

Targeted Translation Research Accelerator Needs Assessment and Prioritisation Project

Discussion Paper | MAY 2023

PREPARED BY THE LOWITJA INSTITUTE FOR MTPCONNECT

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Artwork: The artwork is by Ngarrindjeri artist, Jordan Lovegrove

About the artwork: The artwork shows the growing ripple effect that Aboriginal and/or Torres Strait Islander-led research has on health and wellbeing. The big meeting place in the centre represents Lowitja Institute and MTPConnect. The smaller coloured meeting places connected by footprints that surround it represents our connection and work with Aboriginal & Torres Strait Islander communities and other partners. The other small meeting places with pathways between, represent the communities that this research positively impacts.





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ACKNOWLEDGEMENTS

This discussion paper on the 'Targeted Translation Research Accelerator Needs Assessment and Prioritisation Project' was prepared through a commissioned collaboration and partnership between the Lowitja Institute and MTPConnect. This project included the completion of a needs assessment and prioritisation process for Round 3 of the Targeted Translation Research Accelerator (TTRA) Program, a Medical Research Future Fund initiative delivered by MTPConnect.

This work has been guided by TTRA Indigenous Advisory Group, established by MTPConnect.

ABOUT LOWITJA INSTITUTE



The Lowitja Institute is Australia's national institute for Aboriginal and Torres Strait Islander health research. We are an Aboriginal and Torres Strait Islander organisation working for the health and wellbeing of Australia's First Peoples through high impact quality research, knowledge translation, and by supporting Aboriginal and Torres Strait Islander health researchers.

Together with our many partners, we have helped transform research in Australia from research done on Aboriginal and Torres Strait Islander communities to research led by Aboriginal and Torres Strait Islander people, for and with Aboriginal and Torres Strait Islander communities.

ABOUT MTPCONNECT



As Australia's Growth Centre for the medical technology, biotechnology and pharmaceutical (MTP) sector, MTPConnect forges stronger connections between research and industry and supports the development and translation of Australia's health and medical research through a number of strategic granting programs including five initiatives delivered on behalf of the Medical Research Future Fund. One of these is the \$47 million Targeted Translation Research Accelerator (TTRA) Program, launched in

2020 as an integrated research program to improve the prevention, diagnosis, treatment and management of diabetes and cardiovascular disease (D&CVD) and their associated complications in Australia, by establishing two new national research centres and three rounds of contestable funding opportunities to support individual D&CVD research projects.

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Executive Summary

The TTRA Program

The Targeted Translation Research Accelerator program provides an integrated research program to improve the prevention, management and treatment of diabetes and cardiovascular disease (D&CVD) and their related complications in Australia. The \$47 million TTRA program is funded through the Preventative and Public Health Research initiative of the Medical Research Future Fund (MRFF) and is being delivered by MTPConnect.

The first two rounds of TTRA Research Projects funding provides between \$200,000 - \$750,000 to help eligible organisations develop innovative preventative, diagnostic, therapeutic and/or disease management products/solutions to address one of the Priority Areas identified for each round. These products/ solutions fall into one of the following modalities: digital health, medical devices, therapeutics or stand-alone behavioural interventions.

Round 3 of the TTRA Research Projects funding provides between \$200,000 - \$1 million to help eligible organisations develop or progress innovative preventative, diagnostic, therapeutic and disease management products, services and/or models of care to benefit the health and wellbeing of Aboriginal and Torres Strait Islander people living with diabetes and/or cardiovascular disease.

To achieve maximum impact for the TTRA program, MTPConnect ensures that the investment made through the program builds upon existing successful initiatives and is targeted towards the areas of greatest unmet need in D&CVD. Research Projects address one of the specific priority areas for each round to be eligible for funding.

For Rounds 1 and 2, these priority areas were determined through an evidence-based, sector wide, consultative needs assessment. This process reinforced the need for funding to be focused on Indigenous health outcomes and highlighted that priority setting must be Indigenous led.

As a result, Round 3 of the Research Projects funding opportunity focus on addressing D&CVD-related unmet health and medical needs of Aboriginal and Torres Strait Islander people in rural, remote, regional and urban Australia. In line with directions from the TTRA Expert Advisory Board (TTRA Board).

The needs assessment process

For Round 3 of the TTRA Research Projects funding opportunity, MTPConnect are funding D&CVD products, services and/or models of care that benefit the health and wellbeing of Aboriginal and Torres Strait Islander people. High-quality projects that are well matched to the selection criteria will include deep community engagement and Aboriginal and Torres Strait Islander leadership at all stages. This will ultimately lead to an increased number of grants made to Aboriginal and Torres Strait Islander researchers.

The Lowitja Institute was engaged to facilitate the needs assessment process for this round to determine the Indigenous-specific priority areas for research into D&CVD. In doing this, we have assessed and prioritised the related unmet health and medical needs of Aboriginal and Torres Strait Islander people in rural, remote, regional, and urban Australia.

Outcomes of this process have been used to guide the delivery and implementation of the TTRA Research Projects Round 3 funding opportunity and maximise its impact. Priority areas for D&CVD have been identified and have shaped calls for applications and the assessment of applications, to ensure that projects align to the agreed priorities and include innovative preventative, diagnostic, therapeutic and/or disease management products, services and/or models of care.

Approach to prioritisation

A Prioritisation Framework was developed by the Lowitja Institute to guide this work in identifying, assessing, and prioritising related areas of unmet health and medical needs of Aboriginal and Torres Strait Islander peoples living with D&CVD in rural, remote, regional and urban Australia.

This framework includes the following:

- The needs assessment and prioritisation process, detailing four key steps to be undertaken. These steps include identification, development, prioritisation, and endorsement.
- The criteria to be applied to areas of unmet need when assessing their priority.
- The criteria to be applied when allocating a priority rating.

Literature Review

As part of the identification step in the prioritisation framework, areas of unmet health and medical needs for Aboriginal and Torres Strait Islander peoples with D&CVD, in rural, remote, regional and urban Australia were identified. This was achieved through a literature review project, conducted by the College of Health & Medicine at the Australian National University in partnership with the Lowitja Institute.

A list of 33 current areas of unmet need were identified. These are focused on:

- Complications associated with cardiovascular disease and diabetes.
- Interactions between Type 1 diabetes, Type 2 diabetes, and cardiovascular disease.
- Innovative preventative, diagnostic, therapeutic and/or disease management products/solutions for D&CVD.
- Medical and health needs for regional, remote, rural and urban patients with D&CVD.

The Prioritisation Roundtable

As part of the prioritisation steps of this process, a roundtable was held bringing together Indigenous Advisory Group members, clinicians, researchers, patient advocacy groups and people with lived experience to discuss areas of unmet health and medical needs of Aboriginal and Torres Strait Islander peoples in rural, remote, regional and urban Australia.

During the roundtable participants completed a prioritisation assessment, via an online questionnaire and utilising the Prioritisation Framework. As experts in the field, participants provided their feedback on the priorities for health and medical research for Aboriginal and Torres Strait Islander peoples with D&CVD, and where research investment can have the most positive impact.

Areas of unmet health and medical needs discussed included:

- Unmet needs for cardiovascular disease.
- Unmet need for diabetes.
- Unmet needs where there is an interaction between D&CVD.
- Any other areas of unmet need irrespective of disease end point.

Key Findings

Results from the prioritisation roundtable were reviewed and informed the final list of Indigenous-specific priority areas for research into D&CVD. These priority areas include:

Priority 1: Strengths-based perspectives to chronic disease – a need to adopt a strengths-based perspective to chronic disease, which builds and develops the existing strengths, skills and capacities of Aboriginal and Torres Strait Islander peoples.

Priority 2: Culturally safe programs and supports – development of culturally safe programs and supports for D&CVD prevention and promotion of 'healthy lifestyles' among Aboriginal and Torres Strait Islander peoples, using empowering, evidence-based, health promotion campaigns.

Priority 3: Culturally safe strategies to address cardiometabolic disease – culturally safe strategies to address cardiometabolic disease / risk factors to improve the health of Aboriginal and Torres Strait Islander women prior to and during pregnancy. This should also include a focus on babies through the life course, including management of women with pre-existing and gestational diabetes.

Background

Diabetes and Cardiovascular Disease

Aboriginal and Torres Strait Islander peoples are significantly and disproportionately burden by D&CVD. These chronic conditions, particularly when undiagnosed or poorly managed, not only cause suffering and disability, but are also some of the leading causes of death for Aboriginal and Torres Strait Islander peoples in Australia.

Heart disease was the leading cause of death for Aboriginal and Torres Strait Islander people in 2018¹, followed by diabetes as the second leading cause of death for Aboriginal and Torres Strait Islander peoples².

With reported cases of both D&CVD either remaining steady³, as is the case for diabetes, or rising in the case of cardiovascular disease⁴, research into the diagnosis and management of these diseases has become a key focus of state, territory and Commonwealth governments of Australia.⁵⁶

The importance of Aboriginal and Torres Strait Islander led research

Since 1788 Aboriginal and Torres Strait Islander peoples have been subjected to huge amounts of research. Research was used as a tool of colonial violence and data was weaponised against Aboriginal and Torres Strait Islander peoples. It was embedded in a deficit discourse, which makes the racist presumption that Aboriginal and Torres Strait Islander peoples are a problem that requires fixing.

A 2013 review by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AITASIS) and Lowitja Institute stated,

Early research in Australia included negative race-based research practices such as eugenics and scientific racism, which sought to prove that Aboriginal people were mentally and physically inferior human specimens to Europeans. Memories of these times have been ingrained in the psyches of successive generations of Aboriginal and Torres Strait Islander peoples and more recent examples of poor research practices have contributed to the degrees of distrust that developed towards researchers and research institutions.⁷

These presumptions dehumanised and othered Aboriginal and Torres Strait Islander peoples and meant that often research practices did more harm than good. In some cases, Aboriginal and Torres Strait Islander peoples were subjected to harmful and inhuman medical experimentation. ⁸ Research, even if well-meaning, was conducted based on non-Indigenous researchers' priorities and presumptions, which did not and do not match the priorities of Aboriginal and Torres Strait Islander peoples. This meant that research did not benefit Aboriginal and Torres Strait Islander peoples and findings were used to support policies and practices that further harmed them.

For example, it is well documented that health outcomes for Aboriginal and Torres Strait Islander peoples are significantly lower than for the non-Indigenous population; Aboriginal and Torres Strait Islander peoples' lifespan is approximately ten years less than non-Indigenous peoples' and more Aboriginal and Torres Strait Islander children are born below healthy birthweights.⁹

One of the reasons for the continued gap in health outcomes is that Aboriginal and Torres Strait Islander health researchers have not been supported nor funded to lead research projects.

Aboriginal and Torres Strait Islander peoples' have a holistic approach to health and wellbeing that takes a whole of life cycle lens.¹⁰ They understand physical, social, emotional and cultural wellbeing as equally important and influential for individuals and communities.¹¹ Further, Aboriginal and Torres Strait Islander communities are diverse with different and distinct cultures and systems of law/lore.

There are differing and unique social and cultural determinants of health that impact on different communities, and access or barriers to health systems and culturally safe health systems. For example, a remote Aboriginal community in Western Australia will have very different health needs to an Aboriginal community in urban Victoria. This means that there cannot be a uniform approach to setting priorities.

Health solutions need to be local and community-driven, as does research.

The above history means that Aboriginal and Torres Strait Islander peoples have enduring and significant mistrust of research and researchers. Inequities in education, a deep mistrust of research institutions and a lack of cultural safety have locked Aboriginal and Torres Strait Islander peoples out of research. Despite this there is a strong and growing community of Aboriginal and Torres Strait Islander health researchers in Australia who have the power to make a large impact to their peoples' health outcomes. One major barrier to this is lack of available funding and bias in funding decision making and grant allocations.

The Prioritisation Framework

This Prioritisation Framework was developed to guide our work in identifying, assessing, and prioritising related areas of unmet health and medical needs of Aboriginal and Torres Strait Islander peoples living with D&CVD in rural, remote, regional, and urban Australia.

This Framework outlines the following:

- The needs assessment and prioritisation process, detailing four key steps to be undertaken. These steps include identification, development, prioritisation, and endorsement.
- The criteria to be applied to areas of unmet need when assessing their priority.
- The criteria to be applied when allocating a priority rating.

How was this framework developed

In developing this Framework, a desktop review of key documents across governments and relevant Australian institutions was completed. The purpose of this was to understand the strategic horizon for health and medical research, research into D&CVD, as well as research focused on improving the health of Aboriginal and Torres Strait Islander peoples. Results of this review were used to determine the appropriateness of the process and the criteria for prioritisation included within this Framework.

19 key documents were reviewed across governments and relevant institutions

National Strategies

- 1. National Aboriginal and Torres Strait Islander Health Plan (2013-2023)
- 2. Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan (2013-2023)
- 3. National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031
- 4. National Agreement on Closing the Gap 2020
- 5. 2021 National Research Infrastructure Roadmap
- 6. 2018 Research Infrastructure Investment Plan

Relevant institutions in Australia

- 7. Medical Research Future Fund, Australian Medical Research and Innovation Priorities 2020–2022
- 8. Medical Research Future Fund, Cardiovascular Health Mission International review of the Roadmap and Implementation Plan 2020
- 9. Australian Medical Research and Innovation Strategy 2021-2026
- 10. Australian Medical Research and Innovation Priorities 2020-2022 Consultation Report
- 11. Australian Medical Research and Innovation Strategy 2021-2026 and the Related Priorities Consultation Report
- 12. Medical Technology, Biotechnology & Pharmaceutical Sector Competitiveness Plan, MTPConnect 2020
- 13. MTPConnect, Annual Report FY2021
- 14. Road Map 3: A strategic framework for improving Aboriginal and Torres Strait Islander health through research.
- 15. Action Plan 2018 2021 Triennium to implement Road Map 3
- 16. Road Map 3: A strategic framework for improving Aboriginal and Torres Strait Islander health through research. Report of Community Consultation.
- 17. NHMRC Corporate Plan 2020-2021
- 18. NHMRC Annual Report 2020-21
- 19. NSW Health, Setting Research Priorities: A Guide 2019

Needs Assessment and Prioritisation Process

Setting priorities for research funding is important in ensuring that investment has impact, is of benefit to the public and contributes to improving health outcomes for individuals and communities. It is important that the process for assessing and prioritising areas of unmet need, is not just a process of reviewing burden of disease data and cost-benefit analysis.

The aim of this needs assessment and prioritisation process was to determine Indigenous-specific priority areas for research into D&CVD, through an approach that facilitated input from Aboriginal and Torres Strait Islander researchers, clinicians, policy makers and thought leaders.

The needs assessment and prioritisation process is summarised below:



The Identification stage of the process was focused on identifying unmet health and medical needs for Aboriginal and Torres Strait Islander peoples living with D&CVD. Using a variety of channels, topics and areas for unmet need for assessment were identified. This step continued throughout **Development** and **Prioritisation** to ensure there was adequate opportunity for unmet needs to be identified and considered during prioritisation.

During the **Development** stage we worked with the TTRA Program Indigenous Advisory Group to develop criteria for prioritisation. These criteria were used to assess each area of unmet need and provide a priority rating. Further analysis of areas of unmet need was conducted to capture relevant information to support the prioritisation process.

In the **Prioritisation** stage a roundtable discussion was held, bringing together the Indigenous Advisory Group and other stakeholders from a variety of sectors to discuss areas of unmet need and complete an assessment of priority. Each unmet need received a priority rating. Topics rated highest will be used to guide the delivery and implementation of Round 3 Research Projects of the TTRA program.

Following the Priorisitation stage, **Endorsement** was completed. This included the publication of this discussion paper, detailing results from the needs assessment and prioritisation process. This paper details a list of priority areas which have been reviewed and approved by the TTRA Expert Advisory Board and Indigenous

Methodology

Step 1 - Identifying areas of unmet need

In order to design and undertake the needs assessment and prioritisation process for the TTRA Research Projects Round 3 funding opportunity, the unmet health and medical needs of Aboriginal and Torres Strait Islander peoples with D&CVD were identified. These unmet needs were identified across rural, remote, regional, and urban Australia.

These were identified through a literature review project, conducted by the College of Health & Medicine at the Australian National University, in partnership with the Lowitja Institute.

The results of this literature review included a list of 33 current areas of unmet need.

The literature review

The literature review process aimed to identify the top 30-40 unmet needs for Aboriginal and Torres Strait Islander peoples, focused on the below four areas:

- Complications associated with cardiovascular disease and diabetes.
- Interactions in the pathogenesis of Type 1 diabetes, Type 2 diabetes, and cardiovascular disease.
- Innovative preventative, diagnostic, therapeutic and/or disease management products/solutions for D&CVD.
- Medical and health needs for regional, remote, rural and urban patients with D&CVD.

In consultation with MTPConnect and the project reference group, relevant resources were identified for the literature review. Additional searches were conducted of publications between 2012 and 2022 in PubMed databases as well as relevant government and non-government publications and reports located through bibliographies and snowball reference identification.

The search strategy

The search strategy identified predominantly biomedical publications, particularly those associated with CVD rather than diabetes or intersects between CVD and diabetes.

Search terms used, singular and in combination, included 'diabetes*', 'cardiovascular*', 'cardiovascular disease*', 'Aboriginal*' 'Indigen*', 'Torres Strait', 'care', 'health', 'intervention*', 'First Nation*', 'Australia*', in conjunction with the terms 'and' and 'or'.

The search strategy over-represented academic peer-reviewed publications. The initial search identified 664 records, with an additional 11 records identified from hand searching and recommendations of the Indigenous Advisory Group. Of these, 266 articles were excluded, and a total of 409 articles were reviewed.

Areas of unmet need identified by Indigenous academics and Aboriginal and Torres Strait Islander peak organisations were privileged throughout the refinement process. As were areas of unmet need which were identified by multiple stakeholder groups, such as academics, clinicians, and patient groups. Fundamental and purely descriptive unmet medical and research needs were excluded.

Summary of Findings

Detailed below are the areas of unmet need for D&CVD identified throughout the literature review. These have been categorised into unmet needs for diabetes, CVD, interactions between D&CVD and other areas irrespective of disease end point.

Cardiovascular disease

The unmet needs listed below include needs specific to cardiovascular disease and related conditions: coronary artery disease, cardiomyopathy, stroke and transient ischaemic attack.

Unmet need	Description of unmet need
Systematic delivery of multidisciplinary, patient-centred care for people with heart failure	Systematic delivery of multidisciplinary, patient-centred care for Aboriginal and Torres Strait Islander peoples with heart failure is crucial for improving health outcomes, especially for those living in rural and remote areas. Importantly, there is a need to ensure that Aboriginal Australians with heart failure experience a satisfactory quality of life and are engaged with their family in end-of-life care decisions. ^{12 13 14}
Specific data gaps in epidemiology of CVD	 Address data gaps to improve the understanding of the epidemiology of CVD and service gaps for particular groups. This would include: Understanding of CVD among Aboriginal and Torres Strait Islander peoples living in urban areas. Aboriginal and Torres Strait Islander men. Those with poorer outcomes following cardiac bypass. Primary care practitioner following after hospital discharge post cardiac event ¹⁵¹⁶¹⁷¹⁸
Risk assessment for broad CVD	Improved evidence base for, and delivery of, CVD risk assessment for Aboriginal and Torres Strait Islander peoples, including novel risk modifiers [psychosocial factors, socioeconomic indicators, sleep disruption, waist to hip ratio, low HDL-C levels, low vitamin D levels, culture] and calibration of existing algorithms to Aboriginal and Torres Strait Islander populations. ^{19 20 21 22 23 24 25}
Management of comorbidities for people with CVD/DM	Improve management of comorbidities for people with CVD/DM. For example, associations between SLE (an autoimmune inflammatory disease) and CVD mortality for Aboriginal and Torres Strait Islander peoples, HIV/AIDS, cancer, psychological distress, and polycystic ovary syndrome as CVD risk factors. ^{26 27 28 29 30 31}
Strengths-based perspective to chronic disease	A need to adopt a strengths-based perspective to chronic disease, which builds and develops the existing strengths, skills and capacities of Aboriginal and Torres Strait Islander peoples. ³²
Geographic disparities in stroke outcomes	Address geographic disparities in stroke outcomes for Aboriginal and Torres Strait Islander peoples living in remote areas, who have reduced access to acute imaging for stroke and subsequent thrombolysis/endovascular thrombectomy. Strategies may include mobile CT service and aeromedical thrombolysis. ³³
Experience and outcomes for acute coronary syndrome	Comprehensive programs to improve the experience and outcomes for Aboriginal and Torres Strait Islander peoples presenting to hospital with acute coronary syndrome (ACS). ³⁴
Culturally safe stroke services	Improved access to culturally safe stroke services, rehabilitation, and resources, including a focus on communication resource. $^{\rm 35\ 36\ 37\ 38\ 39}$
Discharge against medical advice risk factors, and post-discharge interventions	Need for greater understanding around discharge against medical advice risk factors, and post-discharge interventions. This should form an integral part of the management of DAMA patients with clear guidelines for contact with the primary care providers, and active follow-up of patients and families. ⁴⁰
Cardiac patients' continuity of care	Address severe breakdowns in Aboriginal and Torres Strait Islander cardiac patients' continuity of care following discharge. Various communication and system level barriers affect patients' ability to receive test results, follow-up care and cardiac rehabilitation services. ⁴¹

Diabetes

Unmet needs which have been listed include needs specific to diabetes, including diabetic kidney disease, peripheral neuropathy, and diabetic foot syndrome.

Unmet need	Description of unmet need
Prevention knowledge for young people	To improve models of care and educational strategies and increase prevention knowledge from a young age, there is a need to investigate perspectives of Aboriginal and Torres Strait Islander young people and families to understand how diabetes and health are conceptualised amid the many competing priorities of life. ⁴²
Screening for diabetes and other related conditions	Improve systems of screening for diabetic retinopathy for Aboriginal and Torres Strait Islander peoples living in remote areas, including a scale-up of telehealth screening systems for diabetic retinopathy. ^{43 44}
Culturally safe comprehensive care for diabetic foot disease	Holistic, culturally safe, comprehensive care for diabetic foot disease, including patient education and staff training. ^{45 46 47 48}
Screening and treatment strategies to reduce risk of diabetic retinopathy	Screening and treatment strategies to reduce risk of diabetic retinopathy before an irreversible visual loss occurs, including referral pathways with diabetic retinopathy. Pregnant women with pre-existing diabetes have a particular service gap in retinopathy screening. ^{49 50}
Screenings for diabetic neuropathy	Increased awareness of recommendations regarding annual screenings for diabetic neuropathy. ⁵⁴
Impacts of leaving home for treatment of renal disease	Better understanding of the social impacts of patients being required to leave their communities and homes for treatment of renal disease, and their associated health/patient journey upon return. ⁵⁵

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Interactions between diabetes and cardiovascular disease

Unmet needs which have been listed as areas of interaction between D&CVD include mental health associations of CVD/diabetes mellitus, chronic kidney disease, and cardiac and vascular complications. This also includes areas of unmet need which relate to both D&CVD.

Unmet need	Description of unmet need
Intervention studies addressing both D&CVD	Increase number and quality of intervention studies addressing both CVD and diabetes among Aboriginal and Torres Strait Islander peoples. Need for increased quantitative data rather than surrogate endpoints. Aboriginal and Torres Strait Islander health research needs to move beyond deficit-descriptive statistical portraits and rather interrogate and hold health systems to account. ^{56 57 58 59 60 61}
Improved screening for atrial fibrillation	Improve screening for atrial fibrillation, potentially including novel wearable technologies. ^{62 63}
Guideline-based care to Aboriginal and Torres Strait Islander peoples	Improve delivery of guideline-based care to Aboriginal and Torres Strait Islander peoples throughout the disease process and across the health system. Gaps in guideline-based care are more pronounced in remote settings. ^{64 65 66 67 68 69 70 71}
Renal disease management and dialysis services	Direct policy interventions to encourage increased service provision of renal disease management and dialysis services in rural and remote locations. ^{72 73}
Culturally safe programs and supports	Development of culturally safe programs and supports for D&CVD prevention and 'healthy lifestyles' among Aboriginal and Torres Strait Islander peoples, using empowering, evidence-based, health promotion campaigns. ^{74 75 76 77 78 79 80 81}
Culturally safe strategies to address cardiometabolic disease	Culturally safe strategies to address cardiometabolic disease / risk factors to improve the health of women prior to pregnancy and during pregnancy. This should also include a focus on babies through the life course, including management of women with pre-existing and gestational diabetes. ^{82 83 84 85 86 87 88 89}
Self-management, shared decision making and peer support groups	Support engagement of Aboriginal and Torres Strait Islander peoples in their own health and the wider health system - potentially including support for self-management, shared decision making and peer support groups. There is a need for investment into patient's knowledge of their illness, with a cultural angle if needed, and the ability to initiate self-care. ^{90 91 92 93 94}

Unmet needs which have been listed include other areas of need, nonspecific to D&CVD and irrespective of disease end point. This also includes areas of unmet need which relate to acute rheumatic fever and rheumatic heart disease.

Unmet need	Description of unmet need
Capability building for Aboriginal and Torres strait Islander health practitioners	Extended role / scope / capacity / engagement / training of Aboriginal and Torres Strait Islander health practitioners / workers / liaison officers. ^{95 96 97 98 99 100}
Clinically and culturally safe care	Strategies to eliminate racism within the Australian health system. Practitioners need to be trained and supported in providing both clinically and culturally safe care for Aboriginal and Torres Strait Islander patients with CVD. This requires adequate time, two-way communication, and resources to support and facilitate effective communication. Examples include Indigenous patient-led cultural awareness training for clinicians and investment in reflective practices. ¹⁰¹ ¹⁰² ¹⁰³ ¹⁰⁴ ¹⁰⁵ ¹⁰⁶ ¹⁰⁷ ¹⁰⁸ ¹⁰⁹
Strategies to address geographic distance from health services	Strategies to address geographic distance from health services across a range of service needs, including primary care, cardiac rehabilitation and specialist cardiac and other outreach services. Novel and innovative approaches/models of care may include telehealth, online application development. ¹¹⁰ ¹¹¹¹¹² ¹¹³ ¹¹⁴ ¹¹⁵
Partnerships and collaboration	A need for partnerships and collaboration between Aboriginal and Torres Strait Islander peoples, community development, social, environmental, housing, and clinical services, to bring together core health messages applicable to multiple conditions (in effect a multi- sectoral prevention focus) across a range of disease endpoints. ¹¹⁶ ¹¹⁷
Research leadership	Investment in multidisciplinary teams led by Aboriginal and Torres Strait Islander peoples and driven by community priorities that demand transformational change in health and health systems. There is benefit – and imperative – of building integrative, diagonal approaches to care across all maternity, Aboriginal, and primary and public healthcare services (including RHD programmes), to support an optimal pathway of care, particularly early diagnosis and assessment. ^{123 124 125 126}
Place based solutions	Investment in the development of local place-based solutions to rheumatic heart disease, that are identified and led by community. ¹²⁷ ¹²⁸ ¹²⁹
Impacts of food supply and quality	Strategies to increase access to food supply and quality. Low fruit and vegetable consumption by Aboriginal and Torres Strait Islander peoples has been identified and a diet high in fruits and vegetables can reduce the risk for many leading causes of death. ¹³⁰ ¹³¹ ¹³² ¹³³
Prevention of rheumatic heart disease	Comprehensive approaches to preventing rheumatic heart disease. ^{134135 136 137 138 139}
Surgical referral for rheumatic heart disease	Explore and address barriers to surgical referrals for Aboriginal and Torres Strait Islander people with rheumatic heart disease. Roberts-Thompson 2021 highlights delays to referral and notes 'Although the reasons for non-referral in patients with surgical indications was not included in this study, language, cultural factors and implicit bias have previously been reported as barriers to surgical and tertiary health care Aboriginal people ¹⁴⁰
Delivery of secondary prophylaxis antibiotic injections	Programs to improve delivery of secondary prophylaxis antibiotic injections for people with acute rheumatic fever or rheumatic heart disease. ^{141 142143 144}

Step 2 - Developing a criteria for Prioritisation

During the **Prioritisation** stage of this process, a multidisciplinary stakeholder group reviewed areas of unmet health and medical needs in D&CVD for Aboriginal and Torres Strait Islander peoples and engaged in broad discussions, providing input to the assessment of potential priorities for the TTRA program.

To guide these discussions and allow for an assessment of each area of unmet need to be completed, criteria for prioritisation were developed. They incorporated themes identified during the development of the Prioritisation Framework, to ensure the criteria proposed identified priorities that align with the overarching strategic direction of the TTRA program.

Each criteria includes a series of questions to guide the assessment, as well as a priority rating scale. In using these criteria, each area of unmet need was allocated a priority rating.

The criteria for prioritisation include:

Status

The status of unmet clinical and research needs in D&CVD

Potential Impact The potential impact

of research funding

Criteria for Prioritisation

Sustainability

The sustainability and effectiveness of the investment

Equitability

The equitability of opportunities and investments

Criteria 1 – Status

Aboriginal and Torres Strait Islander peoples are significantly and disproportionately burdened by D&CVD. To improve the health outcomes for Aboriginal and Torres Strait Islander people with D&CVD we must understand the extent of the problem and how this translates into an increased burden of disease and disparities in mortality and morbidity.

Assessment Questions

In assessing areas of unmet health and medical needs under these criteria, the following should be considered:

- Will research investment in this area have the potential to reduce the burden of disease?
- Does this area of unmet need impact on mortality and morbidity outcomes for Aboriginal and Torres Strait Islander peoples with D&CVD?
- Will research investment in this area of unmet need address an existing research gap?
- Is research focused on improving health outcomes for Aboriginal and Torres Strait Islander peoples with D&CVD?

Assessing Priority

A priority rating may be allocated to each unmet medical and research need identified using the below rating scale.

Priority Rating		
High	• Addresses an area with a high impact on burden of disease.	
	Focuses on a significant research knowledge gap.	
	• Potential to have a substantial impact on mortality and morbidity outcomes.	
	• Significant focus on improving the health outcomes for Aboriginal and Torres Strait Islanders peoples with D&CVD.	
Medium	• Addresses an area with a moderate impact on burden of disease.	
	• Focuses on a reasonable research knowledge gap.	
	• Potential to have a moderate impact on mortality and morbidity outcomes.	
	• Reasonable focus on improving the health outcomes for Aboriginal and Torres Strait Islanders peoples with D&CVD.	
Low	• Addresses an area with a limited impact on burden of disease.	
	• Focuses on a small research knowledge gap.	
	• Limited impact on mortality and morbidity outcomes.	
	• Limited focus on improving the health outcomes for Aboriginal and Torres Strait Islanders peoples with D&CVD.	

Criteria 2 – Potential Impact

To advance research which addresses the specific needs of Aboriginal and Torres Strait Islander peoples with D&CVD, the potential impact of investment must be considered. Assessing the potential impact of research on quality of life for Aboriginal and Torres Strait Islander peoples should include consideration of both the cultural and geographical relevance, potential for improvements and innovations to practices and the impact on health care costs.

Assessment Questions

In assessing areas of unmet health and medical needs under these criteria, the following should be considered:

- What is the likelihood of research contributing to a reduction in the burden of disease and improving the health outcomes for the Aboriginal and Torres Strait Islander peoples in rural, remote, regional, and urban Australia, living with D&CVD?
- Will research investment contribute to reduced health care costs as a result of disease prevention for Aboriginal and Torres Strait Islander peoples in rural, remote, regional, and urban Australia, living with D&CVD?
- Will research investment contribute to improved practices in prediction, identification, prevention, and management of D&CVD for Aboriginal and Torres Strait Islander peoples?
- Does research investment support innovation in preventative, diagnostic, therapeutic and disease management products or solutions for Aboriginal and Torres Strait Islander people with D&CVD.

Assessing Priority

A priority rating may be allocated to each unmet medical and research need identified using the below rating scale.

Priority Rating		
High	• Potential to result in significant reduction in burden of disease and improved health outcomes.	
	Result in reasonable reduction in health care costs.	
	• Potential for significant impact on practices in prediction, identification, prevention, and management.	
	 Capable of major innovation in preventative, diagnostic, therapeutic and disease management products or solutions. 	
Medium	• Potential to result in moderate reduction in burden of disease and improved health outcomes.	
	Result in some reduction in health care costs.	
	• Potential for moderate impact on practices in prediction, identification, prevention, and management.	
	• Capable of reasonable innovation in preventative, diagnostic, therapeutic and disease management products or solutions.	
Low	• Minor potential to result in reduction in burden of disease and improved health outcomes.	
	• No impact on health care costs.	
	• Likely to have minimal impact on practices in prediction, identification, prevention, and management of the D&CVD for Aboriginal and Torres Strait Islander peoples.	
	• Unlikely to provide innovation in preventative, diagnostic, therapeutic and disease management products or solutions.	

Criteria 3 – Sustainability

An assessment of **sustainability** will consider the cost-effectiveness of investments in a particular area of unmet health and medical needs for Aboriginal and Torres Strait Islander peoples living with D&CVD. It will also consider if investment in a particular area can significantly improve health outcomes for Aboriginal and Torres Strait Islander peoples with D&CVD by improving health systems in Australia.

Assessment Questions

In assessing areas of unmet health and medical needs under these criteria, the following should be considered:

- What is the current level of knowledge and investment in this area?
- Does this area of unmet need address a significant gap in funding for D&CVD research and allow for increased research efforts?
- Will investment in this area of unmet need contribute to improving health systems in Australia by improving policies and practices?
- Will research contribute to building capacity in Aboriginal and Torres Strait Islander researchers, health practitioners and Aboriginal and Torres Strait Islander and non-Indigenous clinicians?
- Will research contribute to improved patient experiences and improvements in the quality of life for Aboriginal and Torres Strait Islander peoples with D&CVD?

Assessing Priority

A priority rating may be allocated to each unmet medical and research need identified using the below rating scale.

Priority Rating

High	• There is limited knowledge in this area and current levels of investment in research are small.
	• Investment is this area will fill a significant gap.
	• Potential to have significant contribution to improving policies and practices.
	 Likely to have a substantial focus on building capacity of Aboriginal and Torres Strait Islander researchers, health practitioners and Aboriginal and Torres Strait Islander and non-Indigenous clinicians.
	• Potential to have significant impact on improving patient experiences and quality of life.
Medium	• There is reasonable levels of knowledge in this area and current levels of investment in research are moderate.
	• Investment is this area will fill a modest gap.
	Potential to have sufficient contribution to improving policies and practices
	 Likely to have an acceptable focus on building capacity of Aboriginal and Torres Strait Islander researchers, health practitioners and Aboriginal and Torres Strait Islander and non-Indigenous clinicians.
	• Potential to have sufficient impact on improving patient experiences and quality of life.
Low	• There is substantial knowledge in this area and current levels of investment in research are high.
	• Investment is this area will fill a small gap.
	• Potential to have small contribution to improving policies and practices.
	• Likely to have a limited focus on building capacity of Aboriginal and Torres Strait Islander researchers, health practitioners and Aboriginal and Torres Strait Islander and non-Indigenous clinicians.
	• Potential to have limited impact on improving patient experiences and quality of life.

Criteria 4 – Equitability

Assessing the **equitability of opportunities and investments** in research funding should be considered in determining priority areas for investment. Ensuring equity for Aboriginal and Torres Strait Islander peoples means that Indigenous leadership and decision making is embedded and Aboriginal and Torres Strait Islander peoples are involved as researchers, consumers and practitioners.

In ensuring equity in opportunities and investments, research which supports improvements to health systems that address the cultural determinants of health should be prioritised.

Assessment Questions

In assessing areas of unmet health and medical needs under these criteria, the following should be considered:

- Will investment in this area improve participation and partnership with Aboriginal and Torres Strait Islander peoples.
- Will Aboriginal and Torres Strait Islander leadership and decision making be embedded?
- Does research address the cultural determinants of health and structural drivers of inequity?
- Does research include a focus on place-based solutions and allow for community priorities to be embedded?
- Is research focused on health systems and improving policies and practices to ensure equitability and to address racism?

Assessing Priority

A priority rating may be allocated to each unmet medical and research need identified using the below rating scale.

Priority Rating		
High	•	Significant opportunity to improve participation and partnership with Aboriginal and Torres Strait Islander peoples.
	•	Meaningful opportunity for Aboriginal and Torres Strait Islander leadership and decision making.
	•	Substantial focus on cultural determinants of health and structural drivers of inequity.
	•	Significant opportunity for place-based solutions and embedding community priorities.
	•	Substantial focus health systems and improving policies and practices.
Medium	•	Reasonable opportunity to improve participation and partnership with Aboriginal and Torres Strait Islander peoples.
	•	Acceptable opportunity for Aboriginal and Torres Strait Islander leadership and decision making.
	•	Modest focus on cultural determinants of health and structural drivers of inequity.
	•	Reasonable opportunity for place-based solutions and embedding community priorities.
	•	Reasonable focus health systems and improving policies and practices.
Low	•	Limited opportunity to improve participation and partnership with Aboriginal and Torres Strait Islander peoples.
	•	Limited opportunity for Aboriginal and Torres Strait Islander leadership and decision making.
	•	Lacks focus on cultural determinants of health and structural drivers of inequity.
	•	Limited opportunity for place-based solutions and embedding community priorities.
	•	Lacks focus health systems and improving policies and practices.

Step 3 – Prioritising areas of unmet need

To assist in refining the broader list of unmet needs and identify priority areas for D&CVD, a prioritisation process was undertaken.

Roundtable discussion

A Prioritisation Roundtable was held on 6 December 2022, bringing together members of the Indigenous Advisory Group, as well as clinicians, researchers, patient advocacy groups and people with lived experience to discuss areas of unmet health and medical needs of Aboriginal and Torres Strait Islander peoples in rural, remote, regional and urban Australia.

During the roundtable participants completed a prioritisation assessment, via an online questionnaire and utilising the Prioritisation Framework. Invitees who were unable to attend the roundtable were also able to submit their responses to the questionnaire.

As experts in the field, participants were asked to provide their feedback on what are the priorities for health and medical research for Aboriginal and Torres Strait Islander peoples with D&CVD, and where research investment can have the most positive impact.

Areas of unmet health and medical needs discussed included:

- 1. Unmet needs for cardiovascular disease.
- 2. Unmet need for diabetes.
- 3. Unmet needs where there is an interaction between D&CVD.
- 4. Any other areas of unmet need irrespective of disease end point.

The need for priority areas to enable a holistic approach to health and wellbeing, rather than focusing on specific aspects or complications of D&CVD, was a key point of feedback received during the roundtable. This is reflected in the results of the prioritisation process, with areas of health of medical needs which promote culturally safe, holistic and strengths based approached to improving the experience and quality of life for Aboriginal and Torres Strait Islander peoples with D&CVD, receiving the highest priority ratings.

Embedding Aboriginal and Torres Strait Islander leadership and perspectives

A core principle of this needs assessment and prioritisation process was to determine Indigenous-specific priority areas for research into D&CVD, through an approach that facilitated input and leadership from Aboriginal and Torres Strait Islander researchers, clinicians, policy makers and thought leaders.

How did we do this?

To help get a sense of the importance or priority for individual areas of unmet need, and to ensure the voices of Aboriginal and Torres Strait Islander peoples were elevated and emphasised, a weighing matrix was used in analysing results from the prioritisation step of the process. Results were adjusted to ensure that the views of Aboriginal and Torres Strait Islander participants in the process were adequately reflected in results and constitute leadership in setting priorities.

Sample weighting was applied to results to ensure proportional representation of Aboriginal and Torres Strait Islander peoples.

What constitutes Aboriginal and Torres Strait Islander leadership in the process?

A minimum of 51% of participants identifying as Aboriginal and a maximum of 49% of participants being non-indigenous.

Weighting of assessment criteria

Along with a sample weighting, individual prioritisation criteria were also weighted.

Criteria	Description	Weight
Status	The status of unmet clinical and research needs in D&CVD.	1
Potential Impact	The potential impact of research funding	1
Sustainability	The sustainability and effectiveness of the investment	1
Equitability	The equitability of opportunities and investments	2

Results

Responses to the roundtable discussion were analysed to identify the areas of need which were allocated the highest priority rating. Of the participants in the prioritisation process, 5 of 13 or 38%, identified as Aboriginal and/or Torres Strait Islander.

In conducting this analysis, responses were weighted to adjust the results and ensure that the views of Aboriginal and Torres Strait Islander participants were adequately reflected.

The final priority areas for funding that emerged from the prioritisation process are included below:

Unmet needs for cardiovascular disease

The unmet needs listed below include needs specific to cardiovascular disease and related conditions such as coronary artery disease, cardiomyopathy, stroke and transient ischaemic attack.

These areas of need were rated **highest priority** (in no particular order) during the roundtable.

Priority areas:

- Strengths-based perspectives to chronic disease A need to adopt a strengths-based perspective to chronic disease, which builds and develops the existing strengths, skills and capacities of Aboriginal and Torres Strait Islander peoples.
- **Culturally safe stroke services** Improved access to culturally safe stroke services, rehabilitation, and resources, including a focus on communication resource.
- **Cardiac patients' continuity of care** Address severe breakdowns in Aboriginal and Torres Strait Islander cardiac patients' continuity of care following discharge. Various communication and system level barriers affect patients' ability to receive test results, follow-up care and cardiac rehabilitation services.

Unmet needs for diabetes

Unmet needs which have been listed include needs specific to diabetes, including diabetic kidney disease, peripheral neuropathy, and diabetic foot syndrome.

These areas of need were rated **highest priority** (in no particular order) during the roundtable.

Priority areas:

- **Prevention knowledge for young people** To improve models of care and educational strategies and increase prevention knowledge from a young age, there is a need to investigate perspectives of Aboriginal and Torres Strait Islander young people and families to understand how diabetes and health are conceptualised amid the many competing priorities of life.
- Screen for diabetes and other related conditions Improve systems of screening for diabetic retinopathy for Aboriginal and Torres Strait Islander peoples living in remote areas, including a scale-up of telehealth screening systems for diabetic retinopathy.

Unmet needs where there is an intersection between diabetes and cardiovascular disease

Unmet needs which have been listed as areas of interaction between D&CVD include mental health associations, chronic kidney disease, and cardiac and vascular complications. This also includes areas of unmet need which relate to both D&CVD.

These areas of need were rated **highest priority** (in no particular order) during the roundtable.

Priority areas:

- **Culturally safe programs and supports** Development of culturally safe programs and supports for D&CVD prevention and 'healthy lifestyles' among Aboriginal and Torres Strait Islander peoples, using empowering, evidence-based, health promotion campaigns.
- **Culturally safe strategies to address cardiometabolic disease** Culturally safe strategies to address cardiometabolic disease / risk factors to improve the health of women prior to pregnancy and during pregnancy. This should also include a focus on babies through the life course, including management of women with pre-existing and gestational diabetes.
- Self-management, shared decision making and peer support Support engagement of Aboriginal and Torres Strait Islander peoples in their own health and the wider health system potentially including support for self-management, shared decision making and peer support groups. There is a need for investment into patient's knowledge of their illness, with a cultural angle if needed, and the ability to initiate self-care.

Other unmet needs and unmet needs irrespective of the disease end point

Unmet needs which have been listed include other areas of need, nonspecific to D&CVD and irrespective of disease end point.

These areas of need were rated **highest priority** (in no particular order) during the roundtable.

Priority areas:

- Capability building for Aboriginal and Torres Strait Islander health practitioners Extended role / scope / capacity / engagement / training of Aboriginal and Torres Strait Islander health practitioners / workers / liaison officers.
- Strategies to address geographic distance from health services Strategies to address geographic distance from health services across a range of service needs, including primary care, cardiac rehabilitation and specialist cardiac and other outreach services. Novel and innovative approaches/ models of care may include telehealth, online application development.
- **Research leadership** Investment in multidisciplinary teams led by Aboriginal and Torres Strait Islander peoples and driven by community priorities that demand transformational change in health and health systems. There is benefit – and imperative – t building integrative, diagonal approaches to care across all maternity, Aboriginal, and primary and public healthcare services (including RHD programmes), to support an optimal pathway of care, particularly early diagnosis and assessment.
- Impacts of food supply and quality Strategies to increase access to food supply and quality. Low fruit and vegetable consumption by Aboriginal and Torres Strait Islander peoples has been identified and a diet high in fruits and vegetables can reduce the risk for many leading causes of death.

Step 4 - Results of the prioritisation process

Results from the prioritisation roundtable were reviewed and areas of unmet need which were most highly rated overall and across all categories were included in the final list of Indigenous-specific priority areas for research into D&CVD.

Each area of unmet need is listed below in order of the priority rating received, irrespective of category and classification:

- 1. Culturally safe programs and supports.
- 2. Capability building for Aboriginal and Torres Strait Islander health practitioners.
- 3. Culturally safe strategies to address cardiometabolic disease.
- 4. Strengths-based perspectives to chronic disease.
- 5. Impacts of food supply and quality.
- 6. Research leadership.
- 7. Strategies to address geographic distance from health services.
- 8. Cardiac patients' continuity of care.
- 9. Culturally safe stroke services.
- 10. Self-management, shared decision making and peer support.
- 11. Prevention knowledge for young people.
- 12. Screen for diabetes and other related conditions.

These results were reviewed and considered, with three of the four most highly rated unmet needs proposed as the priority areas of TTRA Research Projects Round 3. These were endorsed by the Indigenous Advisory Group and TTRA Board.

These priority areas include:

Priority 1: Strengths-based perspectives to chronic disease – a need to adopt a strengths-based perspective to chronic disease, which builds and develops the existing strengths, skills and capacities of Aboriginal and Torres Strait Islander peoples.

Priority 2: Culturally safe programs and supports – development of culturally safe programs and supports for D&CVD prevention and promotion of 'healthy lifestyles' among Aboriginal and Torres Strait Islander peoples, using empowering, evidence-based, health promotion campaigns.

Priority 3: Culturally safe strategies to address cardiometabolic disease – culturally safe strategies to address cardiometabolic disease / risk factors to improve the health of Aboriginal and Torres Strait Islander women prior to and during pregnancy. This should also include a focus on babies through the life course, including management of women with pre-existing and gestational diabetes.

MTPConnect recognise the importance of capability building for Aboriginal and Torres Strait Islander health practitioners, as reflected by its high priority rating. This unmet need is out of scope as a priority area for the TTRA program. However the MTPConnect funding model includes significant capacity building support for all awardees, which will allow the program to partially address this unmet need through Research Projects Round 3. Additionally, the selection criteria for this round were designed to select for applications that have embedded sustantial capability building opportunities within the project.

Limitations

While experts were engaged in the process, wider community consultation was not completed due to time constraints. Community consultation allows for new or emerging areas of unmet needs, which have not yet been documented, to be identified and for diverse stakeholder groups to engage in the process. To ensure that wide ranging views were captured, a detailed literature review was completed. While this approach allowed us to identify potential areas of unmet need, detailed within literature, this was also a limitation of the project as it did not allow for unpublished and emerging areas of unmet need to be considered.

Conclusion

Setting priorities for research funding is important to ensure that investment has impact, is of benefit to the public and contributes to improving health outcomes for individuals and communities. It is essential that the design and execution of processes to identify areas of need and set priorities for future funding into Aboriginal and Torres Strait Islander research are led by individuals and groups that have deep knowledge of the health challenges facing Aboriginal and Torres Strait Islander people.

The approach used to set funding priorities for the TTRA program's Research Projects Round 3 was designed to ensure that Indigenous-specific priority areas for research were identified, and this was done through a process that engaged experts in the field. This includes clinicians, researchers, patient advocacy groups or people with lived experience who understand best where research investment will have a positive impact.

The approach and the respective results demonstrate that an Aboriginal and Torres Strait Islander led, evidence-based approach to identifying and assessing priorities, is achievable. The impact of this approach is to ensure that priority areas are accurately identified and represent key areas of unmet health and medical need for Aboriginal and Torres Strait Islander peoples with D&CVD. While also ensuring input and leadership from Aboriginal and Torres Strait Islander researchers, clinicians, policy makers and thought leaders are embedded, and the voices of Aboriginal and Torres Strait Islander peoples are elevated.

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