Aboriginal and Torres Strait Islander Leadership in ARF and RHD: Priorities, Partnerships and Progress

Remarks to World Congress on Rheumatic Heart Disease

Hilton, Abu Dhabi, UAE

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Welcome everyone. As is our practice in Australia, as the Indigenous peoples and traditional owners of the lands and the waters of Australia, I would like to acknowledge the Indigenous peoples across the world.

I'll also like to acknowledge the organisers, the World Heart Federation and Australia's Heart Foundation, David Lloyd and Professor Jonathan Carapetis for making it possible for myself and Doctor Lorraine Anderson to present today.

I'm Dawn Casey. As has been said, I'm the Deputy CEO of the National Aboriginal Community Controlled Health Organisation, otherwise known as NACCHO. It is the national peak body for 145 Aboriginal community-controlled health services that deliver comprehensive Primary Health care to over half of the Indigenous population in Australia and have been around for about 50 years.

The majority of other Indigenous peoples are serviced mainly by state-run government clinics, but we are working to have those transition to community control. Our services, known as Aboriginal Community Controlled Health Services or ACCHOS as I'm going to shorten the title for you. ACCHOs must be based in a local Aboriginal or Torres Strait Islander community and they must be governed by that community through an Aboriginal and Torres Strait Islander elected board.

I'm proud to say that our earliest ACCHO predated the World Health Organization's declaration on Alma Ata in 1978. Our ACCHO model continues to be acknowledged in multiple forums and in research as the best example of sustainable and equitable healthcare.

This approach also received significant consideration from the current Federal Minister for Health in responding to what was seen as Australia's crisis with Medicare funding. The community-controlled health sector delivers 3,000,000 clinical episodes of care per year through its 550 clinics.

And there's even more not so easily quantified in our community led population and public health work, including intersectoral partnerships and health promotion. We know the requirements for better health as a whole of community; self-determination and individual spiritual, cultural, physical, social and emotional well-being. Yet sadly, in a colonized country, disease rates not seen since 1900 in non-Indigenous populations are still commonplace in 2023 in our Indigenous peoples.

RHD is the greatest cause of cardiovascular inequity for Aboriginal and Torres Strait Islander people and until recently was the leading cause of death, only just overtaken recently by cancer. RHD is the epitome of health gaps between our Indigenous peoples and other Australians. It spans from housing to primary care to open heart surgery.

The Indigenous Peoples of Australia have the highest number of rheumatic heart disease in the world.

I was surprised therefore that we were not recognized in the Global Map in yesterday's opening session but have subsequently been advised of the formula used.

Perhaps, though, I should not have been surprised.

After all, the majority of Australians have just voted in a national referendum to not recognise our Indigenous people's rights. In the lead up to the vote for the to the referendum, it was horrific.
In our country, health services were graffitied, Aboriginal youth were attacked with racist comments.

Australia's Indigenous people have the longest continuous living culture in the world, documented to be around 60 to 80,000 years. Yet both internationally and nationally, we remain hidden and barely acknowledged. Buoyed by the win of the No campaign, the Conservative federal opposition is using this as their strategy for the next election with promises to cut Indigenous programs.

But I digress. Sorry.

So, here's how we can effect real change.

We need the World Heart Federation to place Australian Indigenous Peoples on its map and recognise the level of burden of RHD. Here in the audience, I see and thank those who contributed to the development in Australia of the RHD END Game Strategy launched in September 2020.

This report was completed with the support of the End RHD Centre of Research Excellent Funded by the Australia's prestigious National Health and Medical Research Council, it brought together the collective experience of communities, clinicians and our sector, as well as government and non-government organizations.

It also summarised the substantial knowledge and evidence base that now exists to eliminate RHD in Australia. At the launch of the RHD end game strategy that many of you know about, our CEO Pat Turner said, "We know what needs to be done and we know that it can be done."

NACCHO now leads the first ever Aboriginal Torres Strait Islander sector led initiative based on self determination to combat ARF and RHD across the country.

Our solution is comprehensive Indigenous led, primary care-based strategy of both prevention and treatment.
Here in front of an international audience, I commend all current Australian governments for their willingness and enthusiasm to partner with us in this new approach to ARF and RHD.

To my knowledge the partnership is a global first.

So, what does it look like next? Investing in community control, service delivery, the joint approach led by NACCHO, and the federal government has prioritised investment in communities and on the ground action.

NACCHO is dispersing around $30 million in service enhancement grants to enable Aboriginal Torres Strait Islander communities to address local priorities, building on their own strengths and assigning resources to strategies they know will work.

The service development grants are distributed according to need. Currently, there are around 21 communities that will be recipients. NACCHOs approach acknowledges that prevention is better than the cure and that if it's designed to prevent ARF and RHD in our Indigenous communities, ACCHOs are best placed in the context of comprehensive and culturally safe primary care.

Funding provided is sufficient to enable ACCHOs to employ local healthcare workers properly qualified to design and implement local approaches to environmental health and prevention activities.

Investing in Aboriginal and Torres Strait Islander people is an essential part of our approach.
We have a national community of practice which is an absolute joy to watch. Aboriginal health practitioners share skills, insights and solutions amongst each other. We also have an ECHO training program open to members of this community practice. We have a common performance framework developed within our services and an attitude of continuous quality improvement.

Our services have always been advocates for primordial prevention. Aboriginal and Torres Strait Islander communities have known the links between human health and the environment for millennia. The greatest preventative impact comes from combining housing, health promotion and primary healthcare.

The RHD End Game strategy calculated this combination would prevent more than 2/3 of new cases. It prevents more than any other combination of strategies.
The entire cascade of morbidity and mortality would be prevented. Nothing beats this integrated combination, which is why it is top of our mind.

In our organization, strategies to reduce strep A, ARF and RHD are more appropriately described as fundamental human rights, including access to adequate housing and access to clean water. Extraordinary as it may sound, hundreds of thousands of Indigenous people in Australia in this, the 21st century are without access to clean water. The right to housing is enshrined in a number of international instruments, including Article 25 of the Universal Declaration of Human Rights.

When the Australian Government supported self-determination many Aboriginal Torres Strait Islander people returned to their homelands believing that their entitlements to essential services and basic infrastructure such as potable water, sewerage and waste management would be secure as it was for non-Indigenous Australians.

This belief was misplaced.

The impact on health is self-evident.

Aboriginal and Torres Strait Islander communities know this.

NACCHO knows this and we will not waver from this human right.

Let me turn now to the importance of secondary prophylaxis and whole of person care across Australia.

In 2021, nearly 2000 Indigenous people received less than 50% of their due injections, including more than 500 who didn't receive any. Admittedly, 2021 was a particularly tough year with COVID. However, I'm not confident that the data in the coming year will be much better.

There are many reasons explaining why secondary prophylaxis is so substandard, including culturally safe healthcare, poor engagement by non-indigenous staff of Aboriginal and Torres Strait Islander families, and disjointed follow up reminder programs.

We also need better choices for a penicillin administration.

Another issue for secondary prophylaxis that we worry about in NACCHO is antibiotic supply and access. In Australia, we have a pharmaceutical benefits scheme, which means government subsidized medicines are affordable. Both oral and intramuscular forms of penicillin required for secondary proper access are available on the scheme, but the current challenge is a potential global shortage of intramuscular Bicillin LA and NACCHO has had several of our community health services advising of low local supplies.

And of course, anyone on a regimen of secondary prophylaxis needs more than this antibiotic shield, important as it is. NACCHO is also strengthening the holistic care necessary for optimal health. Children need their immunizations. They need ear diseases diagnosed and treated. They need their growth assessed. They need treatment for anaemia and early intervention for development delay. They need their cultural compass, mental health, and healthy teenage transitions. When we look at the whole person beyond the RHD, we can see huge challenges.

A GP and member of our Expert Working Group examined the medical records of 342 Aboriginal patients with RHD in the NT admitted for surgery. Seventy-three percent (73%) had at least one preoperative comorbidity. Preoperative comorbidity was significantly associated with earlier death. Every additional comorbidity increased this risk.

If ever there was a reason for comprehensive primary health care that focused on the person and their context - not just the RHD - this would be it. The wrap-around care our sector should be funded to provide is the answer.

Now allow me just a few comments about RHD care and treatment in hospitals.

In an average year, there are about 125 admissions for RHD-related cardiothoracic surgery across Queensland, WA, SA and the NT combined. These procedures are carried out entirely in tertiary referral hospitals. There's every reason to expect these admissions to be exemplars of culturally safe care, yet this is not the case. Long term survival of Aboriginal people having RHD valve replacement in the NT has not improved since 1964.

One in every 25 hospital admissions ends with an Aboriginal Torres Strait Islander patient ending care early. That's over five times more than other Australians. This statistic is worse for people coming from remote and very remote regions. In some hospitals, almost one in 10 admission ends with the patient leaving early. These patients are more likely to end up readmitted and have post-operative complications. Increased morbidity and mortality and increased healthcare expenditure may be even more.

I must be blunt. Aboriginal Torres Strait Islander people do not trust the hospital system, they are not being serviced effectively by it.

We know this is largely due to lack of cultural safety. Our people vote with their feet and the rate of failure to complete care for Aboriginal Torres Strait Islander people is increasing.

To conclude, Aboriginal Torres Strait Islander people and their peak bodies are setting new expectations for structural reform in the Australian health system. Our recent workforce census research with member services suggest that it is predominantly non-Indigenous staff who end up leading RHD work in services. This really must be rectified.

Internally, NACCHO has set itself the goal of increasing skilled, effective, and – frankly – permanently funded Aboriginal and Torres Strait Islander workforce to work every day, everywhere to eradicate ARF

and RHD from their communities. I'm particularly excited by this goal. The sustainability we seek requires embedded community control.

However, I'm all too aware that while Australia's health system has a range of safety nets and system supports that may be the envy of other countries represented here, it fails Aboriginal and Torres Strait Islander people because our numbers are relatively low, our health issues too easily fragmented by specialist interests and our access to services, medication and holistic care is constantly being undermined.

Our CEO Pat Turner made it very clear that NACCHO became a founding partner of the RHD End Game Strategy, not because this disease is a simple fix, but because it is hard.

Our resolute focus on Aboriginal Torres Strait onto community-controlled health services delivery may not be making us popular in some circumstances, but we know we need to do this.

So, thank you. And I'd love to introduce Doctor Lorraine Anderson, who's a partner in this work we do.