS have historically taken a prolonged period to execute.	Long
Positive externalities	Optimising PATS would have a wide range of benefits for all medical conditions requiring specialist input.	High
Equity	Changes to PATS to ensure equity across jurisdictions would address the current variation between States and Territories.	High
Recommendations	The RHD National Implementation Unit should be resourced to participate in PATS planning and: <ul style="list-style-type: none"> • Advocate for national-level approaches to a fair and equitable PATS system. Jurisdictional agencies should: <ul style="list-style-type: none"> • Work with State and Territory governments to ensure PATS arrangements are optimised and clearly communicated to all stakeholders. 	

Improve coordination of care for specialist and primary care review

Challenges arising from multiple and inadequate clinical information systems create barriers to coordination of care, particularly at the interface between primary and secondary care.⁹¹¹ Depending on location, up to seven patient data systems need to be navigated in the care of people with RHD, including legacy paper-based systems.⁹¹² The ESSENCE standards identify the need for reliable clinical information systems in the effective care of Aboriginal and Torres Strait Islander people with cardiovascular disease, including for appointment booking, clinical and laboratory results tracking, and measuring progress and outcomes.¹⁴¹

Clinical information systems – Communicare

Clinical information systems such as *Communicare* facilitate patient care for people with RHD.⁹¹³ *Communicare* contains an RHD check-up for GPs, Aboriginal and Torres Strait Islander Health Practitioners (ATSIHPs) or nurses to use, based on the CARPA Standard Treatment Manual, RHD clinical guidelines and One21seventy. The system is designed to enable automatic patient recall, assisting with care coordination.⁹¹³ Recalls can be set up to trigger clinical follow-up, including secondary prophylaxis, cardiologist review, paediatrician review, echocardiography and dental review.⁶⁹⁵ Future iterations of clinical data systems should allow information about the care plan to be appropriately shared between providers, ensuring consistent and coordinated care at all levels of the health service.

Optimise delivery of specialist outreach programs

Specialist outreach programs provide speciality services – which would usually only be available in urban tertiary settings – closer to people living in remote locations. Implementation of these programs varies; in some settings outreach programs visit regional hospitals, while others visit primary-care clinics.

Northern Territory Cardiac Outreach Program

This is a private-public collaboration that provides a comprehensive outreach service to numerous communities.⁹¹⁴ Modelled on a multidisciplinary, patient-centred, sustainable and cost-effective design, the program receives government and private funding.⁹¹⁴ The outreach team includes a cardiologist, echocardiographer, clinical nurse consultant, ATSIHP and junior doctor, with the same cardiologist assigned to each community to ensure care continuity.⁹¹⁴ More than 200 outreach visits are provided across the Northern Territory each year and include patient and family education as part of the process.⁹¹⁴ As a result of these visits, the need to travel to major towns for treatment is reduced.

Indigenous Cardiac Outreach Program – Queensland

The Indigenous Cardiac Outreach Program (ICOP) operates out of Prince Charles Hospital in Brisbane, providing cardiac care to Aboriginal and Torres Strait Islander people in rural and remote regions of Queensland.⁹¹⁵ The program visits 34 communities quarterly, providing education and training, research, and partnerships with local health providers in a culturally safe manner.⁹¹⁶ These visits also include point-of-care chronic cardiac disease management, treatment, referrals to other relevant health providers, and patient education.⁹¹⁵ The ICOP is built upon the founding elements of cultural respect, collaboration, self-determination and a strengths-based approach.⁹¹⁷ Operating since 2007, the program has prevented more than 2,000 tertiary admissions by reaching those requiring preventative and pharmacological interventions before disease progression.⁹¹⁸

Heart Bus – Queensland

The Heart of Australia utilises two mobile cardiology clinics to deliver treatment clinics to regional, rural and remote regions in Queensland.⁹¹⁹ These clinics are situated inside specially designed road trains, able to traverse the difficult roads of the outback while containing equipment necessary to undertake cardiac assessment.⁹¹⁹ People are required to have a referral from their local GP.⁹¹⁹ This program has not been evaluated and funding has been ad-hoc, with the Queensland Government stating this service duplicates those already provided in 40 locations state-wide.⁹²⁰ Federal funding of \$1 million was provided in 2017.⁹²¹

Medical Outreach Indigenous Chronic Disease Program – Western Australia

Rural Health West in Western Australia administers the Medical Outreach Indigenous Chronic Disease Program (MOICDP), which aims to increase access to multidisciplinary primary healthcare teams for Aboriginal and Torres Strait Islander people to prevent, detect and manage chronic disease.⁷⁷⁰ The program has been serving the Ngaanyatjarra Lands, with a designated cardiology team travelling to three communities within the region three times a year since 2014.⁹²² The visiting team includes a cardiologist, cardiology registrar, sonographer, nurse educator, dietitian and team coordinator. Patients are referred by the community GP.⁹²² A portable echocardiography machine is taken on visits to assist with consultations, and allied health professionals discuss rehabilitation and diet for those requiring pre- and post-operative care.⁷⁷⁰ Patients who require intervention or surgery are identified and arrangements for transfer made when appropriate.⁹²² Anecdotal evidence suggests patients have improved self-awareness of their chronic disease, improving self-management and adherence to medical advice.⁷⁷⁰

Budyari Aboriginal Community Health Centre – New South Wales

An outpatient heart clinic at Budyari Aboriginal Community Health Centre in New South Wales was established after it was identified that only 20% of patients were returning to hospital for assessments following heart attacks and other cardiac issues.⁹²³ The location for the clinic was chosen because of existing links with the local Aboriginal community and established cultural trust.⁹²³ Engagement with Aboriginal Health Workers (AHWs) and community over a number of years has succeeded in increasing rates of attendance, with an estimated 90% of patients returning for regular check-ups.⁹²³ Attendees found the clinic to be convenient and appreciated its social aspect.⁹²³

Summary: Improving access to specialist care through outreach services		
Domain	Summary	Rating
Evidence	Providing specialist cardiology services for Aboriginal and Torres Strait Islander people in rural and remote settings appears to increase uptake of cardiology services. This is likely to include an increase in the recommended specialist review for RHD, although no empirical studies have demonstrated this. There is no clear evidence to support different models of outreach care over other models.	High
Benefits	Increasing the number of people receiving guideline-based care for RHD would be expected to improve clinical outcomes and improve timely access to surgery. Outreach may improve capacity for culturally appropriate healthcare delivery.	High
Risks	More resources are required to provide outreach services equitably – if the total supply of resources is not increased, it may exacerbate variations in care provided to remote communities.	Medium

Summary: Improving access to specialist care through outreach services		
Domain	Summary	Rating
Acceptability	Outreach specialist services are generally welcomed by Aboriginal and Torres Strait Islander communities, particularly when delivered in partnership with culturally appropriate comprehensive primary healthcare.	High
Feasibility	Developing and sustaining specialist cardiology outreach programs which meet the needs of people with RHD and communities can be challenging. Persistence of current programs indicates feasibility. Costing models from existing programs such as teleophthalmology ⁹²⁴ provide examples of service delivery.	High
Costs	Costs of delivering specialist care in remote locations are high. Further financial modelling of outreach services, relative to transferring individual people with RHD to urban settings for specialist evaluation, is required.	High
Timeline	Developing new cardiac outreach programs takes years.	Long
Positive externalities	Models of care for specialist outreach are relevant to a range of medical and surgical specialties, with potential impacts on a range of disease endpoints.	High
Equity	Providing necessary specialist cardiac services in locations closer to people with RHD is likely to be equity enhancing by reducing barriers to access.	High
Recommendations	Further provision of comprehensive, specialist cardiology outreach services to rural and remote communities should be considered. Design and resourcing of services should be undertaken in consultation with community, and with consideration of optimum models of service delivery.	

Facilitated specialist review via telehealth

Telehealth facilities make it possible for people living with RHD in remote locations to see cardiologists and other specialists through video conferencing. This has a number of potential benefits: medical staff, family members or interpreters may participate in the consultation, providing additional support and continuity of care, and reduced need for travel. However, physical limitations of telehealth mean clinical examination is limited, and it is impossible to perform echocardiography over telehealth facilities.

A small number of telehealth projects, including cardiac care, have been conducted in Australia.

One qualitative study of predominantly Aboriginal and Torres Strait Islander participants in Queensland identified that telehealth provided scope for 'care in a supportive environment'.⁶⁴⁶ In particular, receiving specialist input via video in a familiar ACCHS rather than a tertiary hospital environment was popular. Telehealth was reported to improve affordability and convenience of specialist services by reducing the need for stressful travel and costs. The presence of an Aboriginal Health Worker helped empower patients during video telehealth consultations to make decisions about their care.

'...it is so much information for someone who has never had health literacy. So, my role is to simplify it as much as possible and go, 'okay, who would you like to be talking to?' Make sure they feel empowered that they get to make the choice.'

Aboriginal Health Worker quoted in Caffery et al., 2018.⁶⁴⁶

PATS-Telehealth Project – Northern Territory

A full review was undertaken of the Northern Territory Patient Assistance Travel Scheme (PATS) with the primary goal of ensuring sustainability. With a significant portion of the allocated budget going towards fares and aircraft charters, it was identified that telehealth could assist with reducing travel costs.⁹²⁵ The PATS-Telehealth Project was designed in early 2014, commencing in July that year and concluding in September 2015. Three sites were involved in the pilot – Alice Springs, Katherine and Tennant Creek. Dedicated staff were tasked with increasing the number of telehealth appointments used by specialists, doctors and remote communities. Importantly, the PATS-Telehealth Project was managed locally to ensure oversight, central coordination and clarity of purpose.⁹²⁵

An evaluation determined the number of telehealth appointments increased, as more specialists and remote communities commenced telehealth.⁹²⁵ The ‘did not attend’ rate for telehealth specialist outpatient appointments was substantially lower in two out of three sites than standard hospital outpatient appointments.⁹²⁵ An improvement in service coordination was noted, and it was recognised that telehealth delivery maintained cultural appropriateness. Telehealth was recognised as having an important role in the management of chronic diseases. It was recommended that the Department of Health alter PATS guidelines to elevate telehealth as a first option (where appropriate) before the consideration of further travel.⁹²⁵

Summary: Improving access to specialist care though telehealth		
Domain	Summary	Rating
Evidence	There is strong evidence that telehealth provides a valid and appropriate method of access to specialist services.	High
Benefits	Telehealth contributes to improved management of chronic disease with culturally appropriate care. It is also associated with reduced financial and time burden on patients related to travel.	High
Risks	Telehealth must be adequately assessed prior to integration to account for risks associated with remote management of patients.	Medium
Acceptability	Qualitative consultation with Aboriginal and Torres Strait Islander people suggests that specialist consultations via telehealth are acceptable. ⁶⁴⁶ Telehealth is particularly acceptable when people participate from ACCHSs. ⁶⁴⁶	High
Feasibility	The existence of telehealth programs around Australia demonstrates feasibility, although sustainability of programs requires ongoing evaluation.	High
Costs	The cost of providing telehealth specialist review is generally less than funding travel for in-person specialist review. However, hardware requirements and internet capacity may be significant upfront costs. Medicare rebates for specialist telehealth services are available in remote locations.	Medium
Timeline	Establishing telehealth services requires infrastructure investment and policy development over a period of months to years. Funding arrangements through MBS already exist.	Medium
Positive externalities	Telehealth consultations have capacity to include Aboriginal and Torres Strait Islander Health Workers and family members, which would not be possible in hospital settings. ⁶⁴⁶	Medium
Equity	Reducing barriers to accessing specialist services for Aboriginal and Torres Strait Islander people is equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> Specialist telehealth services should be further developed, in conjunction with outreach clinics, as an alternative to patient travel where appropriate. Investments in infrastructure for telehealth, staff resourcing and technical support are required for scale up of telehealth services. 	

Medical management and specific specialist needs

Improve maternal, sexual and reproductive health for women with RHD

Women with RHD are at increased risk of complications during pregnancy.⁷⁵ The best information about women with RHD in Australia and their pregnancies comes from the Australasian Maternity Outcomes Surveillance System (AMOSS) RHD in pregnancy studies.²²⁸ A population cohort study conducted over two years (2013–2014) revealed that 150 Aboriginal and Torres Strait Islander women had a pregnancy affected by RHD over that period, with Māori and Pacific Islander women and migrants from low-income countries also disproportionately affected.⁸⁴ The cohort revealed a number of concerning markers for inadequate care delivery and adverse outcomes:

- Late antenatal care, with 39% of Aboriginal and Torres Strait Islander women with RHD commencing care after 20 weeks’ gestation (compared to an overall rate of 12% for non-Indigenous Australian women).^{84,926}
- One-third of women had no specialist cardiology review before pregnancy and 15% of women did not have an echocardiogram during pregnancy.⁸⁴
- Eleven per cent of the Aboriginal and Torres Strait Islander women were diagnosed with RHD during pregnancy, including peri- or postpartum. This confirms under-diagnosis of ARF and RHD in community settings. These women were more likely to have cardiac deterioration during pregnancy and require admission for specialist intensive care. Women who become pregnant without knowing they have RHD are at high risk of adverse outcomes.⁸⁴
- Medical care for Aboriginal and Torres Strait Islander women with RHD during pregnancy was expectedly complex: more than two-thirds of the women who required antenatal transfer needed access to tertiary care to pre-empt complications of RHD or co-morbidities. More than one-third of caesarean sections were undertaken due to complications related to RHD and one in 10 was admitted to a coronary or intensive-care unit.⁸⁴
- Poorer perinatal outcomes, with one-quarter of babies born alive to Aboriginal and Torres Strait Islander women with RHD recording a low birth weight. Nearly one-quarter required resuscitation at birth and 43% were admitted to higher care services. The rate of stillbirth was significantly higher in women receiving anticoagulation.⁸⁴
- These findings are generally consistent with other Australian studies of RHD in pregnancy.^{927,928}

The qualitative arm of the AMOSS project exploring women’s experiences of RHD in pregnancy found that health services were not meeting the needs of Aboriginal and Torres Strait Islander women.⁹⁸ Interviews with eight pregnant Aboriginal women with RHD and their families revealed limited awareness of the cause of RHD and poor communication with health professionals. Care was fragmented across primary and tertiary services with frequent travel for specialist assessment and poor coordination and communication of plans for clinical management.⁹⁸ Similarly, qualitative data from health service providers identified a range of barriers to effective care, such as difficulty in accessing specialist services, transport and interpreters. Additional barriers include disconnected health information and variable knowledge by healthcare providers.^{98,929}

International studies of RHD awareness and women’s perspectives of RHD and all cardiac disease partly parallel AMOSS’ findings. Gaps in awareness regarding RHD and its impact, particularly in pregnancy, among primary healthcare practitioners (and women) have been associated with delayed referrals.⁹³⁰ Another study found that women received contradictory advice and limited education.⁹³¹ Other emerging themes in this qualitative exploration of women’s experiences with RHD included misconceptions about side effects of contraceptives, lack of agency in reproductive decision-making, and stigma related to financial and perceived reproductive limitations.⁹³¹

These are consistent with findings from a qualitative meta-synthesis of the experiences of pregnant women with existing or acquired cardiac disease, which found a lack of integrated and tailored healthcare services and information for women with cardiac disease in pregnancy. The study emphasised the imperative for shared decision-making across the clinical team, acknowledging the limited clinical evidence concerning effective approaches to managing such complex care.⁹³²

Provide maternal, sexual and reproductive healthcare and education for women with RHD

Improving support and co-designed education materials for women with RHD before, during and after pregnancy has been identified as a priority in qualitative research with Aboriginal and Torres Strait Islander women.⁹⁸ Practical suggestions have included ensuring access to culturally competent health practitioners able to discuss complex medical issues in relevant Aboriginal and Torres Strait Islander languages.⁹⁸ Targeted education resources are likely to be needed as an adjunct to individualised communication. A small number of these education resources have been developed.

Sharing a Heartbeat: multiple language films (Burarra, Kriol, English)

Two short films co-directed by Aboriginal and Torres Strait Islander women and produced by RHD Australia focus on fertility, pregnancy and family for young women living with RHD, including intervention for severe RHD. The films are targeted towards young girls and women with RHD, as well as equipping family and friends to better understand the impact of the disease, particularly in pregnancy. While the films have not been formally evaluated, they have been strongly endorsed with feedback from women, communities and health services, based on design structure, content and delivery.⁹³³

Takeheart: Rheumatic Heart Disease in Pregnancy

This short film is one of several resources in a multi-media project comprising a one-hour feature film, other short films, an action toolkit, and a smartphone app, as well as touring screenings and photography exhibitions. It has some reference to tertiary care, including anticoagulation. Sponsored by RHD Australia and AMOSS, the film is mainly targeted to health services.⁹³⁴

Reach education flipchart

This flipchart with brief text and corresponding illustrations guides interaction between health providers and women with RHD in primary health low/middle-income settings. The resource references tertiary care, particularly anticoagulation and other high-risk care in pregnancy. It was developed by Reach, a global RHD technical assistance organisation, building on the AMOSS resource.⁹³⁵

A shared understanding of RHD is essential to improve knowledge and decision-making about the disease and its impact for women's health. The resources described above show how research can learn from and inform a collaborative approach to health literacy at both local and global levels.

Summary: Provide maternal, sexual and reproductive healthcare and education for women with RHD		
Domain	Summary	Rating
Evidence	There is no empirical evidence that education or training resources for Aboriginal and Torres Strait Islander women with RHD improve outcomes. However, providing health education and support is a core responsibility of the health system which does not require new evidence generation. While evidence specific to RHD is limited, there are several papers that illustrate the benefit of appropriate Aboriginal mother and baby models of care in pregnancy. ⁹³⁶⁻⁹³⁹	Unknown
Benefits	Benefits of improving education and support for women with RHD in relation to reproductive health and pregnancy are likely to include improved capacity for self-management and may improve clinical outcomes.	High
Risks	Discussion of reproductive and maternal health risks is personal, and advice is needed for individual clinical scenarios. Information which is not clinically accurate or delivered in a culturally appropriate way might lead to confusion, anxiety or adverse clinical outcomes. Positive, strengths-based and accurate information is needed for women to mitigate this risk.	Medium
Acceptability	No studies of acceptability of maternal, sexual or reproductive health education have been identified but anecdotal reports from Sharing a Heartbeat suggest Aboriginal and Torres Strait Islander women and health providers welcome appropriately presented education.	Unknown

Summary: Provide maternal, sexual and reproductive healthcare and education for women with RHD		
Domain	Summary	Rating
Feasibility	A number of other educational resources for similar topics have already been developed, demonstrating feasibility.	High
Costs	Costs are dependent on the type of resources developed. Resources require translation in order to be effective, with additional costs for each additional language.	Medium
Timeline	Timeline for resource development depends on the medium used but should include sufficient time for adaptation to different communities and translation of resources.	Medium
Positive externalities	Key messages about maternal, sexual and reproductive health for women with RHD include the importance of preconception planning and early antenatal care. These messages are relevant for all women planning pregnancy and could help normalise preconception care for Aboriginal and Torres Strait Islander women planning pregnancy.	Medium
Equity	Ensuring Aboriginal and Torres Strait Islander women have sufficient comprehensible information to make informed decisions about maternal, sexual and reproductive health is equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> All women of reproductive age should have discussions with their health practitioner, including information about the potential implications of ARF and RHD on pregnancy and their options regarding⁷¹¹: <ul style="list-style-type: none"> - Choice of valve prosthesis; - Surgical intervention in pregnancy; - Anticoagulation; and - Risk assessment in pregnancy.⁷¹¹ Individualised advice should be provided according to specialist reviews. <ul style="list-style-type: none"> - The RHD National Implementation Unit should be resourced to: - Develop educational resources to support these discussions; - Work with jurisdictional agencies to adapt these resources to local setting and context; and - Evaluate and iterate educational resources. 	

Support primary-care services to provide maternal, sexual and reproductive healthcare for women with RHD

Aboriginal and Torres Strait Islander women with RHD receive the vast majority of medical care in primary-care clinics – including contraception, pregnancy and termination of pregnancy.

Consultation with midwifery training providers indicates that the significance of RHD for pregnant Aboriginal and Torres Strait Islander women is not routinely included in textbooks or curricula.⁹⁴⁰ Training on RHD in pregnancy for midwives and other healthcare providers is needed. An online training module has been developed by RHD Australia, although uptake and impact have not been evaluated.^{941,942} Posters to encouraged healthcare workers to consider RHD in pregnancy have also been developed.^{940,942}

Summary: Support primary-care services to provide reproductive health and maternal healthcare for women with RHD		
Domain	Summary	Rating
Evidence	While there is evidence of under-representation of RHD in midwifery curricula and barriers to provision of reproductive and maternal health care in primary care, effective programs have not been identified. Existing training resources have not yet been evaluated.	Unknown

Summary: Support primary-care services to provide reproductive health and maternal healthcare for women with RHD		
Domain	Summary	Rating
Benefits	The benefits of improving maternal and reproductive health for women with RHD are likely to include earlier detection and management of complications relating to RHD in pregnancy and in life following pregnancy. The principles of Birthing on Country ⁹⁴³ provide an appropriate transition to motherhood and parenting for Aboriginal and Torres Strait Islander women, and an integrated, holistic and culturally appropriate model of care for all. These principles align well to principles of best-practice care for women with RHD. ⁷¹¹	High
Risks	The risks of providing reproductive health and maternal care for women with RHD in primary care will depend on the scope of training and support provided. They may include diversion of time and resources from other patients or conditions. Maternal, sexual and reproductive health can be sensitive subjects and times when women are particularly vulnerable. Care provided must also be culturally safe and appropriate, and tailored to the local setting.	Medium
Acceptability	The acceptability of providing maternal and reproductive care for women with RHD in primary care is unknown.	Unknown
Feasibility	Training programs and resources have been implemented for a range of other conditions in primary care, demonstrating high feasibility. However, structural and funding barriers to the provision of reproductive and maternal healthcare in primary-care settings exist, which pose more significant challenges.	Medium
Costs	The costs of supporting primary health providers in maternal and reproductive care for women with RHD will depend on the type of training and resources developed.	Unknown
Timeline	The timeline for implementing a program supporting provision of maternal and reproductive healthcare in primary care will need to include sufficient time for consultation with primary-care providers, adaptation of program materials for local settings, and time to provide training.	Medium
Positive externalities	Better reproductive and maternal health in the primary-care setting for women with RHD is likely to improve provision of this care for all women attending the clinic.	Medium
Equity	Improving reproductive and maternal healthcare in primary health services for women with RHD would have a proportionately greater benefit for women living in remote areas, whose access to specialist obstetric care is limited.	High
Recommendations	The RHD National Implementation Unit should: <ul style="list-style-type: none"> Evaluate existing modules and training around RHD in pregnancy. Work with primary healthcare providers to develop and disseminate appropriate training and resources to support health workers care for women with RHD in pregnancy. 	

Echocardiography screening of pregnant women at high risk of RHD

A relatively large proportion of Aboriginal and Torres Strait Islander women living with RHD were diagnosed with the condition during pregnancy. This has led to calls for echocardiographic screening of pregnant women in settings with a high burden of RHD.⁸⁴ Antenatal echocardiographic screening might have some practical advantages, particularly if women could have a limited view echocardiogram (heart ultrasound) at the same time as routine obstetric ultrasounds, potentially utilising the same ultrasound machine and operator.

An audit of Aboriginal and Torres Strait Islander women referred for echocardiography in the Northern Territory confirmed a relatively large proportion of women (13%) with moderate or severe RHD, some of whom required intervention during pregnancy.⁹⁴⁴

There have been no studies exploring echocardiography screening of pregnant Aboriginal and Torres Strait Islander women in Australia. One small pilot study in Eritrea has provided proof of concept for antenatal echocardiographic screening.⁹⁴⁵ A large Ugandan longitudinal study is in progress using existing infrastructure to screen pregnant women and follow outcomes.⁹⁴⁶ This study found pre-existing cardiovascular disease – nearly 90% of which was due to RHD unknown prior to pregnancy – was responsible for a substantial risk of adverse maternal outcomes in low-resource settings.

A prospective study is commencing in the Top End of the Northern Territory to determine the role of echo screening in pregnancy in high-risk Aboriginal and Torres Strait Islander women.⁸⁴

Summary: Echocardiography screening of pregnant women at high risk of RHD		
Domain	Summary	Rating
Evidence	No studies have explored echocardiography screening of pregnant Aboriginal and Torres Strait Islander women in Australia, although a study is currently commencing in the NT.	Unknown
Benefits	Antenatal screening for RHD may make it possible to identify undiagnosed women with RHD early in pregnancy, allowing for specialist medical management and potentially improved outcomes. These benefits are theoretical pending research.	Unknown
Risks	The risks of antenatal RHD screening are unknown and are likely to depend on the parameters of the screening protocol used, particularly in the case of women with a false positive screening test and a potential increase in health-related anxiety.	Unknown
Acceptability	Echocardiographic screening for RHD appears to be broadly acceptable for Aboriginal and Torres Strait Islander people, though specific acceptability for pregnant women is unknown.	Unknown
Feasibility	Feasibility of antenatal echocardiography screening for RHD is unknown.	Unknown
Costs	Costs of antenatal echocardiography screening for RHD are unknown.	Unknown
Timeline	The timeline for establishing an antenatal echocardiographic screening program for RHD is unknown.	Unknown
Positive externalities	Antenatal echocardiography screening may detect non-rheumatic cardiovascular disease in a small number of women during pregnancy.	Low
Equity	The equity effects of antenatal echocardiographic screening for RHD are unknown. Early detection of RHD in Aboriginal and Torres Strait Islander women at high risk of RHD could be equity enhancing. However, it is possible that women with the greatest economic or geographic disadvantage could be more likely to have RHD but less likely to receive antenatal care and therefore inequalities could be exacerbated.	Unknown
Recommendations	<ul style="list-style-type: none"> Explore the possibility of embedding antenatal echos into current standard routine obstetric ultrasounds. Research to explore the technical specifications, acceptability, feasibility and costs of antenatal echocardiography screening should be commissioned. 	

Optimise transition from paediatric to adult services

ARF/RHD is a chronic disease of children, adolescents and young adults. Most people with ARF/RHD require specialist care from both paediatric and adult services. This care must be tailored to address the unique medical, educational, social and cultural needs of Aboriginal and Torres Strait Islander young people.⁹⁴⁷

Transition generally refers to a process of transferring medical care (from paediatric to adult services) and shifting responsibility for medical management from parents and families to adolescents themselves.⁹⁴⁸ The goal is to ‘provide uninterrupted healthcare that is patient-centred, age- and developmentally appropriate, flexible, and comprehensive’.⁹⁴⁹ High-quality transition care should optimise management of chronic medical conditions and support self-management into adulthood.⁹⁵⁰ Inadequate or failed transition to adult services is associated with poor outcomes when people are lost to follow up in adult clinics or do not engage with ongoing care.

There is some evidence that transition care by specialist services is not well optimised for young people living with RHD in Australia. Adherence with secondary prophylaxis decreases in the adolescent period.^{77,811} This may reflect a change in responsibility from parents/caregivers arranging secondary prophylaxis to young people themselves.¹⁰⁴ Additionally, paediatric cardiologists anecdotally report that some young people are ‘lost to follow-up’ when they age out of paediatric services and frameworks for engagement with adult services are not always in place. There is often a lack of communication between paediatric and adult services and a reliance on patients being automatically picked up by adult services through referrals from primary care or RHD registers. Due to concerns of being lost to follow-up, some paediatric services will continue care of people with RHD into young adulthood, leading to a lack of consistency for timing of transition.

Ethnographic research suggests a need to improve transition care for Aboriginal and Torres Strait Islander young people with ARF and RHD.¹⁰⁴ Clinician participants in the END RHD CRE focus group also identified improvements in transition care from paediatric to adult cardiology services as a priority for improving clinical outcomes.⁹⁵¹ Improving transition care is also highlighted in the *National Strategic Plan for Childhood Heart Disease*.¹⁴²

The impact of transition care for young people with congenital heart disease is better understood than the impact for young people with RHD. Although the disease process and populations with congenital and RHD differ, the similarities are considerable, and results can therefore cautiously generalised. International evidence suggests that transition strategies can improve outcomes for young people with cardiac disease. For example, in a Canadian cohort of young people with congenital heart disease, a nurse-led education intervention around transition was associated with a statistically significant increase in knowledge for self-management and reduced delays in entering adult services.⁹⁵² Similar results have been demonstrated in a range of other international studies.⁹⁵³

Guidelines for transition care of young people with congenital heart disease have been developed by the Cardiac Society of Australia and New Zealand (CSANZ) which provide some relevant guidance for care of young people with RHD.⁹⁵⁴ CSANZ guidelines recommend employment of a Transition Nurse within Paediatric Cardiac Units, and formation of Comprehensive and Regional Adult Congenital Heart Services.⁹⁵⁴ Transition care of young people with RHD is also addressed in the third edition of the Australia Guideline.⁷¹¹

Strategies for achieving improved transition care relevant to Aboriginal and Torres Strait Islander young people in remote locations include:

Tertiary Service Redesign

Ensuring specialist cardiology services can meet the needs of adolescent people with ARF and RHD is a structural approach to improving transition care. There are a number of examples of this approach in practice:

Improving Adolescent Health – Royal Darwin Hospital

A program to improve inpatient service delivery for inpatient Aboriginal and Torres Strait Islander adolescents in Royal Darwin Hospital began in 2015.⁹⁵⁵ Following consultation and literature review, the program focused on ensuring culturally and age-appropriate environments, fostering a culture of change, and education for healthcare providers. Practical innovation included creation of adolescent bed areas, renaming the paediatric ward to ‘Paediatrics and Adolescent Ward’ and development of an adolescent lounge.⁹⁵⁵ Substantial education of healthcare providers was conducted to address misconceptions about adolescent health and support professional culture change. Evaluation of this broad approach is planned.⁹⁵⁵

NT Cardiac – Outpatients

The NT Cardiac program has established a streamlined process for remote adolescent cardiology outpatients to ensure transition is effective. People aged 16–20 years are on both paediatric and adult cardiology recall lists in remote clinics.⁹⁵⁶ If a person is successfully transitioned to the adult clinics, they will be removed from the paediatric cardiology list. If the patient has not transitioned, they are maintained on the paediatric list until successful transitioning takes place. This program has not yet been evaluated.

Transition Support Service – Royal Children’s Hospital, Melbourne

The Royal Children’s Hospital in Melbourne runs a Transition Support Service comprised of a transition manager, a transition support coordinator and two transition youth mentors.⁹⁵⁷ The service caters for patients aged over 15 years who have a chronic and/or complex health condition that requires assistance in developing a clear and coordinated transition plan and transfer pathway from adolescent to adult care.⁹⁵⁷ Support in developing a transfer plan, transition education services, consultation and advice for treating clinicians, resources for parents/caregivers, and participation in collaborative events are provided.⁹⁵⁷ Self-referral is possible via contact with the manager of Transition Support Services.⁹⁵⁷

Paediatric Chronic Conditions Transition Framework

The Western Australian Child and Youth Health Network’s Paediatric and Adolescent Chronic Diseases Transitional Care Working Party developed a *Paediatric Chronic Conditions Transition framework* in 2009, which was evaluated in 2015.⁹⁵⁸ It was acknowledged that while the program was working well, further awareness-raising on the availability of the service and support for transition coordinators was required.⁹⁵⁸ The project was further committed to as part of the *WA Health Strategic Intent 2015–2020*.⁹⁵⁸

Summary: Tertiary service redesign to optimise transition from paediatric to adult services		
Domain	Summary	Rating
Evidence	No formal model of care for transition care for young people with ARF/RHD in Australia was identified. However, examples from congenital heart disease and other chronic conditions suggest that structured transition care and service redesign approaches can have measurable benefits in clinical outcomes for young people with heart disease.	Medium
Benefits	Good transition care for adolescents with ARF and RHD may improve delivery of secondary prophylaxis and is likely to improve capacity for self-management.	Medium
Risks	Development of structured processes for transition care is unlikely to be associated with significant risk.	Low
Acceptability	The acceptability of transition services for Aboriginal and Torres Strait Islander young people with RHD is unknown – though literature indicates a desire for more information about the disease which could be addressed through transition processes.	Unknown

Summary: Tertiary service redesign to optimise transition from paediatric to adult services		
Domain	Summary	Rating
Feasibility	General programs to improve paediatric transition services indicate that tertiary service redesign is possible and likely to be feasible for Aboriginal and Torres Strait Islander young people with RHD.	High
Costs	Costs of transition programs vary according to design but resources for transition staffing should be included.	Medium
Timeline	Existing programs suggest that development of transition programming can occur over months to years.	Medium
Positive externalities	Improving services for adolescents and transition care for Aboriginal and Torres Strait Islander young people with ARF/RHD is likely to improve transition experiences for young people with other chronic conditions.	High
Equity	Transition programs for young people with chronic disease, including congenital heart disease, are widely available in metropolitan centres. Ensuring these services are adapted and available for Aboriginal and Torres Strait Islander young people in remote communities is likely to be equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> Improving service delivery for Aboriginal and Torres Strait Islander adolescents moving from paediatric to adult services should be a priority to improve care for RHD. Paediatric and adult cardiology services that provide care in regions of high RHD burden need to have structures in place that enable coordinated transition of care. This should include default referral pathways, shared access to medical records, and combined multidisciplinary team meetings to ensure the most complex patients transition appropriately. An RHD National Implementation Unit should work with specialist cardiology services, in partnership with Aboriginal and Torres Strait Islander youth leaders, to develop a model of care for transition programs. 	

Improve access to safe anticoagulation and monitoring

People with advanced RHD may require anticoagulation (blood thinning) medication to reduce the risk of blood clots which can cause stroke. People who have had a mechanical heart valve replacement are dependent on daily anticoagulation for life to prevent blood clots forming in the valve. The dose of some anticoagulation medication (warfarin) needs to be measured and adjusted regularly, meaning people must come to the clinic for a blood test known as INR, and to collect the updated medication dose every week or so. This is a significant workload for clinics and burden for patients: in remote Northern Territory clinics, 63% of Aboriginal and Torres Strait Islander people needing warfarin therapy have RHD.⁹⁵⁹

Access to safe anticoagulation in rural and remote settings is variable. Monitoring a person's INR using a conventional laboratory is challenging due to the large distances involved in transporting blood samples from the remote clinic to the nearest hospital laboratory, the time delay in reporting the INR result back to the community, as well as the burden on the person being required to attend a follow-up appointment to receive their INR result and change their next dose of warfarin.⁹⁶⁰

An audit was conducted of 26 Aboriginal and Torres Strait Islander individuals on anticoagulation therapy in an urban primary health clinic.⁹⁶¹ It found that the average proportion of those with an INR within the therapeutic range over the six-month period was 44.9%.⁹⁶²

Pregnant women with mechanical heart valves are a very high-risk group, in whom all anticoagulation options carry significant maternal and/or foetal risks (WHO risk classification III).⁹⁶³ The choice of anticoagulation involves balancing those risks.⁷¹¹

Improve access to point-of-care testing (PoCT) for anticoagulation monitoring

Point-of-care testing (PoCT) is a relatively new approach, allowing patients or health workers to measure INR on a small machine and receive a rapid result. As well as the speed of the result, PoCT allows INR monitoring to be done completely in the local health centre.⁹⁶⁴

i-STAT PoCT

A PoCT program has been in place in the Northern Territory since 2008, administered through the NT Government Department of Health and Flinders University, with 34 remote health centres participating.⁹⁶⁰ An i-STAT device is used to measure INR for people on warfarin therapy in these clinics. The program involves training for health practitioners including web-based, teleconference and face-to-face sessions.⁹⁶⁰ Since the establishment of the program, about 13,000 INR PoCTs have been performed on more than 900 people, 212 of whom have had more than 10 serial INR tests.⁹⁶⁰

Both the volume of INR testing and the number of Remote Area Nurses trained as PoCT device operators (600-plus) have increased over the course of the program.⁹⁶⁰ The between-site imprecision from quality control INR testing conducted monthly in each participating remote clinic demonstrated good consistency across sites. The clinical benefits of INR PoCT demonstrated during this program have included earlier detection and stabilisation of dangerously fluctuating INR levels, and increased time with INR in the therapeutic range.⁵⁶ Other benefits include increased patient empowerment to manage their anticoagulation therapy.⁹⁶⁰

Summary: Improving access to PoCT for anticoagulation monitoring		
Domain	Summary	Rating
Evidence	Evidence for the utility of PoCTs for other measures is strong. There is evidence from pilot studies of INR PoCT that medication compliance and time spent in the therapeutic range improved. ⁹⁶⁰	Medium
Benefits	Access to INR PoCT enables prompt monitoring of anticoagulation, reducing the time burden on patients and the healthcare provider. It also might improve self-management of RHD.	Medium
Risks	PoCT must be embedded in the primary-care system, otherwise there is risk of further fragmentation of care. Training required in PoCT is time consuming for healthcare providers and may divert time and resources away from other priorities in the short term.	Medium
Acceptability	Pilot programs have demonstrated high patient satisfaction. ⁹⁶⁵	High
Feasibility	PoCT has been successfully used in community settings for other tests such as albumin-to-creatinine ratio (ACR), cholesterol and blood glucose.	High
Costs	PoCT for INR is more expensive than centralised laboratory testing. The upfront cost of machines being distributed to clinics, as well as their maintenance and consumables, results in higher costs. Additionally, staff must be trained in the operation and interpretation of the PoCT devices and ongoing support to providers is required. The cost benefit of improved INR with PoCT has not yet been established.	High
Timeline	PoCT for other conditions has been rolled out successfully over a number of years. It should be noted that pilot programs of INR PoCT have been in place since 2005–2008 and are not yet widely embedded in routine practice.	Medium
Positive externalities	PoCT has the potential to optimise anticoagulation in people with severe RHD. Positive externalities have not been identified.	Low

Summary: Improving access to PoCT for anticoagulation monitoring		
Domain	Summary	Rating
Equity	PoCT allows improved provision of necessary tests regardless of geographic location, or size and resources of the health facility, and is therefore equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> Improve access to point-of-care INR monitoring services – including development of INR monitoring strategies for remote clinics and individuals. Capacity for self-management of anticoagulation using point-of-care INR machines should be improved, requiring designated funding and support. Culturally appropriate education for patients and families should be provided around the importance of anticoagulation. 	

Improve dental care

Oral health is important in people living with RHD. RHD increases the risk of infective endocarditis, a serious bacterial infection of the heart valves. The bacteria that cause infective endocarditis are often found in the mouth. Good dental hygiene is essential in keeping teeth and gums healthy and reducing the risk of infective endocarditis.

Given this risk of infective endocarditis, optimising oral health prior to heart surgery is particularly important. However, a Northern Territory-based study found inadequate dental preparation was one of the reasons planned cardiac surgery was postponed, with the patient required to return home.⁹⁰³ Integration of dental care into coordinated care plans for people with RHD may improve oral health and reduce surgery postponement. This is already in place in some jurisdictions, such as automatic prompts for regular dental review in patient databases.⁶⁹⁵

The 2019 AMA Report Card on Indigenous Health⁹⁶⁶ addressed the oral health needs of Aboriginal and Torres Strait Islander people. The report identifies five priority actions for governments to take to improve the oral health status of Aboriginal and Torres Strait Islander people. They include fluoridation of water supplies, oral health promotion, a tax on sugar-sweetened beverages, and improved data to capture progress. Particular attention was given to the importance of strengthening the Aboriginal and Torres Strait Islander dental workforce, improving service models, and funding arrangements for dental care provision.

Summary: Improving dental care	
Recommendations	<ul style="list-style-type: none"> Culturally appropriate education should be provided for people diagnosed with RHD on importance of dental hygiene and prevention of infective endocarditis. Routine care plans for people living with RHD should include regular dental review.

Surgical considerations

In people with severe RHD, surgical intervention to repair or replace a damaged heart valve is often needed. A study using data from the Northern Territory RHD register found that 5.1%, 15.7% and 62.7% of people who were diagnosed between 5–24 years of age with mild, moderate and severe RHD respectively, would have surgery within 10 years of diagnosis.⁸⁸ There is limited provision of surgical procedures in some States – for example, paediatric valve repairs and replacements for children with RHD are only performed in Melbourne, Sydney or Brisbane. This necessitates travel for the patient and escort across vast distances.

For many people with RHD, the distances between their community and surgical centre make assessment and planning around cardiac surgery difficult. Logistics and care coordination around surgery can be extremely demanding on the referring practitioner. Often, discussions around surgical decisions are separated from patients' families, and families do not meet the surgeon face-to-face prior to transfer for surgery (personal correspondence, Dr. Ari Horton, 2019).

Ensuring that surgery is considered, discussed, planned and delivered in a timely manner can improve clinical outcomes, both immediate and long term. Additionally, well-planned and considered surgical discussions are likely to improve the lived experience of people with RHD, compared to surgery occurring late in the disease process or in emergency situations. Care for people requiring surgery for RHD could be improved by implementing strategies to enhance preoperative care, perioperative care and handover to primary care.

Optimise preoperative care

Care coordination

Care coordination to streamline preoperative preparation and planning may provide an opportunity to increase timely access to surgery and ensure quality of care delivery.

In 2007 a trial of a pilot Remote Area Nurse Liaison Service in the Northern Territory explored whether Aboriginal people travelling from remote areas to metropolitan hospitals for cardiac surgery benefitted from improved arrangements around travel to and from hospital.⁹⁰³ Results indicated that improved cultural competency in a clinical setting enhanced cultural liaison and cultural respect for Aboriginal patients, enhanced patient safety and care, reduced travel costs, resulted in less disruption in the hospital system, and improved hospital efficiencies.⁹⁰³

Following these findings, Top End Cardiac Nurse Consultants (CNCs) were established through Federal funding in 2015, replacing the previous arrangement where patients were cared for by several different medical designations.⁹⁶⁷ CNCs worked alongside cardiologists and assisted with arranging clothing, accommodation, education, allied health involvement, financial support, and counselling services required prior to a trip to an interstate hospital for surgery.⁹⁶⁷ Dental assessments were also organised before valve surgery, with a significant reduction in waiting time for surgery due to dental fitness being achieved more quickly.⁹⁶⁷

Successes of the CNC role includes patients from regional and remote areas feeling more supported through their journey, healthcare clinics having a point of contact with acute care, reduced loss to follow-up of patients, and a more streamlined passage through the system. Time pressures, high patient loads and poor delineation of roles are noted challenges.⁹⁶⁷

Summary: Optimise preoperative care		
Domain	Summary	Rating
Evidence	Programs of cardiac care coordination to date have demonstrated successes.	Medium
Benefits	Care coordination streamlines processes and reduces inefficiencies for the health system. Importantly, culturally appropriate models of care coordination also enhance patient experience.	Medium
Risks	No risks have been identified for improved preoperative care. Coordinator roles must be resourced and embedded within the health system.	Low
Acceptability	Efforts to improve care coordination are likely to be acceptable to Aboriginal and Torres Strait Islander people.	High
Feasibility	Success of the Top End CNC role indicates that feasibility is high.	High
Costs	Care coordination requires human resources, though the costs may be offset if coordination improves efficiency through reduced travel and care delivery costs.	Medium
Timeline	Initial programs for care coordination occurred over years for design, planning and pilot programs. This could be adapted over a shorter timeframe for other jurisdictions with inclusion of paediatric cardiac services.	Medium

Summary: Optimise preoperative care		
Domain	Summary	Rating
Positive externalities	Improving care coordination for people with RHD is likely to be associated with improved systems and processes relevant to other conditions.	High
Equity	Care coordination for patients living in rural and remote areas provides support to those who are typically marginalised in the mainstream health system and is therefore equity enhancing.	High
Recommendations	Permanent care-coordination roles should be funded to support children and adults who are having heart surgery for RHD to ensure alignment of clinical, administrative and logistic plans alongside attention to cultural needs and communication between different levels of the health service.	

Optimise perioperative care

Improve inpatient experiences

Aboriginal and Torres Strait Islander people with cardiac disease face significant barriers to accessing healthcare, often associated with services which do not meet their needs, foster therapeutic relationships, or account for language differences or variation in health literacy.⁹⁶⁸ Most people prefer to hear important information about their health in a language they speak fluently; for speakers of Aboriginal and Torres Strait Islander languages this is rarely arranged in tertiary settings.^{319,969} Limited access to health information in language impedes enhanced individual knowledge about their condition and therefore the type of care they are receiving.⁹⁶⁹ Engagement in care and care planning is also influenced by past negative experiences of tertiary care, previous experiences of racism in the health system, and a lack of cultural awareness.⁹⁶⁹

‘She gets frightened cause she doesn’t know what the doctor is talking about, you know. She might have to have an operation and she don’t know.’

Community member quoted in Artuso et al., 2013.⁹⁶⁹

Negative experiences of Aboriginal and Torres Strait Islander people in the health system contribute to their disproportionately higher rates of discharge against medical advice,⁹⁷⁰ especially in rural and remote settings.⁹⁷¹ ‘Discharge against medical advice’ is defined as a patient choosing to leave the hospital before the treating doctor recommends discharge.⁹⁷² Discharge against medical advice rates are strongly associated with post-operative complications, increased morbidity and mortality, and are considered a reflection of the responsiveness of hospitals to the needs of their Aboriginal and Torres Strait Islander people. The causes of discharge against medical advice are complex, including an interplay of institutionalised racism, mistrust of the health system, a lack of cultural safety, family and community obligations, and isolation and loneliness, especially in rural and remote settings.⁹⁷¹

Lighthouse Hospital Project

The Lighthouse Hospital Project aims to drive change in the acute-care setting through implementation of actions that improve care and outcomes for Aboriginal and Torres Strait Islander people experiencing ischaemic heart disease. It is a joint initiative between the Heart Foundation and the Australian Healthcare and Hospitals Association (AHHA) which receives Australian Government funding.⁹⁷³ The project recognises the disproportionate number of deaths from coronary heart disease in the Aboriginal and Torres Strait population, aiming to improve the level of care in hospital settings and coordinate care by strengthening relationships between hospitals, local Aboriginal Community Controlled Health Organisations, and Primary Health Networks.⁹⁷⁴

To date, the Lighthouse Hospital Project has achieved several improvements, including enhanced roles of Aboriginal Liaison Officers (ALOs), Health Workers, Patient Pathway Officers and equivalent roles, better identification of eligible patients, fostering clinical champions, spearheading patient-focused care, and building rapport with appropriate clinical channels. Funding has been received for Phase 3 which includes involvement of 18 hospitals in WA, SA, QLD, VIC, NSW and the NT.⁹⁷⁴ This project is currently under evaluation.⁹⁷⁴

Summary: Improving patient experience within tertiary settings		
Domain	Summary	Rating
Evidence	Evidence is strong for the driving factors behind suboptimal inpatient experiences of Aboriginal and Torres Strait Islander people. The importance of AHWs and ALOs in providing better care for Aboriginal and Torres Strait Islander patients is also clear. ⁹⁷⁵	Medium
Benefits	Creating a culturally safe environment in acute-care settings not only optimises the experiences of patients but reduces rates of discharge against medical advice, which are associated with poorer health outcomes.	High
Risks	No risks have been identified for improving inpatient experiences for Aboriginal and Torres Strait Islander people. Enhanced cultural safety needs to be underpinned by meaningful and effective cultural competency training for all hospital staff.	Low
Acceptability	Aboriginal and Torres Strait Islander patients have consistently identified lack of cultural safety in the health system as a negative and harmful experience. Improving inpatient experience is likely to be acceptable.	Medium
Feasibility	Systemic institutional changes are required to make meaningful improvements in cultural safety. Existing programs have demonstrated feasibility with considerable resourcing attached.	Medium
Costs	Programs to improve inpatient experience require resourcing for training of all staff, as well as funding for AHW roles and coordinator roles between tertiary and primary care.	Medium
Timeline	Designing and implementing programs around inpatient experiences and cultural safety requires adequate time for consultation with Aboriginal and Torres Strait Islander stakeholders and adaptation to the local setting. Embedding these programs in the hospital requires time for staff training and education.	Medium
Positive externalities	Provision of culturally safe care in the health system may provide a framework for translation to other systems such as education and justice.	High
Equity	Non-Indigenous patients mostly receive culturally safe, appropriate care. Programs to improve the experiences of Aboriginal and Torres Strait Islander patients are likely to be equity enhancing.	High
Recommendations	<ul style="list-style-type: none"> Improvement of current cultural safety frameworks and training in acute care. Increased recruitment and retention of AHWs/ALOs in acute care, especially in rural hospitals. Development of more flexible community-based care models to provide culturally appropriate care for Aboriginal and Torres Strait Islander patients. 	

Optimise national centres of excellence for RHD surgery

Interventional surgery for RHD is a highly specialised field, required for a relatively small number of people in Australia each year. In the HeartKids 2011 white paper, it was identified that low-volume, complex procedures should be carried out only in selected centres, given both the technical expertise required and the associated costs.⁹⁷⁶ Surgical outcomes for more complex paediatric cardiac procedures are better in centres that perform more of those procedures, compared to smaller centres. A recent study of mitral valve repair for children with RHD at Royal Children’s Hospital, Melbourne demonstrated 0% perioperative mortality.⁹⁷⁷

It is also essential that surgical centres are equipped with a comprehensive, culturally appropriate service for patients and their families.⁹⁷⁶ This requires a devoted team of staff tasked with providing pre- and post-operative care and coordinating follow-up for patients upon return to community. Such a highly specialised and comprehensive service develops over time and is resource intensive. As such, consolidation to a smaller number of hubs for surgical care should be considered to improve overall patient outcomes.

The burden on families required to travel long distances for surgery is immense. Families consulted for the HeartKids white paper suggested that transition units with appropriate services would be beneficial in centres such as Darwin, allowing patients and their families to return closer to home at an earlier stage.

Summary: Improved surgical care

Recommendations	It is recommended that the Australian and/or State governments ensure the designated care hubs have the required level of qualified staff and appropriate facilities to meet the population needs, including the required psychological care and social support. Standards of care for centres providing surgery for RHD should be developed.
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Minimise educational disruption for young people with RHD

Children with a chronic health condition may be required to miss long periods of schooling to receive medical care, which can have a detrimental effect on their educational performance.⁹⁷⁸ This includes young people living with ARF and RHD, who have the added complexity of potentially requiring long-term tertiary care in a State different from their home community. While in-hospital schooling is provided to varying degrees in all States and Territories,⁹⁷⁸ it can be inconsistently delivered, fail to liaise with the child's regular school, and may be challenging for those students with English as an additional language.⁹⁷⁸ There are no current projects addressing educational disruption for young people with RHD.

Improve continuity of care, post-operative follow-up and rehabilitation

Following cardiac procedures and cardiac surgery, Aboriginal and Torres Strait Islander people are discharged to the care of primary-care services and need ongoing specialist review. This is also important for women with RHD who are discharged from hospital postpartum.

Clinical management of people with severe RHD requires considerable information management to record and action specialist recommendations, including medication changes and scheduled reviews. As for other post-surgical situations, handover and discharge planning is variable for people with RHD who return to community after heart surgery, especially if they have complex medical needs.⁹⁶⁹

There is reasonable evidence that clinical handover following cardiac surgery for Aboriginal and Torres Strait Islander people with heart disease is insufficient.^{969,979} Barriers preventing the receipt of essential test results, rehabilitation services, and follow-up care were a result of failures with communication and system oversight.⁹⁶⁹ Specifically, disjointed or non-existing relationships between the tertiary hospital and primary-care services prevented cardiac patients receiving essential post-event services integral to their care.⁹⁶⁹

'There was no appointment made for me to go back to hospital. I don't even know what my results was. I went to [primary-care service] and told one of them doctors over there and he was following it up for me... this was a few months ago now.'

Aboriginal cardiac patient quoted in Artuso et al., 2013.⁹⁶⁹

Improve clinical handover

Clinical handover is defined as *'the transfer of professional responsibility and accountability for some or all aspects of care for a patient, or group of patients, to another person or professional group'*.⁹⁸⁰ Handover in the form of a written summary to a patient's GP is provided by acute services upon patient discharge from hospital. Appropriate clinical handover is a requirement under the *National Safety and Quality Health Service Standards (NSQHS)*. Breakdown in clinical handover is a major contributing factor in serious adverse events, and a major preventable cause of patient harm.^{980,981}

Equally important is education and planning with the patient and family prior to discharge.

Princess Alexandra Hospital Better Cardiac Care team

'Better Cardiac Care' is a collaborative project between the cardiology department of Princess Alexandra Hospital in Brisbane, the Lighthouse Project (AHHA/Heart Foundation) and the Queensland Department of Health,⁹⁸² with the aim of improving cardiac services for Aboriginal and Torres Strait Islander patients focused on optimising specialist and GP follow-up, discharge medications, and partnerships with primary-care providers.⁹⁸²

The cardiology department of the Princess Alexandra Hospital conducted a retrospective audit of discharge summaries, demonstrating that a written recommendation for early GP follow-up in the summary was associated with higher rates of early follow-up after an acute cardiology admission.⁹⁸³ A departmental policy was implemented from June 2017 that required discharge summaries to recommend early GP follow-up for all patients after discharge. There was an increase in discharge summary recommendation for early GP follow-up with the intervention (49.7% in May vs 73.2% in June 2017).⁹⁸³ This was associated with 14-day follow-up increasing from 66.8% to 75.5% of patients.⁹⁸³

Between 2015 and 2017, the team also trialled making GP appointments for patients while they were still in hospital, finding that these patients had significantly higher GP follow-up rates compared to those who chose to organise their own GP follow-up appointments. Overall, seven-day GP follow-up rates improved from about 50% prior to the program being implemented, to more than 80%. This rate was maintained from 2015 through to the end of the project review period in late 2017.⁹⁸³

As part of discharge planning, the Better Cardiac Care team also developed a 'Transitioning Care Admission to Community Setting (TRACS)' My Heart Wellness Plan. This document was filled out by/with the patient in non-clinical language and included information on reason for admission, procedures during hospital stay, prescribed medication/advice and follow-up plans.

The program had an overall positive effect on preventable readmission to hospital, with a reduction of 28-day readmission rates in Aboriginal and Torres Strait Islander patients from 11.9% in 2013, to 6.5% in 2016 (lower than the non-Indigenous rate of 7.4%). However, this rate then increased to 9.0% in the final year of evaluation (2017).

Government of Western Australian – Eastern Metropolitan Health Service

The cardiology service of Royal Perth Hospital identified that cardiology clinic attendance for Aboriginal people discharged from the cardiology service was significantly lower than for non-Aboriginal people (63% vs 85.9%).⁹⁷⁹ Strategies to improve follow-up were implemented in September 2018. Although most of these people had ischaemic heart disease, procedural changes are equally relevant to Aboriginal and Torres Strait Islander people attending for RHD. A range of changes were made to address this disparity, including referral to remote visiting cardiac services so that people could receive follow-up care closer to home. Critical clinical handover changes also included:

- Ensuring that appointment and procedure dates were arranged prior to discharge in consultation with the patient;
- Ensuring discharge summaries were provided prior to discharge, sent to the relevant care providers and a copy provided to the patient; and
- A phone call to patients following discharge to discuss medication supply, access to primary care, and confirm planned cardiology follow-up.

This program is at an early phase, although preliminary data suggest that improvements in cardiology clinic attendance following discharge have been possible – albeit with small absolute numbers of patients and variably between outcomes in the Pilbara and Kimberley regions.^{979,984}

Summary: Optimise clinical handover		
Domain	Summary	Rating
Evidence	There is moderate evidence for the efficacy of programs to improve discharge planning and clinical handover from tertiary care to primary-care providers. The downstream effects of better handover for RHD patients – i.e. improved longer-term health outcomes, reduced morbidity and mortality – have not yet been demonstrated.	Medium
Benefits	Improved handover for patients with RHD is likely to have a positive impact on planned follow-up and adherence to medication.	Medium
Risks	No risks have been identified to improved clinical communication between health professionals. Clinical systems to ensure that information transfer is confidential remain critical to this process.	Low
Acceptability	Patient journey mapping indicates that Aboriginal and Torres Strait Islander people find poor handover of clinical information frustrating and efforts to address this would likely be acceptable. Preliminary data show improved attendance to follow-up appointments and better engagement with health plans, indicating acceptability to patients.	Medium
Feasibility	Clinical handover is facilitated by coordinated primary healthcare and acute services. It is core practice and a requirement under NSQHS. Specific projects to date have demonstrated high feasibility of integrating good discharge planning and clinical handover into routine practice.	High
Costs	Improving clinical handover should be and has been conducted within the standard operating capacity of departments.	Low
Timeline	Existing programs have been implemented over a period of months.	Short
Positive externalities	Optimising clinical handover for patients with RHD improves clinical management from the provider and also patient engagement and understanding. Initiatives that improve handover and follow-up for cardiac patients translate easily to patients in other specialities.	High
Equity	Initiatives for optimising clinical handover which are specific to Aboriginal and Torres Strait Islander patients, living in remote areas, are likely to have a positive effect on equity.	Medium
Recommendations	<ul style="list-style-type: none"> All people with RHD who have been admitted to hospital should have a clinical handover document prepared prior to discharge. A copy of this document should be provided to the patient and a copy provided to their usual primary-care provider (in accordance with NSQHC standard 6). The RHD National Implementation Unit should work with tertiary centres to share and adapt successful models of enhanced discharge planning and clinical handover. 	

Improve cardiac rehabilitation

Cardiac rehabilitation refers to structured, usually short-term programs that incorporate modification of risk factors, exercise programs, health education, counselling, and behaviour modification strategies.⁹⁸⁵ Cardiac rehabilitation is generally considered for people who have suffered heart attack; in this setting it is an evidence-based intervention that can help to reduce further cardiac events and readmission to hospital, and increase survival for patients with cardiovascular disease.⁹⁸⁶ Cardiac rehabilitation is also relevant for people who have had surgery for RHD, including support to manage post-operative recovery, return to physical activity, peer support information about medications, and ongoing medical monitoring. However, access to cardiac rehabilitation is extremely limited in rural and remote locations. While uptake of cardiac rehabilitation is low across the population, Aboriginal and Torres Strait Islander people are disproportionately under-represented in their access.⁹⁸⁵

Lack of enrolment in and completion of cardiac rehabilitation for Aboriginal and Torres Strait Islander people relate to inadequate availability of these services, particularly in rural and remote areas.⁹⁸⁷ Complex referral pathways, poor cultural awareness and appropriateness, and low patient education have also been identified as barriers to Aboriginal and Torres Strait Islander people engaging with cardiac rehabilitation.⁹⁸⁷

Better Cardiac Care – Burlu Kirra Kirra – NSW

The 'Heart of Country' program aimed to increase the number of Aboriginal and Torres Strait Islander patients in Broken Hill referred to the Integrated Care for Patients with Chronic Conditions Service following a cardiac diagnosis from three to 30 by the end of December 2019. The secondary objective was to ensure 15 of these 30 patients were engaged in a culturally appropriate cardiac education and exercise program. It was identified that the current program was not culturally safe, meaning low numbers of Aboriginal and Torres Strait Islander patients were engaged in cardiac rehabilitation. The location of the existing cardiac rehabilitation centre in the hospital was seen as a barrier, given that patients often view the hospital as a place of dying. There was also a lack of standardised referral pathway for Aboriginal and Torres Strait Islander patients, resulting in patients being missed and inefficient processes to follow up missed referrals.

Fundamental changes were made to the cardiac rehabilitation program, including relocation to a community setting, incorporation of traditional foods, bush walking on country as exercise, and informal yarning for education.⁹⁸⁸

An Aboriginal-specific, standardised referral pathway was developed. The pathway includes AHW involvement with the cardiac patient upon admission to the ward, followed by referral to the Integrated Care for People with Chronic Conditions (ICPCC) team. While in hospital, the patient is seen by an Aboriginal Hospital Liaison Officer, who follows up with them within 48 hours of discharge. Referral is made to a cardiac rehabilitation program in the community, and this referral is followed up by the AHW within 72 hours of discharge from hospital.

Strong Aboriginal community leaders and collaborative partnerships to secure recurrent funding are central to sustaining the program. Evaluation is currently under way.

Yedding Gauar (Good Heart) – Canberra

This project, launched in May 2018, is aimed at evaluating the feasibility of a women-only, culturally safe cardiac rehabilitation program for Aboriginal and Torres Strait Islander patients in a mainstream health service.⁹⁸⁹ The study was conducted over 18 weeks with weekly cardiac rehabilitation sessions consisting of one hour of exercise and 30 minutes of education delivered by a multidisciplinary team, including an Aboriginal Health Worker.⁹⁸⁹ Outcome measures for participants include body mass index, waist-to-hip ratio, random point-of-care lipid profile and blood glucose level, quality of life (MacNew questionnaire), exercise capacity (six-minute walk test), and anxiety and depression (Hospital Anxiety and Depression Scale).⁹⁸⁹ In addition, health professionals' cultural awareness and safety before and after the program are assessed using a questionnaire. Feasibility measures include recruitment of participants, adherence to the cardiac rehabilitation program, and drop-out rates. Qualitative data from participants will be collected at the end of the program and analysed thematically by an Indigenous researcher. Qualitative data will also be collected and analysed from staff at the end of the program.⁹⁸⁹

Improving Care for Aboriginal and Torres Strait Islander Patients framework – Victoria

This project involved an Aboriginal Liaison Officer (ALO) and a specialist cardiac nurse providing care coordination specifically directed at improving attendance at cardiac rehabilitation services for Aboriginal and Torres Strait Islander patients in a large metropolitan hospital in Melbourne.⁹⁶²

Prior to the program, referral to cardiac rehabilitation was recorded for 42% of Aboriginal and Torres Strait Islander patients admitted to the cardiology department. During the implementation of the model of care, 13 of 15 patients (86%) received a referral to cardiac rehabilitation and eight of the 13 (62%) attended.⁹⁶² This program has now been integrated within the hospital and across disciplines with the permanent employment of an ALO within the newly developed Aboriginal Health Unit.⁹⁹⁰

Overall Evidence & Priority	Recommendation	Equity	Positive externalities	Timeline	Costs	Feasibility	Acceptability	Risk	Benefits	Evidence
Medical management and specific specialist needs										
Medium	Culturally appropriate education should be provided for people diagnosed with RHD on importance of dental hygiene and prevention of infective endocarditis. Routine care plans for people living with RHD should include regular dental review.									
Surgical considerations										
High	Permanent care-coordination roles should be funded to support those having heart surgery for RHD.	High	High	Medium	Medium	High	High	Low	Medium	Medium
Medium	Improvement of current cultural safety frameworks and training in acute care is necessary.	High	High	Medium	Medium	Medium	Medium	Low	High	Medium
Medium	It is recommended that the Australian and/or State governments ensure the designated care hubs have the required level of qualified staff and appropriate facilities to meet the population needs, including the required psychological care and social support. Standards of care for centres providing surgery for RHD should be developed.									
High	All people with RHD who have been admitted to hospital should have a clinical handover document prepared prior to discharge.	Medium	High	Short	Low	High	Medium	Low	Medium	Medium
High	Jurisdictions should explore potential models to improve cardiac rehabilitation, including outreach and on-site programs.	High	Medium	Medium	Medium	High	Unknown	Low	Medium	High

Synthesis of tertiary care recommendations

RHD National Implementation Unit Recommendations

The RHD National Implementation Unit should:

- Be resourced to participate in PATS planning and advocate for national-level approaches to a fair and equitable PATS system.
- Develop educational resources to support discussions with women of reproductive age about the potential implications of ARF and RHD on pregnancy, and work with jurisdictional agencies to adapt these resources to local setting and context.
- Evaluate existing modules and training around RHD in pregnancy.
- Work with primary healthcare providers to develop and disseminate appropriate training and resources to support health workers to care for women with RHD in pregnancy.
- Work with tertiary centres to share and adapt successful models of enhanced discharge planning and clinical handover.
- Work with primary healthcare providers to improve access to point-of-care monitoring services.
- Work with specialist cardiology services, in partnership with Aboriginal and Torres Strait Islander youth leaders, to develop a model of care for transition programs.
- Advocate for increased resourcing for cardiac rehabilitation to rural and remote areas.
- Develop standards of care for centres providing cardiac surgery for people with RHD.

State and Territory recommendations

Jurisdictional agencies should:

- Work with State and Territory governments to ensure PATS arrangements are optimised and clearly communicated to all stakeholders.
- Fund permanent RHD care-coordination roles to support children and adults who are having heart surgery for RHD to ensure alignment of clinical, administrative and logistic plans alongside cultural needs and communication between different levels of the health service.
- Ensure access to diagnostic and monitoring services in rural Australia, including echocardiography.
- Work with health service management to increase recruitment and retention of AHWs/ALOs in acute care, especially in rural hospitals.
- Develop more flexible community-based care models to provide culturally appropriate care for Aboriginal and Torres Strait Islander patients.
- Explore potential models to improve cardiac rehabilitation, including outreach and on-site programs.
- Ensure the designated care hubs have the required level of qualified staff and appropriate facilities to meet the population needs, including the required access to echocardiography, cardiology, surgical care, psychological care and social support.

Tertiary setting recommendations

Senior managers of tertiary settings should:

- Ensure that all people diagnosed with ARF or RHD receive high-quality, culturally appropriate education about the condition, in their preferred language.
- Ensure all women of reproductive age receive information about the potential implications of ARF and RHD on pregnancy.
- Provide tailored advice to patients according to specialist reviews.
- Improve current cultural safety frameworks and training in acute care.⁶³
- Ensure that all people with RHD who have been admitted to hospitals have a clinical handover document prepared prior to discharge. One copy of this document should be provided to the patient and another to their usual primary-care provider (in accordance with NSQHC standard 6).

Primary-care setting recommendations

Community care providers should be resourced and supported to:

- Provide culturally appropriate education around the importance of anticoagulation.
- Increase the capacity for self-management of anticoagulation using point-of-care INR machines, providing designated funding and support.
- Educate people with RHD on the importance of dental hygiene.
- Ensure routine care plans for people living with RHD include regular dental review.

Research stakeholder recommendations

- Research to explore the technical specifications, acceptability, feasibility and costs of perinatal echocardiography screening of mothers from high-risk communities should be commissioned.
- A model of care for transition programs should be researched and developed.



5 HEALTH AND ECONOMIC
IMPACT



Introduction

The Endgame Strategy model

In this chapter the health and economic impacts of a representative ‘bundle’ of rheumatic heart disease (RHD) prevention strategies, identified in Chapter 4, are analysed using a model-based approach. A model-based approach is useful in synthesising the available evidence to predict the potential effects of different courses of action, including inaction. This approach is intended to support communities and governments to explore the effects of different decisions relating to RHD.

The *Endgame Strategy* model describes the current epidemiology of acute rheumatic fever (ARF) and RHD in Australia. Recently analysed data were used to estimate the probability of a person developing ARF, progressing to RHD, and developing RHD-related complications, as well as the associated health and economic burdens. Using a range of data sources, the model then predicts the change in health and economic burdens using the expected impact that the prevention strategies will have on the epidemiology of ARF and RHD.

The validity of these predictions is dependent on the underlying model assumptions and parameter estimates. The following should be taken into account:

Simplification

The *Endgame Strategy* has identified a wide range of potential strategies to address Strep A infections, ARF and RHD. However, it is impossible to model the individual and cumulative effect of each of these strategies. Instead, a simplified bundle has been chosen to illustrate the potential impact of some of the strategies being implemented. This bundle is a pragmatic ‘best guess’ collection of strategies which seem most likely to have a significant impact at a national level. It is not intended to be a prescriptive recommendation for individual communities and jurisdictions.

Decision-making

Modelling is intended to provide information and context to decision-makers at a broad level and is no substitute for community-led decision-making. On the contrary, the *Endgame Strategy* recognises that local decision-making and strategy engagement is a critical determinant of success. We hope this work supports Aboriginal and Torres Strait Islander people in a decision-making process with communities and jurisdictional and Federal governments to propose solutions grounded in local priorities.

Data limitations

Data about many of the elements of this *Endgame Strategy* model are sparse. Estimates and assumptions have been made throughout to address limited data. Measures were taken at all times to avoid making assumptions that could overestimate the impact of individual strategies. On the contrary, assumptions have been deliberately made to err on the side of underestimating the potential effect of strategies and it is possible that the true impact of the indicative bundle may be greater. These assumptions are presented in Table 10. Decision-makers should review these assumptions and consider how they apply (or do not apply) in different settings.

Prevention strategies

An indicative bundle of strategies which might be implemented in communities to reduce RHD is presented with estimated effect sizes and explanatory notes in Table 10. These strategies were identified by the END RHD CRE investigators in consultation with the END RHD Advisory Committee and other stakeholders because they show greatest promise in preventing new cases of RHD over the next decade to 2030. In particular, these strategies appear to be acceptable, practical and readily implementable with appropriate investment. Further, these strategies reflect the kinds of approaches most likely to have an impact on Strep A, ARF and RHD, noting that the efficacy of some strategies is based on speculative assumptions. This bundle of strategies is not intended to be prescriptive.



Table 10: Modelled prevention strategies.

Strategy abbreviation	Description	Notes and estimated effect size
i. RC	Reduce household crowding	Reducing household crowding is expected to reduce transmission of Strep A. This could be achieved by building new or extending existing housing. People who no longer live in overcrowded houses would have an estimated 39% reduction* in the risk of Strep A infection based on meta-analysis of studies. ²⁹
ii. HLP	Healthy living practice	Improving capacity to undertake the nine Healthy Living Practices (HLPs) should reduce exposure to and transmission of Strep A. This would include improvements in health hygiene infrastructure and health promotion campaigns. The effect of this approach is an estimated 34% reduction in risk of skin sores based on the reported reduction in skin sores in a randomised controlled trial of daily handwashing in Pakistan. ³⁵⁸ HLPs encompass a range of measures beyond handwashing, so this reduction may be an underestimate of the true effect size.
iii. PHC	Primary Health Care: Improve timely treatment of Strep A infections (including coinfection with scabies) Improve diagnosis of first ARF	Strengthening capacity in primary healthcare (PHC) to address Strep A infections and ARF could have a number of effects on the trajectory of disease at a population level. Three main approaches in primary care include: <ul style="list-style-type: none"> • Clinic-based health engagement and education in order to increase care-seeking behaviour for Strep A infections and possible ARF; • Strep A outreach programs to identify skin sores and sore throats at a household level; and • Strengthened PHC management of Strep A and ARF through staff training and increased staffing. Together, these steps could reduce the risk of progression from Strep A infection to ARF and from ARF to RHD. Although empirical evidence about health-seeking behaviour and the effect of strategies is limited, a conservative estimate based on expert opinion is: <ul style="list-style-type: none"> • Currently 20% of people with a skin sore or sore throat are assessed and treated in clinic. • This could be increased to potentially 50% with education and outreach. • Therefore, an additional 30% of people with skin sores or sore throats in the population would receive antibiotics for primary prevention. • Additionally, increased health-seeking behaviour and strengthened PHC management of ARF would result in an estimated additional 10% of people with ARF who were previously undiagnosed being diagnosed. This diagnosis would facilitate secondary prevention, thereby reducing progression from undiagnosed ARF (now diagnosed) to RHD.
iv. SP	Improve delivery of secondary prophylaxis	A package of strategies is required to improve delivery of secondary prophylaxis. Reduced progression from ARF to mild RHD and from mild RHD to severe RHD could be achieved by: <ul style="list-style-type: none"> • Improving PHC quality and staffing; • Increased RHD register-based control program capacity; • Empowering self-management, peer support; • Increasing capacity of health clinics to have greater connection and engagement with families and people living with RHD and ARF; and • Strengthened transitional care from paediatric to adult services. In the absence of studies showing the direct effect of high secondary prophylaxis delivery, an effect has been estimated by combining independent data from the Northern Territory and Brazil. [†] Combining these data, it was assumed that achieving at least 80% delivery of secondary prophylaxis results in a 16% reduction in progression from ARF to mild RHD and a 33% reduction in progression from mild to severe RHD. These effects were applied to the proportion of the population estimated to reach at least 80% adherence, which we assumed would increase to 60% of people (currently approximately 30%). ¹⁶⁹

* The proposed 39% reduction has been deduced from internal meta-analysis of the appropriate studies assessed in Coffey et al.²⁹
† A study from the NT showed that a recurrence of ARF occurred in approximately 14% of people with at least 80% adherence to SP and 38% of those with less than 80% adherence.⁸¹¹ Brazilian data reported that the prevalence of significant carditis was 30% in people with primary ARF and 58% in those with recurrent ARF, and that the prevalence of significant valve disease was 10% in people with primary ARF and 40% in those with recurrent ARF.⁸⁰⁹

Impact of prevention strategies on risk of RHD

Figure 41 demonstrates the modelled impact of RHD prevention strategies on the risk of RHD at the population level.

- By reducing crowding, we assumed that, in reducing the incidence of Strep A infection by 39%, the equivalent relative reduction would occur in the incidence of ARF and, therefore, RHD.
- Implementing the Healthy Living Practices reduces the relative risk of RHD by 34%, or by an additional 21% when done in addition to reducing crowding.
- Improving the timely treatment of Strep A infections and diagnosis of first ARF by strengthening primary healthcare would reduce the relative risk of RHD in the population at risk by 24%, or an additional 12% if implemented in addition to both reduced crowding and HLPs.

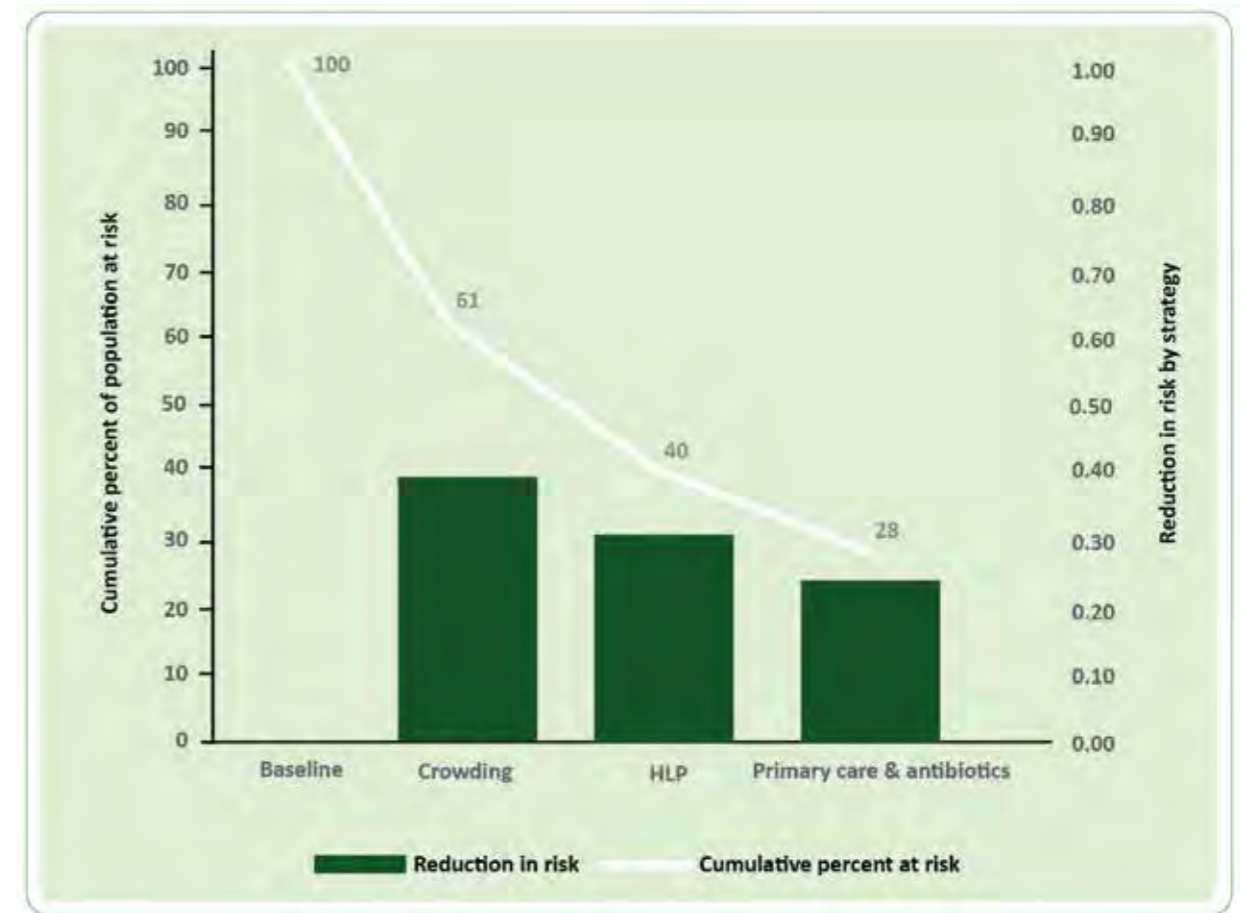


Figure 41: Impact of RHD prevention strategies on the risk of RHD.

Efficacy of these strategies depends on a supporting architecture of core activities, specifically:

- **Community-level health engagement, education and promotion:** all the most promising strategies to reduce RHD require community-level engagement and sharing of key health education and health promotion messages. A comprehensive approach requires engagement about Healthy Living Practices, Strep A infections, ARF and RHD. These messages are interdependent and therefore costing is best considered as a bundle of health promotion.
- **RHD National Implementation Unit:** a national-level organisation or consortium is needed to provide high-level technical support, resource development and ongoing strategic direction to end RHD. This unit would provide an avenue to mechanise high-level Aboriginal and Torres Strait Islander governance to end RHD.
- **Jurisdictional activities:** register-based RHD control programs are currently in place in the NT, SA, WA, QLD and NSW. The control programs are tasked with the improved detection, monitoring and management of ARF and RHD. Register-based control programs are a critical component of a comprehensive RHD elimination strategy.

Results

Implementing HLPs (ii) and PHC improvements (iii) in all communities would more than halve the estimated number of people to develop RHD and reduce healthcare costs by approximately **\$140 million**.

Modelled reduction in RHD prevalence and mortality

As outlined in Table 11, it is estimated that of the Aboriginal and Torres Strait Islander people born between 2019 and 2031, 5,832 will develop ARF and 2,835 will develop RHD. Of these people, 1,356 people will develop severe RHD (heart failure and/or valvular disease requiring a surgical procedure) and 663 people will die prematurely as a result of RHD. Figure 42 and Figure 43 show the estimated reductions in RHD prevalence and RHD-related deaths projected to occur in Aboriginal and Torres Strait Islander people born between 2019 and 2031 in the NT, SA, WA, QLD and NSW.

Note, '+' means in addition to all of the previous strategies (i.e. +HLP is on top of reduced crowding).

- Implementing all the RHD prevention strategies would reduce both RHD prevalence and related deaths by **71%**.
- Reducing household crowding alone would reduce the prevalence of RHD and associated deaths by **39%**.
- Adding the Healthy Living Practices reduces the prevalence of RHD and related deaths by a further **21%**, equating to a **59% reduction** compared to the current rates.
- Improving primary healthcare in addition to improving Healthy Living Practices and reducing crowding would reduce the prevalence of RHD and associated deaths by a **further 12%**, equating to a **71% reduction** compared to the status quo.

Figure 42: Changes in projected RHD prevalence in Aboriginal and Torres Strait Islander people born between 2019 and 2031 in the NT, SA, WA, QLD and NSW.

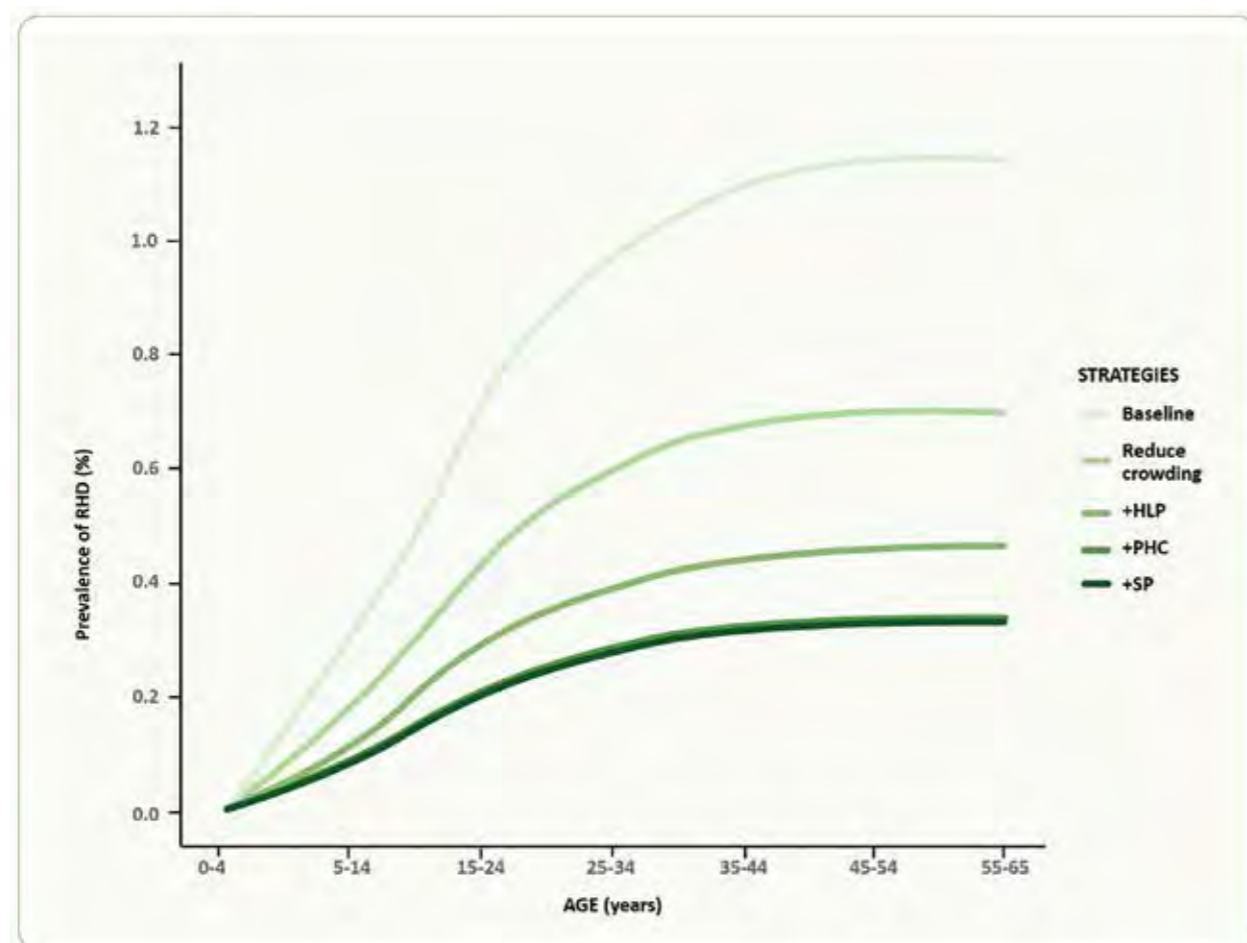
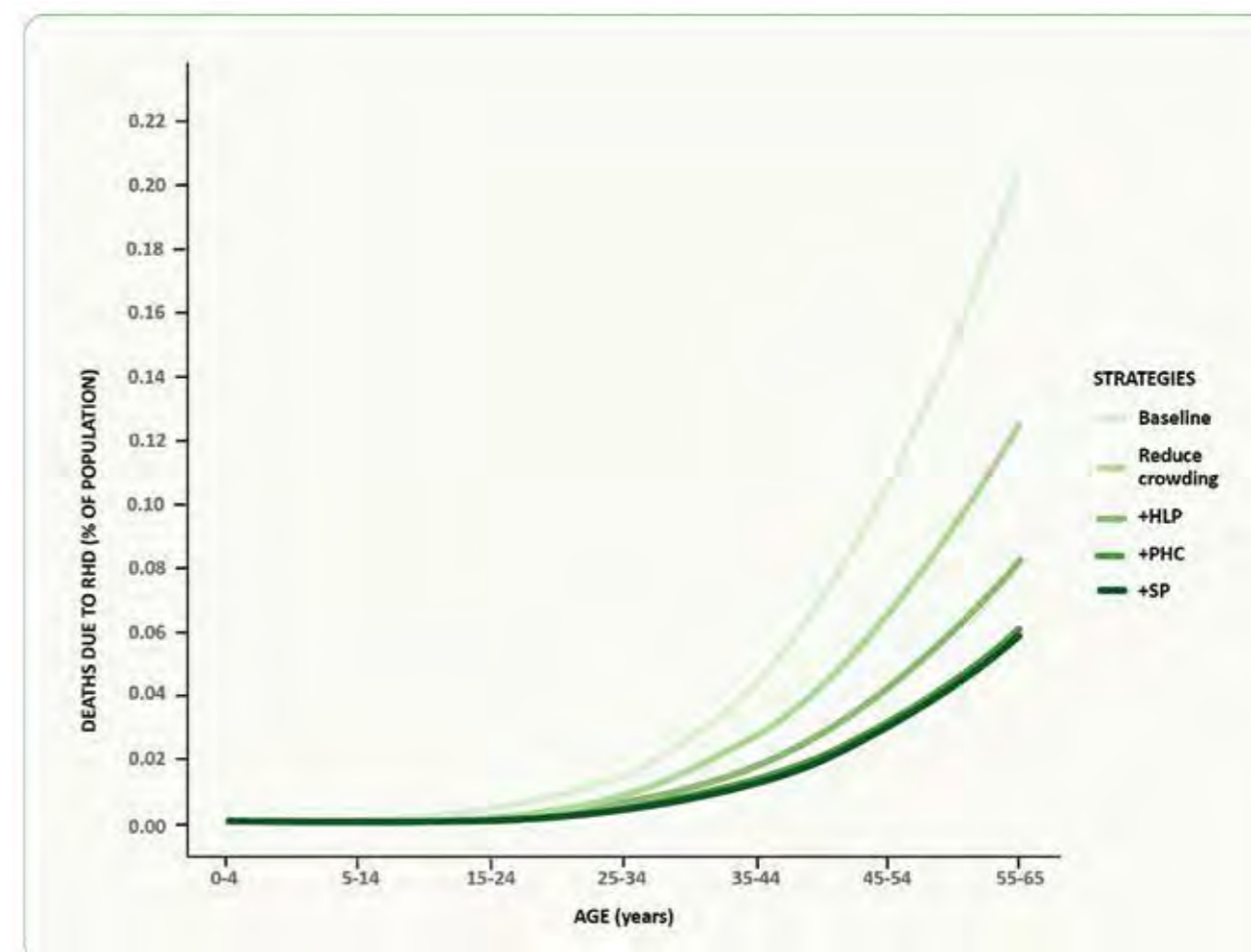


Figure 43: Changes in projected RHD mortality in Aboriginal and Torres Strait Islander people born between 2019 and 2031 in the NT, SA, WA, QLD and NSW.



Modelled health and economic outcomes

Table 11 outlines the predicted health and economic outcomes due to ARF and RHD that are projected to occur in Aboriginal and Torres Strait Islander people born in the NT, WA, QLD, SA and NSW between 2019 and 2031 if current trends continue. The baseline risk among the Aboriginal and Torres Strait Islander population of the NT, WA, SA, QLD and NSW of an episode of ARF (including undiagnosed ARF) between birth and 64 years of age was just over two in 100 births.

The subsequent risk of developing RHD was one in 100 births. Modelling estimates indicate that **\$273 million** will be spent on medical care for ARF and RHD to 2031 with these baseline rates of ARF and RHD. These modelled economic outcomes account for healthcare expenditure on ARF and RHD hospitalisations, including surgical intervention and long-term management (secondary prophylaxis and specialist follow-up).

Table 11 also presents the modelled impact of prevention strategies on the incidence of ARF and RHD, as well as premature death due to RHD.

- If all prevention strategies were implemented, the number of people living with RHD would **reduce by 71%**, 471 fewer people would die as a result, and there would be a saving of **\$188 million** to the health system.
- Implementing the Healthy Living Practices and primary healthcare improvements alone would **halve** (52% reduction) the total number of people living with RHD and severe RHD. The number of people to die due to RHD in this cohort would also halve (320 from 663), and there would be a reduction of **\$140 million** in healthcare costs.
- Reducing crowding, implementation of the HLPs, and PHC improvements would collectively save **\$190 million** of healthcare costs.

Table 11: Predicted lifetime (0–64 years of age) health and economic outcomes due to RHD experienced by Aboriginal and Torres Strait Islander people born in the NT, SA, NSW, QLD and WA between 2019 and 2031 (n=251,267), inclusive, by Endgame Strategy if implemented in all locations (n=251,267).

Strategy	N first ARF	N RHD cases		N deaths**	DALYs	Healthcare costs ^ (\$m)	Cost savings ^ (\$m)
		All	Severe*				
0. None (baseline)	5,832	2,835	1,356	663	12,932	273.4	N/A
Independent implementation of strategies							
i. Reduce crowding	3,573	1,737	831	406	7,921	167.5	105.9
ii. HLP	3,864	1,878	898	439	8,566	181.1	92.3
iii. PHC	4,444	2,066	984	483	9,450	204.3	69.1
iv. SP	5,832	2,787	1,250	652	12,696	281.6	+8.2
Combined implementation of strategies							
Primordial (i & ii)	2,364	1,149	549	269	5,239	110.8	162.6
Primordial + PHC (i-iii)	1,799	836	398	195	3,823	82.7	190.7
HLP + PHC (ii + iii)	2,942	1,367	651	320	6,254	135.3	138.1
HLP + PHC + SP (ii-iv)	2,942	1,343	599	314	6,132	139.4	134.0
All (i-iv)	1,799	821	366	192	3,748	85.2	188.2

*Comprises people with RHD which is severe at diagnosis and those progressing from mild RHD over time.
 **N deaths = number of people who die with RHD but not necessarily because of RHD.
 ^Cost = healthcare expenditure on ARF and RHD hospitalisations, including surgical intervention and long-term management (secondary prophylaxis; based on the 2nd edition of the Australian Guideline; and specialist follow-up). Does not include the cost of treating Strep A infection or implementing the prevention strategies.
 DALYs = Disability-Adjusted Life Years.

The reduction in cases of RHD and cost is lower when targeting only the 210 communities at highest risk. Table 12 outlines the predicted health and economic outcomes due to ARF and RHD that are projected to occur in Aboriginal and Torres Strait Islander people born between 2019 and 2031 in the NT, WA, QLD, SA and NSW. The predicted outcomes after the introduction of the prevention strategies are given for the populations in the five jurisdictions, but reductions in burden are modelled only for people living in the communities receiving the prevention strategies (communities within the 210 Indigenous Locations (ILOCs) of the NT and the northern regions of QLD and WA).

Although the population of the 210 ILOCs comprises 46% of the estimated Aboriginal and Torres Strait Islander population in the NT and the northern regions of QLD and WA, the predicted burden in locations with and without full implementation of the prevention strategies assumes that these locations cover all people predicted to develop ARF and RHD in the entire region (i.e. these locations capture the entire burden of disease in the NT and the northern regions of QLD and WA; Appendix Nine).

Compared to the total projected burden at baseline, the total projected burden after implementing the prevention strategies in communities within the 210 ILOCs of the northern region of Australia would result in:

- **A 63% reduction** in the prevalence of RHD, with the associated **prevention of 419 premature deaths** and saving of **\$168 million** in healthcare costs, if all prevention strategies were implemented.
- **A 46% reduction** in the prevalence of RHD, with the associated prevention of **305 premature deaths** and saving of **\$123 million** in healthcare costs, if only HLPs and primary healthcare strategies are implemented.

Table 12: Predicted lifetime (0–64 years of age) health and economic outcomes due to RHD experienced by Aboriginal and Torres Strait Islander people born between 2019 and 2031 in the NT, SA, NSW, QLD and WA (n=251,267) with and without (baseline) the implementation of prevention strategies.

Strategy	N first ARF	N RHD cases		N deaths**	DALYs	Healthcare costs ^ (\$m)	Cost savings ^ (\$m)
		All	Severe*				
0. None (baseline)	5,832	2,835	1,356	663	12,932	273.4	N/A
Prevention (in 210 ILOCs#)							
Independent implementation of strategies							
i. Reduce crowding	3,821	1,858	889	434	8,472	179.1	94.3
ii. HLP	4,080	1,983	948	464	9,046	191.3	82.1
iii. PHC	4,597	2,151	1,025	503	9,833	211.9	61.5
iv. SP	5,832	2,792	1,262	653	12,722	280.7	+7.3
Combined implementation of strategies							
Primordial (i & ii)	2,745	1,334	638	312	6,085	128.7	144.7
Primordial + PHC (i-iii)	2,243	1,056	503	246	4,825	103.7	169.7
HLP + PHC (ii & iii)	3,260	1,528	729	358	6,989	150.5	122.9
HLP + PHC + SP (ii-iv)	3,260	1,507	682	352	6,880	154.1	119.3
All (i-iv)	2,243	1,043	475	244	4,758	105.9	167.5

#Predicted outcomes after the introduction of the prevention strategies are given for the population in the five jurisdictions, but reductions in burden occur only in the communities receiving the prevention strategies (i.e. the communities within the 210 Indigenous Location of the NT and the northern regions of QLD and WA).
 *Comprises people with RHD which is severe at diagnosis and those progressing from mild RHD over time.
 **N deaths = number of people who die with RHD but not necessarily because of RHD.
 ^Cost = healthcare expenditure on ARF and RHD hospitalisations, including surgical intervention and long-term management (secondary prophylaxis and specialist follow-up). Does not include the cost of treating Strep A infection or implementing the prevention strategies.

Case for investment

In order to predict the total economic impact and scale of investment required to eliminate RHD, the proposed strategies are costed according to implementation at a community level. These are coupled with the supporting core activities at a national level.

A summary of the estimated costings of these prevention strategies is presented below in Table 13 and a detailed rationale of these costings is presented in Appendix Eight.

Table 13: Summary of the cost of RHD prevention strategies.

Item	Number of communities	Years	Strategy category	Core/set up cost (\$'million)	Maintenance/running cost (\$'million)	Total (\$'million)
National Implementation Unit	N/A	10	All	24.9	N/A	24.9
Health promotion	210	7	All	7.4	N/A	7.4
Jurisdictional control program ^f	N/A	TBD	SP, PHC	N/A	3.4 [†]	TBD
Housing – new			Reduce crowding	2,900	N/A	2,900
Housing – health hardware	210	10	HLP	272.0	444.2	716.2
Comprehensive outreach	210	7	PHC	N/A	36.8	36.8
PHC quality improvement [*]	210	12	PHC	N/A	80.3	80.3
Health service delivery costs	210	7	PHC	N/A	12.1	12.1
Improved adherence to SP						
Champions	20	10	SP	N/A	2.5	2.5
HLP Infrastructure [^]	210	10	HLP	210.0	315.0	525.0
Ablution blocks	210	10	HLP	25.1	52.5	77.6
Community laundries	210	10	HLP	50.8	168.0	218.8
Swimming pools	210	10	HLP	609.0	420.0	1,029.0
Total				3,414.3	890.9	4,305.2
Total including optional strategies				3,889.2	1,216.4	5,105.6

Current funding under RFS NPA for jurisdictional control programs is committed through to mid-2021; not included in total costings

^{*}Recognition and treatment protocol by clinicians: training, streamlined clinical care for patients with Strep A infections or ARF/RHD/SP

[^]Assuming \$1 million investment for each community to invest in HLP infrastructure and \$150k for maintenance annually. Full cost of optional strategies (ablution blocks, community laundries, swimming pools) are also outlined.

The modelled health and economic impact of the *Endgame Strategy* presented above estimates that over the next decade to 2031, between **419** and **471** premature deaths can be avoided, with an associated saving to the health system of between **\$168 million to \$188 million**.

If all 210 communities were to adopt all strategies identified in this chapter, the total investment through to 2031 would be **\$4.3 billion**. Actual investment costs will differ from this based on community context, priorities and preferences. For example, some communities already have, or would not wish to have, community laundry facilities, swimming pools or ablution blocks. This *Endgame Strategy* is intended to provide communities and decision-makers with current evidence about various strategies which may or may not be appropriate to local needs. Therefore, \$4.3 billion is best considered as an indicative guide to the scale of investment needed to end RHD.

It should be noted that 67% of the total investment, or \$2.9 billion, is dedicated to funding for increasing remote housing stock as the most effective means to reduce overcrowding. Although this is a critical component of a comprehensive strategy to tackle RHD, dealing with overcrowding is a central priority for the overall health and wellbeing of Aboriginal and Torres Strait Islander people. Therefore, such an investment should not be considered specific for RHD but extends far beyond a single disease.

A further 17% of the total investment, or \$716 million, is dedicated to improving health hardware within existing community infrastructure such as housing. As with new housing stock, these improvements are essential for a broad range of health outcomes for Aboriginal and Torres Strait Islander people, and their impacts also extend far beyond RHD.

Excluding the costs of building new housing stock, an investment of **\$1.4 billion** over 12 years would fundamentally mechanise the *Endgame Strategy* approach to RHD, encompassing healthy living practices, housing infrastructure, primary prevention and peer support.

Concentrating on RHD-specific activities (i.e. excluding housing health hardware,) an investment of **\$689 million** would equip communities to carry out HLPs, improve primary healthcare delivery, and fund health promotion and peer support.

When considering the case for investment, it is crucial to acknowledge that the outcomes modelled in this chapter are based on conservative assumptions at all steps, and therefore represent an underestimate of the true expected impact of the intervention bundle. They also do not account for the full health, economic, and social benefits of implementing equitable public health measures. For example, implementing the HLPs would prevent a number of health conditions beyond Strep A infections. Specifically concerning ARF and RHD, the potential economic benefits of preventing new diagnoses extend beyond reductions in healthcare costs, to reduced carer time, improved school attendance in children, improved educational outcomes, and increased workforce participation in adults.⁹⁹² Even without quantifying these wider benefits, implementing HLP and PHC strategies in the 210 ILOCs, with a net cost of \$722.5 million and saving 5,943 DALYs, is considered to be cost-effective, with an incremental cost-effectiveness ratio of \$122k per DALY saved, based on agreed cost-effectiveness criteria.⁹⁹²

Finally, and most importantly, Australia has a moral imperative and agreed national goal to prevent avoidable death and disability, and to end the leading cause of cardiovascular disparity between Aboriginal and Torres Strait Islander people and non-Indigenous Australians.

Conclusion

Modelling estimates indicate that the strategies proposed in the *Endgame Strategy*, namely reducing household crowding, improving hygiene infrastructure, strengthening primary healthcare, and enhancing delivery of secondary prophylaxis, would reduce ARF and RHD cases by 69% and 71% respectively (Table 11). This would prevent 471 deaths and save \$188.2 million on ARF- and RHD-related healthcare expenditure. This represents a functional end to RHD in Australia and can be achieved by 2031. It would end the preventable suffering of Aboriginal and Torres Strait Islander people, families and communities affected by RHD.

Priority Action Areas

The *Endgame Strategy* has identified a range of strategies that demonstrate potential to put the elimination of RHD in Australia on track for 2031. No single one of these strategies will eliminate RHD. Instead, a comprehensive approach, applying a number of strategies concurrently, is needed. This will look different across communities and jurisdictions, reflecting the cultural, geographic and political context in which they operate.

Resource an Aboriginal and Torres Strait Islander-led National Implementation Unit to coordinate rheumatic heart disease elimination efforts across Australia

The RHD National Implementation Unit will:

- Work with government at the national, state, territory and local level to address the root environmental and social causes of rheumatic heart disease;
- Deliver technical support to all stakeholders involved in work to end RHD – from communities to policymakers, clinicians, and health workers;
- Support and fund communities across Australia to deliver culturally appropriate strategies to prevent RHD and ensure the best treatment for those already living with the disease;
- Develop resources and guidelines to equip communities, schools and clinicians in their work to end RHD;
- Act as the critical link between researchers and communities – setting research priorities and ensuring translation of evidence and technological advances in acute rheumatic fever and RHD diagnosis and management; and
- Monitor progress and re-evaluate strategies to ensure goals are achieved.



Aboriginal & Torres Strait Islander leadership

Fund communities to develop their own culturally appropriate programs to eliminate RHD

Ending RHD will only be successful if communities are empowered and supported to implement culturally relevant RHD elimination activities aligned to local priorities. There are currently at least 10 communities taking action to address ARF and RHD, with varying levels of funding and support.

With a network of support coordinated by the RHD National Implementation Unit, communities will be able to drive work to:

- Increase awareness about Strep A and the symptoms of ARF so that people:
 - Are diagnosed and receive the right treatment as quickly as possible to prevent RHD developing;
 - Already living with ARF or RHD have access to culturally safe health care within their community.
- Resource peer support networks led by those living with or impacted by ARF or RHD; and
- Evaluate demand for community-based echocardiography screening, ensuring comprehensive follow-up care is available for those diagnosed.

To support this community-driven work, the Commonwealth Government should:

- Provide ongoing investment to better support and grow the Aboriginal and Torres Strait Islander health workforce; and
- Increase funding to community-based health care providers to ensure accessible, best quality care for those living with ARF and RHD.



Community-based programs

Experience and evidence make it clear that community-level action is crucial to eliminating RHD. Therefore, the *Endgame Strategy* proposes a holistic strategy to end RHD with Aboriginal and Torres Strait communities at the core, grounded in local decision-making and with supporting structures to ensure a nationally consistent approach.

Tackle the root causes of RHD by guaranteeing communities have access to healthy housing and built environments

This will involve cross-sector collaboration between national, jurisdictional and local governments and communities to:

- Increase new housing stock and ensure proactive repair and maintenance of existing housing to reduce overcrowding and improve living conditions;
- Ensure access to essential hygiene infrastructure such as hot water, running showers and washing machines, so that people are able to achieve the Healthy Living Practices including washing hands, clothes and bodies; and
- Embed environmental health in community-based health care.



Healthy environments

Establish a comprehensive skin and throat program for high risk communities

The RHD National Implementation Unit will work with communities and their local service providers to:

- Implement comprehensive Strep A outreach activities tailored to the local context;
- Develop tools to better support health workers to diagnose and treat Strep A skin and throat infections, the precursor to ARF and RHD; and
- Explore strategies aimed at making it easier for people in high risk communities to have their skin sores and sore throats checked. For example: flexible appointment systems and after-hours services; school-based screening programs; and offering transport to and from clinics.



Early prevention

Improve the health and wellbeing of those living with ARF and RHD

Communities, researchers, service providers and the RHD National Implementation Unit will together work to:

- Make sure those already living with ARF and RHD have access to clear support pathways throughout their journey. This is especially important for transitional periods such as adolescence to adulthood and for women planning pregnancies;
- Resource positions for regional coordinators to monitor and improve treatment and health promotion activities in high risk communities; and
- Ensure people who require specialist treatment off country receive culturally safe treatment in mainstream services.



Care and support



6 Appendices and References



Appendix One: Data sources

Various methods are used to collect and report data on ARF and RHD in Australia, including hospital admission and death datasets, disease notification systems, ARF/RHD registers, cardiology clinics, and echocardiography screening studies. These data collection systems generally operate and are managed independently, capturing different populations and types of data.

RHD control programs with disease registers have been established in five Australian States and Territories; however, legislated notification of ARF and RHD is inconsistent and under-notification is a known issue. Jurisdictional program registers have been established across Australia at different times, with different priorities, and for different populations.¹²⁶ Therefore, producing accurate national burden of disease estimates is difficult due to a lack of standardisation in public health surveillance data. Statistics which draw on Australian ARF and RHD data may not be comparable, either between the jurisdictions, or over time.

Data analysis is usually conducted on only the data contained in each source and jurisdiction, and each system has limitations. For example, hospital and death data are not linked within and between sources, and disease registers may not capture all cases. As a result, data analysis provides a partial picture of the true burden of ARF/RHD within a jurisdiction and nationally.

Hospital admission and death data that are not person-linked (i.e. they do not have a mechanism to identify records that belong to the same individual within and across the various systems) cannot provide accurate information on incidence, prevalence and outcome estimates because longitudinal analyses are not possible.⁹⁹³ Both linked and unlinked data are affected by miscoding of cases and misdiagnosis.⁹⁹⁴

The ERASE Project

Data in Chapter 1 has been primarily sourced from the NHMRC-funded **End RHD in Australia: Study of Epidemiology (ERASE) Project**. The ERASE Project aims to provide a comprehensive database of ARF and RHD cases in Australia as a basis for improved monitoring and to assess prevention and treatment strategies. The ERASE Project uses linked administrative data, including information from ARF/RHD registers, hospital data, death records, and various other sources from 2001 to 2017 (mid-year) to create a comprehensive database for characterising the population living with a history of ARF/RHD and estimating the burden of ARF and RHD. Linked data provide more reliable estimates of the ARF and RHD burden as the linked dataset allows for a person's records to be followed across different data collections, compensating for the incompleteness of data from a single source. The longitudinal nature of the data allows an accurate estimation of disease onset and progression.¹

Data were available for the five Australian jurisdictions where the disease burden is the highest and where ARF/RHD registers have been established: NSW, NT, QLD, SA and WA. Together these five jurisdictions are home to 86% of Australia's Aboriginal and Torres Strait Islander population (at 30 June 2016).⁹⁹⁵

Some misclassifications of regions of residence might have occurred due to limitations and variation in geographical data provided by the linkage units and/or migration of patients. This particularly affects cases residing in South Australia who might be counted in Central Northern Territory where they have undergone treatment, thus under-estimating South Australian rates.

Appendix Two: Consolidated Indigenous regions used for the ERASE dataset

Indigenous Regions are loosely based on geographic boundaries identified by the Aboriginal and Torres Strait Islander Commission (ATSIC) in the late 1990s, when 35 ATSIC Regional Councils provided a mechanism for local decision-making in Indigenous affairs.⁹⁹⁶ As of 2016 there were 58 Indigenous Regions across Australia, of which 37 were on the Australian mainland (others were comprised of shipping, no usual address and other territory codes).⁹⁹⁷ Indigenous Regions do not cross jurisdictional boundaries. The ERASE dataset includes information on ARF incidence for 33 Indigenous Regions (Figure 44). However, the small numbers of Aboriginal and Torres Strait Islander people diagnosed with ARF in each individual Indigenous Region precludes presenting data at Indigenous Region level. Instead, data is presented in nine composite groups of Indigenous Regions (Table 14).



Figure 44: Indigenous Region (IREG) names and boundaries.

Table 14: Consolidated Indigenous regions used for the ERASE dataset.

Consolidated Indigenous Region	Indigenous Region
NT Top End	Darwin, Jabiru-Tiwi, Katherine, Nhulunbuy
NT Central	Alice Springs, Aputula, Tennant Creek
QLD North	Cairns-Atherton, Cape York, Mount Isa, Torres Strait, Townsville-Mackay
WA North	Broome, Kurrurra, South Hedland, West Kimberley
WA Other	Geraldton, Kalgoorlie, South-Western WA
NSW Other	Dubbo, North-Eastern NSW, North-Western NSW, NSW Central and North Coast, Rivernina-Orange, South-Eastern NSW
SA Other	Port Augusta, Port Lincoln-Ceduna
QLD Other	Rockhampton, Toowoomba-Roma
Metro	Sydney-Wollongong, Brisbane, Adelaide, Perth

Appendix Three: Population estimates of Indigenous young people

Table 15: Estimated number of Indigenous young people (0–34 years) living in the five jurisdictions in 2016, 2021, 2026 and 2031, by Indigenous Region Category according to ranking of ARF rates.

Rank ARF Highest to lowest	2016				2021				2026				2031			
	0-14 years	15-24 years	25-34 years	Total <35 years	0-14 years	15-24 years	25-34 years	Total <35 years	0-14 years	15-24 years	25-34 years	Total <35 years	0-14 years	15-24 years	25-34 years	Total <35 years
1	5,959	3,819	3,626	13,404	5,724	3,647	3,904	13,275	5,377	3,681	3,942	13,000	5,164	3,623	3,859	12,646
2	16,168	9,926	9,259	35,353	15,923	10,119	9,801	35,843	15,641	10,095	10,071	35,807	15,399	9,858	10,227	35,484
3	9,238	5,143	5,262	19,643	9,493	4,932	6,049	20,474	9,778	4,809	6,337	20,924	10,021	4,787	6,480	21,288
4	31,114	16,586	12,368	60,068	32,884	18,297	14,352	65,533	34,725	19,984	16,360	71,069	37,555	20,727	17,908	76,190
5	3,911	2,196	1,894	8,001	3,850	2,094	2,054	7,998	3,672	2,111	2,108	7,886	3,522	2,075	2,063	7,660
6	11,172	5,729	4,324	21,225	11,103	6,234	4,796	22,133	11,107	6,683	5,146	22,936	11,371	6,721	5,482	23,574
7	18,623	9,136	5,871	33,630	18,903	10,628	6,959	36,490	19,446	11,812	8,334	39,592	20,799	12,296	9,440	42,535
8	80,270	48,905	34,449	163,624	84,681	53,644	42,875	181,000	91,015	58,395	49,213	198,623	100,683	61,275	54,078	216,036
9	65,786	35,264	23,506	124,556	69,750	37,854	28,705	136,309	74,334	40,910	32,893	148,137	80,891	43,235	35,430	159,556

*Metro = IRC surrounding Perth, Adelaide, Sydney and Brisbane

The Australian Government uses Australian Indigenous Geographic Classifications to define the areas where Aboriginal and Torres Strait Islander people live. The highest level (largest) of these geographic classifications are the Indigenous Regions.⁹⁹⁷ Indigenous Regions are loosely based on geographic boundaries identified by the Aboriginal and Torres Strait Islander Commission (ATSIC) in the late 1990s when 35 ATSIC Regional Councils provided a mechanism for local decision-making in Indigenous affairs.⁹⁹⁸ As of 2016, there were 58 Indigenous Regions accounting for the whole of Australia.

Appendix Four: Transmission mechanisms for Strep A infections, scabies and crusted scabies

Route	Risk of transmission		
	Strep A	Scabies	Crusted scabies
Respiratory droplets	<p>Medium</p> <p>Low - Medium</p> <p>High if skin is damaged or if people have uncovered infected skin sores.</p> <p>*risk is reduced by washing with soap</p> <p>*risk likely to be increased by skin wounds, bites, and sports</p> <p>The Strep A bacteria is not normally found within or on the skin surface. However, Strep A may be transiently detectable on skin surfaces when contaminated by large respiratory droplets, nasal secretions or preceding the development of skin sores.^{998,531,999} The more recent the nose-blowing episode, the more Strep A are transferred. This may provide a route of contamination of a hand-shake recipient who then touches their nose, eyes or mouth or has skin disruption.¹⁰⁰⁰ Nose-picking in the context of nasal carriage of Strep A may also contribute to transfer of Strep A from skin to skin.⁶⁸</p>	<p>None</p> <p>High</p> <p>*risk is NOT reduced by washing with soap</p> <p>Scabies mites spread predominantly through skin-to-skin contact, generally prolonged close personal contact.^{61,362,474}</p> <p>There is no evidence that hygiene, hand or body-washing practices reduce scabies infections.³⁶²</p> <p>Scabies outbreaks occur in communities with vigorous hygiene practices, including in coastal communities with frequent bathing, and medical institutions.^{362,363}</p>	<p>None</p> <p>Very high</p> <p>*risk is NOT reduced by washing with soap</p> <p>Crusted scabies implies a very high mite burden. Transmission probability is a function of mite burden and length of contact, meaning that even relatively brief contact with someone with crusted scabies may be associated with transmission.³⁶²</p>
Skin-to-skin contact	<p>Low (from Strep A throat infections)</p> <p>Medium (from Strep A skin sores)</p> <p>A study conducted in the 1950s found that Strep A was not transmitted from carriers to non-carriers when blankets were shared.⁴⁴⁵ A study in a controlled laboratory environment in 1984 suggested that transfer of Strep A bacteria from fabric to hands did not easily occur unless very large numbers of Strep A bacteria were present on the fabric.¹⁰⁰¹ One contemporary study in the United States used a bacteria similar to Strep A (Streptococcus equi) to show that bacterial transmission from fabrics, particularly when contaminated with pus and infected body fluids, was possible for several hours.¹⁰⁰²</p>	<p>None</p> <p>High</p> <p>Transmission through bedding and clothing is likely from people with crusted scabies who have very high mite burden.^{61,362,1004}</p>	<p>High</p> <p>Transmission through bedding and clothing is likely from people with crusted scabies who have very high mite burden.^{61,362,1004}</p>
Unwashed clothes & bedding	<p>Low</p> <p>In a 1940s study, only four of 272 people became infested with scabies mites after sleeping in bedding used by people with a high burden of scabies mites.¹⁰⁰³ Although washing, occlusion of potential fomites in plastic or sunlight exposure is commonly recommended, no studies have explored the effectiveness of these recommendations using a control group.³⁶⁰</p>	<p>None</p> <p>High</p> <p>Transmission through bedding and clothing is likely from people with crusted scabies who have very high mite burden.^{61,362,1004}</p>	<p>High</p> <p>Transmission through bedding and clothing is likely from people with crusted scabies who have very high mite burden.^{61,362,1004}</p>

Appendix Five: School exclusion guidelines

Table 16: Guidelines by jurisdiction for the exclusion of children experiencing infectious diseases.

	Impetigo	Scabies	Strep throat/ Streptococcal infections/ Scarlet fever
WA	Exclude for 24 hours after antibiotic treatment commenced. Lesions on exposed skin surfaces should be covered with a waterproof dressing. Young children unable to comply with good hygiene practices should be excluded until the sores are dry. ¹⁰⁰⁵	Exclude until the day after treatment has commenced. ¹⁰⁰⁵	Exclude until 24 hours after commencement of antibiotics. ¹⁰⁰⁵
NT	Exclude until appropriate treatment has commenced. Any sores on exposed skin should be covered with a watertight dressing. ¹⁰⁰⁶	Exclude until the day after appropriate treatment has commenced. ¹⁰⁰⁶	Exclude until the child has received antibiotic treatment for at least 24 hours and the person feels well. ¹⁰⁰⁶
SA	Exclude until appropriate treatment has commenced. Any sores on exposed surfaces should be completely covered with a dressing. ¹⁰⁰⁷	Exclude until the day after appropriate treatment has commenced. ¹⁰⁰⁷	Exclude until the person has received appropriate antibiotic treatment for at least 24 hours and feels well. ¹⁰⁰⁷
QLD	Exclude until 24 hours of appropriate antibiotics have been completed. Cover sores on exposed areas with a waterproof dressing until sores are dry, and encourage handwashing. ¹⁰⁰⁸	Exclude until the day after treatment has commenced. ¹⁰⁰⁸	Exclude until 24 hours of appropriate antibiotics have been completed. ¹⁰⁰⁸
VIC	Exclude until appropriate treatment has commenced. Sores on exposed surfaces must be covered with a watertight dressing. ¹⁰⁰⁹	Exclude until the day after appropriate treatment has commenced. ¹⁰⁰⁹	Exclude until the child has received antibiotic treatment for at least 24 hours and feels well. ¹⁰⁰⁹
NSW	Exclude until antibiotic treatment starts. Sores should be covered with watertight dressings. ¹⁰¹⁰	Exclude until the day after the treatment has begun. ¹⁰¹⁰	Exclude until at least 24 hours of treatment has begun and the child is feeling better. ¹⁰¹⁰
ACT	Exclude until appropriate treatment has commenced and sores on exposed surfaces are covered with a watertight dressing. ¹⁰¹¹	Exclude until effective treatment has commenced. ¹⁰¹¹	Exclude until the person has recovered or has received antibiotic treatment for at least 24 hours. ¹⁰¹¹
TAS	Should not attend until sores on exposed surfaces have been treated and are covered with a dressing. ¹⁰¹²	Should not attend school until 24 hours after treatment has started. ¹⁰¹²	Should not attend until 24 hours after antibiotic treatment and the student feels well. ¹⁰¹²

Appendix Six: Measuring the impact of the Endgame Strategy

Background

Identifying success and accountability in the initiatives outlined in the *Endgame Strategy* will require longitudinal measurement and monitoring capacity. A broadly agreed vision, along with goals and targets, could provide a foundation for Aboriginal and Torres Strait Islander peoples and other stakeholders to measure progress. Metrics have been explored by RHD Australia, which released the third edition of the clinical guidelines for RHD in Australia in early 2020, including the Key Performance Indicators listed in the 2012 edition of the guidelines. Similarly, END RHD (a coalition of peak bodies) was commissioned by the Department of Health to produce a draft RHD Roadmap for consideration by the Council of Australian Governments (COAG) Health Council in February 2019. This draft included a small number of potential metrics for measuring progress towards ending RHD. As a research stakeholder, the END RHD CRE undertook a consultation process around proposed RHD-related metrics in 2018 and 2019. This included:

- Mapping of proposed RHD-related metrics conducted by END RHD CRE was circulated to investigators and collaborators from the ERASE RHD Data Linkage project. There were three rounds of written feedback, predominantly on technical issues (coding issues with existing data sets, registers, hospital data).
- Discussions with the Australian Institute of Health and Welfare (AIHW) and jurisdictional control programs about elements which would be in scope for the existing jurisdictional register-based control programs, and those which would not be addressed by current data (primary prevention, maternal outcomes, mortality data linkage).
- Discussion with the Australian Guideline writing group, where it was agreed to segment the existing KPIs so that some became clinical indicators and others became higher-level disease control goals.

Mapping of proposed metrics

Targets and indicators related to Strep A, ARF and RHD have already been proposed in a range of documents (Table 17).

Table 17: Documents containing targets and indicators related to Strep A, ARF and RHD.

2012	RHDAustralia Clinical Guidelines – second edition – key performance indicators ⁷⁵ *The RHDA KPIs include more detailed demographic information which is outside the scope of this document but expected to be retained in future iterations.
2014	NT Aboriginal Health Key Performance Indicators ¹⁰¹³
2016	Australian Medical Association Indigenous Report Card on RHD ³⁰¹
2016	South Australia Aboriginal Cardiovascular Health Profile for the South Australian Aboriginal Heart and Stroke Plan 2017–2021 ¹⁰¹⁴
2017	Health Policy Analysis commissioned analysis of the Rheumatic Fever Strategy ⁶
2018	Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018–2021 ¹²⁷
2018	Better Cardiac Care measures for Aboriginal and Torres Strait Islander people ¹³⁸
2019	Draft RHD Roadmap commissioned by the Department of Health [unpublished]
2020	RHDAustralia Clinical Guidelines, third edition ⁷¹

Current KPIs collected by RHD control programs do not include specific targets and do not link clearly with environmental health or primary prevention goals. To address this KPIs should be redrafted to reflect best-practice standards and be framed to provide evidence for policy change where required. It was proposed that KPIs be split into the core components of registers (clinical function) and aspiration targets for RHD elimination (indicators).

Resourcing

Collecting, analysing and sharing data necessarily requires human and financial resources. Some of this work is currently funded through the Rheumatic Fever Strategy National Partnership Agreement and additional resources in some jurisdictions. Changes to current metrics would have resourcing implications and this would need to be addressed as part of implementing the RHD Roadmap proposed through the COAG Health Council.

Data sovereignty

The overwhelming majority of new cases of ARF and RHD occur in Aboriginal and Torres Strait Islander peoples. Therefore, the END RHD CRE recognises that Aboriginal and Torres Strait Islander peoples should govern decision-making about which information is collected and how it is used. Information about ARF and RHD should be accessible to Aboriginal and Torres Strait Islander peoples and should support accountability in measuring progress towards agreed outcomes. This aligns with the COAG Implementation Principles and underpins the proposed RHD Roadmap.^{151,645}

Table 18: Metrics selected for the Endgame Strategy.

Intervention point	Target	Primary-care Indicators	Jurisdictional control program indicators	National indicators	Rationale	Considerations
Strep A infections	80% of children with sore throat or skin sore assessed and appropriately treated by a trained healthcare professional	Proportion of sore throat and skin sore infections in children assessed and treated by a trained healthcare professional. Potential process measure while this issue is being addressed: Community and school-based education plans in place in partnership with key service providers.	Proportion of ARF episodes which are recurrence.		<ul style="list-style-type: none"> Incentivises primary prevention. Meaningful process measure of how primary prevention is being delivered. 	<ul style="list-style-type: none"> Outside the scope of current register-based control programs. Challenging to define appropriate 'assessment and treatment'. Very difficult to define a timeline (assessed within one day or within three days – especially for skin sores). Multiple determinants of this metric (health-seeking behaviour, health worker training, access to health services). Unclear how school-based services could fit into this for data collection and/or improving the metrics. In some jurisdictions, school attendance is too low for education or data collection to be reliable through schools. May need audit tool along the lines of New Zealand approach.
	No new cases of ARF by 2030		Number and rate of new cases of (definite) ARF notified per time period – by age and sex, Indigenous category, region of onset.		<ul style="list-style-type: none"> Incentivises primary prevention through treating Strep A infection. Ties in with target to prevent new cases of RHD. Builds on existing disease-notification systems for ARF in QLD, NT, SA, WA and NSW. 	<ul style="list-style-type: none"> Target broadly endorsed. Regular reporting (perhaps even quarterly) would be technically possible if there was a strong rationale and supporting resources. Need to acknowledge that diagnosis of ARF can be clinically challenging, leading to some imprecision unless new diagnostic tools emerge. ARF rates will rise with increased funding and case detection. That rise could extend for many years if the underlying social determinants which are driving the disease do not change.
ARF	No primary cause of death attributed to ARF by 2030			Number of deaths recorded with ARF as a cause, underlying cause or associated cause of death.	<ul style="list-style-type: none"> Reasonably achievable (baseline is low, and prompt medical care could avert a number of these deaths). Intended to be a sentinel 'never' event which would trigger consideration of whole-of-program efficacy. 	<ul style="list-style-type: none"> Will need to facilitate National Death Index linkage with all the jurisdictions to be confident.

Intervention point	Target	Primary-care Indicators	Jurisdictional control program indicators	National indicators	Rationale	Considerations
Recurrences of ARF	Reduce the proportion of people who are diagnosed with recurrent ARF to 0.6 per 100 patient-years. ^{1015,1016}	Number and proportion of patients with ARF recurrence.			<ul style="list-style-type: none"> Draws on key international studies Uses existing register data with a clear/stable baseline. Known denominator (albeit likely to rise). 	<ul style="list-style-type: none"> Increased case detection associated with increased resourcing will lead to an increased denominator, which may make it difficult to track this over time. This addresses people with recurrences who have been prescribed secondary prophylaxis (rather than those who did not have ARF diagnosed on first episode, did not have secondary prophylaxis prescribed) Details about when secondary prophylaxis has been prescribed can be difficult to access in different jurisdictions. (Additional metric could include recurrences in people who have ceased secondary prophylaxis – perhaps a second-phase priority).
	Greater than 90% of people prescribed secondary prophylaxis receive 100% of injections	Number of people indicated to receive secondary prophylaxis by age, sex and Indigenous category. Proportion of patients who received 100%, >80%, 50-79%, and less than 40% of doses in 12-month period.	<p>Proportion of people who need secondary prophylaxis receiving 100% of scheduled injections.</p> <p>Proportion of people who need secondary prophylaxis receiving >80% of scheduled injections.</p>	<ul style="list-style-type: none"> If prophylaxis is provided effectively for people with a history of ARF, new cases of RHD can be prevented. Good evidence of effect at 80% threshold. 'Quality of care' metric which incentivises action by the health service. 	<ul style="list-style-type: none"> Recommendation for two-tier metrics – 100% adherence and 80% adherence to reflect aspirational target and to be able to capture progress even when it is not perfect. Evaluation of the Rheumatic Fever Strategy, however sense that would be premature at this stage given difficulties defining the measure, extracting the data and making meaningful interpretations. A pilot of the approach at a population level is probably warranted before adoption into national usage. This would need to include support to develop a script to extract DAR data. 	
RHD	Reduce the RHD incidence rate of Aboriginal and Torres Strait Islander young people from 59/100,000 people to the non-Indigenous rate of <1/100,000				<ul style="list-style-type: none"> Aligns with overarching goal for no new cases of RHD from 2025 Intersects with AMA Report Card 	<ul style="list-style-type: none"> Target broadly endorsed. Regular reporting of RHD incidence rate is relatively feasible

Intervention point	Target	Primary-care Indicators	Jurisdictional control program indicators	National indicators	Rationale	Considerations
RHD	No new cases of RHD from 2025 in people under 35 years of age		Number and rate of incident cases of RHD, by age and sex, Indigenous category, valve involved. Severity of RHD at time of diagnosis.		<ul style="list-style-type: none"> Clearly associated with target. Prevention focused, so goal could be reached by a whole range of primordial, primary and secondary strategies. 	<ul style="list-style-type: none"> Target broadly endorsed. Baseline data available in WA, NSW, NT and QLD where RHD reportable, however completeness of reporting RHD varies considerably across jurisdictions (including those where active case finding through clinical records is undertaken). Need to acknowledge that there may be a rise in new cases associated with increased resourcing and case finding activities.
	Reduce progression of mild RHD to moderate or severe RHD		What proportion of people with mild RHD remain mild over 12-month period.		<ul style="list-style-type: none"> Strengths-based framing of a progression metric. Could be achieved by focusing on early detection/active case finding. 	<ul style="list-style-type: none"> Existing RHD register capacity can capture priority of disease – but this doesn't always match clinic metrics of disease progression. A snapshot of number of people in each priority category is a blunt metric – more meaningful to look at change between categories over time. A change from mild to severe RHD is the most significant 'real' progression. Alternative metric would be the proportion of people diagnosed with ARF who never progress to develop RHD – could be a compelling demonstration of the power of prevention.
	All people with RHD have timely surgery (or surgical review)	Consider surgical outcomes as a proxy measure for timely surgery.				<ul style="list-style-type: none"> Broad agreement that surgically focused metric is needed/important but no current capacity to measure. Uncertainties about whether surgery has been offered 'on time' (difficult to define when waiting time starts, difficult to know when surgery indicated/offered, multifactorial causes for 'delays' can cloud interpretation). Possibly need to look at surgical outcomes as first priority and then explore how best to measure waiting times.

Intervention point	Target	Primary-care Indicators	Jurisdictional control program indicators	National indicators	Rationale	Considerations
Complications of RHD	All people with RHD have regular echocardiography to guide management	Provision of echos to Priority 1,2 and 3 as per current Australian Guideline			<ul style="list-style-type: none"> Echocardiography commonly determines timely access to surgery (by facilitating cardiology interest and providing objective measures of severity). Baseline access to people with severe/symptomatic RHD is poor – a proxy measure of access to services and/or engagement in care. 	<ul style="list-style-type: none"> RHD registers cannot currently capture echocardiography access reliably enough for this to be meaningful – not included in recent AIHW report. Might drive improvements in echocardiography access without flow-on effects to improved medical and surgical care. Probably requires clinical record audit to understand. May be possible with resources.
	No deaths of pregnant women with death attributable to RHD			Number of maternal deaths coded (or attributed, or coronial investigations) associated with RHD	<ul style="list-style-type: none"> Maternal and foetal deaths associated with RHD should be a 'never event'. Deaths could be captured through the National Maternal Mortality Data Collection. Incentivises advanced medical and surgical care rather than prevention. These are rare events at baseline so trends won't be measurable. Stillbirths in women with RHD may be difficult to categorise as being due to RHD or not. 	<ul style="list-style-type: none"> No capacity to capture this information through the existing RHD register systems. Considered only including deaths of women with 'known RHD' but concluded that deaths associated with unknown RHD also important measure of how well systems are working and should be included. National Maternal Mortality Data Collection reports every few years but potential to link with real-time reporting At this stage, pregnancy outcomes unable to be captured. Could consider the rate of foetal loss for women with and without RHD in matched populations but that would require ongoing concept development.
	No deaths with primary cause attributable to RHD by 2031			Number of deaths recorded with RHD as a cause, underlying cause or associated cause of death.		<ul style="list-style-type: none"> Will need to facilitate National Death Index linkage with all the jurisdictions to be confident.

Appendix Seven: Modelling methods

Overview of modelling

The *Endgame Strategy* used a disease progression model to describe the progression between Strep A infection, ARF and RHD, and estimate the health and economic impact of selected prevention strategies. Models of disease progression use epidemiological data to describe the likelihood of various health outcomes based on risk factors at the individual or population level. These risk factors can be modified by implementing prevention strategies, enabling estimation of the impact of different strategies on RHD outcomes. This is demonstrated in Figure 45.

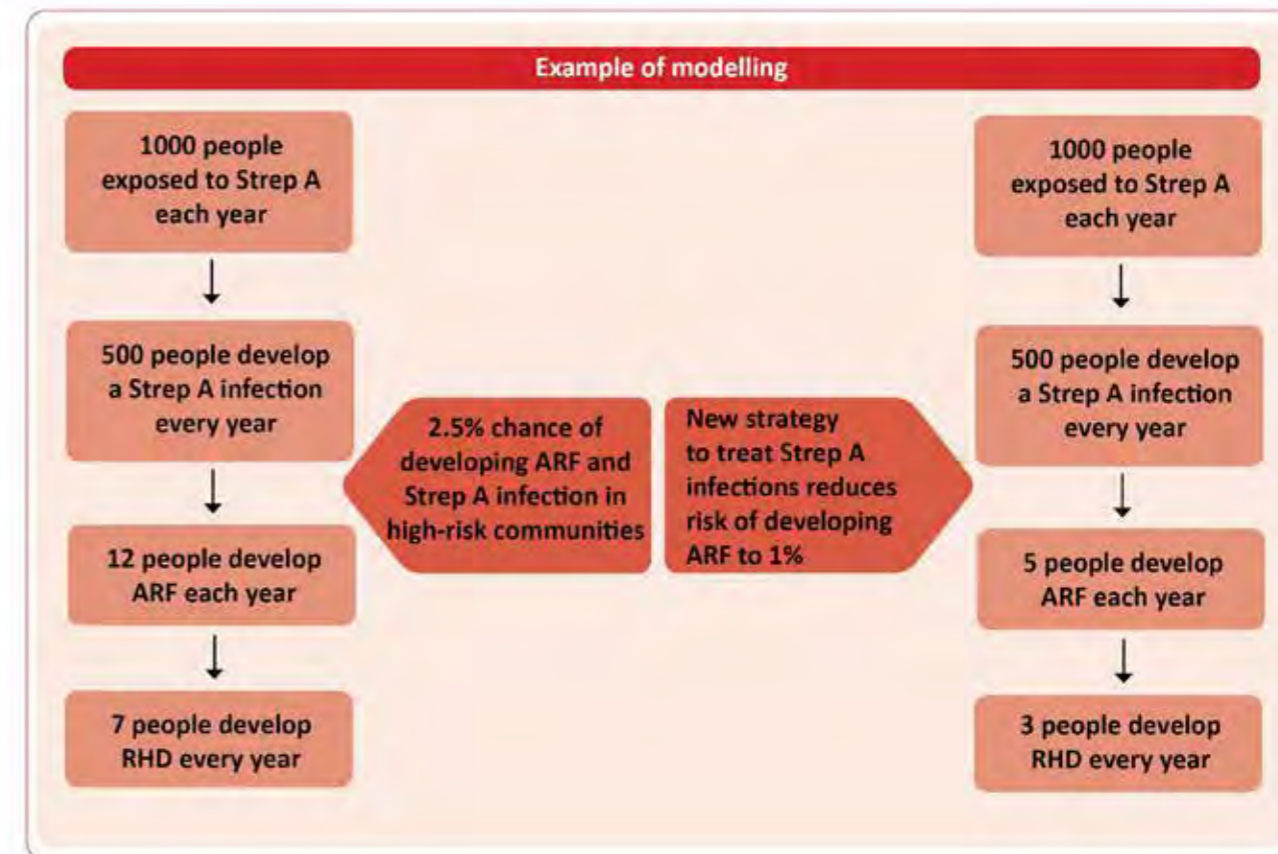
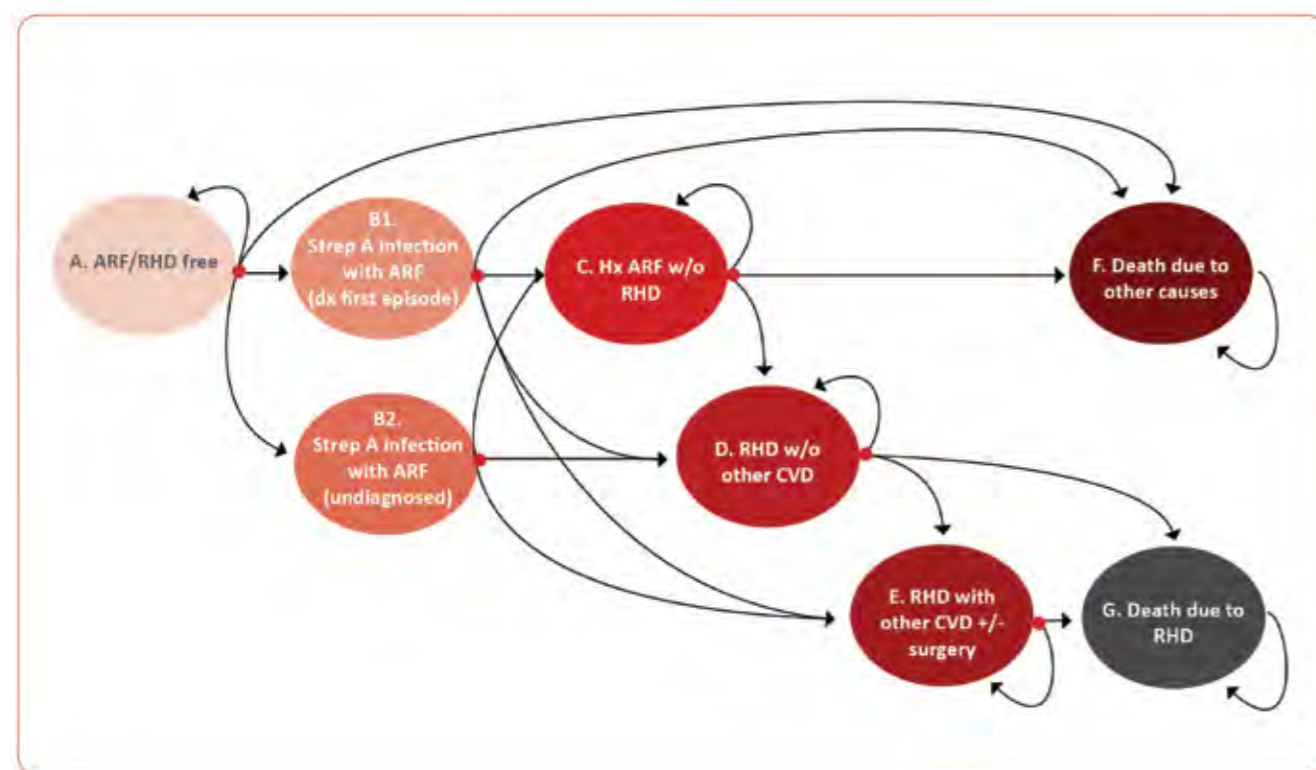


Figure 45: An introduction to modelling.

Step 1

A state-transition model was developed to predict the transition (progression) of a cohort of people between health states related to ARF and RHD (Figure 46). Existing data was used to estimate the probability of a person acquiring a Strep A infection, developing ARF, and progressing to RHD and later complications.



Legend
dx: diagnosed, hx: history, w/o: without, CVD: cardiovascular disease
Figure 46: State-transition model of RHD.

Step 2

Each state was assigned health and economic outcomes:

- Health outcomes were defined as clinical events/disease and as disability-adjusted life years (DALYs) as used by the Institute for Health Metrics and Evaluation (IHME).¹⁰¹⁷
- Economic outcomes were defined as the healthcare-related costs that accrue as a result of disease in each health state.

Healthcare costs for Strep A infections, ARF and RHD were estimated from economic data collated from previous and current work.^{2,90} The perspective of the analysis taken includes only health and healthcare costs and benefits related directly to the prevention of skin and throat Strep A infections, ARF, RHD, and cardiovascular disease or death resulting from RHD. It excludes health, economic and social benefits that may arise indirectly from the prevention of these conditions (potentially including a reduction in invasive Strep A diseases, reduction in Strep A transmission and diseases in community members not directly targeted by the prevention strategy, improvements in education and productivity).

The cost of diagnosis and treatment for Strep A infections was applied only for a proportion of the cohort expected to seek treatment (20%; expert assumption, Rosemary Wyber). This is demonstrated in Table 19.

Table 19: Cost of ARF and RHD diagnosis and management based on Cannon et al., 2018³⁹ and adjusted to 2019–2020 prices.

	Child	Adult
Diagnosis and management of acute disease		
Strep A infection	\$68–257*	
B1. ARF diagnosed	\$12,075	\$12,912
B2. ARF undiagnosed	\$0	\$0
D. RHD without other CVD	\$11,798	\$9,787
E. RHD with other CVD	\$74,915	\$72,042
Annual management**		
C. Hx of ARF – mild or D. RHD without other CVD	\$2,048	\$2,048
E. RHD with other CVD	\$3,920	\$3,920

NB: Estimate 10% of people with mild RHD diagnosed without hospital admission at a cost of \$1,242 per person.

*The cost of diagnosis and treatment of Strep A infections was based on the cost of a primary-care consultation (\$38.20–\$227²⁸⁸) and one dose of benzathine benzylpenicillin (\$29.87).⁸⁸⁴

** Duration of annual management as per 2nd edition of the Australian Guideline. >72.5% population receive >50% injections.⁷⁷ Data from de Dassel et al. indicates that, on average, people received 67.3% of their scheduled secondary prophylaxis, 53% of secondary prophylaxis in the largest clinic, followed by 56% in the second largest.⁸¹¹ This data was from the NT with some of the highest rates of secondary prophylaxis delivery. This model assumes a baseline of 50% delivery of secondary prophylaxis.

Step 3

This step drew from a range of data sources to estimate the effect of different strategies in modifying individual and/or population risk factors, reducing the probability of disease progression.

These strategies were modelled in two different settings:

- If they occurred in all remote Aboriginal and Torres Strait Islander communities in the NT, SA, NSW, QLD and WA.
- If strategies only occurred in the 210 highest-risk ILOCs, which comprises approximately 12% of the Aboriginal and Torres Strait Islander population in these jurisdictions.

Results are based on new cases of RHD arising from people born between 2019 and 2031 and do not include prevention in the existing population.

Step 4

The estimated reduction in health and economic burden for each prevention strategy was modelled. The estimated costs of the prevention strategies were contrasted against their cost of implementation to determine cost savings or cost-effectiveness.

Uncertainty in these outcomes was explored through sensitivity analyses by varying the change in probability of progression within a plausible range.

Epidemiology

This model does not include the increasing trend in incidence rates of ARF. The addition of this trend will increase the health and economic benefits. Longitudinal analyses have been limited to 10 years or less. For example, the risk of progression from ARF to RHD is limited to the 10 years following ARF diagnosis. This may be a reasonable restriction of the model since we have tried to capture the undiagnosed cases of ARF. However, the incidence of undiagnosed cases of ARF is, by its nature, unobservable. The modelled rate is based on the incidence of RHD in young adults (5–24 years) without a history of ARF, which is likely an underestimate.

Strategies

The model does not include existing strategies under way to reduce Strep A, ARF and RHD in communities. Reduced crowding has been modelled as immediate effect rather than over the long timeframe needed to implement housing improvements. Additionally, the reduced risk of all HLP and associated health promotion is based on reduction in skin sores from handwashing in one international study. Ideally, further research would have been included, including results from the SToP trial due in 2022.⁶²⁴

It is possible, given the high incidence of Strep A sore throat in non-Indigenous children, that there is some level of infection rate/strain circulation sufficient to eradicate ARF, however this has not been modelled. Additionally, there is little to no evidence to draw on to estimate the effect of improved secondary prophylaxis delivery on the risk of disease progression.

Costs

The model does not include costs to communities to follow up patients, however this may be covered by the inclusion of specialist follow-up costs (including flights for remote patients) that may not be used as often as assumed (50% of recommended follow-ups). Non-healthcare-related costs have also been excluded.

Overcoming these limitations in the future may involve the undertaking of sensitivity analyses, assuming much better reductions in disease for each strategy.

Appendix Eight: Cost of prevention strategies

Table 20: Simplified summary of estimated costs for bundle of RHD reduction strategies.

Strategy summary	Description	Cost
<p>Core costs A core set of activities amplify strategy-specific activities to reduce RHD</p>	<p><u>Community-level health engagement, education and promotion</u></p> <p>All the most promising strategies to reduce RHD require community-level engagement and sharing of key health education and health promotion messages. A comprehensive approach requires engagement about Healthy Living Practices, Strep A infections, ARF and RHD. These messages are interdependent and therefore costing is best considered as a bundle of health promotion, estimating about 60% of efforts relate to prevention and management of Strep A infections and 20% to increasing health-seeking behaviour for symptoms of ARF and RHD.</p> <p>Assuming health promotion messages are developed by the RHD National Implementation Unit (see below) and then customised, translated and delivered at a community level, costs are estimated at an average \$15,000 annually per community.* A seven-year process is expected before health promotion can be tapered and potentially embedded in routine service delivery. At \$15,000 in 210 communities over seven years, the total cost is estimated at \$7.4 million.</p> <p><i>*Costs will vary by baseline engagement and community size. Development of integrated health promotion messages addressing different health issues could reduce these costs.</i></p>	<p>\$7.4 million over 7 years</p>
<p>Core costs A core set of activities amplify strategy-specific activities to reduce RHD</p>	<p><u>Jurisdictional activities</u></p> <p>The Rheumatic Fever Strategy National Partnership Agreement (NPA)¹⁷⁸ funds register-based RHD control programs in the NT, SA, WA and QLD. The jurisdictional programs are tasked with the improved detection, monitoring and management of ARF and RHD through:</p> <ul style="list-style-type: none"> • Improved clinical care, including improved delivery of and adherence to secondary prophylaxis antibiotics; • Provision of education and training for healthcare providers, individuals, families and communities; • Collection and provision of agreed data annually to the AIHW for national monitoring and reporting of ARF and RHD, and measuring program effectiveness in the detection and management of ARF and RHD; and • Maintenance of a dedicated state-wide patient register and recall system for ARF and RHD. <p>NSW also operates an RHD register under a State framework initiated and funded by the NSW Government. The current NPA expires in mid-2021.</p> <p>Register-based control programs are a critical component of a comprehensive RHD elimination strategy. Costs are based on current funding levels but may not be indicative of future costs due to complexity of federal financial framework and subject to negotiation post 2021.</p>	<p>[\$3.4 million per year]</p>
	<p><u>RHD National Implementation Unit</u></p> <p>For costing and modelling purposes, the role of this theoretical RHD National Implementation Unit includes development of core health promotion messages, coordination at jurisdictional and community level, updating of clinical guidelines, engagement on the structural, social and environmental determinants of Strep A, ARF and RHD, and evaluation and monitoring of the <i>Endgame Strategy</i> implementation.</p> <p>Assuming a virtual centre operating as an RHD National Implementation Unit and employing 14 full-time equivalent staff in policy, clinical, support and engagement roles, the annual cost of the unit is estimated at \$3 million for the first three years. These costs would reduce to approximately \$2 million annually for the subsequent seven years, once governance structures have been established and foundational work completed. Over the 10 years of the <i>Endgame Strategy</i>, this would be approximately \$24 million.</p>	<p>\$23.9 million over 10 years</p>

Strategy summary	Description	Cost
Reduce crowding	<p><u>Building new houses</u></p> <p>The 2017 Remote Housing Review estimated that 5,100 new houses are needed in remote communities in the NT and WA to reduce household crowding by 25–30% by 2028.¹⁷⁶ More than half of these houses are needed in the NT. It is widely accepted that this is an underestimate of housing need and that a new review is required to establish current need.¹⁷⁶</p> <p>The estimated cost for a new house in a remote community was \$419,110 in 2010–2011 prices. Accounting for an average cost growth of 4.8% per year, each new house is currently estimated to cost \$578,000. Therefore, a housing investment of about \$2.9 billion is required.¹⁰¹⁸</p>	\$2.9 billion
	<p><u>Housing maintenance and major repairs</u></p> <p>Household maintenance and major repairs are needed to facilitate Healthy Living Practices. This includes plumbing in order to wash hands and bodies and installing washing machines.</p> <ul style="list-style-type: none"> There are approximately 13,000 houses in the 210 locations.¹⁰¹⁹⁻¹⁰²¹ This model assumes that 30%¹⁰²² need major repair at an estimated cost of \$29,750 per house (\$116.6 million). All houses (13,064) need maintenance at a cost of \$17,000 every five years, i.e. twice over the 10-year period. This equates to \$444.2 million, or \$44.42 million per year. 	\$272 million + \$44.42 million annually in maintenance
Healthy Living Practice (HLP)	<p><u>HLP Community Infrastructure – optional strategies</u></p> <p>There is some evidence that construction and maintenance of shared community infrastructure may facilitate Healthy Living Practices, particularly washing of bodies, clothes and bedding. This may include community swimming pools, ablution blocks or laundries.</p> <p>The model estimates an investment in community infrastructure of \$1 million per community, across 210 communities (totalling \$210 million set-up costs). Maintenance costs will depend on the community infrastructure invested in. The model estimates an allocation of \$150,000 per year per community for infrastructure maintenance. This investment may be allocated towards optional combination of investments in the following:</p> <ul style="list-style-type: none"> Swimming pools. Costs estimated at \$2.9 million per community with an ongoing operating cost of \$200,000 annually.¹⁰²³ <ul style="list-style-type: none"> If implemented in all 210 focus communities, this would cost \$609 million to build and \$42 million annually to run. However, a number of communities already have pools, pools will not be feasible in some smaller communities, and lower-cost water park options may be possible in others. Seasonal opening may reduce operating costs but would likely reduce efficacy of infection reduction. Community laundries for washing clothes and bedding may be prioritised by some communities. At an estimated cost of \$242,000 per community, this would equate to \$50.8 million in 210 communities.⁴⁵⁴ Running costs at \$80,000 per year per laundry would include wages, power, water and machine maintenance, equating to \$16.8 million per year.⁴⁶³ Ablution blocks with washing and showering facilities may be prioritised by some communities. At an estimated cost of \$119,500 per block with an estimated annual running/maintenance/cleaning cost of \$25,000 per unit, this equates to \$77.6 million for 210 communities (personal correspondence, Ausco Modular, 2020). 	\$210 million in infrastructure costs plus \$31.5 million annually in maintenance/operating costs

Strategy summary	Description	Cost
	<p><u>Improved capacity and quality of primary prevention</u></p> <p>Time and staffing constraints are a major barrier to delivering high-quality primary prevention. In addition to strengthening core funding for primary care (outlined in Chapter 4a, endorsed but not costed), increased staffing with a focus on Strep A skin and throat infections and secondary prophylaxis are likely to be needed at a clinic level. This is intended to include clinical service delivery time along with training and some community engagement roles.</p> <p>For modelling purposes, this is estimated at 0.2 full-time equivalent nurse or ATSIHP role with a salary of \$95,000 (including on-cost associated with remote employment) in 210 communities. This equates to \$6.69 million annually, \$80.3 million over 12 years.</p>	\$80.3 million over 12 years (\$6.69 million per year, 2020–2031 inclusive)
Primary healthcare (PHC)	<p><u>Comprehensive Strep A outreach</u></p> <p>Approximately \$20,000–\$25,000 per community</p> <ul style="list-style-type: none"> Consultation with the community in designing the program messages and how it should operate. This would take four days and involve one facilitator from the RHD National Implementation Unit, three local health workers + GP, and community leaders +/- school principal if chosen as a screening location. (Modelled on NT Healthy Skin Recommendations.) Half-day training for three local health workers on signs, symptoms, any messages to be conveyed to the participants, and referral and data recording process. Screening day(s) where the three local health workers screen all participants, refer potential cases to a GP, and provide dressings for skin sores if required. Screening days also include some health promotion in the form of intro to the day(s) and the key messages (as formulated in the consultation and the training) given to each child/parent at time of screening. 	\$5.25 million per year; \$36.8 million over 7 years
	<p><u>Health system service delivery costs</u></p> <p>Additional cost of diagnosing and treating throat/skin infections:</p> <ul style="list-style-type: none"> Cost of between \$70 and \$250 per diagnosis.⁸⁸⁴ Based on diagnosing 50% of the Aboriginal and Torres Strait Islander population at risk aged under 24 years (82,284 people), once annually for seven years, assuming that 20% of the population currently access diagnosis and treatment – i.e. a further 30%. At a cost of \$70 per diagnosis, this equates to \$1.73 million per year and \$12 million over seven years. If 100% of the population at risk are reached (an additional 80%), this would equate to \$32.3 million. 	\$1.73 million per year; \$12.1 million over 7 years
Secondary prevention	<p><u>Community Champions /peer support /self-management programs</u></p> <p>1. Expanding on the current Champions program,⁸²⁴ the model assumes there will be activities in 20 communities per year, involving four Champions with the following costs:</p> <ul style="list-style-type: none"> \$1,000 per champion per activity (covers return flight, one night of accommodation and dinners). \$5,000 per RHD National Implementation Unit officer per activity (covers flights, accommodation, meals, salary). \$1,000 per activity for catering and health promotion materials. With each event costing \$10,000, this would cost between \$120,000 and \$200,000 per year. <p>2. A national annual event in a research/educational setting where all champions come together. Assuming 30 champions (at \$1,000 per person), three RHD National Implementation Unit support people (at \$5,000 per person), and \$5,000 catering costs, this equates to \$50,000.</p> <p>Total = \$170,000 to \$250,000 per year to cover 12–20 communities and health professionals; \$1.7 million–\$2.5 million over 10 years.</p>	\$250,000 per year; \$2.5 million over 10 years

Appendix Nine: Defining the population at risk of ARF and RHD

Ethnicity distribution

As at 2017–2018, 6,660 people with ARF or RHD were recorded on RHD registers in NSW, NT, QLD, SA and WA. The majority (88%) were recorded as being Aboriginal or Torres Strait Islander people, varying between 95% of NT registrants, 88% of SA registrants, and only 44% of NSW registrants.

Age distribution

ARF is highest among Aboriginal and Torres Strait Islander people in the 5–14 year age group, following the pattern of Strep A infection.² RHD prevalence increases with age, with the sharpest increase seen between 15 and 24 years of age.¹ The majority of people living with RHD under 25 years of age have mild or moderate disease, with an increasing proportion developing severe RHD over time (Figure 47).¹

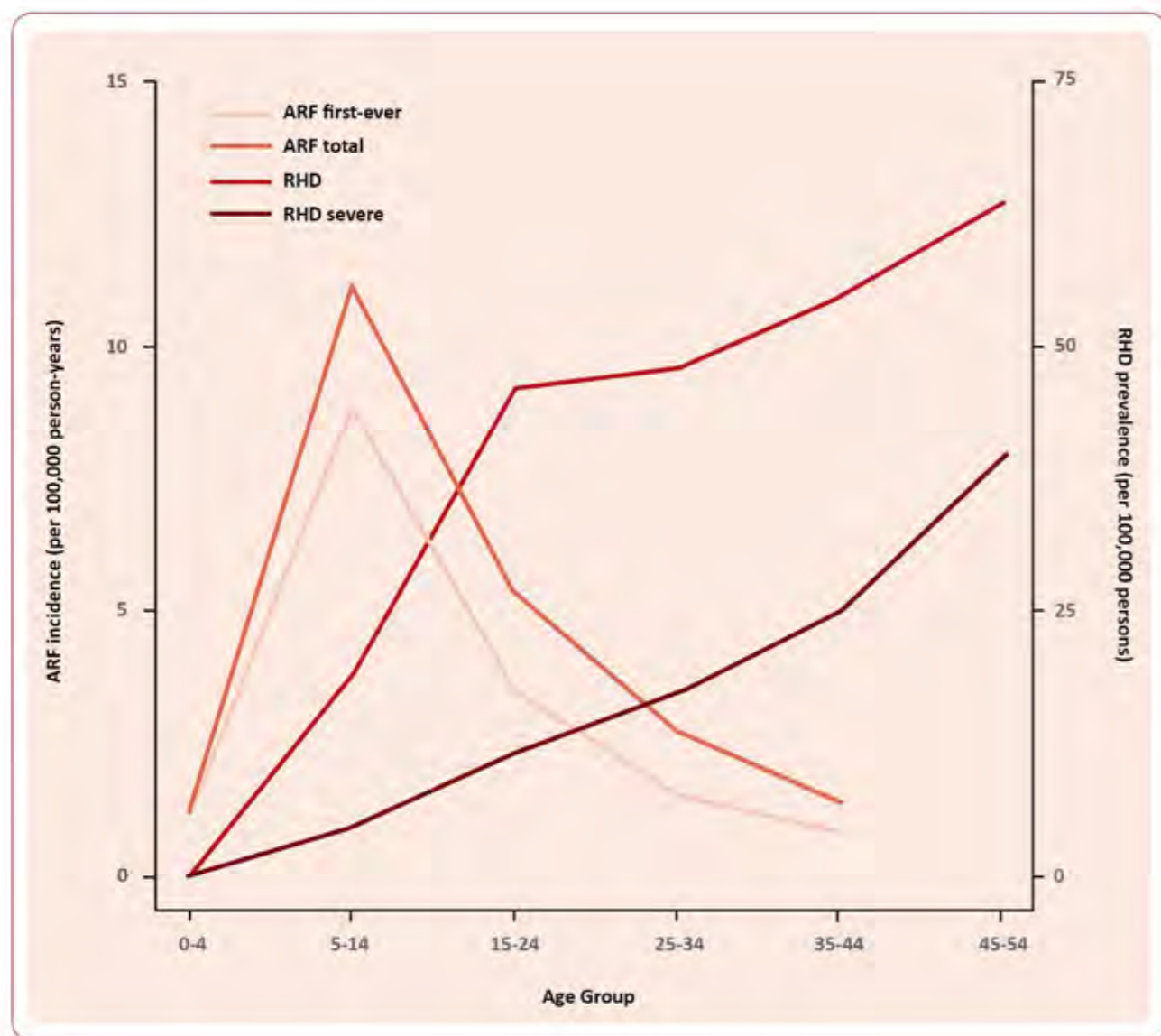


Figure 47: Age-specific rates per 100,000 of ARF incidence (first-ever and total) 2015–2017 and RHD (severe and total) as at mid-year 2017: NT, SA, QLD, WA and NSW.¹

Geographic distribution

The Australian Government uses Australian Indigenous Geographic Classifications to define the areas where Aboriginal and Torres Strait Islander people live. The highest level (largest) of these geographic classifications are the Indigenous Regions.⁹⁹⁷ For the purposes of analysis, these regions were further consolidated into nine groups, further explained in Figure 48. The areas covered by the five Indigenous Region Categories (IRCs) with highest ARF rates cover 91% of all ARF episodes (Figure 48). These regions include all of the Northern Territory, northern Queensland and northern Western Australia, and non-metropolitan South Australia.

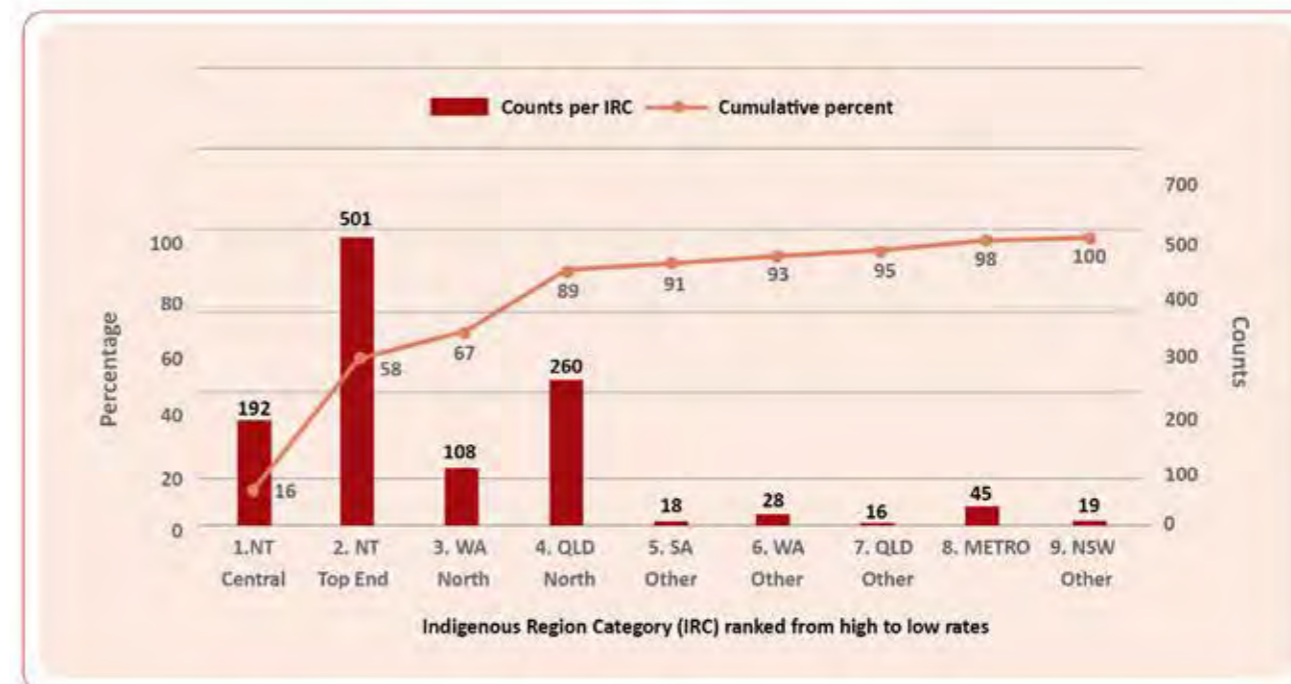


Figure 48: ARF episode counts and cumulative percent by Indigenous Region Category (2015–2017).

The areas covered by the five IRCs with highest ARF rates were home to 136,468 Aboriginal people younger than 35 years who can be considered at high risk of ARF. Providing prevention strategies to 136,468 Aboriginal and Torres Strait Islander people younger than 35 years in the five highest-ranking regions for ARF rates would have potentially prevented 91% of the 2016 diagnosed cases. The number of people that are similarly at risk increases to 143,123 in 2021, 148,686 in 2026 and 153,268 in 2031. The number of Aboriginal and Torres Strait Islander children (0–14 years) at risk in the highest-ranking five regions was 66,390 in 2016, projected to increase to 71,660 by 2031 (Figure 49).



Figure 49: Indigenous population younger than 35 years and cumulative percentage ARF cases, by Indigenous Region Category (2016).¹⁰²⁴

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