# Ending Rheumatic Heart Disease:
## Queensland First Nations Strategy 2021-2024

Queensland Government

## Acknowledgement to Country

**Queensland Health and its partners acknowledge and pays respect to Aboriginal and Torres Strait Islander people and to the Traditional Owners/Custodians and Elders, both past and present and Emerging Leaders, on whose lands we work to support the provision of safe and quality health services.**

## Artwork

The Making Tracks artwork was produced for Queensland Health by Indigenous creative agency Gilimbaa.

## Artwork story

This artwork represents Aboriginal and Torres Strait Islander cultures in Queensland. It speaks of the importance of traditional and cultural sensitivities, how these are communicated in the modern-day health system and how health professionals can best provide health services for Indigenous people through best practice.

The central circular motif represents Health in Queensland, and the meeting place where people come to trade knowledge about health best practices and procedures. The pathways leading in and out of this central motif represent people travelling from different professions, different communities and different country, and the importance of everyone contributing equally to this journey. A journey of change and growth for a brighter, healthier and happier future for all First Nations peoples.

The surrounding markings and motifs represent the important network of people from these communities, their connection to each other, and how they work together to empower First Nations Queenslanders to have long, healthy, productive lives.

Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024

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# Foreword

## Minister for Health and Ambulance Services

**Honourable Yvette D'Ath**

**Minister for Health and Ambulance Services**

*The Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 (the Strategy)* guides and frames the next steps Queensland Health and its partners will take to advance the vision of ending acute rheumatic fever and rheumatic heart disease in Queensland.

In 2018, as part of the reforms under *My health, Queensland's future: Advancing health 2026 and the Making Tracks Implementation Plan 2018-2021*, the Palaszczuk Government honoured its election commitment and invested $4.5 million over three years for delivery of the *Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021 (the Action Plan)*. Queensland is the first state or territory to implement an action plan and set statewide priorities and actions to lessen the impact of both acute rheumatic fever and rheumatic heart disease resulting in improved health service delivery, experiences and access to care.

The Palaszczuk Government recognises rheumatic heart disease as a signature health equity issue, with rheumatic heart disease being the leading cause of cardiovascular inequity between First Nations peoples and non-Indigenous Australians and is committed to achieving health equity and ending rheumatic heart disease in Queensland. This commitment is demonstrated by a further investment of $4.5 million over three years enabling Queensland to continue building on its successful narrative and to support implementation of the Strategy.

It was developed collaboratively through the significant inter-departmental, inter-agency and external partnerships of the Action Plan and places emphasis on further strengthening Queensland's whole of system response to acute rheumatic fever and rheumatic heart disease with First Nations peoples and voices at the centre.

The Strategy will build on the achievements of the Action Plan detailed throughout this document. I am pleased to present this strategy as part of Queensland's Health Equity agenda.

# Chairperson, Queensland Aboriginal and Islander Health Council

**Matthew Cooke**

**Chairperson, Queensland Aboriginal and Islander Health Council**

The Queensland Aboriginal and Islander Health Council (QAIHC) welcomes the release of this strategy, which has been produced in collaboration with Aboriginal and Torres Strait Islander peoples. Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are entirely preventable in our communities, and it is gratifying to see the Palaszczuk Government coming to the table and working with Aboriginal and Torres Strait Islander stakeholders to achieve health equity by 2031.

When key stakeholders have the willingness and resolve to commit to partnership with Aboriginal and Torres Strait Islander peoples, and recognise our right to self-determination, it may be possible to eliminate ARF and RHD in Queensland entirely. QAIHC is firmly committed to working with all levels of government, our members and other stakeholders to implement the Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 which, if fully realised, will reduce the disease burden of ARF and RHD on our people and improve the overall health of Aboriginal and Torres Strait Islander Queenslanders.

This strategy is an appropriate further step on the road to achieving health equity for Aboriginal and Torres Strait Islander peoples by embedding our voices in its implementation to ensure culturally safe prevention and treatment strategies are at the forefront of the fight against ARF and RHD.

# Chair, Queensland First Nations Rheumatic Heart Disease Alliance

**Joy Savage**

**Chair, Queensland First Nations Rheumatic Heart Disease Alliance**

**Haylene Grogan**

**Chief Aboriginal and Torres Strait Islander Health Officer and Deputy Director General of the Aboriginal and Torres Strait Islander Health Division**

**Professor Keith McNeil**

**Deputy Director General of the Prevention Division**

Queensland continues to take great strides on the journey to end RHD through the collaboration and partnership of key stakeholders from many government and non-government organisations across the state. Working together and building on the Queensland narrative to end RHD this is a First Nations strategy with First Nations peoples and communities at its centre.

The Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 (the Strategy) has five priority areas, aligned to the National Endgame Strategy [1], which were chosen through extensive consultation and informed by the Queensland experience to date. They are based on the national evidence [1] and health economic modelling [2] which determines they will have the highest impact on the prevention of ARF and RHD. These priorities are achievable through optimisation of current processes and with appropriate funding.

I take this opportunity to thank Haylene Grogan, Chief Aboriginal and Torres Strait Islander Health Officer and Deputy Director General of the Aboriginal and Torres Strait Islander Health Division and Professor Keith McNeil, Deputy Director General of the Prevention Division, Queensland Health for their sponsorship of the Strategy. I also thank my co-chairs Dr Gregory Starmer and Dr Richard Gair for their vision and unwavering support over the last three years.

I look forward to continuing the journey in partnership and working together to end RHD and achieve health equity for First Nations peoples.

# Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021 (the Action Plan)

## Snapshots of Success in Partnership

The Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 will build on the achievements of the Action Plan and further strengthen Queensland's whole of system response to ARF and RHD with First Nations peoples and voices at the centre.

### Gidgee Healing

Gidgee Healing is tackling RHD head-on with Dr Marjad Page, Chief Medical Officer and Georgia McManus, RHD Registered Nurse leading the charge. With a focus on improving systems, Gidgee Healing have developed a 'Suspected ARF Complete Package' and a 'Rheumatic Heart Disease Ongoing Management Package' to ensure all their clinicians are orientated to ARF and RHD. These packages are culturally appropriate and are complemented by a 'Dreamtime Story' created to educate clients to RHD.

Close collaboration between Gidgee Healing and North West HHS clinicians is resulting in improved care co-ordination for clients through integration of primary and secondary healthcare and implementation of initiatives such as Bicillin clinics in schools.

### Apunipima Cape York Health Council

**The Apunipima Cape York Health Council RHD project team are building community and staff capacity by offering awareness sessions**

These sessions provide an overview of Streptococcal A, ARF and RHD, highlighting the prevalence in Queensland and Cape York and providing context to the severity of the disease. The aim is to build understanding within the broader Apunipima workforce and within community to start conversations around ARF and RHD.

#### Raising Awareness of RHD

Since March 2021, Apunipima has delivered sessions for over 400 participants – including Apunipima staff, community groups and schools. Content of these sessions is generally focused at primordial and primary prevention levels, in line with the healthy living practices [18], and is guided through consultation with community members.

### Acute Cardiac Care

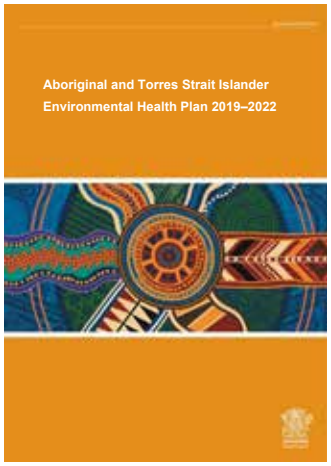
**As part of a suite of initiatives under the Action Plan Cairns Hospital has implemented the first transition care clinic specific for patients with ARF and RHD.**

This clinic helps young people living with ARF and RHD in the transition from paediatric to adult cardiology. This is an area of concern as many young people do not transition safely and are lost to follow up, often re-entering the health system in an emergency scenario such as a high-risk pregnancy.

Experience-Based Co-design Event:
Simone Lukies, Action Plan Project Officer and Jalil

Other initiatives implemented under the Action Plan include a holistic cardiac sonographer-led model of care delivered across the Outer Islands of the Torres Strait integrating primary and secondary care. Clients can access echocardiograms with a cardiac sonographer on their Island and receive education and care co-ordination with the adult RHD CNC at the same time. A telehealth appointment is then coordinated with the cardiologist in Cairns for the necessary specialist review.

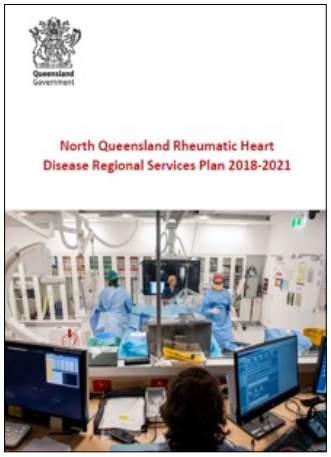
Using experience based co-design methodology to evaluate the paediatric RHD model of care will help build genuine partnerships with consumers and inform service delivery across the state and country.




**Development of an Aboriginal and Torres Strait Islander Environmental Health Plan**

Tackling the environmental factors that increase the risk of Streptococcal A infection gives us the best option to stop rheumatic heart disease, and other diseases such as scabies, otitis media, and trachoma

Creating healthier environments is important.


**A system wide approach in partnership**

Implementation of a strong governance structure with twenty-six partners both internal and external to Queensland Health enabling a system wide approach

Implementation of Regional Service Plans in Hospital and Health Services with high burden of disease

Listing of RHD as a notifiable disease in Queensland, improving detection of RHD cases and access to care.

**Collaboration with the Ministerial Rapid Results Networked Cardiac Care program**

The Action Plan works in close collaboration with the Ministerial Rapid Results Networked Cardiac Care Program within and across HHSs, working with Cairns, Torres Strait, Townsville, Northwest, and Metro South focusing on decreasing the number of overdue echocardiograms.

**Torres Strait and Cape York overdue echocardiograms decreased by 78% total February 2020 now = 230**

**First Nations Health Worker and Health Practitioner RHD Training and Facilitator Package**

The Queensland RHD Register and Control Program has held 15 First Nations Health workshops within Queensland since 2019. The training package was amended in 2020 to:

- Reflect the changes in the Australian ARF and RHD guidelines that occurred in 2020
- Create a facilitator guide so that once the workshop has been accredited it can be delivered by anyone with a certificate IV in Training and Assessment
- Inclusion of 3 options for content delivery (novice, intermediate and expert)

**Data Linkage Project**

The Queensland RHD Register and Control Program data manager has worked with the Viewer (the Statewide electronic patient information system) to integrate the Register allowing access to non Queensland Health clinicians to view pertinent clinical information

# Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 at a glance....

**Vision**

**Ending rheumatic heart disease in Queensland and achieving health equity for First Nations people**

**Aim**

**A strengthened, integrated, equitable, whole of system response, capable of prevention, early detection, diagnosis, treatment and management of acute rheumatic fever and rheumatic heart disease across Queensland**

## Five Key Priority Areas of the Strategy

The Queensland First Nations Rheumatic Heart Disease Alliance will provide oversight of the Strategy. An implementation plan will be developed in partnership, according to available resource. It will be underpinned by the National Agreement on Closing the Gap 2020: Priority Reforms [4] and the Queensland Health Equity Legislation [5] and design principles [6]. Implementation will be achieved collaboratively through partnered Regional Action Plans supported by a Regional Health System Dashboard.

**Aboriginal and Torres Strait Islander Leadership**

Strengthen the skills, capacity and leadership within the Aboriginal and Torres Strait Islander health workforce to maximise primary and secondary prevention of ARF and RHD

**Community-based programs**

With partners and community, develop place-based, sustainable and scalable person and community centric solutions guided by an evidence based approach

**Healthy Environments and Primordial Prevention**

Integrate services and responses across Government for First Nations Peoples, specifically housing and health, and inclusive of the Queensland Aboriginal and Torres Strait Islander Environmental Health Plan

**Early Prevention**

With partners and community implement comprehensive sore throat and skin programs, including health promotion, community empowerment, and improvement of primary healthcare processes including clinician training

**Effective care and support for all those living with ARF/RHD in Queensland**

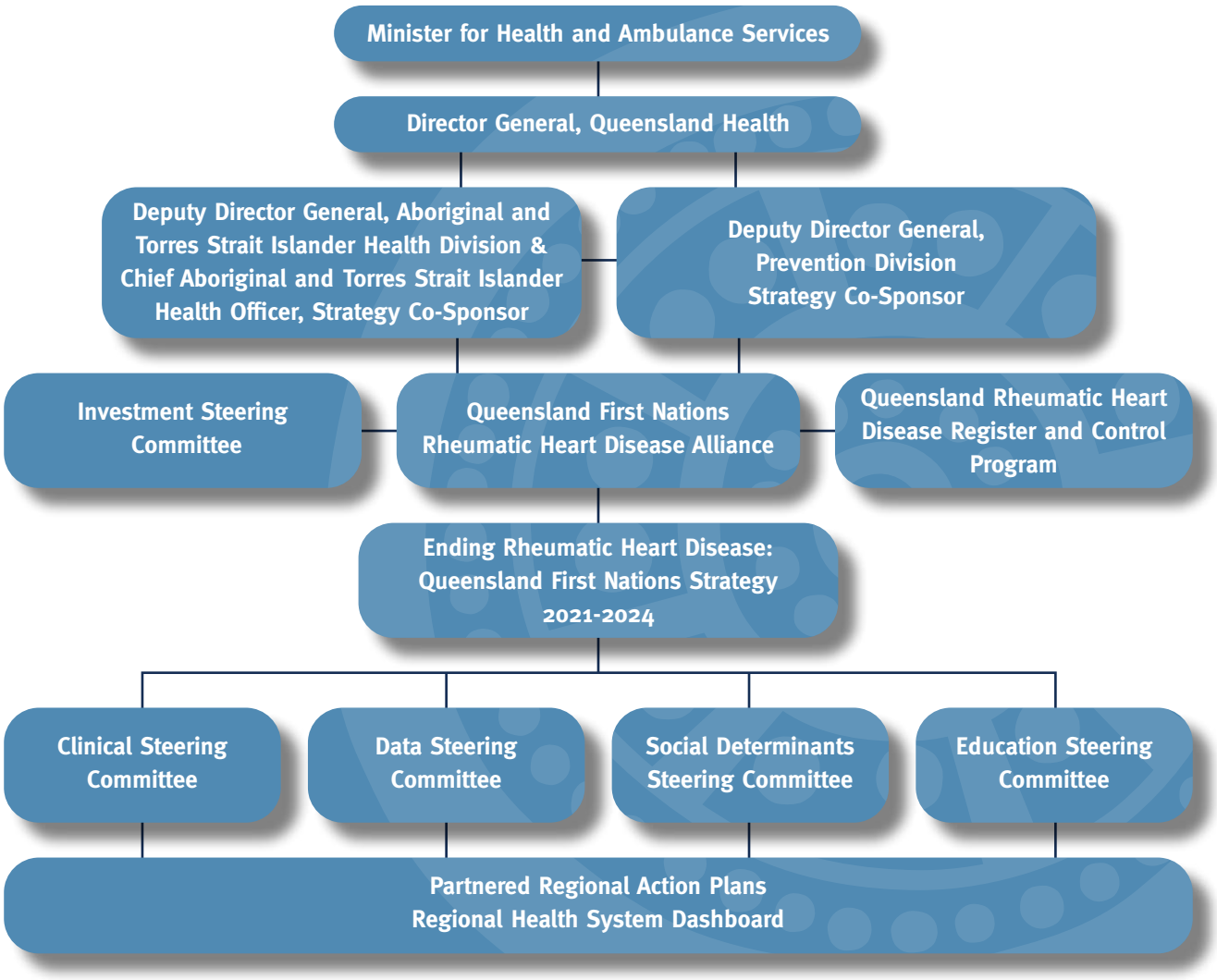
Increase access to effective care as per the Australian Guideline [3], close to home, within clinically recommended timeframes, focusing on secondary prevention and applying a holistic, familial approach

# Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 at a glance....

| Key Priority Areas | Headline Outcomes, Deliverables and Measures of Success |
|---|---|
| **Aboriginal and Torres Strait Islander Leadership**<br>Strengthen the skills, capacity and leadership within the Aboriginal and Torres Strait Islander health workforce to maximise primary and secondary prevention of ARF and RHD | **Outcome:** An increase in the number and type of primary and secondary prevention of ARF and RHD that include the Aboriginal and Torres Strait Islander health workforce across all professions<br>**Deliverable:** A First Nations health workforce plan for ARF and RHD that will enable clinical practice and leadership to maximise ARF and RHD response<br>**What does success look like:** An increased number of First Nations staff working in and leading the primary and secondary response to ARF and RHD. |
| **Community-based programs**<br>With partners and community, develop place-based, sustainable and scalable person and community centric solutions guided by an evidence based approach | **Outcome:** Empowered and supported communities implementing culturally relevant elimination activities aligned to local priorities [1]<br>**Deliverable:** Working in partnership to initiate First Nations led community development to inform local place-based solutions<br>**What does success look like:** Increased community engagement, capacity and resource to enable and empower grass roots solutions |
| **Healthy Environments and Primordial Prevention**<br>Integrate services and responses across Government for First Nations Peoples, specifically housing and health, and inclusive of the Queensland Aboriginal and Torres Strait Islander Environmental Health Plan | **Outcome:** Communities at higher risk are engaged and have increased capacity for the nine Healthy Living Practices [18] supported by an integrated whole of government response.<br>**Deliverable:** Networks and partnerships in place to enhance the integrated response<br>**What does success look like:** Regional Action Plans have the necessary partnerships in place to enable an integrated health, environmental and housing response |
| **Early Prevention**<br>With partners and community implement comprehensive sore throat and skin programs, including health promotion, community empowerment, and improvement of primary healthcare processes including clinician training | **Outcome:** First Nations peoples in communities at higher risk seek care and receive appropriate treatment for sore throats and skin sores, with community-level understanding and action in place to support this<br>**Deliverable:** Sore throat and skin programs in ten communities at higher risk where the scop is determined in partnership with local community stakeholders<br>**What does success look like:** Skin and sore throat programs in place that have been developed with community |
| **Effective care and support for all those living with ARF/RHD in Queensland**<br>Increase access to effective care as per the Australian Guideline [3], close to home, within clinically recommended timeframes, focusing on secondary prevention and applying a holistic, familial approach | **Outcome:** Better health outcomes for First Nations people living with ARF and RHD inclusive of a reduction in the cardiovascular burden of RHD disease and in the number of First Nations young people lost to healthcare follow -up<br>**Deliverable:** Building on the work of the Action Plan 2018-2021 to further transform care through increased statewide implementation of innovative and sustainable ARF and RHD models of cardiac care. Support on the ground clinical services to improve secondary prevention strategies<br>**What does success look like:** Communities at higher risk have integrated, co-ordinated, culturally safe models of ARF and RHD care across all sectors |

# The governance structure for the Strategy:

The Queensland First Nations Rheumatic Heart Disease Alliance will provide oversight of the Strategy with reporting lines shown in the diagram below. Funded activity will be tracked and monitored through the Investment Steering Committee. The Hospital and Health Services will be accountable for developing collaborative Regional Action Plans supported by the Queensland First Nations Rheumatic Heart Disease Alliance. Hospital and Health Services, where disease burden is low, may choose to integrate the Regional Action Plan into their Health Equity Plan.



# Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 Governance Structure

## Strategy Co-Sponsors

- Deputy Director General and Chief Aboriginal and Torres Strait Islander Health Officer, Aboriginal and Torres Strait Islander Health Division, Queensland Health
- Deputy Director General and Chief Medical Officer, Prevention Division and Chief Clinical Information Officer, Queensland Health

## Queensland First Nations Rheumatic Heart Disease Alliance

The Queensland First Nations Rheumatic Heart Disease Alliance will provide oversight of the Strategy and consists of the following membership:

- First Nations Chair (Identified Position)
- Director of Cardiology (Co-chair)
- Director of Public Health (Co-chair)
- Secretariat (Program Manager)
- General Manager, Policy and Research, Queensland Aboriginal and Islander Health Council (QAIHC)
- Executive Director, Local Thriving Communities, Aboriginal and Torres Strait Islander Partnerships, Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships
- Director of Paediatric Cardiology
- Manager, Queensland Rheumatic Heart Disease Register and Control Program
- Co-ordinator, Statewide Cardiac Clinical Network
- Director, Aboriginal and Torres Strait Islander Health Division
- Executive Director, Medical Services
- Chief Executive, Hospital and Health Service
- Rural and Remote Nursing Director
- Queensland Manager, Heart Foundation
- Aboriginal and Torres Strait Islander Housing representative, Housing and Homelessness Services, Department of Communities, Housing and Digital Economy
- Manager, Environmental Health, Tropical Public Health Unit, Cairns

# Queensland First Nations Rheumatic Heart Disease Alliance Partnerships - we all have a part to play

## Queensland First Nations Rheumatic Heart Disease Alliance Partners

**Partners are members of the steering committees or are affiliated individuals/organisations**

- Better Health North Queensland Alliance
- CheckUP Australia
- Apunipima Cape York Health Council
- Tafe Queensland, Cairns Campus
- Gurriny Yealamucka Health Service
- Queensland Aboriginal and Torres Strait Islander Clinical Network
- Queensland Cardiac Outcomes Register
- Environmental Hazards Unit, Prevention Division, Queensland Health
- Communicable Disease Branch, Queensland Health
- Connect4Kids
- Deadly Ears, Queensland Children's Hospital
- Gidgee Healing
- Health and Wellbeing Queensland
- Heartkids
- North Queensland Primary Healthcare Network
- Royal Flying Doctor Service
- RHD Australia
- Office of Rural and Remote Health
- Wuchopperen Health Services, Cairns
- Queensland Department of Education
- Statewide Hospital and Health Services
- Allied Health Professions of Queensland
- Directors of Pharmacy, Queensland Health
- Top End Health Service
- Queensland Catholic Education Commission
- The Snow Foundation

*Gidgee Healing Dreamtime Story explaining Streptococcal A Bacteria*

# Introduction

**Rheumatic heart disease (RHD) is the leading cause of inequality in cardiovascular health between First Nations peoples and non-Indigenous Australians and it is entirely preventable. RHD starts with a simple streptococcal A infection of the throat or skin and without treatment it can be fatal.**

Acute rheumatic fever (ARF) is the pre-cursor to RHD, it is an autoimmune response to the streptococcal A infection, and it can develop if the infection is left untreated, inadequately treated or repeated infections occur. ARF symptoms include fever, joint pain, rash and inflammation of the heart (carditis). The carditis can result in permanent damage and dysfunction of the heart valves resulting in RHD.

Complications of RHD include heart failure, arrythmia, stroke and can lead to the need for heart surgery. Complications occur in people of all ages affected by RHD with the youngest person currently experiencing severe RHD in Queensland being 5 years of age. In Queensland, the high-risk age group where the majority of ARF cases are diagnosed is between the ages of 5 and 24 years with the average age being 16 years [7]. First Nations peoples are 75 times more likely to develop RHD than non-indigenous people in Queensland [8,9].

To eliminate RHD means we need to prevent new cases of the disease, action must be taken to address the environmental, social and economic determinants that cause ARF, and for which a whole of government response is required. The Queensland First Nations Rheumatic Heart Disease Alliance actively enhances the building of networks and partnerships to work together to develop and implement local health, environmental, social and economic place-based solutions to aid the prevention of ARF and RHD.

*Gidgee Healing Dreamtime Story explaining Rheumatic Heart Disease*

# Jalil and Lynette's Story

***"It's so emotional, especially because it is kids. This is no ordinary sickness that you go to a clinic for. And we didn't know anything about this sickness or the treatment. We were just told, go to the clinic, and get injections there. It gets really traumatic". (Lynette)***

Jalil, aged 11, was diagnosed with acute rheumatic fever in 2019. Jalil's mum Lynette describes that time with tears in her eyes, as Jalil was hardly able to walk because of the pain. Jalil was then diagnosed with rheumatic heart disease which requires a complex treatment regimen of regular echocardiograms and dental care plus Bicillin injections* every four weeks until age 21.

Bicillin injections are given via the deep intramuscular route and are known to be extremely painful. Evidence shows that the pain and discomfort can be reduced through having a kind, child-friendly approach, building patient and family trust, and having a consistent person who adopts therapeutic injection strategies to administer the injection. It is important that all clinicians are trained in these strategies to reduce pain and anxiety preventing further trauma.

Once Jalil was diagnosed, Lynette began a traumatic journey of managing his heart condition. Lynette had to learn about the condition, work out how to use health systems, cope with the distress of Jalil having repeated painful needles all while worrying about his heart. Lynette understood the importance of the injections to protect Jalil's heart, but Jalil had developed a significant needle phobia due to suboptimal experiences. Supported by the Queensland Rheumatic Heart Disease Register and Control program staff, Jalil and Lynette were linked in with Paediatric Cardiologist, Dr Ben Reeves and Paediatric Clinical Nurse Consultant for RHD Erin Ferguson and this has led to better outcomes for Jalil and his Mum; it was also the beginning of the 'Happy Heart Clinic'.

Jalil with his mum Lynette (Turtle photo: Libby Sterling)

* Bicillin is a recognised name for Benzathine benzylpenicillin (Bicillin L-A) intramuscular injection.

The ‘Happy Heart Clinic’ was designed to transform care for children with RHD as part of a suite of initiatives under the Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021. Here, Jalil and Lynette found a child-friendly space with a wide range of pain relief available- such as nitrous oxide (laughing gas)- and an ethos of empowering children’s agency in decisions around their needles. Lynette describes the clinic as “it’s that safe place for us you know”. Jalil went from ‘zero to hero’ around his injections and now has 100% adherence to his Bicillin which will reduce the risk of his heart disease getting worse.

The ‘Happy Heart Clinic’ optimises care for young patients living with RHD, combining paediatric cardiologist visits with dentist visits, cutting down on the need for outpatient appointments. The ‘Happy Heart Clinic’ also includes a model of transition care which will support Jalil to make the move to adult cardiac care when he gets older.

The clinic staff are passionate educators and spend time teaching other clinicians, patients and their families on how best to give and receive the injections with Jalil now starring in an educational video. When Lynette saw the finished product she said:

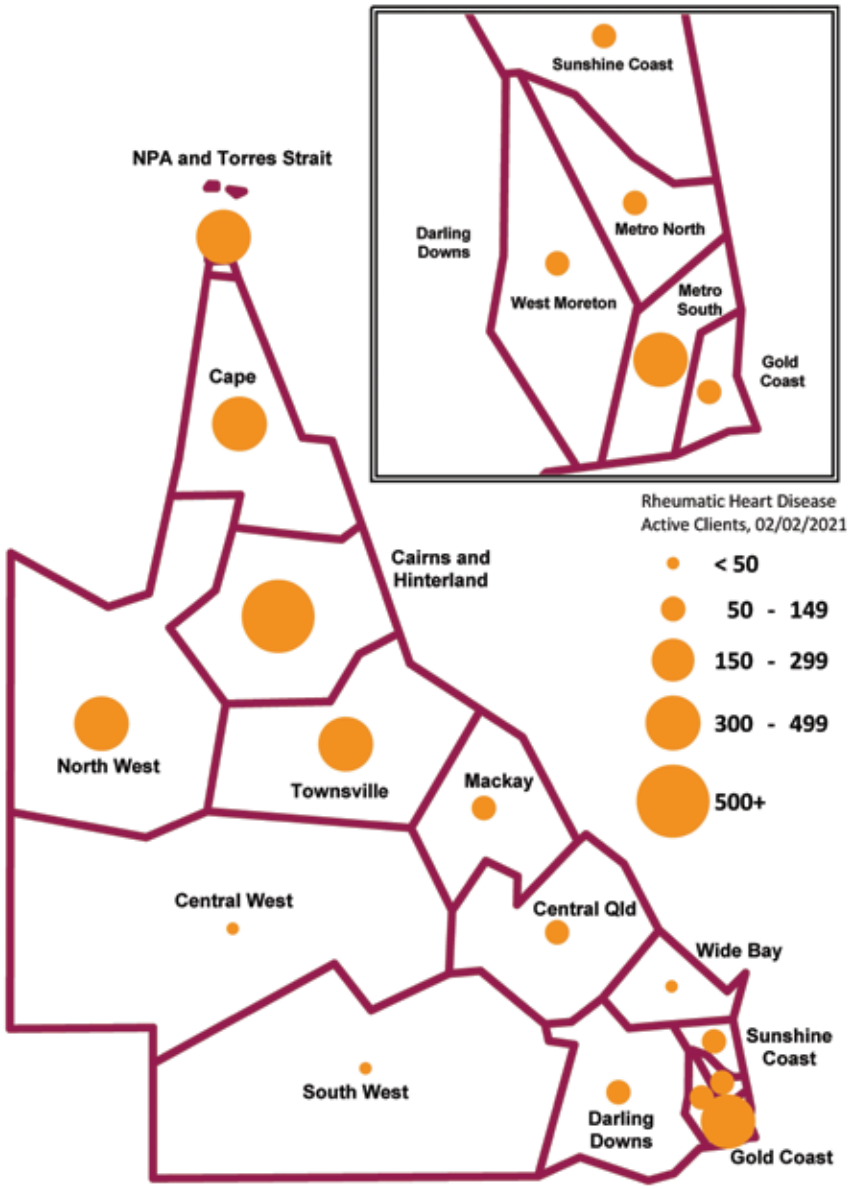
From Zero to Hero, Jalil with Erin Ferguson, Paediatric RHD Clinical Nurse Consultant, Cairns Hospital.

***“I started crying because that’s how life is for this little boy you know. And there’s many others like that too, and parents. What the parents have to go through, most Aboriginal and Torres Strait Islander families are touched by ARF and RHD, yet we don’t talk about it, we need to start the conversation and get the message out there”. (Lynette)***

# Need

**As of 1 September 2021, the Queensland Rheumatic Heart Disease Register and Control Program (the Queensland Register) were actively following up 3,697 people with ARF and RHD in Queensland. Of these 68% identify as Aboriginal and or Torres Strait Islander and 17% are less than 18 years of age. 70% of all clients on the Queensland Register have established RHD with 23% requiring or having had heart valve surgery. Most clients are based in the north of Queensland with 46% of clients, living in Far North Queensland [7].**

## Current Queensland Distribution of ARF and RHD



# Prevalence

First Nations peoples living in Queensland have an incidence of ARF 39 times higher and a prevalence of RHD 563 times higher than other people living in Queensland [8,9].

Australian Institute of Health and Welfare prevalence of RHD in Queensland data indicates an increase between 2017 [8] and 2019 [9]:

**Prevalence of RHD in Queensland per 100,000 population**

| | 31/12/2017 | 31/12/2019 |
|---|---|---|
| First Nations people | 531.0 | 627.4 |
| Non-Indigenous | 7.0 | 15.9 |
| TOTAL | 31.82 | 45.5 |

The Queensland Register advise that the increase in prevalence of RHD is not due to increasing cases but due to increased active case finding and identification of cases through system improvements.

# Impact

**RHD takes the lives of two young Aboriginal and/or Torres Strait Islander people each week and costs $27 million in open-heart surgeries and medical care per annum [1]. In Queensland it is estimated that without further action, a further 2,730 Aboriginal and Torres Strait Islander people will develop ARF or RHD by 2031; of these 637 will have severe RHD and 148 will die, with $86.8 million required to be spent on acute medical care alone [2].**

Implementing the intensive treatment regimens required for long-term prevention and management of both ARF and RHD is challenging. The 2020 Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease [3] which outlines evidence-based clinical guidelines for Australia, recommends that secondary prevention of ARF requires a 3 to 4-weekly injection of benzathine benzylpenicillin G (Bicillin) to be given for at least 5 years (10 years for children) depending on severity of disease. It is also recommended that clients are scheduled for regular echocardiograms and specialist review to monitor disease progression and inform treatment.

Both ARF and RHD are notifiable conditions with data collected by the Queensland Register. In Australia register-based control programs focus on secondary prevention, coordinate care to help reduce recurrence of ARF, decrease hospitalisations, and avoid costly heart surgery for young First Nations people.

RHD however, can only be eliminated by addressing the underlying environmental risk factors, primarily by providing timely and effective health care to ensure that streptococcal throat and skin infections do not progress to ARF. Whilst Queensland is taking large strides on the journey to end RHD there is still much to be done. Empowering First Nations peoples and communities to tackle ARF and RHD is paramount and the key to success.

# Coen and Kara's Story

***"Mum, I wish I could tell other kids about RHD, visit the kids in hospital and let them know that the needles hurt but it helps you feel better in the heart and there is always a way that you could to teach yourself that getting the needle is ok. What if we could give the kids in hospital gifts? Because I know how lonely and boring it gets being in the hospital." (Coen)***

Coen, aged 12, was diagnosed with acute rheumatic fever (ARF) in 2017. Coen's Mum Kara was at work when she received a phone call from her sister that Coen had a high fever and the paracetamol wasn't working for him. Coen's older brother had to carry him because he was in so much pain and couldn't walk by himself.

Kara raced home to find Coen laying on the couch with red rosy cheeks, dried lips, his little body hot and sweaty and saw that Coen couldn't manage to open his eyes. Kara took Coen straight to the emergency department at Mount Isa Hospital and before Kara knew it, Coen was being attached to an electrocardiogram machine, monitored by a paediatrician with nursing staff taking bloods and recording basic medical history. At Kara's recall, a day or two later, Coen was diagnosed with rheumatic heart disease (RHD) which means Coen needs regular echocardiograms, paediatric cardiologist reviews, dental care and Bicillin injections every 21-28 days until he is 21yrs of age.

Bicillin injections are given via the deep intramuscular route and can be extremely painful. In a short period of time Coen managed to think of a strategy that would help him self-regulate the pain by teaching himself ways to keep his mind busy and distracted. Coen has built strong healthy relationships with all the administering nurses from Mount Isa Hospital, Edmonton Family Balance Centre, Gidgee Healing in both Doomadgee, and Mount Isa and tells them how he would like his injection administered.

Coen with his mum Kara

Kara was full of questions when Coen was diagnosed and knew she had to learn all she could about RHD and what was needed to keep Coen well. Kara learnt how to help keep Coen healthy by staying on track with Coen's injections, visiting specialists' appointments and taking Coen for heart scans. Kara could then also teach Coen's five siblings and immediate family about RHD and why Coen was having to have injections and routine check-ups. Coen would take his siblings to his appointments for relationship and emotional based support.

**Coen says "when I was in hospital and I missed my mum, my mum would tell me before she went to work that she loved me, to do my home school work and to listen to our song 'One Call Away' by Charlie Puth and that would make me feel better until she finished work".**

In 2019 Coen found out he had been nominated to the Starlight 'Make A Wish' Foundation. The Queensland Register in collaboration with the Starlight 'Make a Wish' Foundation runs a 'reward and recognition' strategy for clients with 100% uptake of their Bicillin injections. Coen's first wish was to take his family to the Gold Coast for a vacation at the theme parks in 2020 but then COVID19 put his wish on hold.

In 2021 Coen expressed the wish that he could tell other kids about RHD and make their journey easier and more bearable. Kara contacted RHD Australia and told them Coen's story resulting in Coen becoming an 'RHD Champion4Change' for his community and keeping his wish of a vacation for the family on the Gold Coast.

**'The Champions4Change program run by RHD Australia is a culturally safe support program for people living with acute rheumatic fever (ARF) and rheumatic heart disease (RHD). It is entirely designed and led by Aboriginal and Torres Strait Islander peoples and communities. The Champions4Change program is run by people from across Australia with the lived experience of ARF & RHD. The group of champions support each other, advocate for ending RHD and design education and awareness programs for those in their own communities' [10]**

Kara works at the Aboriginal Community Controlled Health Organisation – Gidgee Healing and told fellow co-workers about Coen's story asking if Coen could help educate and promote awareness to children at school with clinical experts. Coen was invited to attend a meeting at Gidgee Healing along with clinician's Paula Marshall, RHD Nurse navigator and Gordon Chong, Aboriginal Health Worker from the North West Hospital and Health Service. At the meeting Coen expressed his wish to help educate and promote awareness resulting in Coen being invited to the children's ward, Mt Isa Hospital to talk to young people with ARF and RHD. Kara has also contacted Coen's school principal to set up a presentation to Coen's peers to help educate on signs and symptoms of RHD.

Paula Marshall, RHD Nurse Navigator and Gordon Chong, Aboriginal Health Worker, North West HHS

# Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024

**In Queensland many foundations for ending ARF and RHD are in place through the work of the Queensland Register since 2009 and the Queensland Aboriginal and Torres Strait Islander Action Plan (2018-2021). The Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 (the Strategy) will build on the Queensland narrative and provide the focus for the next three years.**

The Queensland First Nations Rheumatic Heart Disease Alliance (The Alliance) supported by a program manager will provide strategic oversight of the implementation of the Strategy in collaboration with relevant stakeholders. The Alliance supports the partnerships necessary to address the complex issues associated with ARF and RHD, strengthening the connections between different parts of the health system and building partnerships across the sectors. The Alliance will monitor implementation and report on progress to the Strategy Co-Sponsors and through the Strategy Co-Sponsors to the Director General of Queensland Health and to the Queensland Minister for Health and Ambulance Services.

The Alliance will provide recommendations and advice regarding the strategic direction, priorities, and objectives for strategies to improve ARF and RHD outcomes for First Nations peoples in Queensland.

Investment to support the Strategy is articulated in the Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021 High Level Concept Brief [12] and its Companion Document [13]. The Alliance will ensure the outputs and outcomes of funding associated with the Strategy are completed within the agreed timeframes and budget allocations and an investment steering committee will be stood up as part of the Alliance governance structure to assist with this. The Alliance and its partners will continue to advocate for and seek funding across all sectors and levels of Government and non-Government agencies to implement the Strategy.

Implementation of the Strategy will be achieved through the establishment of regional partnerships and the collaborative development of Regional Action Plans supported by a Regional Health System Dashboard (the Dashboard). Building connections to services and departments outside of health through partnerships will also be a component of the Regional Action Plan.

The Dashboard will enhance two-way data sharing between the Queensland Rheumatic Heart Disease Register and Control Program and the regional partnership to enable understanding of disease demographics and inform health service planning and prioritisation of local action. The Dashboard will enable reporting and monitoring to and from the Alliance, support evaluation of the Strategy and the publication of an annual report.

It is acknowledged that in Queensland ARF and RHD also disproportionally affect the Maori, Pacific Islander and refugee populations. It is anticipated that the Regional Action Plans will include partnerships and activities to improve health outcomes for all those that are impacted by ARF and RHD.

# The Strategy aligns to national and statewide health reform:

**The strategy is underpinned by the National Agreement on Closing the Gap, 2020: Four Priority Reform areas and Implementation Plan [14]:**

## Four Priority Reforms

1. **Priority reform one: Formal partnerships and shared decision making**
2. **Priority reform two: Building the community-controlled sector**
3. **Priority reform three: Transforming government organisations**
4. **Priority reform four: Shared access to data and information at a regional level**

## The Strategy will contribute to the following Closing the Gap Targets and Outcomes [4]:

TARGETS

| | |
|---|---|
| 1 | Everyone enjoys long and healthy lives |
| 2 | Children are born healthy and strong |
| 4 | Children thrive in their early years |
| 8 | Strong economic participation and development of people and their communities |
| 14 | People enjoy high levels of social and emotional wellbeing |
| 15 | People maintain a distinctive cultural, spiritual, physical, and economic relationship with their land and waters |
| 16 | Cultures and languages are strong, supported and flourishing |
| 17 | People have access to information and services enabling participation in informed decision-making regarding their own lives |

## At the heart of the Strategy are the Queensland First Nations Health Equity design principles [6]:


Underpinning these principles is **cultural capability** as demonstrated by cultural respect, cultural competency, cultural safety and the broader Queensland Government commitment to **reframe the relationship with First Nations peoples**

## The Strategy aligns to Queensland Health's vision [15]

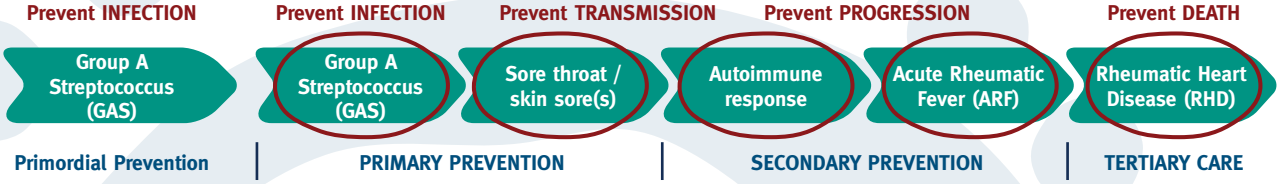
The Strategy supports the Queensland Health vision: to make 'Prevention a Priority' through building the health system of the future, a system focused on wellbeing, prevention, value and equity, addressing the unsustainable demand for hospital services and bringing significant benefits to families, community wellbeing and the economy' [15].

## The Strategy aligns to the National Endgame Strategy [1]

The five priority areas of the Strategy are aligned to the National Endgame Strategy [1] meaning they are based on the national evidence [1] and health economic modelling [2]. The five priority areas were chosen through extensive consultation and informed by the Queensland experience to date. It was determined these five priority areas will have the highest impact on the prevention of ARF and RHD.


## The Strategy takes a comprehensive approach

There are many opportunities to intervene on the pathway from Group A Streptococcus (GAS) infection to Rheumatic Heart Disease and traditionally these have been divided into primordial, primary, secondary and tertiary interventions as seen below.




It is recognised globally that ending ARF and RHD requires a multi-layered, comprehensive approach as advocated for by the World Health Organization (WHO) and the World Heart Federation [16,17].

## The Strategy is implemented through partnered Regional Action Plans

Hospital and Health Services will be accountable for implementing partnered Regional Action Plans to address their chosen top priorities. Hospital and Health Services with low disease burden may choose to integrate the partnered Regional Action Plan with their Health Equity Plan.

The template below is designed as a resource to guide the development of a Regional Action Plan. The Action Plans are intended to be developed and implemented in partnership with suggested partners seen in the template.

### Regional Rheumatic Heart Disease Action Plan Tool

**A strengthened, integrated, equitable whole of system response, capable of prevention, early detection, diagnosis, treatment and management of ARF and RHD**

- **Please refer to the Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 for context**
- **Please refer to your regional health system dashboard, this provides the data to help prioritise and plan activities, it will also help with reporting on achievements**

#### Principles of the Regional RHD Action Plan

- **Integration of primary healthcare and health systems**
- **Working in partnership**
- **Linking to Health Equity plans**
- **Linking to local area needs assessment (LANA)**
- **Community and consumer engagement**
- **Implementation of guidelines**

**Local champions are:**

**Partners are:**

**Queensland Register**
**Cardiology**
**Paediatrics**
**Obstetrics and Gynaecology**
**General Practitioners**
**Aboriginal and/or Torres Strait Islander Health**
**Environmental Health**
**Housing and Education**
**Aboriginal and Torres Strait Islander Community Controlled Health Organisations**

**Consumer champions are:**

**Key Priorities are:**

1.
2.
3.

**Workforce priorities are:**

**Community engagement activities**

1.

## Supported by a Regional Health System Dashboard

The Regional Health System Dashboard (the Dashboard) will be developed by the Queensland First Nations Rheumatic Heart Disease Alliance in collaboration with key stakeholders and supported by the Data Steering Committee. The Dashboard will have generic burden of disease data for each region with outcome measures and key performance indicators tailored according to the agreed activities.

The concept of the Dashboard is to inform and enable the development of Regional Action Plans as well as provide a means of measuring activity through changes in outcome measures over time.

### Regional Health System Dashboard for Rheumatic Heart Disease

**Baseline burden of disease data for the region:**
**Number of cases, Ethnicity, Age, Sex, Disease Severity**

| Strategy Objectives | Outcome Measure |
|---|---|
| **Access to care**<br>• Reduce cardiovascular burden of disease in line with health equity legislation (CTG targets)<br>• Increase access to appropriate care within clinically recommended timeframes | • # of overdue echoes<br>• time to specialist review<br>• RHD severity<br>• # of Heart valve surgeries<br>• Mortality |
| **Communities, primary healthcare and Aboriginal and/or Torres Strait Islander workforce**<br>• Increase detection and treatment of sore throats and skin sores, decreasing preventable ARF rates in the community<br>• Undertake local needs and readiness assessments for community engagement and to implement local place based solutions<br>• Decrease preventable hospital admissions (RHD only)<br>• Increase culturally appropriate care givers able to treat closer to home<br>• Increase Bicillin adherence, (decrease disease progression) | • # of ARF episodes<br>• # recurrent ARF<br>• # of MCS throat/skin swabs<br>• # of consults for skin/throat infection<br>• # of treatments for scabies<br>• # of treatments for sore throats and skin sores with antibiotics<br>• # of days at risk<br>• # and type of community/ consumer engagement and implemented activities |
| **Healthy environments**<br>• Improvement in standard of living (eg. Healthy Homes Initiatives) | # of communities with activities implemented and type of activity |

**Key Performance Indicators (KPI's) developed locally according to priorities and activities**

The Dashboard will be available to all partners of the Regional Action Plans inclusive of primary healthcare sector and community. Provision of data will be governed according to the Public Health Act 2005, the Public Health Regulation 2018, the Hospital and Health Boards Act 2011 and the Information Privacy Act 2009.

# Five Key Priority Areas in detail

## Aboriginal and Torres Strait Islander Leadership

Strengthen the skills, capacity and leadership within the Aboriginal and Torres Strait Islander health workforce to maximise primary and secondary prevention of ARF and RHD

## Outcome

An increase in the number and type of primary and secondary prevention models of care for ARF and RHD that include the Aboriginal and Torres Strait Islander health workforce across all professions. The models of care will have a focus on empowering and enhancing the skills, capacity and leadership of the Aboriginal and Torres Strait Islander health workforce through mentorship and training.

## What will we deliver?

Working in partnership with Aboriginal and Torres Strait Islander Community Controlled Health Organisations and other partners to develop a First Nations health workforce plan for ARF and RHD that will enable clinical practice and leadership to maximise ARF and RHD response. The workforce plan will be guided by relevant national and statewide strategies such as the National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021-2031.

## What does success look like?

**There will be an increased number of First Nations staff working in and leading the primary and secondary response to ARF and RHD. All staff will have the ability to undertake life-long learning in culturally capable practice.**

**Community-based programs**

With partners and community, develop place-based, sustainable and scalable, person and community centric solutions guided by an evidence based approach

## Outcome

Empowered and supported communities that understand their burden of disease and are implementing culturally relevant elimination activities aligned to local priorities [1].

## What will we deliver?

Working in partnership with Aboriginal and Torres Strait Islander Community Controlled Health Organisations to initiate First Nations led community development [9] in communities with the highest risk to enable community engagement and inform local place-based solutions.

## What does success look like?

**Increased community engagement, capacity and resource to enable and empower grass roots solutions.**


Apunipima Cape York Health Council First Women's Group Education Session (Napranum)

**Healthy Environments and Primordial Prevention**

Integrate services and responses across Government for First Nations peoples, specifically housing and health, and inclusive of the Queensland Aboriginal and Torres Strait Islander Environmental Health Plan

## Outcome

Communities at higher risk are engaged and have increased capacity for the nine Healthy Living Practices [18] supported by an integrated whole of government response.

## What will we deliver?

The Queensland First Nations Rheumatic Heart Disease Alliance will advocate for and build networks and partnerships enabling integration of housing responses for First Nations peoples with Environmental Health strategies, plans and initiatives. Examples of these include Healthy Homes initiatives, Safe and Healthy Drinking Water in Indigenous Communities, and other solutions that enable community uptake of the nine Healthy Living Practices [18].

## What does success look like?

**Regional Action Plans have the necessary partnerships in place to enable an integrated health, environmental and housing response.**

**The Nine Healthy Living Practices (HLPs)**

1. **Washing poeple, especially children**
2. **Washing clothes and bedding**
3. **Removing wastewater safely**
4. **Improving nutrition**
5. **Reducing the impact of crowding**
6. **Reducing the impact of animals, insects and vermin**
7. **Reducing the impact of dust**
8. **Improved temperature control**
9. **Reducing hazards that cause trauma**

**Early Prevention**

With partners and community implement comprehensive sore throat and skin programs, including health promotion, community empowerment, and improvement of primary healthcare processes including clinician training

## Outcome

First Nations peoples in communities at higher risk seek care and receive appropriate treatment for sore throats and skin sores, with community-level understanding and action in place to support this.

## What will we deliver?

Sore throat and skin programs in ten communities at higher risk where the scope is determined in partnership with local community stakeholders. Working with partners between Queensland Health, the Aboriginal and Torres Strait Islander Community Controlled Health sector, the Heart Foundation, Environmental Health, the Department of Education and local community groups to

- develop and implement sore throat and skin sore programs including health promotion and community empowerment
- optimisation of primary healthcare processes inclusive of clinician training
- work with the building sustainable primary healthcare team to maximise the Medicare Benefits Schedule such as child health checks and chronic disease management

## What does success look like?

**Appropriate treatment of sore throats and skins sores for First Nations peoples interrupts the link between Group A Streptococcus (GAS) infection and development of ARF, this in turn prevents progression to RHD. Success will be skin and sore throat programs in place that have been developed in partnership and with the community.**

**Effective care and support for all those living with ARF/RHD in Queensland**

Increase access to effective care, close to home, within clinically recommended timeframes, focusing on secondary prevention and applying a holistic, familial approach

## Outcome

Better health outcomes for First Nations peoples living with ARF and RHD inclusive of a reduction in the cardiovascular burden of RHD disease and in the number of First Nations young people lost to healthcare follow up, achieved through equitable and timely access to care closer to home.

## What will we deliver?

Building on the work of the Action Plan 2018-2021,

- Further transform care through increased statewide implementation of innovative and sustainable ARF and RHD models of cardiac care including care co-ordination, transition care for adolescents, and integration with cardiac outreach programs and primary healthcare

- Support on the ground clinical services to improve secondary prevention strategies leading to an increase in client adherence to treatment and decrease disease progression along the trajectory.

## What does success look like?

**Communities at higher risk have integrated, co-ordinated, culturally safe models of ARF and RHD care across all sectors of the health system in place, including cardiac care, maternal care and when transitioning from adolescence to adulthood.**

# Conclusion

Queensland is leading the way being the first state or jurisdiction to implement an action plan that set priorities and activities to tackle ARF and RHD. Much has been achieved with the Queensland RHD Register and Control program implemented in 2009 and the work of the Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021 over the last three years. However, it is recognised that ending rheumatic heart disease in Queensland will take a significant and continued whole of government response as there is still much to be done.

The Ending Rheumatic Heart Disease: Queensland First Nations Strategy for 2021-2024 places First Nations peoples and voices at its centre and its five key priority areas align to the national RHD Endgame Strategy [1], which was created with Aboriginal and Torres Strait Islander people and provides an evidence-based blueprint for eliminating RHD in Australia. Not only will the national (and the Queensland) strategy have an impact on RHD it will also help to eliminate linked diseases like otitis media, trachoma and kidney disease, further 'Closing the Gap' for First Nations Peoples [1].

Ending of rheumatic heart disease in Queensland will take time but the journey to achieve this vision is underway. We all have a part to play in ending rheumatic heart disease with the greatest strengths being First Nations leadership and working in partnership across all sectors with and guided by community. The Ending Rheumatic Heart Disease: Queensland First Nations Strategy 2021-2024 provides a guiding framework for the Queensland response to ARF and RHD.

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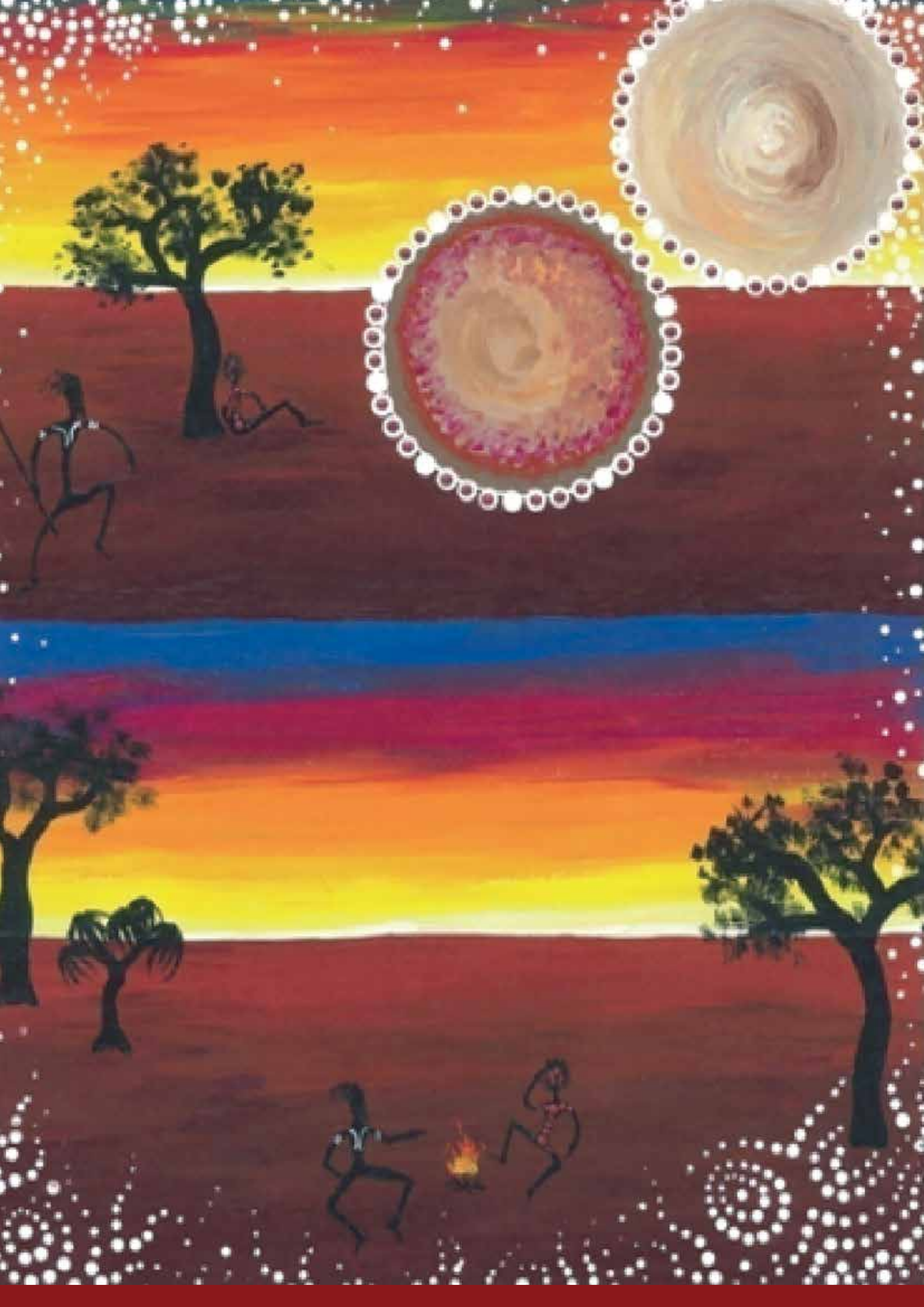

*Left: Gidgee Healing Dreamtime Story explaining Symptoms of Acute Rheumatic Fever*