CLOSING THE GAP

REFRESH

Submission on behalf of the END RHD Centre of Research Excellence and RHDAustralia

APRIL 2018

ABOUT US

The END RHD CRE

In 2014, the National Health and Medical Research Council awarded a Centre of Research Excellence (CRE) for Australian researchers to develop a set of costed, stepwise recommendations to end RHD in Australia. This END RHD CRE will present an RHD Endgame Strategy for RHD to the Commonwealth Government in 2020 with an 11-year plan to achieve disease control by 2031 to contribute to meeting Closing the Gap targets.

RHDAustralia

RHDAustralia supports the control of rheumatic heart disease in Australia. Funded under the Australian Government's Rheumatic Fever Strategy, RHDAustralia is based at Menzies School of Health Research in Darwin. RHDAustralia's vision is that no child dies in Australia as a result of acute rheumatic fever and its complications. RHDAustralia works alongside Aboriginal and Torres Strait Islander peoples, and other at-risk populations, to reduce acute rheumatic fever and rheumatic heart disease in Australia. RHDAustralia develops and disseminates evidenced-based resources to support health systems and health staff in their work, and advocates and provides culturally appropriate educational resources for people with ARF/RHD and their families.

DO YOU HAVE ANY GENERAL COMMENTS?

A review of Closing the Gap goals is timely, we support this consultation process as an opportunity to strengthen the voices of Aboriginal and Torres Strait Islander people and partners in this work. It also provides an opportunity to take stock on the evidence and good work that has occurred in Aboriginal and Torres Strait Islander communities in the last decade.

Our primary recommendations:

- The Closing the Gap Refresh retain a focus on health outcomes; these matter to Aboriginal and Torres Strait Islander people. The overarching goal of closing the gap in life expectancy of Aboriginal and Torres Strait Islander people should be retained.
- Overarching goals should be underpinned by more tangible, focused targets which are measurable and achievable. Interim, incremental targets have the potential to demonstrate success that can be seen at the local community level.
- Rheumatic heart disease (RHD) could provide a critical, tangible target for achieving gains in Indigenous life expectancy. RHD is the leading cause of cardiovascular inequality between Indigenous and non-Indigenous Australians.
- Research and programs that have been working well in addressing the Closing the Gap targets over the last ten years should be considered and a strength- based approach used.
- To improve health outcomes the focus must on the underlying factors (the social determinants and cultural determinants of health) which have created the 'gap' as well as improving current standards of care.

1. WHAT DOES CLOSING THE GAP MEAN TO YOU?

Closing the Gap is an opportunity for Australia to set measurable targets to end the disparity in health, education and employment between Indigenous and non-Indigenous Australians. Our focus is on health outcomes and we believe that Closing the Gap offers a powerful framework for mobilising action in critical domains: similar to the successful approach of the Millennium Development Goals or the Better Public Service Targets in New Zealand. We believe that refreshing Closing the Gap can fuse overarching goals with specific, measurable, achievable targets.

We are conscious that the nomenclature of Closing the Gap is a source of considerable confusion among stakeholders. It is commonly confused with the Close the Gap campaign. We encourage the Government to be sensitive to this distinction, so people have a clear understanding of the meaning of Closing the Gap and Close the Gap. We also encourage the Government to use the strength of the Close the Gap campaign, with its demonstrated commitment to work in partnership with Aboriginal and Torres Strait Islander people, to inform the Closing the Gap refresh and resulting policies and implementation.

2. HOW CAN GOVERNMENTS, ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE, AND BUSINESSES WORK EFFECTIVELY TOGETHER

2a. What is needed to change the relationship between government and community?

Aboriginal and Torres Strait Islander peoples have identified a consensus roadmap to address persisting inequalities between Indigenous and non-Indigenous people. The Uluru Statement from the Heart in 2017 called for a Makarrata Commission to supervise a process of agreement-making. This amplifies calls for participatory shared decision making in the 2016 Redfern Statement.[1]

Social determinants of health account for over a third of the disparity between health outcomes for Indigenous and non-Indigenous Australians.[2] It is impossible to address this gap or to work together effectively to address this disparity without meaningful engagement in constitutional recognition and ongoing dialogue about practical strategies to address disparities in health and other outcomes.

Aboriginal and Torres Strait Islander peoples should be consulted at the earliest possible time and be involved in all decision-making that affects their health. Trust is at the centre and needs to be established at all levels. It is important that co-design is based on a true and honest relationship and that power imbalances are broken down at all levels.

2b. To help close the gap, what is needed to support Indigenous community leadership and decision-making?

Aboriginal and Torres Strait Islander leaders must have a meaningful stake in decision-making for them to solicit and represent the views of their community. It is unreasonable for Indigenous leaders to endlessly convene and consult communities without any evidence that their perspective will be accounted for in decision making.

Full participation in decision making means that Aboriginal and Torres Strait Islander communities identify their own representatives to engage with government. This would increase transparency and trust in the consultative process. For example, consultation on health issues within the Closing the Gap refresh issues was held in early 2018. We understand that attendees at this event were invited by the Government, leading to concern that the voices of frontline health workers may have been underrepresented. Ensuring that Aboriginal and Torres Strait Islander stakeholders can identify their own representatives is critical for progress.

3. HOW COULD THE CLOSING THE GAP TARGETS BETTER MEASURE WHAT IS WORKING AND WHAT IS NOT?

3a. What has worked well under Closing the Gap?

Closing the Gap has increased public consciousness of the manifold disparities for Aboriginal and Torres Strait Islander people in Australia. It has enhanced a level of accountability by driving regular reports and updated data on broad outcomes.

3b. What has not worked well?

The Closing the Gap targets are too broad for any one department, programme or individual to feel personally invested in the outcomes. It is too easy for lack of progress to be attributed to nebulous external factors and accountability is eroded.

Current reporting does not mobilise stakeholders towards common, measurable, achievable goals. Successes and case studies seem serendipitous. Aboriginal and Torres Strait Islander people and frontline health care workers are not engaged, inspired or empowered by results. A third implementation plan for the Aboriginal and Torres Strait Islander Health Performance Framework is in development without any meaningful engagement in the first two iterations. Only a sense of shared ownership and shared goals progress will address these issues. Sustained, predictable, funding is needed to make this possible.

We call for overarching goals of Closing the Gap to be underpinned with specific targets with clear roadmaps and tied funding for action. This reflects the call for more specific targets identified by the Close the Gap report 2018.[3] The 'Tier 1' Health Status and Outcomes currently identified in the Aboriginal and Torres Strait Islander Health Performance Framework are a reasonable cluster of focus conditions.[4] However, they are not sufficiently tied to targets, for example, they do not articulate with the National Key Performance Indicators for Aboriginal and Torres Strait Islander Primary Health Care.[5] Nor

do these 'Tier 1' focus areas have long term action plans which can be adapted and evolve to reflect emerging evidence or the needs of communities.

This issue of goals which are too big and too disconnected is exemplified in cardiovascular disease generally, and in RHD specifically. The biggest cause of disparity health between Indigenous and non-Indigenous Australians is cardiovascular disease.[2] The Essential Service Standards for Equitable National Cardiovascular CarE for Aboriginal and Torres Strait Islander People (ESSENCE) standards have been developed to guide prevention and service delivery but are not routinely embedded in Commonwealth or jurisdictional reporting.[6] This means that the extensive consultation and Aboriginal and Torres Strait Islander leadership in developing the ESSENCE standards is wasted. Focusing some of the specific indicators and targets proposed by ESSENCE would have more impact that the diffuse, opportunistic approach which currently creates considerable uncertainty in Government funding and reporting.

One of the areas addressed by ESSENCE is RHD. RHD exemplifies a missed opportunity to coalesce Aboriginal and Torres Strait Islander people, researchers and policy makers around one focus area to have broad impact.

WHAT IS RHD AND WHY IS IT A SENTINEL MARKER FOR CLOSING THE GAP?

RHD is a preventable condition caused by an abnormal immune response to Strep A infection in childhood. Almost all of the young people living with RHD in Australia are Aboriginal and Torres Strait Islander people.[7] The cause of RHD is rooted in the social determinants of health. Poverty, overcrowding and inequality drive transmission of Strep A infections of the skin and throat. Inadequate access to appropriate medical care means these common childhood infections often go untreated, leaving susceptible people vulnerable to acute rheumatic fever (ARF). Over time, recurrences of ARF cause the irreversible and progressive heart valve damage that is RHD in young adults. This heart valve damage can be surgically treated but this creates a lifetime of follow up and ill health. The average age of death from RHD in Aboriginal people in the Western Australian Kimberly is 41 years.[8]

Rheumatic heart disease starts as an infectious disease in childhood and becomes a non-communicable disease in adulthood. Management spans from prevention of infection in primary care, to open heart surgery in tertiary hospitals. Control measures include reducing risk to mothers and babies during pregnancy and tackling social determinants such as housing and hygiene. There are opportunities for prevention at every stage of disease progression. Addressing crowding, health hygiene infrastructure and access to high quality primary care necessary to prevent ARF also has potential to reduce a range of other common childhood illness in Indigenous communities, including respiratory infections, otitis media and gastrointestinal illness.

Aboriginal community leaders and Indigenous peak body organisations are calling for action to end RHD.[9] The opportunity to use RHD as a lens for community engagement has been well demonstrated in New Zealand. The Māori Party in New Zealand drove political prioritisation of the high rates of ARF in Māori and Pacific people in 2011. In 2012 ARF was identified as a 'Better Public Service' target, with a goal to reduce first episode ARF hospital admissions by two thirds over 5 years. A 65 million-dollar investment over that time spurred community leadership, youth ambassadors, seasonal awareness campaigns, resources in Māori and Pacific language and intensive focus on primary prevention. As a result first episode hospital admissions for ARF fell by 23% by 2017.[10] A focused, whole-of-government approach in partnership by communities living with RHD changed the trajectory of this disease.

We can learn from this approach to achieve similar goals in Australia.

4. WHAT INDICATORS SHOULD GOVERNMENTS FOCUS ON TO BEST SUPPORT THE NEEDS AND ASPIRATIONS OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES?

4a. Should governments focus on indicators such as prosperity, wellbeing or other areas?

Health is a fundamental human right. Aboriginal and Torres Strait Islander peoples in Australia have grossly inequitable health outcomes. We believe that focusing on closing the health gap is the most meaningful measure for Aboriginal and Torres Strait Islander peoples – because it is about reducing death and disability.

4b. What do you think are the most important issues for Aboriginal and Torres Strait Islander Australians, families and communities? Why?

The most pressing issues for Aboriginal and Torres Strait Islander peoples reflect the shared needs of all people: survival, safety, belongingness.[11] Given the burden of poor health, physical and spiritual survival is the most pressing issue for Aboriginal and Torres Strait Island people.[12] As one of our Aboriginal team members describes it 'We have been here for so long. We are still here. We are still resilient'. For Closing the Gap this resilience means that consultation, partnership and amplifying local priorities are critical building blocks for success.

Past and continuing government policies continue to affect the health of Aboriginal and Torres Strait Islander peoples. Intergenerational trauma remains a huge barrier to improving health outcomes, trauma informed care must be at the heart of interventions and programs.

5. SHOULD ABORIGINAL AND TORRES STRAIT ISLANDER CULTURE BE INCORPORATED IN THE CLOSING THE GAP FRAMEWORK? HOW?

Aboriginal and Torres Strait Islander culture should underpin and infuse every aspect of Closing the Gap: from Federal decision making and policy development to clinical service delivery in remote clinics.

The My Life My Lead report identifies culture as one of the Priority Areas "for the ongoing development, implementation and delivery of future policy and programs, including the Closing the Gap refresh and the development of the next iteration of the Implementation Plan (Aboriginal and Torres Strait Islander health)".[13] The Cultural Respect Framework 2013-2023 commits Commonwealth Government and all states and territories to embedding cultural respect principles into health systems, yet we know that Aboriginal and Torres Strait Islander people continue to face institutional racism and the fear of discrimination.[14,15]

Culture should be an enabler of care not a barrier. Cultural respect and considerations should extend to both patient care and workforce development. Clinical outcomes for two people with the same health condition but from different cultural backgrounds can be dramatically different if culture is not at the centre of care.

A young Aboriginal man admitted to hospital with a heart condition is unlikely to have the same journey or length of stay as a non-Aboriginal man of the same age and with the same diagnosis. The cultural obligations, associated family responsibilities and possible social issues, he faces are likely to impact on his journey. Those caring for him need to understand this and act accordingly to adapt and adjust care plans to ensure the best possible, equitable clinical outcomes. Having Aboriginal and Torres Strait islander peoples in the health workforce is a way to increase cultural capability and responsiveness. Aboriginal and Torres Strait Islander peoples as holders of cultural knowledge and cultural brokers need to be supported and the system needs to enable and support them to balance cultural and professional obligations.

6. WHAT DO YOU THINK ARE THE KEY TARGETS OR COMMITMENTS THAT SHOULD BE MEASURED IN A REFRESHED CLOSING THE GAP AGENDA?

Eliminating the gap in life expectancy between Indigenous and non-Indigenous Australians remains a critical unifying goal. We believe this goal should be augmented by specific, measurable, achievable targets which provide lessons about best practice and have capacity to demonstrate success. Cardiovascular disease is the leading cause of death in Aboriginal and Torres Strait Islander people. The greatest driver of disparity within cardiovascular diseases is RHD which occurs almost exclusively in Indigenous populations.[16,17]

Strategies to prevent RHD already exist and could be co-designed for optimum delivery in Aboriginal and Torres Strait Islander communities at the highest risk of RHD. We believe that that including RHD as a target for Closing the Gap offers a tangible opportunity to improve health outcomes and provide a discrete project for collaboration.

6a. What resources, including data or information, are needed to help communities and develop and drive local action?

Communities and families are the unit of action and decision making for Aboriginal and Torres Strait Islander peoples. Communities need local data to identify focused health targets most relevant to each setting and an architecture of networked, evidence-based support to achieve those goals. Partnerships with comprehensive primary health care, policy makers, researchers and non-health departments are needed to achieve this. Local data should be provided so that communities and track progress towards agreed goals. Sustained funding streams to allow communities to act on their own priority areas are needed. These funding streams should be directed to employing Aboriginal and Torres Strait Islander people in roles which progress collective goals and values: in health and in environmental health roles.

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