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Submitted to Public Call – Research priorities in Aboriginal and Torres Strait Islander health 2025

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Organisation:

NA- Parent Advocate/Lived Experience

5 Is your submission on behalf of an individual or organisation?

Individual

Specific questions

6 What is the research priority (a significant research knowledge gap or unmet need) you are nominating? How would a TCR in this area greatly advance our understanding of this issue?

Please provide feedback here:

Current Australian guidelines treat Group A Streptococcus (GAS) as an acute infection, yet evidence shows it is a chronic disease driver with autoimmune, neurological & psychiatric sequelae that remain under-recognised. Priority should be placed on: reclassifying GAS as a chronic disease driver; advancing front-line treatment with focus on PANDAS; investigating links between GAS, neuroinflammation, psychiatric & social outcomes; and embedding M-protein risk-based treatment protocols. In addition, a national life-course data system could capture presentations across public & private sectors to reveal patterns, support prevention, medical advancements such as vaccine development & Closing the Gap objectives.

I have begun shaping a concept for how such a system could be facilitated using existing Medicare infrastructure and would be open to sharing my concept with interested policy makers, researchers, and clinical leaders; as I believe it holds significant merit.

7 What are the relevant Australian Government priorities, and/or Ministerially-agreed State and Territory health research priorities linked to your nominated priority?

Please provide feedback here:

The proposed research priority aligns with multiple Australian Government strategies & Ministerially-agreed State/Territory health research priorities:

Closing the Gap Strategy – Aboriginal & Torres Strait Islanders experience a disproportionate burden of ARF, RHD, & invasive GAS. Embedding culturally safe, Indigenous-led frameworks into GAS management contributes to the Closing the Gap targets for child health, chronic disease prevention, & life expectancy.

RHD Endgame Strategy (Federation Funding 2024-25)

National Mental Health & Suicide Prevention Plan.

Dementia, Ageing & Aged Care Research Priority.

Medical Research Future Fund (MRFF) – Research Data Infrastructure Initiative.

National Aboriginal & Torres Strait Islander Health Plan.

State & Territory health research strategies – Such as:

Queensland Health's RHD Endgame & infectious disease control priorities

NT Rheumatic Heart Disease Strategy

*Both have explicit commitments to tackling GAS-related disease burden.

8 How would a TCR in this area contribute to Aboriginal and Torres Strait Islander health and improve health outcomes for the individual and/or community?

Please provide feedback here:

This research would have a positive impact to Aboriginal & Islander health:

Culturally safe, co-designed protocols developed in partnership with Aboriginal Community Controlled Health Organisations (ACCHOs)

Tailored care according to M-protein risk ensuring high-risk strains trigger appropriate clinical action/structured followup, to prevent progression to chronic GAS-driven conditions.

Reduction of disproportionate Indigenous burden of ARF, RHD, invasive GAS, & post-streptococcal glomerulonephritis.

Empowerment through life-course registries that embed Indigenous data sovereignty & ensure Aboriginal & Torres Strait Islander leadership in design & governance.

Improved child health, education, & justice outcomes by recognising & addressing GAS-related behavioural disruption.

Raising public awareness of the chronic disease burden that can stem from common conditions such as strep throat, thereby increasing patient participation in prevention & reducing the national health burden.

9 How will the TCR reduce the burden of disease on the health system and Australian economy?

Please provide feedback here:

Burden reduction cross multiple areas along with the economical impact.

Prevention: earlier detection & second-line interventions reduce hospitalisations & chronic disease costs.

Neuropsychiatric: early recognition of PANDAS improves outcomes & lowers long-term costs of care, school disengagement & justice involvement.

Dementia: clarifying GAS's role in neurodegeneration informs prevention & reduces aged care expenditure.

Registry-driven planning: a national life-course system enables efficient resource use, reduces duplication & ensures equity.

Further more:

With a registry that records patient health data we can monitor illness accurately, guide vaccine development; advance medical knowledge & improve outcomes.

M-protein risk stratification prevents chronic progression; social, educational & justice burdens are reduced.

Collectively these measures provide major benefits across health, education & the justice system nationally and can improve health outcomes for all Australians.

10 Are there any reports or findings that support your nomination for the suggested topic?

Please provide feedback here:

There is substantial evidence GAS is a chronic disease driver, not an acute diagnosis.

Australian reports:

CDNA SoNG-Invasive GAS 2024; RCH Sore Throat Guide 2024; RHD Australia ARF/RHD 2024; AIHW ARF/RHD 2024-25; Rheumatic Fever Strategy 2024-25.

International & lab:

CDC emm-typing 2024 (surveillance only); Dale 2008 – post-strep dystonia; Cox 2020 – biomarkers for basal ganglia encephalitis in Sydenham chorea/PANDAS; Giedd 2000 – MRI in OCD/tics post-strep; RCPsych 2020 – post-strep psychiatric/movement review.

Neuroinflammation & dementia:

Heneka 2025 (Nat Rev Immunol) – Alzheimer's link; Lancet Neurology 2025 – inflammation & tauopathies.

Community:

Elder A. Bosen endorsement; national petition (<https://chng.it/nttvZhTnDq>).

Collectively this confirms GAS is a chronic driver of autoimmune, neurological, psychiatric & societal disease, providing both scientific evidence & a social mandate for targeted research

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