Final report

NATIONAL INDIGENOUS KIDNEY TRANSPLANTATION TASKFORCE

Written by the NIKTT Secretariat on behalf of the Taskforce
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TSANZ
The Transplantation Society of Australia and New Zealand

ANZ DATA
AUSTRALIA & NEW ZEALAND
DIALYSIS & TRANSPLANT REGISTRY

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Executive Summary

The significant and persistent disparity in access to waitlisting and subsequent kidney transplantation for Aboriginal and Torres Strait Islander peoples has underlined an urgent need to address the systemic gaps and barriers within the Australian healthcare system. Recognising this need, the Commonwealth Government funded an Expert Panel in 2018 to undertake a comprehensive review of the obstacles faced by Aboriginal and Torres Strait Islander people receiving treatment for kidney disease.

This resulted in the identification of thirty-five high-priority actions, providing a strategic roadmap for cross-jurisdictional collaboration. In March 2019, a $2.3 million grant was given to the Transplantation Society of Australia and New Zealand (TSANZ) to establish a national taskforce, whose aim was to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people.

The National Indigenous Kidney Transplantation Taskforce (NIKTT) was comprised of a Secretariat and 26 stakeholder members, including Aboriginal and Torres Strait Islander people living with kidney disease and transplantation, nephrologists, transplant nurses and surgeons, researchers, and policy advisors. The NIKTT worked towards increasing access to kidney transplantation through enhancing data collection, piloting initiatives to improve access and equity, and evaluating cultural bias interventions. This Final Report (Report) outlines the NIKTT's work from 2019 to 2022.

The Report highlights that Aboriginal and Torres Strait Islander peoples are underrepresented on the kidney transplantation waitlist, with only 2% of dialysis patients waitlisted for the first time in 2020. However, there have been recent improvements in addressing this inequity, with more individuals being waitlisted for kidney transplantation each year. The Report also highlights successful regional models of care, including Outreach Assessment Clinics and patient navigator programs, as well as the use of context-specific educational resources. Finally, the Report illustrates the importance of cultural safety in renal care and presents recommended pathways to improve the cultural safety of renal and transplantation units nationally.

Findings from each objective are summarised below.

- Objective 1: Establishment of the Taskforce and a national network of collaborators
    - The NIKTT successfully created a strong network of Aboriginal and Torres Strait Islander consumers and clinicians, alongside supportive advocates from clinical, community, research, and policy perspectives. The NIKTT hosted the inaugural NIKTT Gathering in late 2022, which brought together these networks to share, learn, and plan for the future of transplantation equity as a collective.
- Objective 2: Enhanced data collection and reporting around waitlisting
    - Through an extended ANZDATA collection, the NIKTT found that just 2% of prevalent Aboriginal and Torres Strait Islander dialysis patients were waitlisted in 2020, compared to 8% of non-Indigenous patients. However, waitlisting rates have substantially increased since the initiation of the NIKTT. In terms of whether people were placed on the waitlist, data showed that many more Aboriginal and Torres Strait Islander patients had not yet started waitlisting assessment nor had eligibility assessed.
- Objective 3: Piloting initiatives that improve access and equity
    - Several models of care were found to increase access to the waitlist, including Outreach Assessment Clinics, patient navigator programs, and provision of context-specific educational resources and workshops. The recruitment, hiring, and retention of Aboriginal and Torres Strait Islander staff was found to be challenging across different regions. Time pressures and administrative burdens were also common issues to projects. The NIKTT sponsorship

  - opportunity was oversubscribed, highlighting the need for further investigations into barriers to waitlisting and transplantation.
- Objective 4: Evaluating interventions that address cultural bias
  - The Cultural Bias Report proposes four domains for action and 14 individual recommendations to address cultural bias in kidney care and transplantation for Aboriginal and Torres Strait Islander people. The NIKTT, in consultation with consumers, community, and clinicians, highlighted five recommendations for priority action: (1) Establish Indigenous Reference Groups in every transplantation unit, (2) Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, (3) Establish and fund sustainable kidney patient navigator/peer support roles, (4) Implement and evaluate comprehensive and ongoing cultural safety training programs, (5) Fund, design, implement, and evaluate tailored models of care.

A NIKTT Gathering was held in December 2022 in Adelaide. Following this inaugural Gathering, a Position Statement was endorsed by many attendees that was then sent to all state, territory, and federal Ministers for Health and Indigenous affairs. This Statement outlined recommended actions that would advance Aboriginal and Torres Strait Islander peoples' rights to optimal health and wellbeing through equitable and accessible kidney transplantation.

Given these actions, and the findings from all Taskforce objectives, the NIKTT finalised three key recommendation areas. These were presented to the Jurisdictional Organ and Tissue Steering Committee (JOTSC) in November 2022 and March 2023 for inclusion in the national transplant strategy. The NIKTT Secretariat additionally met with Ministers McCarthy and Kearney in March 2023 to provide these overall recommendations from the Taskforce, as outlined below.

The NIKTT's recommendations focus on three key areas for action:

1. Immediate improvements to access and services through sustainable funding of outreach assessment clinics, Indigenous Reference Groups, and an increased Aboriginal and Torres Strait Islander renal health workforce.
2. Ongoing Secretariat to monitor and progress transplantation equity. Coordinated efforts are essential to identify issues, catalyse activity, maintain profile and focus on transplantation. A national Secretariat would provide leadership, collaboration, monitoring, and reporting, and should be resourced for a minimum of three years to continue national coordination of transplantation equity work.
3. Investigate additional measures to address drivers of inequity, including initiatives that target current barriers to waitlist access as well as initiatives that target barriers in other parts of the transplant pathway. Research into, and implementation of, initiatives that address additional drivers of inequity should be nationally resourced and coordinated to understand best practices.

Alongside this Final Report, the NIKTT has commissioned a peer-reviewed Supplement through the Medical Journal of Australia that reports on key Taskforce activities and outcomes from an academic perspective.

1. Introduction

Globally, 10% of the world's population is affected by chronic kidney disease (CKD). (1) In Australia, it is estimated that 11% of adults have biomedical signs of chronic kidney disease, yet CKD is 2.1 times more likely to occur in Aboriginal and Torres Strait Islander people than non-Indigenous Australians. (2) The prevalence of Aboriginal and Torres Strait Islander people on dialysis was estimated to be 2,455 per million population in 2021, compared with 511 per million population for non-Indigenous people. (3)

In 2021, 28,542 people in Australia were being treated for kidney failure with kidney replacement therapy (KRT) – either dialysis or transplantation – with a stark difference in modalities of KRT between Aboriginal and Torres Strait Islander people and non-Indigenous people. (3) The number of people on facility-based haemodialysis (HD) compared with home HD or peritoneal dialysis (PD) is much greater for Aboriginal and Torres Strait Islander people, meaning many more Aboriginal and Torres Strait Islander people must travel, usually long distances or off-Country, to receive dialysis care. (3)

Kidney transplantation rates are also inequitable for Aboriginal and Torres Strait Islander people in Australia, with just 15% of Aboriginal and Torres Strait Islander people on KRT having received a kidney transplantation in 2021. For all other ethnicity groups, 49% of peoples on kidney replacement therapy had received kidney transplantation. This disparity in transplantation rates has been shown to reflect a disparity in transplantation waitlisting, rather than receiving a kidney once on the waitlist. (4) In 2020, just 2% of Aboriginal and Torres Strait Islander people on dialysis were placed on the waitlist for the first time, in comparison to 8% of non-Indigenous people. (3)

Numerous barriers exist for Aboriginal and Torres Strait Islander people with kidney disease in accessing both waitlisting and transplantation. However, renal units, patient groups, and kidney advocates are working nation-wide to address this disparity, finding ways to increase access and improve kidney transplantation rates and outcomes.

1.1 Kidney Disease in Aboriginal and Torres Strait Islander People

Aboriginal and Torres Strait Islander people, as well as non-Indigenous people, are experiencing an increased burden of chronic, non-communicable diseases. (2) For Aboriginal and Torres Strait Islander people in Australia, chronic kidney disease accounted for 2.5% of the total disease burden in 2018 – a rate 7.8 times higher than that experienced by non-Indigenous Australians. (2) As CKD is a gradual and progressive condition, it can often go unnoticed or undetected, leading to many people not knowing that they have CKD until the disease progresses to the point where most of the normal kidney function is lost. Symptoms of CKD can therefore sometimes only present when a person reaches the later stages of the condition, often when they require KRT– such as dialysis or transplantation – to remain healthy and alive. For those with the most severe form, end-stage kidney disease (ESKD), the choice is between a form of KRT to prolong life, or a "conservative care" pathway providing support until death from kidney failure. (5)

In Australia, Aboriginal and Torres Strait Islander people experience higher rates of hospitalisation for CKD, younger ages at diagnosis, higher rates of kidney failure requiring KRT, and an increased risk of mortality due to CKD in comparison to those who do not identify as Aboriginal and/or Torres Strait Islander people. (6) Despite this burden, Aboriginal and Torres Strait Islander people are less likely to have access to preferable treatment modalities such as home dialysis or kidney transplantation. (6)

The number of Aboriginal and Torres Strait Islander people with kidney disease on KRT has steadily increased over the last few decades. In 2015, for example, there were 1,937 Aboriginal and Torres Strait Islander people on KRT within the ANZDATA registry, growing to 2,568 Aboriginal and Torres Strait Islander people on KRT in 2021. (7) Incidence rates of KRT (per million population) have remained considerably higher for Aboriginal and

Torres Strait Islander people in Australia compared to non-Indigenous people over the last twenty years (Figure 1.1) (7), with Aboriginal and Torres Strait Islander people over the age of 15, especially women, experiencing higher rates of kidney failure across all age brackets (Figure 1.2). (7)

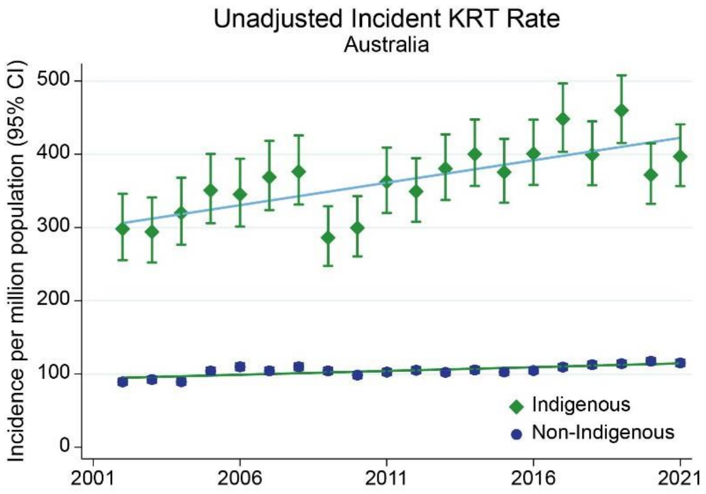


Figure 1.1. Unadjusted incidence rate of kidney replacement therapy in Australia (7)

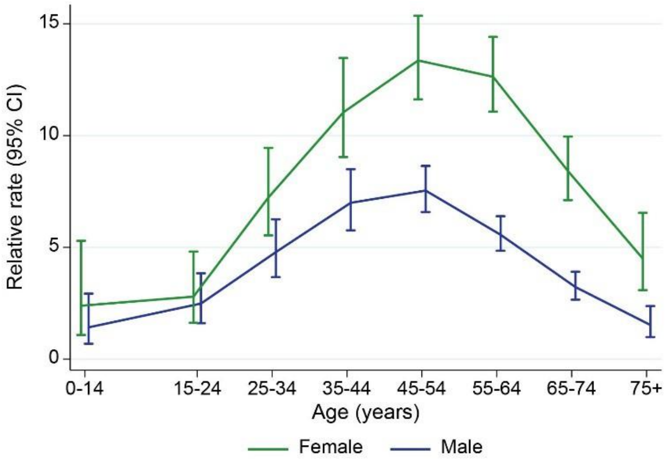


Figure 1.2. Relative incidence rate of treated kidney failure for Aboriginal and Torres Strait Islander people, by sex (comparison to non-Indigenous Australians), 2017-2021 (7)

As well as disparities in the rates of kidney failure, there are also persistent inequities in kidney treatment modality for Aboriginal and Torres Strait Islander people. In 2021, 74% of prevalent Aboriginal and Torres Strait Islander KRT patients were treated with facility-based haemodialysis (and just 5% accessing home haemodialysis), 6% on long-term peritoneal dialysis, and just 15% living with a functioning kidney transplant. (7) Figure 1.3 illustrates the difference between KRT modality between Aboriginal and Torres Strait Islander people and non-Indigenous people.

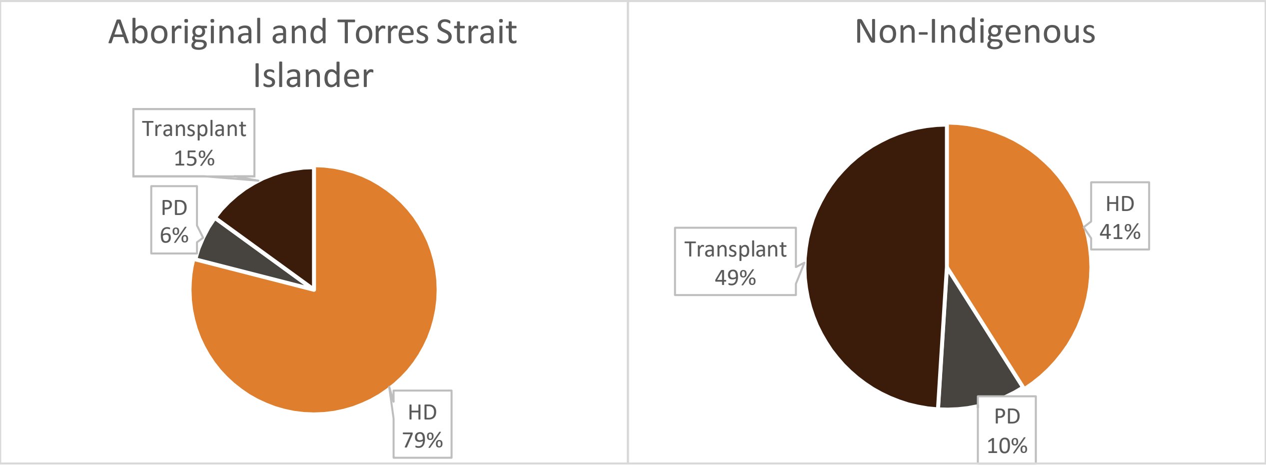


Figure 1.3. Treatment modality for kidney replacement therapy, by ethnicity, 2021 (7)

Treatment at a facility often means that patients need to travel inter-state or spend long periods of time away from their families and communities. Often, dialysis units are not located on Country and patients are removed from their support network and cultural connections. This disconnection from culture and Country, alongside the systemic racism present within our Australian health system, forces some people to choose not to undergo treatment in order to stay on Country, where they can "stay with their family and kin and keep their spirits whole whilst the kidneys fail." (8)

For most people with ESKD, kidney transplantation is the preferred treatment option, providing a better quality of life, quantity of life, and cost-savings for health systems. (9) Aboriginal and Torres Strait Islander people have consistently called for better access to, education about, and outcomes from kidney transplantation. (10) (11) (12)

1.2 Transplantation in Australia

There are numerous pre- and post-transplant barriers that influence whether Aboriginal and Torres Strait Islander peoples receive a kidney transplantation or attain optimal outcomes. Disparity in access to transplantation has been recognised for many years; although absolute rates of waitlisting and transplantation have increased amongst Aboriginal and Torres Strait Islander peoples, substantial inequity remains in rates of waitlisting and transplantation compared to non-Indigenous populations. (13) (14) (15) Furthermore, the *reasons* behind the inequity remain. Studies have consistently shown that inequity in access to transplantation cannot be explained by patient- or disease-related factors, and instead the systemic and institutional barriers that exist due to racism, ongoing colonising practices, social determinants, and inadequate policies or service provision. (13) (14) (16)

Receiving a kidney transplant requires patients to not just meet specific medical requirements, but also to navigate a complex process that includes multiple investigations, appointments, and ongoing reviews (Figure 1.4). Each stage of this pathway can become a barrier to both waitlisting and transplantation, and each is additionally made more difficult within our current system that does not adequately account for Aboriginal and Torres Strait Islander people's ways of knowing, being, and doing. (17)

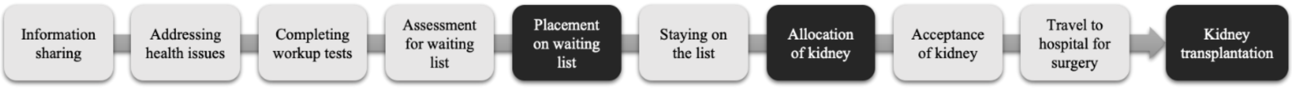


Figure 1.4 Generalised and simplified pathway to kidney transplantation for an Australian adult

Pre-Transplant Barriers to Care

Previously, pre-transplant barriers for Aboriginal and Torres Strait Islander peoples have been found to include:

> Sociocultural barriers, including communication divides between patients and clinical staff; cultural bias experienced throughout the health care system, including a lack of understanding around the cultural elements of decision making, family commitments, and community obligations; culturally inappropriate educational materials; limited availability of appropriate interpreters; and misinformed or culturally unaware health professionals.
>
> Geographical barriers, including living in rural and remote communities not regularly serviced by transplant assessment teams; living in communities where access to dialysis facilities is poor; a need to travel large distances to tertiary hospitals for follow-up appointments; numerous trips off Country to attend workup tests; and the logistical and time-consuming problems that arise from having to complete multiple trips to urban areas, including arranging transport, accommodation, and bookings.
>
> Biomedical barriers, including a high burden of comorbidities such as diabetes, smoking and alcohol consumption, high body-mass index, and cerebrovascular and cardiovascular diseases. (16)

These barriers work in combination to create a system that has been described as "fragmented, confusing, isolating, and burdensome" to Aboriginal and Torres Strait Islander patients seeking care. (16)

As a final barrier to transplantation, organ donation within Aboriginal and Torres Strait Islander communities is relatively low. Although this is changing, the availability of Aboriginal and/or Torres Strait Islander organ and tissue donors across Australia remains below ideal, due to various reasons including a lower consent rate for donation, pre-existing comorbidities that preclude donation, and cultural beliefs around donation or a lack of culturally appropriate information about donation. As noted in the Australian Government's draft *National Strategy for Organ Donation, Retrieval and Transplantation*, a priority goal is that more Australians consent to donation, which includes actions to improve donation rates among Aboriginal and Torres Strait Islander people: "Culturally appropriate donation education programs and resources for Aboriginal and Torres Strait Islander people will be required, so Aboriginal and Torres Strait Islander people receive information that is appropriate. Multiple interventions and active engagement with local communities will be necessary to achieve this." (18) The next stages of transplantation equity work must include research into and evaluation of such initiatives that aim to drive increased donation.

Post-Transplant Barriers to Care

Additionally, there are a number of post-transplant barriers for kidney transplantation amongst Aboriginal and Torres Strait Islander peoples. These have been found to include:

> Health system barriers, such as models of care that do not cater for Aboriginal and/or Torres Strait Islander peoples; an understaffed rural and remote healthcare workforce; limited Aboriginal and/or Torres Strait Islander healthcare professionals; limited translators and cultural educators; limited medical infrastructure for follow-up and long-term care in rural and remote areas; cultural bias that results in miscommunications and misunderstandings; and complex and/or poorly explained medication regimens.
>
> Immunosuppression barriers, including greater human leukocyte antigen mismatching; greater sensitisation; longer waiting times from the start of dialysis to transplantation; sociocultural factors such as higher levels of socioeconomic disadvantage, lower levels of health literacy, sociocultural obligations associated with reduced medication adherence; reduced access to pharmacies; and limited educational resources or support services to improve adherence.

> Infective barriers, such as higher risk of infection from environmental exposures, substandard housing circumstances, inadequate sanitation infrastructure and geographical location, as well as reduced access to health care services due to geography and cultural bias. (16)

All of these barriers can act in tandem or alone to reduce both access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander peoples in Australia. Many, if not all, of these barriers are modifiable, and this Report and the work of the National Indigenous Kidney Transplantation Taskforce sets out evidence-based, actionable recommendations to improve access to kidney transplantation for Aboriginal and Torres Strait Islander peoples.

Evidence from around Australia over the past twenty plus years shows us the clear and persistent inequality in kidney health outcomes, access to treatment, and treatment outcomes for Aboriginal and Torres Strait Islander Australians. (4) (19) (14) (20) (13) (15)

1.3 Previous Reports

In March 2018, the Transplantation Society of Australia and New Zealand (TSANZ), under the leadership of Professor Stephen McDonald, convened a meeting between an expert group of clinicians and the then-Minister for Indigenous Health, the Hon Ken Wyatt MP, to discuss barriers affecting the accessibility and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander peoples. In June 2018, Minister Wyatt established an expert panel, led by the TSANZ and comprised of people working in clinical, research, and public policy settings, to investigate these barriers and generate recommendations to improve access to and outcomes of kidney transplantation for Indigenous Australians.

In March 2019, the expert panel submitted a 'Performance Report' to Minister Wyatt and the Commonwealth Department of Health. (16) The Report complements the Ernst and Young (EY) Review of the Australian organ donation, retrieval and transplantation system (21) and provides a detailed analysis of:

- Evidence and gaps around steps to waitlisting and to long term transplant function.
- Strategies to improve the health of Indigenous dialysis patients, and their capacity to be listed in turn; and
- Measures to address research, practice and policy gaps.

The recommendations from both the TSANZ and EY reviews can be found in Appendix A and B, respectively.

1.4 Creation of the National Indigenous Kidney Transplantation Taskforce

At the Organ and Tissue Authority's (OTA) Donation and Transplantation Conference on 12 March 2019, Minister Wyatt officially endorsed and launched the TSANZ Performance Report (16), and also announced funding of $2.3 million to the TSANZ to implement the Report's priority recommendations.

Representatives from TSANZ and ANZDATA met with Hon. Ken Wyatt AM JP, then-Minister for Indigenous Australians

Therefore, after more than 50 years of Australian transplantation, the Commonwealth Government, represented by the Department of Health, funded the first taskforce of its kind: the National Indigenous Kidney Transplantation Taskforce (NIKTT). The NIKTT was established to address the inequity in access to kidney transplantation for Aboriginal and Torres Strait Islander people through focusing on the Report's priority recommendations.

The NIKTT comprises a secretariat that is housed within the South Australian Health and Medical Research Institute (SAHMRI), a steering committee, a national consumer board, and several working groups. The steering committee includes 26 stakeholders from a variety of disciplines including Aboriginal and Torres Strait Islander kidney community members, nephrologists, nurses, policymakers, researchers, primary care professionals, and allied health professionals.

The NIKTT committed to four principal activities:

- Establishment of the Taskforce and a national network of collaborators working towards kidney transplantation equity;
- Enhanced data collection and reporting around the waitlisting process by defining and capturing variables that help explain barriers to workup and waitlisting;
- Piloting initiatives that improve access and equity for Aboriginal and Torres Strait Islander peoples and kidney transplantations; and
- Evaluating interventions that address cultural bias.

The next section of this Report details the outcomes from these activities, as well as the recommendations and learnings that arose from each.

2. Activity Outcomes

This section of the Final Report details the outcomes of each of the activities the NIKTT focused on between 2019-2022. These four objectives were:

- Objective 1: Establish the National Indigenous Kidney Transplantation Taskforce
- Objective 2: Enhancing data collection and reporting
- Objective 3: Piloting initiatives to improve patient equity and access
- Objective 4: Evaluating cultural bias initiatives

Each section begins with a summary of the objective and associated activities, as well as a description of how each objective's aims have been met.

The Activity Work Plan for this grant can be found in Appendix C.

2.1 Objective 1: Establish the National Indigenous Kidney Transplantation Taskforce

The first objective of the grant was to establish the National Indigenous Kidney Transplantation Taskforce. This was completed in 2019, as detailed below. The NIKTT was run by an Operations Committee and Secretariat. A National Consumer Panel was established, as well as Indigenous Reference Groups. All Taskforce, National Panel, and other stakeholders were invited to a national Gathering in Adelaide in December 2022. Outcomes from this Gathering, as well as findings from the other NIKTT objectives, helped to shape final recommendations from the Taskforce. The NIKTT presented these recommendations to the Commonwealth Government in late March 2023. The NIKTT additionally provided input and advice to the Steering Committee overseeing the creation and finalisation of the draft *National Strategy for Organ Donation, Retrieval and Transplantation*.

Table 2.1 Activity Work Plan for Objective 1 of the National Indigenous Kidney Transplantation Taskforce

Objective	Strategies	Performance Measures	Risks	Outcomes
Establish the NIKTT				
• NIKTT established • Regular meetings facilitated	• Establish a consumer panel to inform the implementation of key objectives • Implement key objectives • Develop the National Indigenous Kidney Transplantation Strategy	• Consumer panel engagement • Key objectives implemented • National Indigenous Kidney Transplantation Strategy provided to the Commonwealth	• Delays in establishment of Taskforce • Inadequate representation of key sectors on the Taskforce • Inadequate consumer representation and engagement Mitigation: • High level of collaboration within the sector • Robust communication and	• Membership of 26 established in 2019 • National Consumer Panel established with over 170 members • First annual NIKTT Gathering hosted in 2022 • Recommendations, advice, and feedback provided to the Jurisdictional Organ and Tissue Steering Committee (JOTSC) on the draft *National Strategy for Organ*

			engagement strategy • Consumer incidentals reimbursed for panel attendance • Shared social goal between clinical, policy and consumer sectors	*Donation, Retrieval and Transplantation* • NIKTT recommendations and future directions provided to Ministers McCarthy and Kearney in March 2023

2.1.1 Membership

Over three years of activity, the NIKTT remained well established and connected, with membership comprising of 26 stakeholders from a variety of disciplines including Aboriginal and Torres Strait Islander kidney community members, nephrologists, nurses, policymakers, researchers, and primary care and allied health professionals.

The full NIKTT membership is listed in Appendix D.

Membership of the NIKTT was established through an Expression of Interest (EOI) process that was led by the Transplantation Society of Australia and New Zealand (TSANZ). This EOI form can be found in Appendix E.

In general, members were tasked with responsibility for:

- Providing advice on the development, implementation and evaluation of NIKTT strategies;
- Providing advice on the implementation of the NIKTT Activity Work Plan, including budget and associated contracts;
- Monitoring and helping to achieve the performance measures (as detailed in the Activity Work Plan) for each of the NIKTT's key objectives;
- Identifying the resourcing requirements of each key objective, and ensuring that resources are directed accordingly;
- Identifying and monitoring potential risks and developing appropriate mitigation strategies;
- Monitoring the quality and timeliness of initiatives, ensuring that project timelines are adhered to as closely as possible;
- Ensuring effective communication and information flow between local, state and national stakeholders; and
- Facilitating a culture of shared learning and ongoing practice and policy improvement among key stakeholders involved in the waitlisting and transplantation pathways.

2.1.2 Operations Committee and Secretariat

The NIKTT was supported by an Operations Committee that was made up of representatives from the Transplantation Society of Australia and New Zealand (TSANZ) Council, the Organ and Tissue Authority (OTA), the Aboriginal and Torres Strait Islander kidney community, as well as the NIKTT Senior Project Officer, NIKTT National Community Engagement Coordinator, administrative support, NIKTT Deputy Chair, and NIKTT Chair (full membership at Appendix F). The Committee met regularly to manage the budget, associated contracts related to grant activities, and overall delivery of the objectives and strategies.

The NIKTT Secretariat, consisting of both Chairs, the Senior Project Officer, the National Community Engagement Coordinator, and the Administration Assistant, ran the day-to-day operations of the Taskforce. The Secretariat drove the writing and submission of progress reports, manuscripts, and key documentation provided to community, government, and other key stakeholders; the management and follow-up on pilot projects; data collection and analysis support for the enhanced data collection objective; as well as the organisation and management of Taskforce meetings and the national Gathering.

At the end of March 2023, the Secretariat travelled to Canberra to meet with Minister Malandirri McCarthy and Minister Ged Kearney to provide the Commonwealth with the Taskforce's final recommendations and to seek support for the continued resourcing of necessary activities to continue to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people in Australia. The document presented to the Ministers can be found in Appendix G.

NIKTT Secretariat with Senator Malandirri McCarthy, Assistant Minister for Indigenous Health and Indigenous Australians, and Minister Kearney, Assistant Minister for Health, March 2023

2.1.3 Working Groups

Five Working Groups (WGs) were created to oversee the design, implementation, and evaluation of the NIKTT's objectives. Each WG was overseen by two WG Chairs and was made up of members of the Taskforce as well as some additional members in exceptional circumstances. WGs provided cultural and clinical input into the management of objectives. The five WGs were:

1. Data
2. Community Engagement
3. Patient Mentors
4. Pre-Transplant Care Coordination
5. Cultural Bias

An overview of the design and responsibilities of the WGs can be found in Appendix H. WG members and chairs were selected by the Operations Committee based on their expertise and experience. WGs met regularly and independently of other Taskforce matters. WG chairs were invited to contribute to the final manuscripts produced for the NIKTT's commissioned Supplement in the Medical Journal of Australia (MJA).

2.1.4 Indigenous Reference Groups

The aim of the Indigenous Reference Groups (IRGs) was to enact change within transplant units by bringing together patients, carers, and families to discuss their kidney journeys, needs, and supports through to transplantation and beyond. Transplantation unit directors and Heads of Unit were consulted prior to the establishment of each IRG and asked to commit, in writing, to engaging with IRG suggestions on an ongoing basis. Support for IRG creation was provided by the Community Engagement Working Group, who helped to craft Terms of Reference (TOR) for each group and transplantation unit. Figure 2.1 illustrates the process that IRGs intended to create through which change within transplant units would reflect community views.

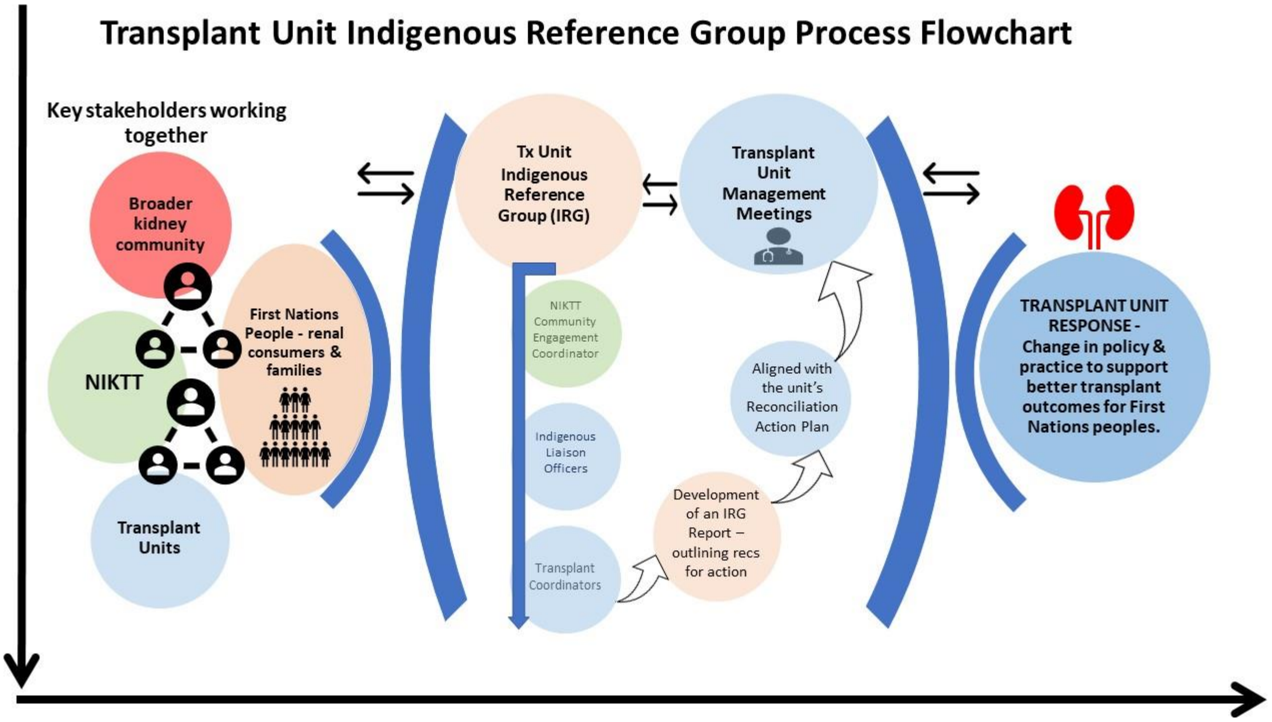


Figure 2.1 IRG flow and change process.

An example TOR for the Royal Adelaide Hospital can be found in Appendix I.

For the initial establishment of these groups, five transplantation units around the country were selected – these represented the hospitals that served the largest proportion of Aboriginal and Torres Strait Islander peoples on kidney replacement therapy. The hospitals included:

- Sir Charles Gairdner Hospital (WA)
    - Capturing Perth & Kimberley patients.
- Royal Adelaide Hospital (SA)
    - Capturing Darwin, Alice Springs, and Adelaide patients.
    - Building on existing reference groups: RAAC (Royal Darwin Hospital), CARV (Alice Springs Hospital) and AKction (Royal Adelaide and Flinders Hospitals).
- Princess Alexandra Hospital (QLD)
    - Capturing Cairns, Townsville, and Brisbane patients.

- Westmead Hospital (NSW) and Royal Prince Alfred Hospital (NSW)
    - Capturing metro and regional NSW patients.

Due to the impact of COVID-19 on travel restrictions, IRGs were only able to be substantially established in Western Australia, Queensland, and South Australia. A previously existing group of patients in Darwin was integrated into the IRG established at the Royal Adelaide Hospital.

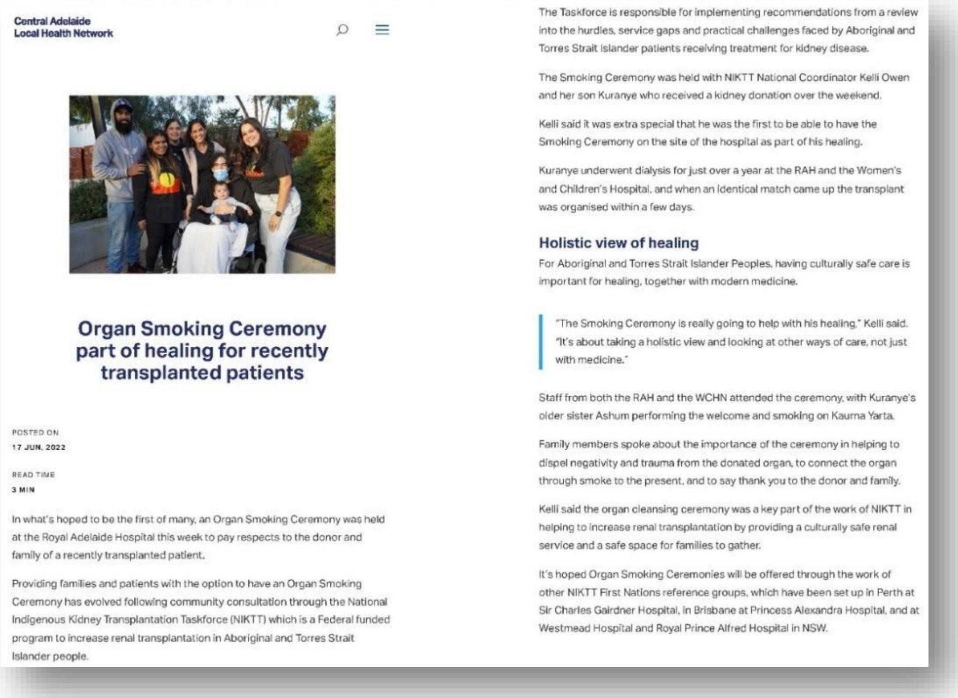
Table 2.2 outlines the details of the IRGs and their membership.

Table 2.2. Status of Indigenous Reference Groups, end of 2022

Jurisdiction	Hospital	Members	Stage
SA	Royal Adelaide	20	Established
QLD	Princess Alexandra	20	Established
WA	Sir Charles Gairdner	20	IRGs also established in East and West Kimberley that feed back into the IRG at SCGH
NSW	Westmead	17 engaged	Elders engaged, invite into community extended
NSW	Prince Alfred	16 engaged	Elders engaged, invite into community extended.

Feedback provided to the NIKTT from IRG participants was overwhelmingly positive, with all jurisdictions interested in continuing the Groups after the initial NIKTT funding period concluded.

Of the NIKTT's three overall recommendations for action, Key Action 1 (immediate improvements to access and services) includes the establishment of IRGs at all transplant hospitals. In the long-term, Reference Groups at individual renal units would also be recommended as mechanisms to ensure the cultural safety of service delivery.



Central Adelaide Local Health Network

Organ Smoking Ceremony part of healing for recently transplanted patients

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17 JUN, 2022

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In what's hoped to be the first of many, an Organ Smoking Ceremony was held at the Royal Adelaide Hospital this week to pay respects to the donor and family of a recently transplanted patient.

Providing families and patients with the option to have an Organ Smoking Ceremony has evolved following community consultation through the National Indigenous Kidney Transplantation Taskforce (NIKTT) which is a Federal funded program to increase renal transplantation in Aboriginal and Torres Strait Islander people.

The Taskforce is responsible for implementing recommendations from a review into the hurdles, service gaps and practical challenges faced by Aboriginal and Torres Strait Islander patients receiving treatment for kidney disease.

The Smoking Ceremony was held with NIKTT National Coordinator Kelli Owen and her son Kuranye who received a kidney donation over the weekend.

Kelli said it was extra special that he was the first to be able to have the Smoking Ceremony on the site of the hospital as part of his healing.

Kuranye underwent dialysis for just over a year at the RAH and the Women's and Children's Hospital, and when an identical match came up the transplant was organised within a few days.

Holistic view of healing

For Aboriginal and Torres Strait Islander Peoples, having culturally safe care is important for healing, together with modern medicine.

> "The Smoking Ceremony is really going to help with his healing," Kelli said. "It's about taking a holistic view and looking at other ways of care, not just with medicine."

Staff from both the RAH and the WCHN attended the ceremony, with Kuranye's older sister Ashum performing the welcome and smoking on Kaurna Yarta.

Family members spoke about the importance of the ceremony in helping to dispel negativity and trauma from the donated organ, to connect the organ through smoke to the present, and to say thank you to the donor and family.

Kelli said the organ cleansing ceremony was a key part of the work of NIKTT in helping to increase renal transplantation by providing a culturally safe renal service and a safe space for families to gather.

It's hoped Organ Smoking Ceremonies will be offered through the work of other NIKTT First Nations reference groups, which have been set up in Perth at Sir Charles Gairdner Hospital, in Brisbane at Princess Alexandra Hospital, and at Westmead Hospital and Royal Prince Alfred Hospital in NSW.

Figure 2.2 Snapshot of an article detailing the first Smoking Ceremony hosted at the Royal Adelaide Hospital (22)

One of the first established IRGs, based at the Royal Adelaide Hospital (RAH), presented their priority themes to the transplantation unit management in 2021. From this, RAH management agreed to implement Smoking Ceremonies on the grounds of the hospital in order to initiate a more culturally safe care system. Ceremonies of this kind were unavailable on the grounds of the hospital before this group advocated for this change; families would have to travel away from the RAH to be able to take part in something fundamental to the healing of the transplant recipient. A more detailed overview of what enabled the RAH IRGs success will be available within the NIKTT Supplement published by the MJA in October 2023.

Real practice change has occurred within the first year of the RAH IRG's existence, due to the strong relationships and trust built between IRG members and clinical staff. These changes include:

- Smoking (organ cleansing) Ceremonies are available on hospital grounds. In June 2022, the first kidney transplant Smoking Ceremony was held to pay respect to the organ donor and their family, while connecting the recipient and organ to the present (Figure 2.2). By facilitating such ceremonies, the RAH has enabled a holistic view of healing, delivering a more culturally sensitive system of care;
- A new cultural safety training course is being developed by Aboriginal kidney patients;
- More Aboriginal Health Practitioners (AHPs) are being employed in the renal unit; and
- Non-Aboriginal staff have expressed gratitude for the opportunity to better understand cultural protocols to facilitate culturally sensitive – and therefore safer – care.

2.1.5 National Community Panel

The National Community Panel was comprised of 175 members who were Aboriginal and/or Torres Strait Islander people living with chronic kidney disease, undergoing dialysis treatment, on the active wait list for a transplant, and post-transplant. The panel also consisted of family, carers, and Aboriginal and Torres Strait Islander health staff supporting kidney care. Members were contacted by the National Community Engagement Coordinator by telephone calls, emails, and face-to-face meetings. This multi-flexible approach allowed for trust in holding the members' kidney journey. It was also an opportunity for members to be heard and talk over issues concerning kidney care in their region and be proactive in possible solutions at the local level.

Table 2.3 displays the total number of National Community Panel members by jurisdiction.

Table 2.3. Composition of the National Community Panel Membership by Jurisdiction

Jurisdiction	**Members**	
	2 July 2021	**31 December 2022**
South Australia	23	21
Queensland	20	21
Western Australia	37	84
New South Wales	31	34
Victoria	1	-
Australian Capital Territory	-	1
Northern Territory	16	14
Tasmania	-	-
Total	128	175

2.1.6 Educational Directory

TSANZ and the NIKTT National Community Engagement Coordinator collaborated on co-creating an online Educational Directory displaying relevant and focused resources to share to community members, families, and clinicians. This website became publicly available on the TSANZ website in late 2022.

2.1.7 NIKTT Gathering

The NIKTT held a Taskforce- and community-wide Gathering in late 2022. In total, over 75 people attended the two-day conference on Kaurna Yarta. Aboriginal and Torres Strait Islander kidney transplant recipients, dialysis patients, and their carers and family from the Kimberley, the Torres Strait, central Australia, far north Queensland, regional NSW and Victoria, and the Top End, travelled to Adelaide to work together with clinicians, researchers, and policy makers to determine priorities and next steps for the NIKTT.

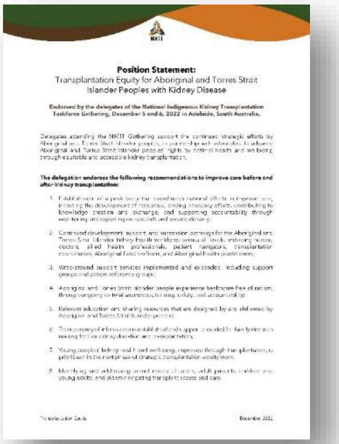
The two-day Gathering, hosted at Adelaide's Aboriginal cultural centre Tandanya, included sessions led by consumers about their stories and the complex pathway to transplantation, as well as consumers and clinicians sharing experiences and solutions from pre-transplant through to post-transplant care. The meeting was designed by Aboriginal and Torres Strait Islander kidney patients, non-Indigenous advocates, and Aboriginal and Torres Strait Islander researchers to be a safe, shared, brave space that allowed us to co-design the future of transplantation equity together.

Group photo of the 2022 NIKTT Gathering attendees, taken on Day Two. © NIKTT Gathering | Nharla Photography

Delegates attending the NIKTT Gathering supported the continued strategic efforts by Aboriginal and Torres Strait Islander peoples, in partnership with advocates, to advance Aboriginal and Torres Strait Islander peoples' rights to optimal health and wellbeing through equitable and accessible kidney transplantation.

A Position Statement was created throughout the Gathering and endorsed by many attendees as a route to future work and subsequent equity.

Read it here: www.niktt.com.au/positionstatement



Position Statement:
Transplantation Equity for Aboriginal and Torres Strait Islander Peoples with Kidney Disease

Endorsed by the delegates of the National Indigenous Kidney Transplantation Taskforce Gathering, December 5 and 6, 2022 in Adelaide, South Australia.

The delegation endorses the following recommendations to improve care before and after kidney transplantation:

2.1.8 NIKTT Website and Social Media

A NIKTT website – www.niktt.com.au – was created to help provide information and resources on the work of the Taskforce. Over the last year, the site has reached over 800 unique visitors, each spending on average 4.5 minutes per session.

The NIKTT is also present on social media, with both a Twitter and Facebook presence. In the last quarter of 2022, the Twitter account earned over 20.7K impressions, with an engagement rate of 2.9%.

2.1.9 Recommendations

The development of the National Indigenous Kidney Transplantation Taskforce was critical to provide a focal point for activity and efforts directed towards improving access to transplantation for Aboriginal and Torres Strait Islander people in Australia. While many clinicians, researchers, patients, and advocates have worked over the years to improve kidney health outcomes for Aboriginal and Torres Strait Islander people, there has not been a cohesive or coordinated approach to these challenges, nor has there been an opportunity to share and collaborate around service development.

Lasting improvement in access to, and outcomes of, kidney transplantation will take sustained focus and coordinated effort. Further gains in transplantation access and outcomes are immediately available with directed attention on racism, cultural safety, equity, and Aboriginal and Torres Strait Islander-led change.

The NIKTT strongly recommends that a resourced Secretariat oversee the coordination of continued efforts, in order to reduce duplicated efforts, build on the strength of current networks, and share resources and knowledge for the betterment of communities across Australia. This work must be done in close collaboration with Aboriginal and Torres Strait Islander people living with kidney disease and transplantation, as well as Aboriginal and Torres Strait Islander health workers, researchers, and advocates, and Aboriginal and Torres Strait Islander communities from all States and Territories.

An ongoing Secretariat would continue activities to improve access to kidney transplantation through:

- Working closely with Aboriginal and Torres Strait Islander communities, the Department of Health and Aged Care, renal and transplant units, and other key stakeholders to maintain networks, coordinate efforts, share knowledge, and progress strategies and plans;
- Development and growth of Indigenous Reference Groups;
- Development of a national data dashboard to track achievements in closing the disparity gap;
- Acting as a "bridge" to facilitate implementation of recommendations from NIKTT through the Department of Health and Aged Care;

2.2 Objective 2: Enhancing data collection and reporting

The NIKTT's second objective was to enhance data collection and reporting around the waitlisting process through defining and capturing variables that help to explain barriers to workup and waitlisting. The NIKTT commissioned the Australia and New Zealand Dialysis and Transplant Registry to extend regular data collection to include metrics relating to why patients were not waitlisted. Data was collected from 26 units in 2019 and 2020. Analysis of this extended data collection was completed by the NIKTT Secretariat and ANZDATA colleagues and published formally in the Medical Journal of Australia.

Overall, 26 of 110 major renal units participated in the study. In 2020, 47 of 2046 Aboriginal and Torres Strait Islander people on dialysis were on kidney transplant waiting lists (2%), and 904 of 11214 non-Indigenous people (8%). For people aged 25 years or more, the predominant reasons for not waitlisting individuals were temporary or permanent contraindications (Indigenous people: 25–44 years, 53%; 45–64 years, 63%; 65 years or older, 83%; non-Indigenous people: 25–44 years, 44%; 45–64 years, 53%; 65 years or older, 81%) and eligibility assessment workup not started or incomplete (Indigenous people: 25–44 years, 33%; 45–64 years, 29%; 65 years or older, 12%; non-Indigenous people: 25–44 years, 39%; 45–64 years, 33%; 65 years or older, 15%). The two most frequently reported specific contraindications were cardiovascular disease (under 65 years: Indigenous, 26.5%; non-Indigenous, 27.2%; over 65 years: Indigenous, 30%; non-Indigenous, 30.4%) and obesity/high body mass index (under 65 years: Indigenous, 22.2%; non-Indigenous, 26.1%; over 65 years: Indigenous, 9.8%; non-Indigenous, 8.9%). The proportions of people not listed because of other medical conditions (under 65 years: 23.5% v 13.1%; over 65 years: 17% v 10.0%) or patient safety concerns (under 65 years: 14.3% v 8.8%; over 65 years: 3.6% v 0.7%) were larger for Aboriginal and Torres Strait Islander than non-Indigenous people.

Table 2.4 Activity Work Plan for Objective 2 of the National Indigenous Kidney Transplantation Taskforce

Objective	Strategies	Performance Measures	Risks	Outcomes
Enhanced data collection and reporting				
• Data points and participating units identified • Collection of data completed	• Identify data points • Transplant units opt into data collection • Data collection tool developed by ANZDATA • Units collect and report to ANZDATA • ANZDATA analyse and publish findings in annual report	• Data capture commence January 2020 • First full year of data collection and reporting by 2020 • Separate chapter in ANZDATA annual report published by 2021	• Lack of engagement by participating units • Mitigation: • Close engagement between grantee and renal sector. • Consideration of sector incentives	• Data collected from 26 units for 2019 and 2020 • Data analysed and results published in the Medical Journal of Australia

2.2.1 Background

The Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry is a clinical quality registry that collects data on all people with end-stage kidney disease in Australia and New Zealand who are treated with either dialysis or transplantation. Data is collected from all renal units through two pathways: (1) 'real-time' notification of key events (usually within 30 days) and (2) a cross-sectional survey of prevalent patients on December 31 each year. ANZDATA uses these extensive records to produce annual reports, undertake specific analyses, and report on quality improvement metrics in order to improve the quality of care and outcomes for people with end-stage kidney disease.

In the 2019 TSANZ Report mentioned previously (16), it was noted that ANZDATA does not collect a range of critical metrics relating to kidney transplantation access and outcomes, especially from an equity lens. The Report specifically recommended the following actions to enhance data collection and reporting:

1. Implement a 12-month pilot project to capture additional pre- and post-kidney transplant data points in an expanded ANZDATA data collection protocol
2. Incorporate a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander people
3. Undertake additional data linkage and research projects that target Indigenous patients' post-transplant outcomes, enabling identification of best practice immunosuppression, infective prophylaxis, and vascular complication protocols. (16)

These recommendations led to the development of the NIKTT's second objective: designing and implementing enhanced data collection and reporting processes on pre- and post-transplant outcomes.

2.2.2 Development

To address this objective, the NIKTT commissioned ANZDATA to deliver a time-limited data pilot project to enable the collection and analysis of additional pre-transplant data points. This was established as an important first step in establishing a consistent framework and process for collecting and reporting on access to waitlisting and transplantation, hoping to improve our understanding of the barriers to access and care faced by Aboriginal and Torres Strait Islander people in Australia.

Specifically, as an ancillary table to the existing ANZDATA collection, units were asked to provide:

1) for prevalent dialysis patients at 31 Dec 2019 and again at 31 Dec 2020, whether individuals were in workup for transplantation, on the waiting list, or ineligible for transplantation (and the reason why). This was a single question (with several response categories).
2) for incident patients during 2020, dates of four key events (determination of eligibility for transplantation, commencement of workup, completion of workup and completion of transplant assessment).

All renal health services in Australia were invited to participate in the voluntary trial and there was a specific focus (through financial incentives) on recruiting the 20 units who treat 90% of prevalent Aboriginal and Torres Strait Islander people on dialysis (based on the number of prevalent dialysis patient numbers). Initially, 30 units (19 funded, 11 non-funded) agreed to participate in the data collection. Due to resource constraints imposed by COVID-19, four units requested to withdraw. A final 26 units participated in data collection, as shown below (Figure 2.3). This data collection through these parent units included data from satellite clinics that sent data through to each parent unit.

ANZDATA developed two additional data collection forms to capture this enhanced data – the Transplant Assessment Stage (TA) form as well as the Transplant Assessment Pathway (TP) form. The TA form sought to capture information on prevalent dialysis patient on December 31, 2019, and again on December 31, 2020. This form collected data on whether patients were undergoing workup for transplantation, active on the waiting list, or ineligible for transplantation. If patients were listed as ineligible, respondents were prompted to list the reasons why, including the option to include free-text responses if the permanent or temporary contraindication was not captured by the pre-listed outcome reasons.

Both forms can be found in Appendix J.

All Aboriginal and Torres Strait Islander and non-Indigenous patients receiving kidney replacement therapy from participating renal health services who were covered under existing ANZDATA consent arrangements, were captured as part of the extended data collection framework. The inclusion of non-Indigenous patients was crucial, serving as a comparator and baseline from which equitable access could be assessed.

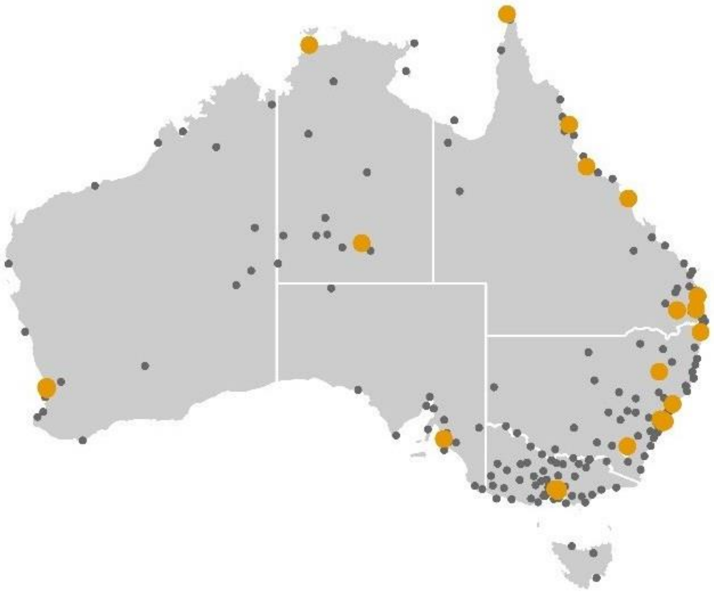


Figure 2.3. Map of participating renal units in extended NIKTT data collection (yellow dots) and all Australian renal units (grey dots)

2.2.3 Data Analysis

Data for Australian patients undergoing kidney replacement therapy was analysed from ANZDATA, including waitlisting data (defined as active placement on a kidney transplant waiting list). Analyses were restricted to people who had not previously received a kidney transplant, but included multiple organ transplants (e.g., pancreas-kidney).

For the end-year 2019 and 2020 surveys, an additional form was provided to participating renal units as an ancillary table to the existing annual ANZDATA collection. This form, known as the “TA – Transplant Assessment Stage” auxiliary form, prompted respondents to select where in the transplant pathway each patient was at the end of each year (Appendix J). If a patient was listed as “Not eligible” on the assessment stage, the “Outcome reason” was sought and respondents provided with a choice of seven reasons. If respondents chose an outcome reason which contained the word “Specify,” the respondent was prompted to provide a free-text reason for non-waitlisting.

All renal units in Australia were invited to participate in this data collection. However, given the extra data collection burden, participation was voluntary. Targeted funding was available from the NIKTT to support the extra data submission for the 20 units who cared for the great majority of Aboriginal and Torres Strait Islander people receiving dialysis in 2019 and 2020. In total, 26 major units (of 110 total) participated in the extended data collection, many of which included data from satellite facilities (full list of participating units can be found in Appendix K). Those units participating in the more detailed data collection for 2019 and 2020 provided treatment to 60% (7653/12737) and 60% (7960/13260) respectively of prevalent dialysis patients in Australia who had not previously received a kidney transplant at the end of each year, including 90% and 90%, respectively, of all Aboriginal and Torres Strait Islander patients recorded within ANZDATA. Rates of waitlisting for people treated in the participating units were similar to the overall Australian data (p=0.09 and p=0.12 for end of 2019 and 2020, respectively).

Primary analysis of reasons for non-listing was performed on the 2020 cohort as this was the more complete data set: among those who were not on the waitlist and were reported to have temporary or permanent contraindications, at least one contraindication reason was not reported for 5% of people in 2019 and 2% in 2020. Confidence intervals were calculated using a binomial distribution, and simple categorical comparisons used chi-square analyses. To account for centre-based practice variation, comparisons for reasons for non-listing were also conducted using a hierarchical logistic regression model, with a random effect for treating centre. No adjustments were made for multiple comparisons.

2.2.4 Descriptive Data

The characteristics of the cohorts at the end of 2019 and 2020 are described in Table 2.5. Overall, Aboriginal and Torres Strait Islander people receiving dialysis were younger, more likely to be female, receiving haemodialysis, and to have spent longer on dialysis.

Table 2.5. Descriptive data for the 2019 and 2020 prevalent dialysis cohort who have not previously had a kidney transplant among units participating in the National Indigenous Kidney Transplantation Taskforce data collection, by survey year and ethnicity. (3)

Factor	2019 non-Indigenous	2019 Aboriginal and Torres Strait Islander	2020 non-Indigenous	2020 Aboriginal and Torres Strait Islander
Total number of people	5852	1801	6128	1832
Age				
0-17	12 (<1%)	2 (<1%)	10 (<1%)	2 (<1%)
18-34	239 (4%)	95 (5%)	259 (4%)	93 (5%)
35-44	348 (6%)	195 (11%)	364 (6%)	189 (10%)
45-54	693 (12%)	536 (30%)	700 (11%)	515 (28%)
55-64	1188 (20%)	591 (33%)	1282 (21%)	611 (33%)
65-74	1621 (28%)	321 (18%)	1690 (28%)	353 (19%)
75-84	1461 (25%)	59 (3%)	1519 (25%)	64 (3%)
85+	290 (5%)	2 (<1%)	304 (5%)	5 (<1%)
Gender				
Female	2080 (36%)	1065 (59%)	2214 (36%)	1073 (59%)
Male	3772 (64%)	736 (41%)	3914 (64%)	759 (41%)

Dialysis Modality				
Peritoneal dialysis	1286 (22%)	138 (8%)	1384 (23%)	129 (7%)
Haemodialysis	4566 (78%)	1663 (92%)	4744 (77%)	1703 (93%)
Taskforce Targeted Status				
Targeted unit	4136 (71%)	1765 (98%)	4303 (70%)	1789 (98%)
Nontargeted unit, participating	1716 (29%)	36 (2%)	1825 (30%)	43 (2%)
State at end of year				
Northern Territory	73 (1%)	676 (38%)	70 (1%)	678 (37%)
New South Wales/Australian Capital Territory	1824 (31%)	132 (7%)	1867 (30%)	128 (7%)
Victoria	1296 (22%)	20 (1%)	1384 (23%)	23 (1%)
Queensland	1226 (21%)	434 (24%)	1316 (21%)	432 (24%)
South Australia	520 (9%)	93 (5%)	537 (9%)	106 (6%)
Western Australia	913 (16%)	446 (25%)	954 (16%)	465 (25%)
Time on dialysis (years)				
0-<1	1371 (23%)	336 (19%)	1457 (24%)	271 (15%)
1-<2	1144 (20%)	247 (14%)	1119 (18%)	301 (16%)
2-<3	790 (13%)	234 (13%)	920 (15%)	219 (12%)
3-<4	613 (10%)	196 (11%)	641 (10%)	209 (11%)
4-<5	465 (8%)	147 (8%)	480 (8%)	167 (9%)
5-<6	374 (6%)	144 (8%)	368 (6%)	129 (7%)
6-<7	245 (4%)	109 (6%)	293 (5%)	119 (6%)
7+	850 (15%)	388 (22%)	850 (14%)	417 (23%)
Primary kidney disease category*				
Diabetic Kidney Disease	2291 (38%)	1281 (72%)	2207 (38%)	1252 (71%)
Glomerular Disease	1162 (19%)	197 (11%)	1128 (20%)	198 (11%)

Hypertension	827 (14%)	116 (6%)	819 (14%)	127 (7%)
Polycystic Disease	358 (6%)	7 (<1%)	338 (6%)	7 (<1%)
Other/Uncertain	1398 (23%)	189 (11%)	1273 (22%)	176 (10%)
Diabetes as a comorbidity at end of year*				
No	2884 (47%)	317 (17%)	2749 (47%)	320 (18%)
Yes	3230 (53%)	1512 (83%)	3088 (53%)	1479 (82%)
Waitlisted at end of 2019				
No	5366 (92%)	1750 (97%)		
Yes	486 (8%)	51 (3%)		
Waitlisted at end 2020				
No			5616 (92%)	1796 (98%)
Yes			512 (8%)	2%)

2.2.5 Assessment Stage

Figure 2.4 provides an overview of the assessment stage for both Aboriginal and Torres Strait Islander and non-Indigenous patients not already listed as active on the transplant waitlist, across age groups at the end of 2020.

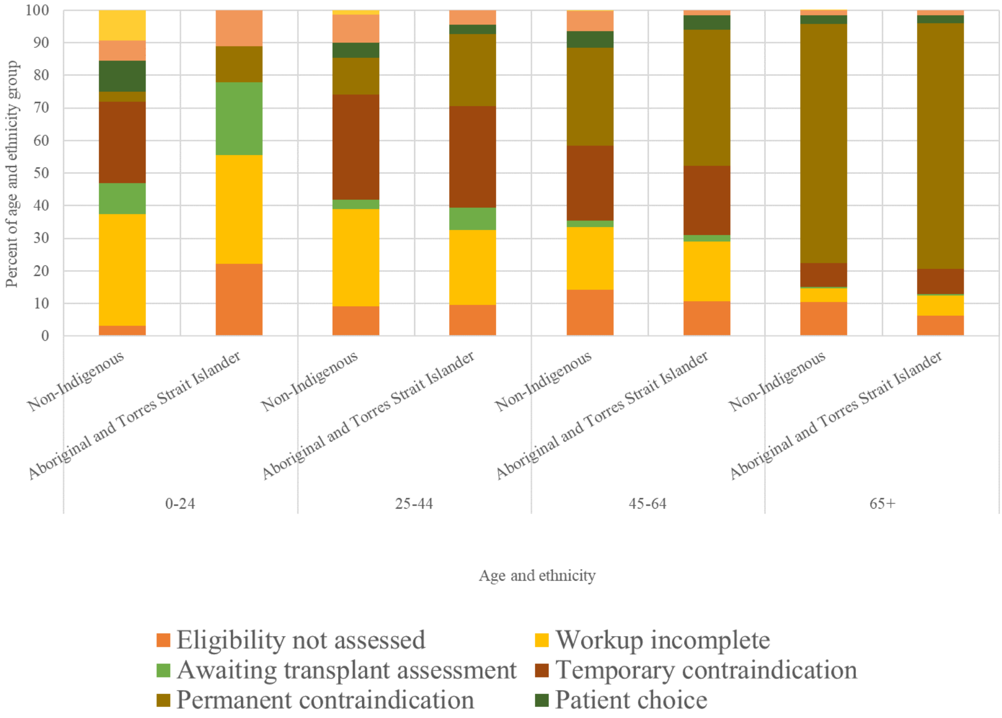


Figure 2.4 Reported reasons by age for people not being listed for transplantation, among those receiving dialysis at 31 December 2020 and not on the waiting list (3)

2.2.6 Reasons for non-listing

Given the clinical issues involved in waitlisting are often quite different among older people, more detailed analysis was further restricted to those aged less than 65 years on 31 December 2020 for those who were listed as ineligible for waitlisting due to a temporary or permanent contraindication. The most common contraindication reason across all people related to "Cardiovascular Disease" (Table 2.6). Among the less than 65-year-old group:

- the proportion with cancer listed as the reason for non-listing was significantly different for non-Indigenous people, approximately three times higher (86 v 28; 11% v 4%; p < .001);
- the proportion not listed due to high body-mass index (BMI) (207 v 163; 26% v 22%) or cardiovascular disease (216 v 194; 27% v 26%) (the two most common causes) were similar among both groups; and
- a substantial rate of "Other comorbidities (Specify)" and "Other (Specify)" responses were seen, with these responses being more frequent among Aboriginal and Torres Strait Islander people (17-24% v 26-32%).

Given the high proportion of responses in these last two "Other" categories, further analysis was performed on the free-text answers clinicians were encouraged to provide. Clinicians gave additional reasons for non-listing for 2002 patients (1390 non-Indigenous patients; 612 Aboriginal and Torres Strait Islander patients). All free-text responses were recoded into common categories (Table 2.6).

Clinicians identified reasons relating to the safety of patients pre- and post-transplantation most often with language referencing "compliance," "adherence," or "attendance". We re-classified these responses into "patient safety", finding that patient safety given as a reason for non-listing did not significantly differ for those

<65 years [70 (9%) v 105 (14%) non-Indigenous v Aboriginal and Torres Strait Islander patients, respectively] but did differ significantly for those over 65 [13 (1%) v 11 (4%); p < 0.001). Substance use was more frequently cited as a reason for non-listing for Aboriginal and Torres Strait Islander patients under 65 [11 (1.4%) non- Indigenous v 39 (5.3%) Aboriginal and Torres Strait Islander people; p = 0.02], and mental health less frequently cited [30 (3.8%) v 10 (1.4%)].

Table 2.6. Prevalence of key responses among main categories and free-text responses, by age and ethnicity, 2020. (3)

	Under 65				Over 65			
	Non-Indigenous		Aboriginal and Torres Strait Islander		Non-Indigenous		Aboriginal and Torres Strait Islander	
Reason	Absolute number	Percent (95% confidence interval)	Absolute number	Percent (95% confidence interval)	Absolute number	Percent (95% confidence interval)	Absolute number	Percent (95% confidence interval)
Total number of people	794		733		1836		307	
Age	18	2.3% (1.2%-3.3%)	26	3.5% (2.2%- 4.9%)	772	42.0% (39.8%-44.3%)	124	40.4% (34.9%-45.9%)
High BMI*	207	26.1% (23.0%-29.1%)	163	22.2% (19.2%-25.2%)	163	8.9% (7.6%-10.2%)	30	9.8% (6.5%-13%)
Cancer	86	11% (8.7%-13%)	28	3.8% (2.4%-5.2%)	178	9.7% (8.3%-11.0%)	18	5.9% (3.2%-8.5%)
Cardiovascular Disease	216	27.2% (24.1%-30.3%)	194	26.5% (23.3%-29.7%)	558	30.4% (28.3%-32.5%)	91	30% (25%-35%)
Cognitive Impairment	12	1.5% (0.7%-2.4%)	10	1.4% (0.5%-2.2%)	13	0.7% (0.3%-1.1%)	5	2% (0.2%-3%)
Infection	22	2.8% (1.6%-3.9%)	45	6.1% (4.4%-7.9%)	22	1.2% (0.7%-1.7%)	9	3% (1%-5%)
Other Medical	104	13.1% (10.8%-15.4%)	172	23.5% (20.4%-26.5%)	183	10.0% (8.6%-11.3%)	53	17% (13%-22%)
Patient Declined Transplantation	7	0.9% (0.2%-2%)	7	1% (0.3%-2%)	50	2.7% (2.0%-3.5%)	6	2% (0.4%-4%)
Patient Safety	70	8.8% (6.8%-11%)	105	14.3% (11.8%-16.9%)	13	0.7% (0.3%-1.1%)	11	3.6% (1.5%-5.7%)
Smoking	29	3.7% (2.3%-5.0%)	42	5.7% (4.0%-7.4%)	24	1.3% (0.8%-1.8%)	5	2% (0.2-3%)
Mental Health	30	3.8% (2.5%-5.1%)	10	1.4% (0.5%-2.2%)	11	0.6% (0.2%-1.0%)	0	0.0% (0.0%-0.0%)
Social Issues	9	1% (0.4%-2%)	22	3.0% (1.8%-4.2%)	4	0.2% (0.0%-0.4%)	0	0.0% (0.0%-0.0%)
Substance Use	11	1.4% (0.6%-2.2%)	39	5.3% (3.7%-6.9%)	2	0.1% (0.0%-0.3%)	1	0.3% (0.3% - 1%)

*As determined by individual respondents

2.2.7 Strengths and Limitations

Collecting and analysing this extended data collection allowed for the ANZDATA and NIKTT teams to investigate, for the first time, the reasons why clinicians reported people were not eligible to be waitlisted. After many years of similar trends and outcomes for Aboriginal and Torres Strait Islander people, it is imperative that we continue to explore and collect evidence on what contributes to disparities in waitlisting and transplantation.

While collection of this extended Registry data proved challenging in terms of the extra burden of work, it provided an important first step in understanding what data is available, the feasibility of extended data collection, and an overview and awareness of where initiatives should potentially focus efforts in order to improve access to waitlisting.

Data reported to ANZDATA may under-represent the true Aboriginal and Torres Strait Islander kidney population, as there are typically no procedures for self-identification of ethnicity. It will be important going forwards to address this limitation for both general Registry reporting as well as NIKTT- and equity-focused investigations.

For our work, the meaning of words such as ‘age’, ‘frailty’, ‘weight’, ‘BMI’, ‘compliance’, and ‘social issues’ were taken at face value and re-categorised to reduce the number of reasons presented. Formal and standardised assessments of the subjectivity of such terms should be investigated, with the hope that further qualitative work and the implementation of the newly created guidelines for First Nations Australians (23) will reduce the impact of systemic racism on these processes.

As detailed further in the MJA NIKTT Supplement paper, there are a number of questions that this data raises, one of which surrounds obesity and other co-morbidities as barriers to waitlisting and transplantation. Going forwards, we must work closely with Communities around Australia to address these biological, physical, environmental, social, and colonial issues and how they impact access to and experience of care.

This data collection and analysis is the first step of many to collect, analyse, and report on evidence systematically recorded from around the country. Many questions have, and will, come from this analysis, and we look forward to exploring the implications, ramifications, and opportunities afforded us from this initial objective.

2.2.8 Recommendations

Addressing modifiable barriers such as obesity, infection, safety, and smoking/substance use will take multidisciplinary co-designed efforts that address institutional racism as well as geographic and cultural barriers. Solutions that reduce time taken to initiate and complete workup must also be further developed and resourced. Ongoing monitoring with public reporting will be important. Sustainable data collection and reporting is difficult, but ultimately crucial to improving access to transplantation. The work of the NIKTT has largely focused on renal unit activity, yet it is recognised that achieved practice change will require consistent and sustained support and resourcing from a broad range of clinical providers, health services, and governments, informed by accurate and timely reporting of outcomes and consultation with communities.

The NIKTT strongly recommends that ongoing monitoring of waitlisting numbers is supported through the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, including progress on improving waitlisting numbers, kidneys transplanted, and post-transplant outcomes. This monitoring should include the development and implementation of an annual scorecard for renal units, and the exploration of designing a metric or system to measure the cultural safety of units.

2.3 Objective 3: Piloting initiatives to improve patient equity and access

The NIKTT's third objective was to improve the equity and accessibility of transplantation for Aboriginal and Torres Strait Islander patients by trialling a range of multidisciplinary service models. The NIKTT's Equity & Access Sponsorships were awarded to eight projects, totalling $1,040,381 of grant money allocated to these pilot projects.

Funded initiatives were located in Western Australia, the Northern Territory, South Australia, and Queensland. The projects included activities such as: delivery of outreach kidney transplant education and assessment in rural and remote areas; establishment of transplant-focused patient mentor projects and Indigenous Reference Groups; and strengthening the Aboriginal and Torres Strait Islander health workforce in kidney transplant settings. Projects were delivered directly by regional-based teams whose existing knowledge of the challenges to waitlisting in their regions allowed for the testing of local solutions to local barriers. These pilot projects were therefore small-scale, local implementation initiatives that showcased potential solutions and provided proof-of-concept evidence of identified barriers to transplantation waitlisting.

Most projects faced significant delays and challenges associated with the onset and continuation of the COVID-19 pandemic, however most were able to deliver their aims and final reports within agreed-upon extended timeframes. Specific approaches and models of care were found to enhance access to transplantation waitlisting, as summarised in the MJA Supplement article.

From these projects, the NIKTT found that particular models of care – including Outreach Assessment Clinics, Patient Navigators, and locally tailoring educational sessions – are valuable building blocks to successful waitlisting and transplantation pathways. Other learnings, such as the importance of a dedicated workforce and wraparound support for workforce, additionally influenced the recommendations that came from this objective.

In this section of the Report, we provide a summary of the projects and their outcomes, as reported by each Sponsorship team.

Table 2.7 Activity Work Plan for Objective 3 of the National Indigenous Kidney Transplantation Taskforce

Objective	Strategies	Performance Measures	Risks	Outcomes
Pilot initiatives to improve patient equity and access				
• Projects selected and funded • Evaluation reports completed	• Indigenous reference groups • Patient navigator pilots • Enhance pre-transplant coordination of care pilot	• Projects funded and implemented • Evaluation reports completed	• Inability to recruit relevant subject matter experts • Availability of suitably qualified patient navigators • Engagement with Indigenous transplant candidates and recipients to partake in reference groups Mitigation: • Robust stakeholder engagement and communication strategies in place	• All projects received sponsorship money across 2020-2022 • 7/8 projects completed detail progress and final reports • Projects provided evidence of improved access to waitlisting, as well as barriers and recommendations for future models of care

			- Leverage existing initiatives and collaborate effectively with key stakeholders	

2.3.1 Background

In 2019, the NIKTT invited the renal health community to participate in an open competitive sponsorship opportunity. Proposals were sought for 12-month pilot projects that would improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander peoples.

Sponsorships of up to $1,000,000 were available for projects under two streams:

1. Increasing or creating new positions within health services for various roles where there was demonstrated shortage, such as:
    - Transplant coordinators
    - Clinical champions
    - Indigenous health workers
    - Interpreters
    - Dietitians.
2. Targeted projects that improve equity and access to kidney transplantation for Aboriginal and Torres Strait Islander patients, such as:
    - Programs that deliver tailored social or emotional support to patients navigating the transplant system, such as patient mentors or buddies
    - Establishment of community, patient, or carer support groups
    - Purchase of assets, resources, and tools, such as tailored educational material or IT infrastructure
    - Other initiatives that improve access to kidney transplantation for Aboriginal and Torres Strait Islander patients.

An Application Assessment Panel consisted of representatives from the NIKTT, the Transplantation Society of Australia and New Zealand (TSANZ), and the Organ and Tissue Authority (OTA).

2.3.2 Funding Process

The Application Assessment Panel reviewed all eligible applications against the selection criteria, consulting relevant NIKTT working groups where necessary to make an informed decision. After preliminary assessment of each eligible application, the Panel met to agree on a consensus assessment outcome. The Panel then ranked each application, considering overall assessment outcome, amount of funding requested and available, and the avoidance of duplicating activities.

In total, eight projects were funded for a total of $1.04 million. The projects were located across Australia, with two each in Western Australia, the Northern Territory, South Australia, and Queensland. Figure 2.5 shows a geographical overview of the projects.

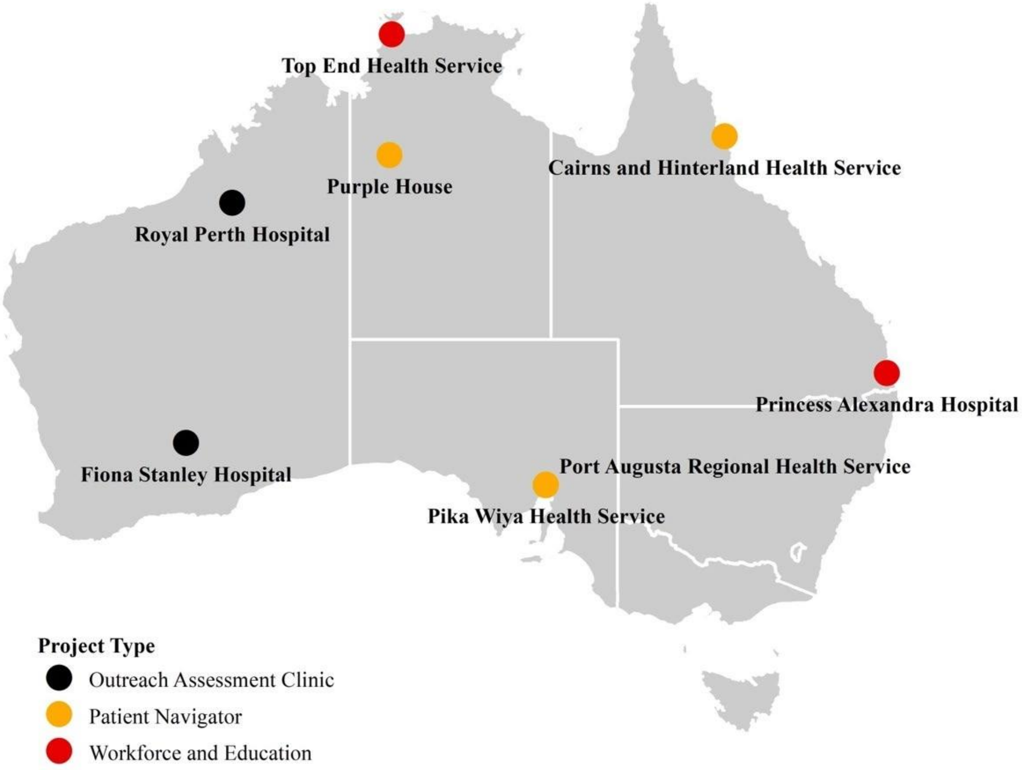


Figure 2.5. Map of the sponsored Equity and Access Projects according to their overall theme

Each project executed a Sponsorship Agreement that outlined activities to be undertaken, key performance metrics and indicators, reporting timelines, and financial responsibilities of the project leads. Initially, all projects were funded for a 12-month period. Due to the COVID-19 pandemic, all projects requested an extension and completed Deeds of Variation, with project deadlines extended to between July 2021 and December 2021.

Once applications for sponsorships were received, the applications were reviewed first for eligibility. Applicants were deemed eligible if they:

- Were a legal entity, able to enter into a legally binding agreement or had an auspicing entity
- Had an Australian Business Number
- Were registered for the purposes of GST (if applicable)
- Had an Australian bank account
- Were not: an individual, a political organisation, an Australian Government agency, or a commercial organisation proposing activities that were for-profit.

Applications were also deemed eligible if the applicants were able to demonstrate:

- Capacity to deliver: a history of sound organisational governance and effective culturally safe high-quality service delivery, including the ability and experience to successfully plan and apply resources, including:
  - Previous experience in managing sponsorships and activities similar to the ones proposed
  - The skills and expertise needed to facilitate the project or activities
  - The ability to identify key resources including personnel
  - The ability to establish and meet proposed timeframes and implementation schedules
  - The endorsement of the relevant health service or unit, if applicable.
- Provision of culturally safe services: a history of delivering culturally safe services to Aboriginal and Torres Strait Islander Australians. Where necessary, the NIKTT sought expert advice in assessing the provider’s claims of culturally safe service provision.

2.3.3 Selection Criteria

Each eligible application was assessed against a merit criterion to select projects that had the capacity to deliver both policy outcomes and value for money. In assessing each application, a score out of 10 was applied to each of the merit criteria, and that score weighted to contribute to a total score out of 100. The table below demonstrates the weighting of the criterion:

Criterion	Weighting
Improve Equity and Access	35%
Value for Money	20%
Engagement and Community Support	35%
Measurement of Effectiveness	10%

Criteria descriptions:

1. Improve Equity and Access
    - Provide a clear and convincing proposal that delivers defined and achievable outcomes aligned with the NIKTT's key objective of improving equity and access to kidney transplantation for Aboriginal and Torres Strait Islander peoples.
2. Value for Money
    - Demonstrate how the proposal delivers value for money. To support this, organisations should provide information showing how the proposed project activities are realistic and achievable within the timeframe and budget in the proposal. This must be supported by a clear rationale for the proposed project approach and identified need.
3. Engagement and Community Support
    - Demonstrate how the applicant has or will work with and engage the community, in particular Aboriginal and Torres Strait Islander Australians, local health professionals, and relevant community groups to ensure culturally safe, high-quality, responsive, and accessible service provision of the activity.
4. Measurement of Effectiveness
    - Demonstrate how the proposed project is responsive, accessible, and culturally appropriate and how improved health outcomes or key deliverables will be measured and evaluated.

Assessment

The Application Assessment Panel reviewed all eligible applications against the selection criteria, consulting relevant NIKTT working groups where necessary to make an informed decision. After preliminary assessment of each eligible application, the Panel met to agree on a consensus assessment outcome. The Panel then ranked each application, considering overall assessment outcome, amount of funding requested and available, and the avoidance of duplicating activities.

2.3.4 Evaluation by Sponsorship Recipients

Under the conditions of each of the Sponsorship Agreements, projects were required to provide one progress Performance Report and one Final Report. These reports were required to contain the following information:

Performance Report (due in the middle of project timeline):

- How the Activity aims are being met in relation to the objectives of the sponsorship
- A statement on the Sponsorship Recipient's involvement and collaboration with other entities
- An explanation as to how the Sponsorship Recipient is addressing any issues, problems, or delays with the Activity
- Any proposed changes to the Activity budget

Final Report (due at the end of the project):

- A summary of the Activity and how successful the Activity was in achieving the objectives of the sponsorship, referring to the performance metrics outlined in the original Agreement
- Identified recommendations and learnings from the Activity
- One original copy of all Project Materials or Collateral produced to the date of the Final Report, including printed materials, advertisements, merchandise, or other promotional or information materials produced by the Sponsorship Recipient
- A detailed income and expenditure statement of the Activity, indicating if the Sponsorship has been fully expended or if funds need to be returned to the TSANZ
- A completed Statutory Declaration form stating the Final Report is true and correct

The following sections provide a summary of these reports as well as links to the submitted reports. For a further summary and analysis of the Equity and Access projects, please see the NIKTT Supplement published in the MJA.

2.3.5 Project 1: Royal Perth Hospital

Royal Perth Hospital received $150,300.00 (GST excl.). Royal Perth, in collaboration with the Kimberley Aboriginal Medical Service and Sir Charles Gairdner Hospital were funded to deliver outreach visits to the Kimberley region of Western Australia utilising a transplant coordinator, Aboriginal Liaison Officer, transplant nephrologist, and transplant surgeon. During the outreach visits, the team aimed to undertake transplant assessments, workup testing of suitable patients, and transplant education. In addition, the funds were to be utilised to increase the FTE of the existing Kimberley Transplant Coordinator from 0.5 FTE to 1.0 FTE. Four community forums were planned to be conducted, with the sponsorship team also working to establish an IRG in the region. Once the IRG was established, the plan was to develop a comprehensive suite of culturally appropriate kidney transplant education materials and an education program for patients and health professionals involved in the care of renal patients utilising a train-the-trainer model.

The Royal Perth Hospital project completed the sponsorship project in 2022, submitting the progress and final reports on schedule and returning an underspend of $89,008.73 that was unable to be utilised due to staffing constraints and community shutdowns as a result of the COVID-19 pandemic. These monies were re-invested into NIKTT operations and activities, as agreed upon with the grant awards team.

Please find the Royal Perth Hospital's *Progress Report* here.

Please find the Royal Perth Hospital's *Final Report* here.

Sponsorship Summary

The Royal Perth Hospital (RPH), located on Whadjuk Country in Western Australia, was awarded $165,330 (GST incl.) to provide an outreach kidney transplant assessment service to the northern Kimberley region. This project, through RPH, worked in collaboration with Kimberley Aboriginal Medical Service (KAMS) and the Sir Charles Gairdner Hospital (SCGH). Together, these services have helped to provide renal services to the population of Aboriginal and Torres Strait Islander kidney patients in the Kimberley for over 30 years. Since 2016, the two hospitals have developed a robust partnership to manage donor and recipient pathways and workup processes. In 2019, the teams provided tertiary service for around 570 Aboriginal and Torres Strait Islander patients with stage 3-5 chronic kidney disease, with a further 170 patients on KRT. At the end of 2019, however, just four of these patients were active on the transplant waitlist.

Based on the significant distances between the Perth-centered renal services and the Kimberley region, the Royal Perth Hospital project aimed to increase access to transplantation through multidisciplinary outreach assessment team visits, the establishment of an Indigenous Reference Group, and the increase in working time of a Transplant Coordinator.

Specifically, the purpose of the Equity and Access Sponsorship granted to Royal Perth Hospital, in collaboration with Kimberley Aboriginal Medical Service and Sir Charles Gairdner Hospital, was to provide an outreach kidney transplant assessment service to the Kimberley region of Western Australia and facilitate the creation of a Kimberley IRG. The project was designed to increase the identification of suitable patients for kidney transplant waitlisting, fast-track the commencement of workup, and improve transplant knowledge through a culturally appropriate kidney transplant education program utilising a train-the-trainer model.

The RPH project was set to begin on the 30th of June 2020 and conclude on the 30th of June 2021. Like all other sponsorship projects, this timeline and the activities undertaken were significantly impacted by the COVID-19 pandemic. For the multi-disciplinary transplant outreach clinic, due to COVID-19 border restrictions into remote communities, only three of the four clinics were conducted. Similarly, because of travel restrictions, there was a significant delay and impediment to establishing the Indigenous Reference Groups.

Multidisciplinary Transplant Outreach Clinics

Three week-long multidisciplinary renal transplant clinics were conducted in the East and West Kimberley in March, June, and October 2021. The multidisciplinary team was comprised of a visiting transplant physician, a transplant surgeon, transplant nurses, and the usual visiting renal physician, local renal GPs, and the local transplant coordinator. Additionally, the NIKTT's National Community Engagement Coordinator, Kelli Owen, attended the visits in June (East Kimberley) and October (West Kimberley).

The outreach clinics:

- Allowed for the rapid assessment of patients suitable for workup and waitlisting
- Provided an opportunity for the team to advise patients on how to progress with workup
- Allowed for physical assessments of patients to be performed for transplant suitability
- Identified potential barriers to transplantation
- Helped mitigate potential barriers by coordinating local and metro team efforts

A total of 71 assessments were conducted during the three visits, with some patients seen for reassessment during the second visit to the West Kimberley. Of these assessments, 23 patients were deemed suitable for workup, while several other patients were noted to have modifiable barriers to commencing workup. During the project, 10 patients became active on the deceased donor transplant waitlist and four patients from the region received a kidney transplant.

Support to increase the FTE of the existing transplant coordinator

During the project, the existing transplant coordinator role, employed through the Kimberley Renal Services, was increased from 0.5 FTE to 1.0 FTE. Because of this increase in time dedicated to the portfolio, pathways were able to be streamlined and visits were much better coordinated.

The project additionally aimed to generate clinical champions amongst local nurses, Aboriginal Health Care Workers, and allied health staff.

Table 2.8. Project 1 design and findings – Royal Perth Hospital

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Deliver one-week outreach visits to the Kimberley utilising a transplant coordinator, Aboriginal Liaison Officer, transplant nephrologist, and transplant surgeon. The visiting team will undertake transplant assessments, commence workup testing of suitable patients, and provide transplant education. • Increase the FTE of the existing Kimberley Transplant Coordinator from 0.5 FTE to 1.0 FTE. • Conduct community forums to establish an IRG. • In collaboration with the IRG, develop a comprehensive suite of culturally appropriate kidney transplant education materials and an education program for patients and health professionals involved in the care of renal patients utilising a train-the-trainer model.	• 3 week-long multi-disciplinary renal transplant clinics conducted in East and West Kimberley (March, June, October 2021). • 20 education sessions held across the three visits with patients and community. • 5 education sessions held with regional satellite dialysis staff (6-10 staff per session). • 3 education sessions with regional hospital staff (3-15 staff per session).	• Number of patients assessed: 71. • Number who commenced workup: 23. • Number entered onto waitlist: 10. • Number transplanted: 4.	• Allowed for the rapid assessment of patients suitable for workup and waitlisting. • Provided an opportunity for the team to advise patients on how to progress with workup. • Allowed for physical assessments of patients to be performed for transplant suitability. • Identified potential barriers to transplantation. • Helped mitigate potential barriers by coordinating local and metro team efforts • During the project, the existing transplant coordinator role, employed through the Kimberley Renal Services, was increased from 0.5 FTE to 1.0 FTE. Because of this increase in time dedicated to the portfolio, pathways were able to be streamlined and visits were much better coordinated. • The project additionally aimed to generate clinical champions amongst local nurses, Aboriginal Health Care Workers, and allied health staff.	• Inequalities and complexities of remote and regional healthcare, specifically to Aboriginal patients, should be micro-discussed by transplant teams. This gave all participants and caregivers insights into factors driving cultural bias, resource and facility inequity, and their implications for health care. This has assisted in generating champions who will be able to educate others on their learning to leave a positive impact. • The involvement of local Aboriginal patients, caregivers and volunteers is an invaluable resource to keep moving forward, and this must be addressed as a priority. Providing health care with cultural appropriateness must be an aim. To facilitate this, Aboriginal teams of medical, nursing, allied, and social health professionals need to be recruited and trained. • Resources should be provided to employ a full-time trained transplant coordinator. Visits by the appropriate transplant outreach team at regular intervals will assist in overcoming the barrier of remoteness.

2.3.6 Project 2: Fiona Stanley Hospital

Fiona Stanley Hospital was awarded $109,224.00 (GST excl.) to employ a dedicated 0.4 FTE transplant coordinator for regional Aboriginal patients and to deliver outreach visits in the Pilbara and Goldfields regions of Western Australia utilising a nurse, surgeon, physician, pharmacist, and Aboriginal Liaison Officer. Outreach visits planned to include the visiting team working alongside established local Aboriginal Medical Services, community health centres, hospitals, and regional dialysis units to identify, educate, and assess patients suitable for renal transplantation and prioritise patients for further assessment to expedite transplant waitlisting.

The Fiona Stanley Project team completed the project in 2022, submitted both the Progress Report and Final Report on schedule.

Please find the Fiona Stanley Hospital's *Progress Report* here.

Please find the Fiona Stanley Hospital's *Final Report* here.

Sponsorship Summary

Fiona Stanley Hospital, located on Whadjuk Country in Western Australia, was awarded $109,224 to provide an outreach kidney transplant assessment service to the Pilbara and Goldfields regions of WA, in collaboration with Aboriginal Medical Services Wirraka Maya Health Service in South Hedland, Pilbara; Mawarnkarra Health Service in Roebourne, Pilbara; and Bega Garnbirringu Health Service in Kalgoorlie, Goldfields.

The Pilbara region of Western Australia covers over 500,000 square kilometres to the north of WA, located just below the Kimberley region and bounded by the Indian Ocean coast and the Northern Territory border. The name for the region, according to Wangka Maya,[20] the Pilbara Aboriginal Language Centre, is derived from the word *bilybara* ("dry") in Nyamal and Banyjima. Today, there are more than 31 Aboriginal cultural groups across the Pilbara.[21] The major towns – Port Hedland, Karratha, Newman, and Tom Price – are located between 1,600 kms (2-hour flight) and 1,200kms (1.75-hour flight) north of Perth. The region has an estimated population of over 60,000 people, 14% of which are of Aboriginal and/or Torres Strait Islander descent.[22]

The Goldfields-Esperance region is located in the south-east of WA and covers an area of over 770,000 square kilometres, making it the largest region in the state. According to Wangka, the Goldfields Aboriginal Language Centre, there are between 14-16 distinct Aboriginal languages throughout the Goldfields regions.[23] The major towns of Kalgoorlie-Boulder and Esperance are 600kms (1-hour flight) and 700kms (1.5-hour flight) away from Perth, respectively. The Goldfields has a population of around 55,000 people, 10% of which are of Aboriginal and/or Torres Strait Islander descent.[24]

The purpose of the Sponsorship was for Fiona Stanley Hospital to provide an outreach kidney transplant assessment service to the Pilbara and Goldfields regions of Western Australia. This project aimed to increase: the number of visits to these regions, the number of patients assessed, the number of health care professional education sessions conducted, and engagement with local Aboriginal Medical Service. The project expected to facilitate improved access to the kidney transplant waitlist and increase the number of Aboriginal patients receiving kidney transplants.

The Project was funded to:

1. Employ a dedicated 0.2 FTE transplant coordinator for regional/Aboriginal patients.
2. Deliver two outreach visits per region utilising a nurse, surgeon, physician, pharmacist, and Aboriginal Liaison Officer. The visiting team, in conjunction with established local Aboriginal Medical Services, community health centres, hospitals and regional dialysis units, will identify, educate, and assess patients suitable for renal transplantation and prioritise for further assessment to expedite transplant waitlisting.

Table 2.9. Project 2 design and findings – Fiona Stanley Hospital

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Employ a dedicated 0.4 FTE transplant coordinator for regional/Aboriginal patients. • Deliver two outreach visits per region (Pilbara and Goldfields) utilising a nurse, surgeon, physician, pharmacist, and Aboriginal Liaison Officer. The visiting team, in conjunction with established local Aboriginal Medical Services, community health centres, hospitals and regional dialysis units, will identify, educate and assess patients suitable for renal transplantation and prioritise for further assessment to expedite transplant waitlisting.	• 8 full-day clinics held in Port Hedland, Karratha, and Kalgoorlie across five outreach visits. • 4 patient and family education sessions held. • 2 education workshops for health professionals held.	• Number of patients assessed: 28. • Number who commenced workup: 26. • Number of Aboriginal patients entering the transplant waitlist: 13. • Number of Aboriginal transplants performed: 12. • Average time from first NIKTT clinic to waitlisting: 7.2. months (3-15 months) • Average time from waitlisting to transplantation: 3 months (2 days to 12 months). • Number of education sessions and attendees: 6 education sessions.	• Having a dedicated transplant coordinator for regional areas is effective. • Visiting regional teams conducting yarning-transplant education in a non-hospital setting, with family members attending is effective. • Patients who have received a successful transplant then visit dialysis units to encourage and motivate the patients, was more effective. • Initial assessments done by the visiting multi-disciplinary team and completing the final assessment in Perth, in one co-ordinated visit is helpful for the patients and lessens the time taken to work up. • Overall, a dedicated transplant coordinator for regions and regular visits by a multidisciplinary team working in conjunction with the regional teams, expedites the transplant assessment process and reduces the time to wait-listing. • Each region has its own unique challenges. Staff retention is an issue especially in the Pilbara. Since late 2021 Regional CKD nurse position in the Pilbara has been vacant.	• A fully funded permanent transplant coordinator role, based in Perth who works closely with regional teams and visits regional centres regularly. • Regularly funded, multidisciplinary team visits to rural and remote regions to conduct both patient discussions/education (formal and informal), as well as clinic reviews. • Regional staff vacancies must be filled. • Work must be undertaken in close partnership with local Aboriginal corporations and Aboriginal health services to provide culturally appropriate services.

2.3.7 Project 3: Port Augusta Hospital and Regional Health Service

Port Augusta Hospital and Regional Health Service received $84,667.00 (GST excl.) to deliver a patient mentor pilot project (‘On Track to Transplant’). The project involved identifying and employing four patient navigators to ‘walk alongside’ and provide support to kidney transplant candidates in Port Augusta and surrounding communities. Patient navigators are directly involved in the prevention, screening, treatment and transplantation stages of a patient’s healthcare journey.

A Transplant Coordinator was employed on a part-time basis (0.4 FTE) to oversee the management of the project. Fortnightly educational sessions were held in the local community for patients with kidney disease, in partnership with Pika Wiya Health Service Aboriginal Corporation. Approximately 28 patients attended the sessions each fortnight, with topics including healthy living, quit smoking, diabetes, medication self-management, organ donation awareness and staying healthy after transplant. Since the start of this project in September 2020, there has been an increase in the number of patients on the wait list for kidney transplant from zero to eight patients.

Please find the Port Augusta Hospital and Regional Health Services’ *Progress Report* here.

Please find the Port Augusta Hospital and Regional Health Service’s *Final Report* here.

Sponsorship Summary

The Flinders and Upper North Local Health Network Incorporated, through the Port Augusta Hospital and Regional Health Service on Barngarla Country, was awarded $84,667 to pilot a patient navigator role that would assist Aboriginal and Torres Strait Islander patients to understand and navigate the transplant workup process. The Port Augusta Hospital Renal Unit partnered with Pika Wiya Health Service to develop and initiate education sessions for the Port Augusta community.

Port Augusta is a small city on the coast of South Australia (SA), located on the lands of the Barngarla peoples, whose original name for the place is *Goordnada*. The city is situated on a natural harbour on the Eyre Peninsula, 310kms (around a 4-hour drive) north of Adelaide. Port Augusta has an estimated population of over 13,000 people, with around 18% identifying as Aboriginal and/or Torres Strait Islander.

The Port Augusta Hospital is a 99-bed hospital with emergency, in-patient, and out-patient services, including a renal unit which provides out-patient dialysis through the Central Northern Adelaide Renal and Transplantation Service (CNARTS). Pika Wiya is an Aboriginal Community Controlled Health Service that offers a range of health and wellbeing services at their main location in Port Augusta, as well as through clinics at Davenport, Copley, and Nepabunna communities. Pika Wiya also provides services to the communities of Quorn, Hawker, Marree, Lyndhurst, and Beltana.

This Sponsorship project aimed to deliver a patient navigator project through the Port Augusta Hospital and Regional Health Service. The project involved the identification of Aboriginal and Torres Strait Islander kidney transplant recipients who could provide support to transplant candidates currently navigating the journey to kidney transplant waitlisting. A team of navigators was established to work alongside transplant nurses and Aboriginal Health Workers from both the Port Augusta Hospital Renal Unit and Pika Wiya Health Service. This team then aimed to improve the community's awareness of kidney transplantation as a treatment option, as well as provide practical and emotional support for those undergoing or wanting to commence workup and assessment.

Before the Sponsorship project was designed, a community consultation forum was held in Port Augusta as part of the Improving Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) research group. During this consultation, Aboriginal and Torres Strait Islander consumers identified the need for a patient navigator or Patient Mentor role in Port Augusta. The project was designed to focus on the cultural needs of the Aboriginal and Torres Strait Islander patients in Port Augusta, delivered through a partnership model with Aboriginal and Torres Strait Islander kidney transplant recipients and the existing renal clinical team.

The design of the project was influenced by the experience and successes of the patient navigator role from the Purple House team in Darwin, although this project was based within the clinical/hospital setting. Regular meetings, outside of dialysis sessions, were established to develop relationships and encourage yarning between patients, patient navigators, and clinical staff.

The specific activities outlined for the Port Augusta Sponsorship project were:

1. Identify and employ four patient navigators to 'walk alongside' and provide support to kidney transplant candidates in Port Augusta and surrounding communities. The patient navigators will assist kidney transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling more patients to commence the kidney transplant assessment and workup process.
2. Oversee the management of the patient navigator project, including development of education programs and provision of training and support to the navigators, by committing time of a Transplant Coordinator – Level 2 Associate Nurse Unit Manager (0.4 FTE).
3. Deliver fortnightly information sessions, in partnership with Pika Wiya Health Service Aboriginal Corporation, covering issues such as: healthy behaviours (quitting smoking, good diet, active lifestyle), self-management (cooking classes, medication management), pre-transplant requirements and the journey to kidney transplantation, organ donation and staying healthy post-transplant.

The *On Track to Transplant* project ran from September 2020 to October 2021.

Table 2.10. Project 3 design and findings – Port Augusta Renal Unit

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Identify and employ four patient navigators to 'walk alongside' and provide support to kidney transplant candidates in Port Augusta and surrounding communities. The patient navigators will assist kidney transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling more patients to commence the kidney transplant assessment and workup process. • Oversee the management of the patient navigator project, including development of education programs and provision of training and support to the navigators, by committing time of a transplant coordinator –	• Three patient navigators recruited, who all commenced in February 2021. Two Navigators based in Port Augusta and one Navigator situated in Adelaide who attends meetings by linking up via an iPad. This patient navigator was also able to attend appointments in person at the Royal Adelaide Hospital (RAH) with patients when available. • Initially the patient navigators were asked to visit the unit regularly to become familiar with staff and patients, to build on the relationships with patients and be accessible for conversation. Patient navigators also assisted in preparation for the education sessions. This involved inviting patients, setting up the room with resources, arranging transport, and ensuring satisfaction surveys were completed. • To establish the role in Port Augusta, the transplant coordinator attended the RAH to meet the kidney transplant team. This was to foster better communication between Adelaide and Port Augusta and an understanding of the roles. Education was also arranged by the RAH transplant team on the kidney transplant work-up process, transplant surgery, and post-transplant. The visit also included a day	• Number of patients referred for workup: increased from 0 to 11. • Number of Aboriginal patients entering the transplant waitlist: increased from 0 to 1. • Number of education sessions and attendees: 32 patients attended an average of 5.3 topics each.	• Preliminary evaluations with patients about the patient navigator role showed it was a welcome addition to the team. Clinicians in the area had also heard patients requesting a 'support person' to accompany them to appointments and trips to Adelaide for many years. Adding activities within the meetings that were of interest to the target group was a useful patient engagement tool. Painting, cooking and campfire days proved particularly popular and uplifted spirits in the dialysis unit. • Being able to spend time with the patients in a relaxed non-clinical environment has helped the staff to understand how to engage on a different level. • The patient navigator role is still in development phase. This phase has seen the role grow and as a result, the demands have increased, and utilisation has expanded. As activity increases with more patients going through the work up process, so will the activity of the patient navigator.	• Continued funding of the patient navigator role. • Financial resources to target education and transplant workup services in country areas. • The expansion of the patient navigator role to support the patient through the spectrum of chronic renal failure. • Greater support for the lifestyle transition post-transplant. • Development and evaluation of educational material for spiritual cleansing of the transplant organs. • Development and evaluation of a "transplant journey folder" in an electronic application for smartphones and iPads. • Support and resources to evaluate the full project from a First Nations perspective. • Support and resources for consumer groups lead by patient navigators • Support and resources to link consumer's journey with clinicians via electronic devices. • Recreational therapy for patients on dialysis to support social and emotional wellbeing and consumer networks

Level 2 associate nurse unit manager (0.4 FTE). • Deliver fortnightly information sessions, in partnership with Pika Wiya Health Service Aboriginal Corporation, covering issues such as healthy behaviours (quitting smoking, good diet, active lifestyle), self-management (cooking classes, medication management), pre-transplant requirements and the journey to kidney transplantation, organ donation, and staying healthy post-transplant.	in the operating suite to observe live donor and recipient kidney transplant. • A ‘My Track to Kidney Transplant’ booklet was created by the transplant coordinator, project manager and PWHS AHP. It included all meetings and work-up tests in a visual format. • Fortnightly meetings were held, whereby culturally appropriate education was provided on topics such as transplant workup, healthy eating/behaviours, quit smoking, medication self-management, diabetes, advance care directives (ACD), and staying healthy post-transplant.			

2.3.8 Project 4: Purple House – Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (Paunuku)

Purple House received $200,000.00 (GST excl.) to expand on their existing patient mentor program and provide a specialized kidney transplant support team ('Hunting Transplant Team'), comprised of patient mentors and a transplant coordinator. Patient mentors 'walk alongside' and provide support to kidney transplant candidates from targeted communities. Key deliverables of the project included: improving health literacy scores; improving attendance rates at pre-transplant workup and assessment appointments; increasing the number of people undergoing workup and achieving transplant waitlisting; and reducing the average time spent completing pre-transplant workup and assessment. The kidney transplant support team aimed to collaborate fortnightly with key stakeholders in South Australia and Queensland, to establish a kidney transplant support network and to facilitate further opportunities for education and information sharing.

Please find the Purple House *Progress Report* here.

Please find the Purple House *Final Report* here.

Sponsorship Summary

Purple House, an Aboriginal Community Controlled Health Service, was awarded $200,000 to support an existing team of Aboriginal well-patient mentors working for Purple House to create a program targeted at supporting people hunting for kidney transplant in a culturally safe and respectful approach.

Purple House started as the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation, meaning *making all our families well*, and now exists as an entirely Aboriginal and Torres Strait Islander-run non-profit that provides dialysis through 18 remote clinics and a mobile dialysis truck.

The purpose of the Sponsorship was for Purple House to expand their existing patient mentor program and provide a specialised kidney transplant support team (known as the 'hunting transplant team'), comprised of patient mentors with a lived experience of the kidney disease journey and a transplant coordinator. The transplant coordinator aimed to support the patient mentors by walking alongside them, assisting with the translation of health service requirements, and providing clinical expertise as required.

Purple House was funded to:

1. Identify and employ four patient mentors with connections to Lajamanu, Kalkarindji, Yirrkala or Groote Eylandt to 'walk alongside' and provide support to kidney transplant candidates from targeted communities. The patient mentors will assist kidney transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling patients to efficiently complete pre-transplant workup and assessment requirements. The hunting transplant team will adhere to the workup schedule and recommendations specified by the primary nephrologist and transplant unit staff.
2. Employ a renal transplant coordinator (0.6 FTE) to oversee the management of the hunting transplant team and provide support to the patient mentors.
3. Collaborate with key stakeholders, including transplant staff at the Royal Adelaide Hospital, the Renal Advisory and Advocacy Committee and the Central Australian Renal Voice to establish a

kidney transplant support network and facilitate further opportunities for education/information sharing.

4. Partner with the Menzies School of Health Research and the NIKTT Patient Mentor Working Group to develop a culturally appropriate evaluation framework that will assess the efficacy of the original patient mentor program and the new hunting transplant team from both community and health care provider perspectives.

Table 2.11 Project 4 design and findings – Purple House

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Identify and employ four patient mentors with connections to Lajamanu, Kalkarindji, Yirrkala or Groote Eylandt to 'walk alongside' and provide support to kidney transplant candidates from targeted communities. The patient mentors will assist kidney transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling patients to efficiently complete pre-transplant workup and assessment requirements. The hunting transplant team will adhere to the workup schedule and recommendations specified by the primary nephrologist and transplant unit staff. • Employ a renal transplant coordinator (0.6 FTE) to oversee the management of the hunting transplant team and provide support to the patient mentors. • Collaborate with key stakeholders, including transplant staff at the Royal Adelaide Hospital, the Renal Advisory and Advocacy Committee and the Central Australian Renal Voice to establish a kidney transplant support network and	• The program was modelled on the framework of hunting. Hunting involves acknowledgement that a particular process must be undertaken and that certain things are required to achieve success. Elements of a successful hunt include: - Knowledge about the target and its environment - understanding how to navigate health services and pre/post-transplant care - Providing targeted education and support that complements and enhances mainstream service delivery and the process - determining how the target will be captured (undertaking work-up and maintaining transplant fitness and motivation) - Assisting with motivational support and assistance to meet work up requirements - Determining resources – transport and tools, including support, transport to appointments (plus a companion when required)	• Number of patients assessed/mentored: 109. • Number who commenced workup: increased from 14% to 16% of patient population seen by Panuku. • Number of Aboriginal transplants performed: 12% of all patients seen. • Number of patients interested in transplantation: increased from 3% to 19%. • Number of patients not yet assessed: reduced from 32% to 0%.	• Access to NT government mainstream health service clinical information is an ongoing challenge as it creates a data gap for the performance metrics identified in the scholarship application. • The team's commitment to working within an Indigenous-designed evaluation framework is a work in progress. • The mentor's wellbeing and physical health is always a priority and at times will naturally impact on their work commitments. The group is committed to collaborative decision-making when important decisions are required, they will wait until everyone is able to participate in the process.	• Embed mentor roles in renal services. • Ensure there is formal acknowledgement of the mentor role. • Recruit more mentors to balance gender, age, and community representation.

facilitate further opportunities for education/information sharing. • Partner with the Menzies School of Health Research and the NIKTT Patient Mentor Working Group to develop a culturally appropriate evaluation framework that will assess the efficacy of the original patient mentor program and the new hunting transplant team from both community and health care provider perspectives.	- Maintaining good communication lines with mainstream transplant coordination team - Follow through - maintaining commitment in the pre/post-transplant phase Outcome - hit the mark or miss, retry, or target an alternative hunt • The role and activities of the mentors have been central to the Hunting Kidney Transplant project and focused on: introducing patients to the transplant system and clinical team; building confidence and trust in the process; sharing information; providing emotional support; empowering patients with knowledge; and connecting patients with relevant pre- and post-transplant services.			

2.3.9 Project 5: Cairns and Hinterland Hospital and Health Service

Cairns and Hinterland Hospital and Health Service received $107,940.00 (GST excl.) to deliver a patient mentor pilot project ('Tracks to Transplant Patient Mentoring Project'). The project involved identifying and employing two patient mentors to 'walk alongside' and provide support to kidney transplant candidates. The project also aimed to recruit a renal transplant clinical nurse consultant (CNC) and Indigenous Liaison Officer. Initially, the project was set to commence at the beginning of 2020. Due to COVID and travel restrictions, this was delayed until mid-2020. Extended leave of the project lead due to unforeseen circumstances led to the project being further delayed until February 2021. Despite delays, the project progressed and was able to be completed, albeit with reduced outputs. The Cairns and Hinterland project returned an underspend of $ $72,761.29 that was unable to be utilised. These monies were re-invested into NIKTT operations and activities, as agreed upon with the grant awards team.

Please find the Cairns and Hinterland Hospital and Health Service's *Progress Report* here.

Please find the Cairns and Hinterland Hospital and Health Service's *Final Report* here.

Sponsorship Summary

The purpose of the Sponsorship was for Cairns and Hinterland Hospital and Health Service to deliver a patient mentor project, which aimed to involve the identification of Indigenous kidney transplant recipients who could mentor transplant candidates throughout the pre-transplant journey. In addition, a review of potential barriers to kidney transplant referral was to be undertaken to complement the patient mentor project and reveal the most significant hurdles that impede Indigenous patients from completing workup and assessment for kidney transplantation. Together, the two initiatives aimed to improve access to the kidney transplant waitlist for Indigenous patients.

Cairns and Hinterland Hospital and Health Service was funded to:

1. Identify and employ two patient mentors (based in Cooktown and Thursday Island) to 'walk alongside' and provide support to kidney transplant candidates in their community. The patient mentors will assist transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling patients to efficiently complete pre-transplant workup and assessment requirements.
2. Oversee the management of the patient mentor project and provide support to the mentors by committing time of a renal transplant CNC (0.1 FTE) and Indigenous Liaison Officer (0.2 FTE).
3. Deliver education sessions in Cooktown and Thursday Island, utilising tailored resources (such as pamphlets/information sheets).
4. Undertake an audit of the dialysis population at Cairns Hospital to determine barriers and delays in the pre-transplant workup process, preventing successful completion of transplant workup and assessment.

Table 2.12. Project 5 design and findings – Cairns and Hinterland Hospital and Health Service

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Identify and employ two patient mentors (based in Cooktown and Thursday Island) to 'walk alongside' and provide support to kidney transplant candidates in their community. The patient mentors will assist transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling patients to efficiently complete pre-transplant workup and assessment requirements. • Oversee the management of the patient mentor project and provide support to the mentors by committing time of a renal transplant CNC (0.1 FTE) and Indigenous Liaison Officer (0.2 FTE). • Deliver education sessions in Cooktown and Thursday Island, utilising tailored resources (such as pamphlets/information sheets).	• Mentor meetings and education sessions were held throughout 2021. • 0.2 FTE Aboriginal and Torres Strait Islander Liaison Officer seconded to the project. • Five mentors were inducted through the Far North Queensland Health Foundation as volunteers. • Mentor for Thursday Island identified in August 2021 and initial patient/mentor sessions were conducted at Cairns Private (Public) Unit.	• Number of patients assessed/mentored: 84. • Number who commenced workup: increased from 5 to 10. • Number of people on the waiting list: 4. • Number of patients not undergoing workup: decreased from 14 to 1. • Number of patients transplanted: increased from 0 to 2.	• The project provided a culturally safe approach to patient education that was well received by patients and their families. • The project identified that most pre-transplant patients wanted to know about post-transplant medications, what happens at the transplanting hospital, and what is required to get on the list. • Increased collaboration with other sites (Port Augusta and Panuku) was important. • Greater awareness of transplantation through mentor assisted visits to dialysis units was achieved. • The current pay structure at the organisation made it difficult to employ mentors. • Fewer mentors were found due to a lack of Aboriginal and Torres Strait Islander transplant patients who had time to give to the project due to current employment or family duties. • COVID significantly impacted the ability of mentors to arrange group activities. Four were organised but all	• Ongoing funding for Aboriginal and/or Torres Strait Islander mentors. • Expansion of the mentor program for all units with a significant proportion of Aboriginal and/or Torres Strait Islander patients. • The ability to pay for mentors through Queensland Health pay classification system that recognises the expertise that expert patients have. • Mentors must be involved across the continuum of kidney health, including in primary health. Kidney stories can be impactful across generations. • Establishment of mentor-led consumer groups at local dialysis unit level. • An education package for mentors about dialysis and transplant options. • Increased culturally appropriate education material for pre- transplant patients about transplant, especially the journey to transplant, transplant medications, and what to

- Undertake an audit of the dialysis population at Cairns Hospital to determine barriers and delays in the pre-transplant workup process, preventing successful completion of transplant workup and assessment.			were impacted by lockdowns or restrictions on group meetings. - Such a program needs a dedicated transplant nurse to work with mentors if the project is to be upscaled. - Ongoing funding is needed for mentors and support staff	expect after transplant. This would be best produced at a state level to reflect state-based processes

2.3.10 Project 6: Top End Health Service

Top End Health Service received $200,000.00 (GST excl.) to recruit two Aboriginal and Torres Strait Islander Health Practitioners (ATSIHPs) (1.0 FTE responsible for servicing the Darwin region and 0.6 FTE responsible for servicing the Katherine region). The project aimed to provide training and support to the ATSIHPs to deliver transplant education, coordinate workup appointments, review education materials, and support Aboriginal and Torres Strait Islander patients being referred to multidisciplinary health care teams. There were initial delays with the sponsorship project due to COVID-19 which had an immense impact on the recruitment process. The ATSIHPs were able to commence in their role on the 14th of December after a lengthy recruitment process. The Top End Health Service project returned an underspend of $77,039.60 that was unable to be utilised. These monies were re-invested into NIKTT operations and activities, as agreed upon with the grant awards team.

Please find the Top End Health Service's *Progress Report* here.

Please find the Top End Health Service's *Final Report* here.

Sponsorship Summary

The Top End Health Service, located on Larrakia Country in the Northern Territory (NT), was awarded $200,000 to employ two Aboriginal and/or Torres Strait Islander health professionals to bridge cultural gaps between Aboriginal and Torres Strait Islander kidney patients and the mainstream health system. These health professionals were hired to service the populations of both Darwin and Katherine.

Darwin, the capital city of the Northern Territory, is known as *Garramilla* ("white stone") to the Larrakia people, the traditional custodians of the land around the city. Darwin is located 3,000kms (3.5-hour flight) away from Adelaide, where the Territory's renal transplantation patients go to the Royal Adelaide Hospital for transplantation. Most of the NT's population (60%) live in Darwin, with an estimated 150,000 people, of which about 9% are of Aboriginal and/or Torres Strait Islander descent.

Katherine is the fourth-largest city (or town) in the NT, where it marks the convergence of the traditional lands of the Dagoman, Jawoyn, and Wardaman people. For thousands of years, it was, and still is, an important meeting place for Aboriginal peoples. Katherine is about 300km south-west of Darwin, or 2,700kms north of Adelaide, requiring people to fly first to other cities before flying to Adelaide for transplantation. Katherine has as estimated population of just over 10,000 people, of which Aboriginal and Torres Strait Islander people make up around 25%.

The purpose of the sponsorship was for Top End Health Service to employ two ATSIHPs to bridge the cultural gap between Aboriginal and Torres Strait Islander patients and the mainstream health system, complementing existing and expanding transplant services. The ATSIHPs aimed to cover two regions (Katherine and Darwin), providing kidney transplant education, pre-transplant workup support and increased liaison with primary health services.

The Top End Health Service was funded to:

1. Recruit two ATSIHPs (1.0 FTE responsible for servicing the Darwin region and 0.6 FTE responsible for servicing the Katherine region).
2. Train the ATSIHPs to deliver kidney transplant education and have them shadow transplant coordinators to increase their knowledge of the transplant workup and assessment process.
3. Support the ATSIHPs to deliver kidney transplant education, coordinate workup appointments, review education materials, and support Aboriginal and Torres Strait Islander patients being referred to multidisciplinary health care teams, including Adelaide clinics.

Table 2.13. Project 6 design and findings – Top End Health Service

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Recruit two Aboriginal and Torres Strait Islander Health Practitioners (ATSIHPs) and/or Aboriginal Liaison Officers (ALOs) (1.0 FTE responsible for servicing the Darwin region and 0.6 FTE responsible for servicing the Katherine region). • Train the ATSIHP/ALOs to deliver transplant education and have them shadow transplant nurses to increase their knowledge of the transplant workup and assessment process. • Support the ATSIHP/ALOs to deliver transplant education, coordinate workup appointments, review education materials, and support Indigenous patients being referred to multidisciplinary health care teams, including Adelaide clinics.	• Aboriginal Liaison Officer (ALO) was employed full time from July 2021, with the remaining funding to support an ATSIHP. The ALO was currently working in the Renal Home Therapies service, so recruitment was able to happen relatively quickly. • Together the ATSIHP and ALO organised the NIKTT Indigenous Patient Reference Group with 6 patients identified as members, and 4 meetings organised for the 28th of July, 8th of sept, 15th of Oct and 19th of Nov. • July saw the resignation of the ATSIHP, and so the ALO was the sole Indigenous Australian working in the project. The ALO went on to lead the IPRG meetings, organise a meeting with the Panuku group members, and support the existing renal transplant nurses.	• Number of patients assessed: 89. • Number who commenced workup: 34. • Number who received targeted culturally appropriate transplant education: 70.	• COVID-19 had a profound effect on the outcome of the sponsorship activities. This was due to access to care and specialist services either not being allowed, available, or limited.	• Recruitment of ATSIHP into the transplant team workforce. The skills, qualification, and cultural expertise that they bring to the team is invaluable, as is their ability to bridge the cultural gap and gain learnings /stories that Aboriginal and Torres Strait Islander peoples may not share with health professionals from different cultures. • Addition of ALO to transplant team. The skills and qualifications required for this role have a different focus compared to ATSIHP. The role centers around meeting social and everyday needs, helping patients access healthcare, and addressing social requirements in care (e.g., assisting patients in getting identification documents, liaising with Centrelink and Medicare, and helping patients find housing/settle into town if they're new to KRT). • Addition of patient mentors into the transplant team. as This role provides patients with support and lived experience of the transplant process and pathway to help make the journey a smoother and less stressful.

				• Development of culturally appropriate educational resources with videos of patients telling their own stories in multiple languages. • Education and training for health professionals on how to deliver culturally appropriate education and how to interact /communicate with patients in a private consult to overcome the cultural barrier. • Alternative ability to assess patients for transplant suitability. When specialists make visits, the team can't always reach remote locations. In order to avoid creating additional obstacles for patients trying to access transplantation services, telehealth consultation could be arranged with the primary nephrologist referring the patient, while the transplant nephrologist and surgeon could provide directions on any necessary physical assessments. If a surgeon's physical assessment is necessary, they could coordinate with the surgical team at the referring hospital to explore the feasibility of a collaborative telehealth consultation that fulfills the assessment requirements.

2.3.11 Project 7: Princess Alexandra Hospital

Princess Alexandra Hospital received $40,250.00 (GST excl.) to deliver outreach education on Kidney Transplantation to regional and remote centres more than 250km from Brisbane. Education seminars were tailored to the needs of the target community, harnessing local knowledge. Culturally appropriate education resources were developed for dissemination at outreach education sessions.

Please find the Princess Alexandra Hospital's *Progress Report* here.

Please find the Princess Alexandra Hospital's *Final Report* here.

Sponsorship Summary

The Princess Alexandra Hospital (PAH), located on Turrbal Country in Queensland (Qld), was awarded $40,250 to provide renal transplant education to Aboriginal and Torres Strait Islander kidney patients in Queensland.

The aim of this project was to provide Renal Transplant education, which is culturally safe and appropriate, to the First Nations people of Queensland. The education was to be provided by the team that will be delivering the specialised care. By providing face-to-face outreach education, the sessions were designed to be delivered on, or near to, Country, which is more suitable and accessible for patients than venturing to Brisbane.

Princess Alexandra Hospital (PAH) provides a state-wide Kidney Transplantation service for Queensland, as well as for selected patients in Northern NSW and the Northern Territory. Prior to the pilot project, education was provided at local health services by an appropriately trained staff member (such as a renal transplant coordinator). There was also a specific education workshop, held at PAH four times a year, that delivers comprehensive education about the transplantation process. For people living in Brisbane and Southeast Queensland, it is easy to attend and meet face to face with the staff who are involved in the transplant journey and will provide the actual care. For other health services (>250km) from PAH, this experience is only accessible by video conferencing, which lacks personability. Feedback from the regional centres expressed a dislike for video conferencing.

The Princess Alexandra Hospital was therefore funded to:

1. Deliver outreach education on kidney transplantation to regional and remote centres more than 250km from Brisbane (initially Townsville, Mt Isa, Cairns, and Thursday Island). Education seminars will be tailored to address the needs of the target community, harnessing local knowledge.
2. Develop culturally appropriate resources for dissemination at outreach education sessions.
3. Deliver face-to-face yarning circles, improving rapport between Aboriginal and Torres Strait Islander communities and the Princess Alexandra transplant team. This will also facilitate the sharing of cultures, constituting a two-way learning experience.

Table 2.14. Project 7 design and findings – Princess Alexandra Hospital

Design and Objectives	Activities and Implementation	Quantitative Findings	Qualitative Findings	Recommendations
• Deliver outreach education on kidney transplantation to regional and remote centres more than 250km from Brisbane. Education seminars will be tailored to address the needs of the target community, harnessing local knowledge. • Develop culturally appropriate resources for dissemination at outreach education sessions. • Deliver face-to-face yarning circles, improving rapport between Aboriginal and Torres Strait Islander communities and the Princess Alexandra transplant team. This will also facilitate the sharing of cultures, constituting a two-way learning experience.	• Yarning Session – Townsville – 2nd November 2020. • Yarning Session – Mount Isa – 3rd November 2020. • Yarning session – Cherbourg – 14th & 15th June 2021. • Yarning Session – Toowoomba – 16th June 2021. • Yarning Session – Woorabinda – 28th & 29th June 2021.	• Number of patients who commenced workup: 9 • Number of Aboriginal patients entering the transplant waitlist: 4 • Number of Aboriginal transplants performed: 2 • Number of education sessions: 7 • Number of visits conducted: 6 trips	• The project helped to strengthen life experience through ‘living in the shoes’ of others. • The project found it is important to have an understanding of where people come from; physically, mentally, spiritually and culturally. • Sharing of life experiences builds rapport, trust, and integrity between patients and clinicians. • Utilising Aboriginal and Torres Strait Islander staff and letting them have freedom to utilise their cultural skills is crucial.	• An initial pre-assessment is needed before conducting educational sessions on Country – making contact initially; going onto country; meeting the appropriate stakeholders; and sharing the concept and gaining permission to enter Country to deliver culturally appropriate care. • Co-Design education with Aboriginal and Torres Strait people as cultural resources, appropriate to that specific part of Australia. • Aboriginal and Torres Strait Islander clinicians must lead the programs. • Deliver education on Country, and keep it personable, simple, and relatable.

2.3.12 Project 8: Pika Wiya Health Service Aboriginal Corporation

Pika Wiya Health Service Aboriginal Corporation received $148,000.00 (GST excl.) to recruit an Aboriginal and Torres Strait Islander Health Practitioner (AHP) to service the Port Augusta Indigenous Kidney Community. The role of the AHP was to bridge service delivery gaps and educate patients with kidney disease about transplantation as a treatment option. The AHP would be provided with training to provide culturally appropriate education in an outreach/home visit environment and to also support the referral of patients to multidisciplinary health care teams. Fortnightly information sessions were designed to be run in partnership with the Port Augusta Hospital Renal Unit's patient navigator team, covering issues such as: healthy behaviours (quitting smoking, good diet, active lifestyle), self-management (cooking classes, medication management), pre-transplant requirements and the journey to kidney transplantation, organ donation and staying healthy post-transplant.

Please find the Pika Wiya Health Service Aboriginal Corporation's *Progress Report* here.

Please find the Pika Wiya Health Service Aboriginal Corporation's *Final Report*here.

Sponsorship Summary

The purpose of the Sponsorship was for Pika Wiya Health Service Aboriginal Corporation to employ an Aboriginal Health Practitioner (AHP) to bridge service delivery gaps and educate patients with kidney disease about transplantation as a treatment option. The initiative planned to capture all dialysis patients in the Port Augusta community, with the AHP helping to overcome language, knowledge and cultural barriers that previously prevented Indigenous patients from pursuing a kidney transplant.

Pika Wiya Health Service Aboriginal Corporation was funded to:

1. Recruit one AHP to service the Port Augusta Indigenous kidney community.
2. Train the AHP to provide culturally appropriate education in an outreach/home visit environment and support referral of patients to multidisciplinary health care teams, including Adelaide clinics.
3. Deliver fortnightly information sessions, in partnership with the Port Augusta Hospital Renal Unit's patient navigator team, covering issues such as: healthy behaviours (quitting smoking, good diet, active lifestyle), self-management (cooking classes, medication management), pre-transplant requirements and the journey to kidney transplantation, organ donation, and staying healthy post-transplant.

Unfortunately, due to significant staff turnover and challenges associated with COVID-19, the Pika Wiya Sponsorship project was unable to complete the proposed activities and reporting requirements. The project worked closely with the team from the Port Augusta On Tracks to Transplant project, helping to run education sessions as well as providing logistical support for education sessions and the patient mentors.

2.4 Objective 4: Evaluating Cultural Bias Initiatives

The NIKTT's fourth and final objective was to review and evaluate existing initiatives within Australia that addressed cultural bias to determine best practices for health services going forward. The Lowitja Institute was commissioned to undertake this work, who subsequently contracted the University of Adelaide to support the review. This review focused on both peer-reviewed and grey literature within Australia, finding that there were limited evaluated initiatives that addressed cultural bias, with especially few evaluating interventions within kidney care settings. From the findings of the review, the Lowitja and University of Adelaide team created four domains for action, which overall contained 14 recommendations.

Table 2.15 Activity Work Plan for Objective 4 of the National Indigenous Kidney Transplantation Taskforce

Objective	Strategies	Performance Measures	Risks	Outcomes
Evaluate cultural bias interventions				
• Scoping review completed	• Evaluate and leverage existing initiatives that target cultural bias in health services	• Completion of scoping review • Completion of recommendations	• Inexperienced contractor • Scoping review does not adequately address the key objective Mitigation: • Engagement of experienced and culturally aware contractor • Final payment dependent on acceptance of scoping review	• Review and subsequent report were completed in 2021 • Report provided to Commonwealth Government in 2022 • Recommendations from Report informed NIKTT recommendations and input for the draft *National Strategy*

2.4.1 Summary

Cultural bias was a particular priority of the Taskforce, as directed by the then-Minister for Indigenous Health. In order to address a variety of pre-transplant barriers to transplantation, the TSANZ Expert Panel report recommended:

- Improving the equity and accessibility of transplantation for Aboriginal and Torres Strait Islander patients by:
  - Evaluating and leveraging existing initiatives that target cultural bias in health services to facilitate the rollout of best practice pre-transplant care, and support interventions for Aboriginal and Torres Strait Islander transplant candidates.

The NIKTT was therefore tasked with reviewing existing initiatives that target cultural bias in health services to facilitate best practice care and support. To best achieve this aim, from an outside-of-renal perspective and guided by Aboriginal and/or Torres Strait Islander researchers, the NIKTT commissioned the Lowitja Institute to conduct this review, committing $50,628.75 to delivery of the review. In turn, the Lowitja Institute contracted researchers from the University of Adelaide to facilitate completion of the work. These organisations were commissioned to deliver a scoping review which addressed the following questions:

- What health service cultural bias interventions currently exist in health care settings?

- What is the effectiveness of these interventions in relation to outcomes, including but not limited to wait-listing for kidney transplantation?
- What do patient, carer/support person and provider experiences of these interventions reveal about the acceptability of existing interventions, as well as barriers and facilitators of implementation?

A Cultural Bias Working Group was established within the NIKTT to determine the scope and parameters of this review. The WG met regularly in 2020 to provide guidance on how the review was undertaken, with the final scoping review completed in late 2020 and officially launched on World Kidney Day in March 2022.

The report found that there was limited evidence within renal settings of evaluated cultural bias interventions. Based on the available published and grey literature, as well as community consultation, the Report identified 14 individual recommendations to address cultural bias. The NIKTT has prioritised 5 of these recommendations for immediate implementation, including:

(1) establishing Indigenous Reference Groups in all renal settings;
(2) increasing the Aboriginal and Torres Strait Islander health workforce in renal settings;
(3) funding sustainable kidney patient navigator or peer support roles;
(4) creating and evaluating renal-specific ongoing cultural safety training for all staff in transplant units and other kidney health settings; and
(5) designing and implementing tailored models of care for Aboriginal and Torres Strait Islander kidney patients seeking transplantation.

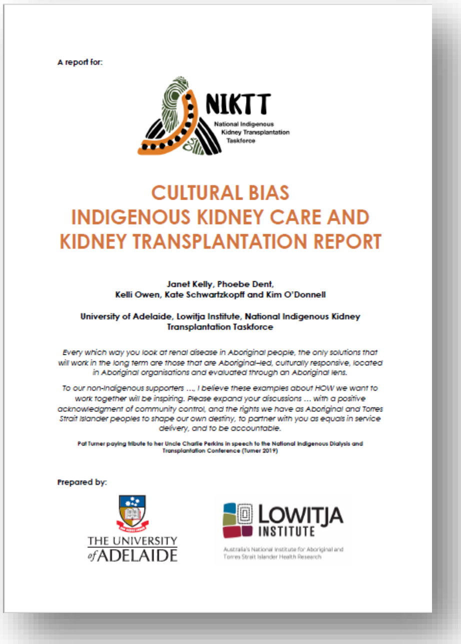
2.4.2 The Report

The Cultural Bias Report was delivered to the NIKTT in late 2020 and submitted to the Commonwealth Government in 2021. Alongside the full scoping review Report, a Policy Brief was published that summarised the findings and recommendations across four key domains for action.

Below, we reproduce the Executive Summary of the Report and provide links to the final documents.

Download the report and policy brief from:

www.niktt.com.au/culturalbias



A report for:

NIKTT
National Indigenous
Kidney Transplantation
Taskforce

CULTURAL BIAS
INDIGENOUS KIDNEY CARE AND
KIDNEY TRANSPLANTATION REPORT

Janet Kelly, Phoebe Dent,
Kelli Owen, Kate Schwartzkopff and Kim O'Donnell

University of Adelaide, Lowitja Institute, National Indigenous Kidney
Transplantation Taskforce

Every which way you look at renal disease in Aboriginal people, the only solutions that will work in the long term are those that are Aboriginal–led, culturally responsive, located in Aboriginal organisations and evaluated through an Aboriginal lens.

To our non-Indigenous supporters …, I believe these examples about HOW we want to work together will be inspiring. Please expand your discussions … with a positive acknowledgment of community control, and the rights we have as Aboriginal and Torres Strait Islander peoples to shape our own destiny, to partner with you as equals in service delivery, and to be accountable.

Pat Turner paying tribute to her Uncle Charlie Perkins in speech to the National Indigenous Dialysis and Transplantation Conference (Turner 2019)

Prepared by:

THE UNIVERSITY
of ADELAIDE

LOWITJA
INSTITUTE
Australia's National Institute for Aboriginal and
Torres Strait Islander Health Research

Executive Summary

Kidney disease is a serious and increasing health problem for many Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander peoples are significantly more likely to experience kidney failure compared to other Australians, be diagnosed at an earlier age, and have a higher prevalence of other comorbidities (ANZDATA Registry 2018).

Despite this disparity, Aboriginal and Torres Strait Islander peoples are much less likely to receive a kidney transplant (Khanal et al. 2018). In 2017, the proportion of Aboriginal and Torres Strait Islander peoples who had received a kidney transplant for treatment of kidney failure was 13 per cent compared to 51 per cent for non-Indigenous Australians (ANZDATA Registry 2018)

To address these inequities in health outcomes and access to treatment, the National Indigenous Kidney Transplantation Taskforce (NIKTT) was established in July 2019. The taskforce was formed as a result of the report on *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia* (Garrard & McDonald 2019) led by the Transplantation Society of Australia and New Zealand (TSANZ). Amongst other findings, the report identified cultural bias as barrier to Aboriginal and Torres Strait Islander peoples receiving equitable access to kidney transplantation.

This review represents the first step, under the NIKTT, to identify, understand and address underlying reasons for the gap in transplantation rates related to cultural bias and identify effective initiatives for future improvements.

Racism and cultural bias in healthcare

This project aims to bring understanding to the term cultural bias, how it is founded in racism and colonisation, and how racism occurs across the Australian healthcare system.

Although the causes of the health disparities between non-Indigenous and Aboriginal and Torres Strait Islander peoples are complex, multiple sources of evidence suggest that racism is a significant factor, even when it is unintended. Racism manifests in various ways in healthcare through inflexible institutional and organisational systems and implicit and explicit bias from health professionals. Data on the experiences of Aboriginal and Torres Strait Islander healthcare users in Australia in regard to racism and cultural safety is limited [i]. This information is critical to reducing racism and the harm it causes.

One national survey found that 32.4 per cent of Aboriginal and Torres Strait Islander patients reported racial discrimination in medical settings most or all of the time[ii] and, in 2012–13, 20 per cent of Aboriginal and Torres Strait Islander Australians reported being treated unfairly by healthcare staff in the last 12 months[iii].

To address racism, culturally safe healthcare systems and practices are needed. Cultural safety, unlike cultural awareness, focuses on equity, systemic and individual behaviour change through critical reflection, and acknowledges the impact of colonisation and power differentials between healthcare providers and patients. Importantly, cultural safety is defined by recipients of care, rather than the care provider.

For the purposes of this work, cultural bias refers to the various mechanisms through which health professionals, organisations and systems perpetuate or deliver inequitable healthcare access and outcomes for Aboriginal and Torres Strait Islander peoples. These mechanisms include, but are not limited to, attitudes, beliefs, behaviours, policies, resourcing, governance and accountability and encompass both institutional and interpersonal racism. While the negative impact is often unintended, it remains incredibly harmful to Aboriginal and Torres Strait Islander people's health and wellbeing.

[i] Australian Institute of Health and Welfare (AIHW) 2019, *Cultural Safety in Healthcare for Indigenous Australians: Monitoring framework*, Cat.no. IHW 222, AIHW, Canberra.

[ii] Cunningham, J. & Paradies, Y.C. 2013, 'Patterns and Correlates of Self-reported Racial Discrimination among Australian Aboriginal and Torres Strait Islander Adults, 2008–09: Analysis of national survey data',
International Journal of Equity in Health, vol. 12(47), DOI: https://doi.org/10.1186/1475-9276-12-47

[iii] AIHW 2019, op. cit..

Methodology

A mixed methods approach was undertaken to identify, analyse and present the available evidence regarding cultural bias initiatives in renal care for Aboriginal and Torres Strait Islander peoples in Australia. The method aimed to decolonise the data collection and analysis process to ensure that diverse information and voices were not missed. In order to achieve this goal, the scoping review was conducted in two parts:

1. Systematic review of peer reviewed literature.
2. Grey literature review that also included resource recommendations by experts in the field, and information from patient-expert and Aboriginal healthcare professional consultations.

The search for the peer reviewed literature extended beyond renal care in recognition that 1) there was limited information available, and 2) initiatives from other areas of healthcare may offer valuable strategies applicable for renal transplantation. Given the volume of potential grey literature, sources of this material were limited to publicly available documents focused on renal care for Aboriginal and Torres Strait Islander peoples. These documents were identified through an advanced Google search and consultation with NIKTT staff members and the Cultural Bias Working Group. Patient-expert and Aboriginal health professional voices came from community consultation work conducted by the NIKTT National Community Engagement Coordinator.

Results

This scoping review has revealed that there are very few published examples of initiatives to address cultural bias for Aboriginal and Torres Strait Islander Peoples in relation to kidney transplantation or renal care that have been formally evaluated and published.

Of the peer reviewed literature, only two papers outlined cultural bias initiatives in renal care that have been evaluated. The first describes the effectiveness of the South Australian Renal Dialysis Bus from the perspective of Aboriginal patients and staff who travelled to rural and remote locations on the bus (Conway et al. 2018). The second focuses on the structure, implementation, and outcomes of telenephrology clinics for the management of patients with chronic kidney disease (CKD) in rural, regional, and remote areas of the Darling Downs region in Queensland, Australia (Venuthurupalli et al. 2018).

A diverse range of initiatives to address cultural bias were identified across a range of other tertiary healthcare settings. Initiatives from other areas of care can provide examples and opportunities to learn from where cultural bias initiatives are more strongly developed. This was particularly the case for maternity care which focused on new or improved models of care which included Aboriginal and Torres Strait Islander roles, extended midwifery practice, working collaboratively with other services, advocating for improvement in women’s care, and meeting holistic health and access needs of Aboriginal and Torres Strait Islander women.

The review of the grey literature and community consultations found that many small cultural bias initiatives are being undertaken in kidney health and kidney transplantation locations and care settings across Australia, but few have been formally evaluated and published. Over the last two decades, a series of renal focused research projects have identified issues and problems of access to care for Aboriginal and Torres Strait Islander peoples, with recommendations for improvement from biomedical, health service, healthcare professionals and patient, family and community perspectives. Arguably, the same or similar issues and problems have been identified over the last 20 years. For example, in 2004 the IMPAKT study identified that there was a need to examine and remodel the health system so that kidney transplant services were equitable and effective for all Australians. In 2019, the TSANZ report on *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander Peoples in Australia* outlined a similar range of barriers for Aboriginal and Torres Strait Islander kidney transplant candidates, highlighting the little progress that has been made. In fact, data shows that the gap in rates of transplantation is widening from one-third the rate in 2008 to one-quarter the rate in 2017 (ANZDATA Registry 2018; Devitt et al. 2008).

To improve kidney transplantation rates, it is necessary to focus on the full spectrum of kidney care to analyse the steps that need to be taken to address cultural bias across the entire patient pathway from diagnosis to transplantation. The steps preceding receiving a kidney transplant are complex and each step represents its own barrier to ultimately receiving a transplant (Cass et al. 2004; Stacey 2019).

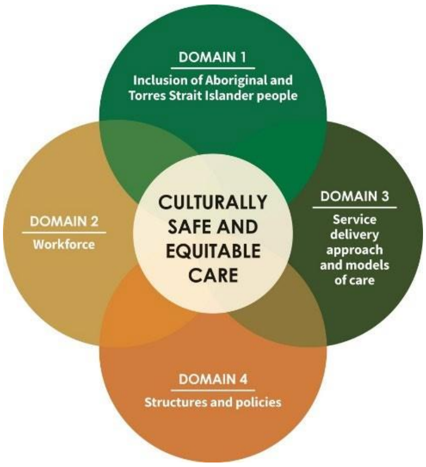
Initiatives to improve Aboriginal and Torres Strait Islander people's access to dialysis have occurred for some time, particularly for people living in rural and remote areas. There has also been a focus on improving access to early detection and slowing the progression of kidney disease particularly in primary care and Aboriginal Community Controlled Health Organisations (ACCHOs).

The review also found that there is an increasingly conducive policy environment in Aboriginal and Torres Strait Islander health for further action to address cultural bias in kidney care. Several national initiatives, such as the implementation of National Safety and Quality Health Service (NSQHS) standards and Australian Health Practitioner Regulation Agency's (AHPRA) cultural safety strategy show promise but are yet to be fully felt by Aboriginal and Torres Strait Islander kidney patients and clients on the ground.

A framework for planning, implementing and evaluating cultural bias initiatives

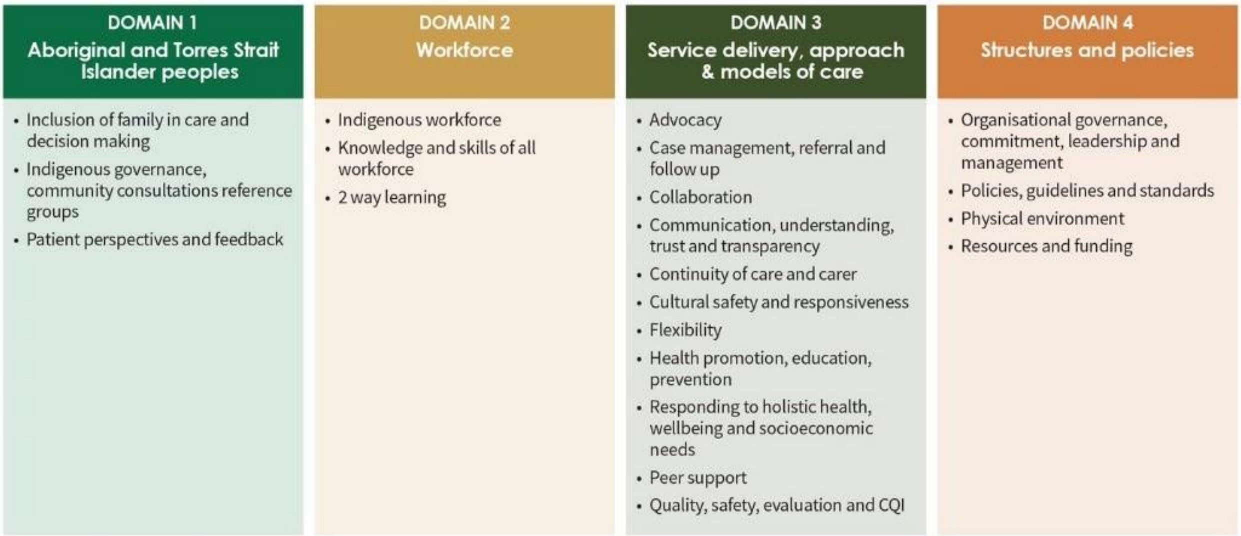
The enablers identified in the grey and peer reviewed literature of this review have been used to create a framework for planning, implementing, and evaluating cultural bias initiatives. These enablers combine key elements from 1) the 20 peer reviewed studies across a range of healthcare areas, 2) renal specific examples of transplantation, dialysis and prevention/detection care, projects, and priorities from across Australia, and 3) the principles within the Health Care Action Framework for Aboriginal and Torres Strait Islander Peoples (Bourke et al. 2020). This cultural bias framework is informed by an evaluation of effectiveness from a recipient of care, or health professional or administrative and clinical data perspective, and identification of key facilitators and barriers at an individual, service and systems level.

Figure 3: The framework for planning, implementing and evaluating cultural bias initiatives



The framework includes four main domains of care: Inclusion of Aboriginal and Torres Strait Islander peoples; Workforce; Service delivery, approach, and models of care; and Structures and policies that are necessary to support people on their kidney transplantation journey.

Figure 4: Framework domains and sub-domains



DOMAIN 1 Aboriginal and Torres Strait Islander peoples	DOMAIN 2 Workforce	DOMAIN 3 Service delivery, approach & models of care	DOMAIN 4 Structures and policies
• Inclusion of family in care and decision making • Indigenous governance, community consultations reference groups • Patient perspectives and feedback	• Indigenous workforce • Knowledge and skills of all workforce • 2 way learning	• Advocacy • Case management, referral and follow up • Collaboration • Communication, understanding, trust and transparency • Continuity of care and carer • Cultural safety and responsiveness • Flexibility • Health promotion, education, prevention • Responding to holistic health, wellbeing and socioeconomic needs • Peer support • Quality, safety, evaluation and CQI	• Organisational governance, commitment, leadership and management • Policies, guidelines and standards • Physical environment • Resources and funding

Inclusion of Aboriginal and Torres Strait Islander peoples

There is increasing recognition in Australia of the need for Aboriginal and Torres Strait Islander peoples to be meaningfully involved in all levels of healthcare decision making and governance. This may include, for example, informed consent and decision making, involvement of family in care plans, and co-design of health services. There are significant opportunities currently to address institutional racism and to more effectively de-colonise our healthcare system, thereby enabling more equitable access and outcomes.

Workforce

This review found that initiatives that successfully address cultural bias focused on the roles, support, abilities, and training of both Aboriginal and Torres Strait Islander and the non- Indigenous workforce and supported the development of new roles in peer support and coordination where necessary. These initiatives valued the well-developed cultural skills, knowledge and relational networks of Indigenous staff and the unique perspective and understanding they offer Aboriginal and Torres Strait Islander patients. They also ensured that non-Indigenous staff were well skilled and had a positive and respectful attitude toward Indigenous colleagues, patients, and families, recognising both the challenges and strengths experienced by these groups. The most effective initiatives embedded two way learning into training and practice, enabling the combination and enhancement of clinical and cultural skills.

Kidney health and kidney transplantation services delivery and models of care

This review has identified many different components of and ways to address cultural bias in primary, secondary, and tertiary healthcare settings (as summarised in Figure 4). These offer a range of options for other services seeking to adapt and improve their models of practice, approaches, and models of care. We identified 11 key elements or subdomains of successful service delivery, approaches, and models of care (Figure 4, Domain 3). The initiatives evaluated as most effective by patients and staff were those that included more of these aspects in all stages of kidney heath and transplantation care (Figure 4). These initiatives also included Aboriginal and Torres Strait Islander peoples in the design, delivery and evaluation of their initiatives, and ensured that the workforce (Aboriginal and Torres Strait Islander and non-Indigenous) were well trained and supported, with clear roles that were understood by other staff.

One concerning theme that has emerged in this and other studies is that Aboriginal and Torres Strait Islander patients often feel unsafe when providing critical feedback, or highlighting gaps in care, and their experience is that lodging a complaint often leads to negative care responses by staff and is inherently unsafe. This situation counters effective quality and safety and feedback mechanisms and can lead to patient anxiety and disengagement (Owen 2020).

Policies, standards, and guidelines

A series of policies, standards and guidelines have been developed nationally to guide and direct kidney and transplantation care in Australia, some of which focus specifically on the needs of Aboriginal and Torres Strait Islander peoples. There is an increasing trend to include and respond to the voices, perspectives and priorities of Aboriginal and Torres Strait Islander patients and community members, health professionals and services in these documents. The community consultations and health professional consultations for the new national clinical guidelines for Aboriginal and Torres Strait Islander kidney care, combined with Indigenous governance and oversight over the writing of these guidelines, signals an important recognition of and response to cultural bias. The revision of transplantation guidelines regarding eligibility for Aboriginal and Torres Strait Islander peoples is another example. The peer reviewed literature highlights the importance of reviewing and embedding supportive policies at unit, service, and health system levels to effectively support cultural bias initiatives.

Wider healthcare standards have the potential to help address cultural bias that are not kidney health specific. These include the NSQHS six specific actions for Aboriginal and Torres Strait Islander healthcare and the AHPRA cultural safety strategy. Our analysis of the peer reviewed and grey literature and community consultations has identified that while these standards exist, their impact is not being felt or perceived consistently and reliably by Aboriginal and Torres Strait Islander patients and clients. Australia's major healthcare settings are not yet being perceived as a uniformly safe place for care by Aboriginal and Torres Strait Islander peoples.

Resources and funding, clear leadership and management support are necessary to mobilise policies into practice. The ongoing challenge for many health services is how best to embed and sustain new initiatives.

Recommendations

Recommendation MAPPING (who is responsible?)

	For transplant units and kidney health services:	Recommendations 1, 2, 3, 4, 5, 6, 7, 8, 10, 11
NIKTT	National peak bodies and organisations (NIKTT):	Recommendations 2, 6, 9, 12, 14
	For governments and funders:	Recommendations 3, 4, 6, 7, 8, 13

Based on the review of the literature and the resulting framework for planning, implementing, and evaluating cultural bias initiatives, this report makes the following recommendations to address cultural bias in kidney care and transplantation for Aboriginal and Torres Strait Islander people:

1. Establish Indigenous Reference Groups in every transplantation unit to help co- design culturally appropriate pathways and models of care that are tailored to the needs of Aboriginal and Torres Strait Islander transplant recipients and candidates.
2. Increase Indigenous representation on relevant kidney health advisory boards and steering groups, especially within boards and management of transplant units.
3. Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, including the development of specialised clinical roles such as Aboriginal Regional Transplant Care Coordinators, Case Managers and Health Practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).
4. Establish and fund sustainable kidney patient navigator/peer support roles in transplant units and kidney health services. These roles involve peer support from an Aboriginal and Torres Strait Islander person with lived experience of kidney disease and require long term funding.
5. Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.
6. Fund, design, implement and evaluate tailored models of care for Aboriginal and Torres Strait Islander kidney transplant recipients and candidates that:
    a. are client and family centered and include continuity of care.
    b. are based on the feedback and perspectives of patients and consistently involve family in healthcare discussions, decision making and health education.
    c. are responsive to holistic health and wellbeing and the socioeconomic needs of Aboriginal and Torres Strait Islander peoples, including specific needs around transport, accommodation, social and emotional wellbeing, and involvement of traditional healers.
    d. are based on partnerships and collaboration between services, especially with Aboriginal Community Controlled Health Organisations.

    e. recognise and include the role of the Aboriginal and Torres Strait Islander workforce, including establishing new roles such as Aboriginal Transplant Coordinators and Patient/Peer navigators.
    f. include multidisciplinary pre- and post-transplant teams in urban areas and outreach services in regional, rural, and remote areas.
    g. These models of care should be co-developed to address the needs of local communities and may vary across the country. They should be a means of addressing inequities in access to and outcomes from kidney transplantation and will require long term funding.

7. Expand and embed the use of telehealth and videoconferencing services for kidney transplant recipients and candidates and ensure the inclusion of Aboriginal and Torres Strait Islander health workers/practitioners (and interpreters when required) in these consultations.
8. Support and fund the further use of interpreters.
9. Co-develop specific health promotion and health education resources and approaches on kidney transplantation with Aboriginal and Torres Strait Islander people.
10. Review existing CQI processes, policies, protocols and guidelines in transplant units and kidney health services to ensure equity of access for Aboriginal and Torres Strait Islander people and safe feedback channels for Aboriginal and Torres Strait Islander people.
11. Assess institutional racism within transplant units and kidney health services using an institutional racism audit tool.
12. Develop and implement specific clinical guidelines for Aboriginal and Torres Strait Islander kidney care and evaluate their effectiveness in increasing equity of access to kidney transplantation.
13. That the Australian Government Department of Health allocate a dedicated funding stream to implement the recommendations in this report across multiple jurisdictions to increase equity of access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander Australians.
14. That the NIKTT undertake further work to assess the baseline status of these recommendations within transplant units, and further develop an evaluation framework and supporting data development to monitor the implementation of the recommendations and provide public reporting.

Future research

Multiple studies conducted over the last 20 years have clearly identified gaps in care for Aboriginal and Torres Strait Islander peoples in kidney care and/or kidney transplantation. Many of these propose specific strategies for improvement. In order to effect change and improve kidney transplantation rates and kidney health outcomes, future research needs to focus on implementation and evaluation of effectiveness from the perspective of patients, families and communities, and on healthcare services and systems' models of care, quality improvement, guidelines and standards. Co-designed and co-created participative approaches to research, implementation and evaluation offer the greatest opportunities for the development of new models of transplantation care that meet the complex clinical and cultural care needs of Aboriginal and Torres Strait Islander peoples living with kidney disease.

Increasingly, research that addresses disparities and meets the needs of Aboriginal and Torres Strait Islander peoples is being led, informed, undertaken and evaluated by First Nations people (APPRISE 2020). If this approach were supported and funded adequately within kidney care and transplantation across Australia, significant and targeted improvements in addressing cultural bias could be achieved.

2.4.3 Recommendations

Upon receiving the final Report from the Lowitja Institute, the NIKTT compiled feedback from Taskforce members, National Panel members, and other attendees of a Cultural Bias Workshop that focused on summarising and discussing the Report.

The Cultural Bias Workshop was held on the 22nd of November 2021 to bring together Aboriginal and Torres Strait Islander kidney patients and transplant recipients, Aboriginal and Torres Strait Islander health workers, nephrologists, nurses, researchers, TSANZ representatives, OTA representatives, and other policy and clinical professionals. The Cultural Bias Workshop endorsed the final Cultural Bias Report and prioritised five of the 14 recommendations for immediate implementation:

1. establishing Indigenous Reference Groups in all renal settings;
2. increasing the Aboriginal and Torres Strait Islander health workforce in renal settings;
3. funding sustainable kidney patient navigator or peer support roles;
4. creating and evaluating renal-specific ongoing cultural safety training for all staff in transplant units and other kidney health settings; and
5. designing and implementing tailored models of care for Aboriginal and Torres Strait Islander kidney patients seeking transplantation.

The NIKTT sent the final Report and the NIKTT's response of five priority recommendations back to the Commonwealth Government in late 2021. The outcomes from this piece of work show us that more evidence is needed from renal settings, with a systematic tool implemented to measure cultural bias and safety at both system and patient levels.

The Response from NIKTT advocates for the next steps to include:

1. The formation of a new Working Group that will be tasked with:
    a. Mapping the current landscape of cultural safety within renal settings in Australia, including what measurements, tools, and interventions are being used, by who.
    b. Deciding on a set of core cultural bias interventions to be implemented and a core set of measurement tools to use to monitor these.
    c. Existing as a Cultural Bias networking body to help share lessons learned and translate knowledge across jurisdictions and settings.
2. Ongoing funding of both IRGs and Aboriginal and/or Torres Strait Islander patient mentors or renal staff.

The NIKTT's full response is reproduced below and can be found at www.niktt.com.au/culturalbias.

Addressing Cultural Bias in Kidney Transplantation

Response to the *Cultural Bias in Indigenous Kidney Care and Kidney Transplantation Report*

Aboriginal and Torres Strait Islander people in Australia seek high-quality care for kidney health, including access to kidney transplantation, improved outcomes of kidney transplantation, and the ability to experience respectful and culturally safe health systems. Yet, there is a substantial and increasing burden of kidney failure amongst Aboriginal and Torres Strait Islander peoples in Australia, coupled with a considerably lower chance that those in need will receive kidney transplantation. In part, this is because alongside physical and geographical obstacles to transplantation, Aboriginal and Torres Strait Islander peoples experience cultural bias as a barrier to care as well.

There are multiple and additive mechanisms through which cultural bias acts as a barrier to kidney care and transplantation for Aboriginal and Torres Strait Islander people. The Australian health system has been built to a Western model of health without reference to Aboriginal knowledges of health. Therefore, processes have not been systematically embedded in usual care that equitably support Aboriginal and Torres Strait Islander people to fully access and benefit from transplantation. A crucial component of the National Indigenous Kidney Transplantation Taskforce (NIKTT) is to explore the best ways to evaluate and leverage interventions that address cultural bias in kidney transplantation settings to ensure that cultural bias no longer acts as a barrier to care.

The NIKTT commissioned the Lowitja Institute to produce the *Cultural Bias in Indigenous Kidney Care and Kidney Transplantation Report* (the Report), with the aim to explore cultural bias interventions in renal transplantation services throughout Australia. Based on the available published and grey literature, the Report identified 14 individual recommendations to address cultural bias by renal health services, national organisations, and funding bodies. The Report identified only two peer-reviewed publications from Australian renal settings which addressed the specific research question, along with a few publications from other healthcare fields such as maternal health and oncology. This dearth of published research reveals a lack of coordinated reflection and action using cultural bias as a lens through which interventions can improve health care delivery and outcomes. This gap therefore embodies the most significant implication of the Report for the NIKTT: health care services need to prioritise reporting of programs and research that identifies and addresses cultural bias.

Cultural Bias defined: any action or inaction that contributes to disparate treatment or treatment outcomes for Aboriginal and Torres Strait Islander people.

The creation of an archive of intervention outcomes that improve access to, and outcomes from, kidney transplantation is essential. Multiple stakeholders need this information: (1) health services need this to review practices and innovate as necessary; (2) the Aboriginal and Torres Strait Islander community (who live with sustained kidney transplant inequity) need confidence through transparency in health care decision making and evidence that systems are co-designed and co-evaluated; (3) health system policy makers and accreditation bodies need this to demonstrate effective partnerships with consumers (Standard 2 of the National Safety and Quality Health Service Standards) and to address patient-important outcomes of care; and finally (4) government and other funding bodies throughout national, state, and Territory levels can use findings to demonstrate how public obligations are best met, drawing on an evidence base that includes patient-centered outcomes, effective consumer partnerships, and culturally safe delivery of care.

Cultural bias is a modifiable barrier to care, and particularly transplantation, for Aboriginal and Torres Strait Islander people. The NIKTT recommends the following priority areas as immediate opportunities that the government and communities can work together on to improve the lives of Aboriginal and Torres Strait Islander kidney patients.

NIKTT's Priorities

The NIKTT convened a Cultural Bias Workshop in late November 2021 to discuss the Report and its implications, with representatives present from Aboriginal and Torres Strait Islander kidney transplant patients, Aboriginal and Torres Strait Islander health professionals, transplantation coordinators, nephrologists, researchers, and other clinical and policy professionals. The Workshop allowed both Aboriginal and Torres Strait Islander patient and health worker voices to be privileged in order to guide the NIKTT's response to the Report and our priorities moving forwards.

Overall, we strongly recommend that further examination into what works, and in which contexts, is undertaken throughout settings that are referrers to renal transplantation, as well as in settings that deliver renal transplant health care in Australia. In terms of the recommendations listed within the Report, the highest priority recommendations for the NIKTT are as follows:

→ Recommendation 1: Establish IRGsin every transplantation unit to co-design culturally appropriate models of care and safe feedback channels that are tailored to the needs of Aboriginal and Torres Islander transplant recipients and candidates.

The NIKTT established IRGs in five jurisdictions across Australia, together with an overarching national group. Their sustained existence and expansion are essential components of ongoing kidney transplantation care, as the role of the patient voice is integral to improving models of care and addressing cultural bias. The ongoing funding of IRGs is an immediate and critical need.

→ Recommendation 3: Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, including the development of specialised clinical roles such as Aboriginal Regional Transplant Care Coordinators, case managers, health practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).

Increasing the Aboriginal and Torres Strait Islander health workforce is essential to allow for the value of cultural skills, understandings, and ways of doing to improve the experience of kidney patients around the country. Patients have consistently raised the importance of – at a minimum – having ALOs or AHPs present in renal units to help translate cultural customs, advocate for patients, and help patients and their families feel more comfortable.

→ Recommendation 4: Establish and fund sustainable kidney patient navigator/peer support roles in transplant units and kidney health services. These roles involve peer support from an Aboriginal and Torres Strait Islander person with lived experience of kidney disease and require long-term funding.

Peer and patient support roles have been established through the NIKTT in several locations as pilot programs and initial evaluations are underway. Early findings include 1) important gains, including community acceptance in facilitating access through the complex process of transplant workup and 2) a keen interest from other jurisdictions to implement similar programs.

→ Recommendation 5: Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.

While cultural safety training has been implemented at a health-service level in settings throughout Australia, there are no kidney-specific cultural safety trainings. The nature of care for dialysis patients is unique within the hospital system, with ongoing contact multiple times a week for years. Content- and context-specific trainings therefore need to be co-designed and co-created for a renal-specific audience. Most importantly, these trainings must be evaluated and adjusted so that health professional recipients of training, are held accountable to the learnings and are not just a cursory introduction.

→ Recommendation 6: Fund, design, implement and evaluate tailored models of care for Aboriginal and Torres Strait Islander kidney transplant recipients and candidates.

The NIKTT's Equity and Access Sponsorships were designed to pilot models of care to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people. These projects are currently being evaluated and the findings will inform future directions, including scale up and expansion, to ensure care is tailored to Aboriginal and Torres Strait Islander people.

Each of these recommendations is critical to improving access and outcomes and need to be initiated concurrently rather than sequentially. This creates collaboration, partnership, transparency, accountability, and trust.

Next Steps

Embedded within the recommendations to address cultural bias is the need for continuous improvement and evaluation. As the Report demonstrates, there is limited published evidence for cultural bias interventions within renal medicine in Australia and in kidney transplantation units in particular. Findings from all aspects of the NIKTT'swork will contribute to this existing evidence gap, however continued evaluation of cultural bias is an essential part of ongoing work towards health equity for Aboriginal and Torres Strait Islander peoples. While there are several immediate next steps needed based on the Report, lasting change will require a long-term commitment and oversight from a national body that can amalgamate research and recommend best practices.

Next steps for action based on the recommendations from this Report

- Creation and piloting of a core set of cultural bias interventions as well as a core set of outcome measures for kidney transplantation settings that are generalisable to different health care sectors (including state, Territory, and community-controlled services). These must be co-designed and led by Aboriginal and Torres Strait Islander peoples.
- Establishment of a Working Group to oversee this future work.
- Ongoing funding for IRGs and Aboriginal and Torres Strait Islander health professional positions and community mentors and navigators as a part of core business.

The implicit and explicit effects of racism, discrimination, and colonisation (cultural bias) are entrenched within the Australian community. Thus, we recognise that improving care so that Aboriginal and Torres Strait Islander people have intergenerational kidney health and individual wellbeing – instead of intergenerational kidney disease and poor wellbeing – is challenging and multi-faceted for the kidney transplant community. Given this, the recommendations listed within the Report reflect these complex, interdependent challenges, and offer ways forward to improve access to transplantation and outcomes for transplantation that are equitably available to Aboriginal and Torres Strait Islander patients. As such, a number of these recommendations will need to be addressed by renal units and other state- and federal-level interventions. Most require meaningful community engagement and buy-in from clinical and professional staff.

Continued evaluation of interventions to improve kidney transplantation services will ensure actions taken to mitigate cultural bias are appropriate and realised. Sustained coordination of local, state, and national efforts to address both cultural bias and other barriers to care for Aboriginal and Torres Strait Islander people will allow for these recommendations to be most effective across all settings. We therefore recommend that implementation and evaluation is funded and coordinated across renal and kidney transplantation settings around Australia to ensure that knowledge exchange, best practices, and evidence-based interventions are capitalised upon. While addressing cultural bias is just one part of the transplantation pathway, it is fundamental to improving access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people.

This recommendation is endorsed the Aboriginal and Torres Strait Islander members and non-Indigenous members of the community, clinical and research network of the National Indigenous Kidney Transplantation Taskforce.

National Indigenous Kidney Transplantation Taskforce

2.4.4 Community Translation

Following the publication of the Cultural Bias Report, the 14 recommendations were translated into community-focused documents in order to share the outcomes with communities and partners around the country. These were translated into less 'academic' language by the NIKTT's Community Engagement Coordinator and given out at IRG meetings, community consultations, and conference events. These "Middle Ground" and "Real Talk" documents are available for download by clicking the images below or scanning the QR codes.

14 Recommendations for Improving Kidney Transplantation Care and Services for Aboriginal and Torres Strait Islander People

These recommendations came from a review of cultural bias initiatives. Based on the review, we found four key domains of action that can address cultural bias in kidney transplantation for Aboriginal and Torres Strait Islander peoples. The 14 recommendations within these domains aim to address bias by making sure kidney services and care are culturally safe, respectful, and co-designed with Aboriginal and Torres Strait Islander people.

This pamphlet gives an overview of what the 14 recommendations are.

1 Inclusion of Aboriginal and Torres Strait Islander People

1. Establish Indigenous Reference Groups in every transplantation units across Australia to co-design culturally safe models of care and feedback mechanisms.

2. Increase the number of Aboriginal and Torres Strait Islander patients, families and health professionals on kidney health advisory boards and steering groups, especially in transplantation units.

2 Workforce

3. Increase and support Aboriginal and Torres Strait Islander people to work as clinicians, transplant coordinators, and case managers in kidney health.

4. Employ Aboriginal and Torres Strait Islander people with lived experience of kidney disease in patient navigator and peer-support roles, and ensure these are funded long term.

5. Deliver cultural safety training for all staff in transplantation and kidney health services.

3 Service Delivery and Models of Care

6. Co-design new holistic, culturally safe, and responsive models of kidney care and transplantation that actively involves patients and families in decision making; addresses inequities and access issues; respects cultural priorities and obligations; and includes traditional healers and a wider range of health professionals, healing, and support services.

7. Increase the use of telemedicine and videoconferencing, with Aboriginal health professional and interpreter support.

8. Improve access to, support of and payment for interpreters.

9. Involve Aboriginal and Torres Strait Islander people in co-developing new health promotion and health education resources and approaches about kidney transplantation.

4 Structures and Policies

10. Review and update quality improvement and feedback processes, policies, protocols and guidelines in transplant units and kidney health services.

11. Use an Institutional Racism audit tool to assess levels of racism in transplantation units and kidney health services.

12. Develop and implement new clinical guidelines for Aboriginal and Torres Strait Islander kidney care and transplantation, and evaluate how effective they are in increasing access to kidney transplantation.

13. Adequately fund the implementation and evaluation of recommendations in this report.

14. Fund the NIKTT to assess how each transplant unit scores in relation to cultural bias and monitor improvements over time if/when recommendations are implemented.

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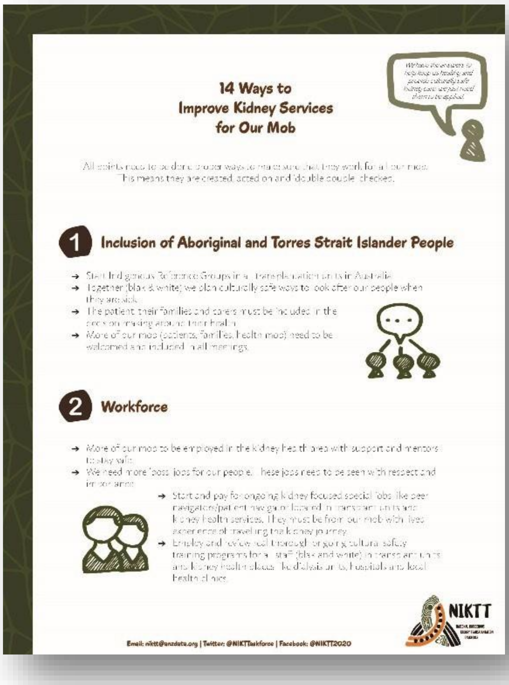

14 Ways to Improve Kidney Services for Our Mob

All points need to be done proper ways to make sure that they work for all our mob. This means they are created, acted on and 'double double' checked.

1 Inclusion of Aboriginal and Torres Strait Islander People

- → Start Indigenous Reference Groups in all transplantation units in Australia.
- → Together (blak & white) we plan culturally safe ways to look after our people when they are sick.
- → The patient, their families and carers must be included in the decision making around their health.
- → More of our mob (patients, families, health mob) need to be welcomed and included in all meetings.

2 Workforce

- → More of our mob to be employed in the kidney health area with support and mentors to stay safe.
- → We need more 'boss' jobs for our people. These jobs need to be seen with respect and importance.
- → Start and pay for ongoing kidney focused special jobs like peer navigators/patient navigator located in transplant units and kidney health services. They must be from our mob with lived experience of traveling the kidney journey.
- → Employ and review real thorough ongoing cultural safety training programs for all staff (blak and white) in transplant units and kidney health places like dialysis units, hospitals and local health clinics.

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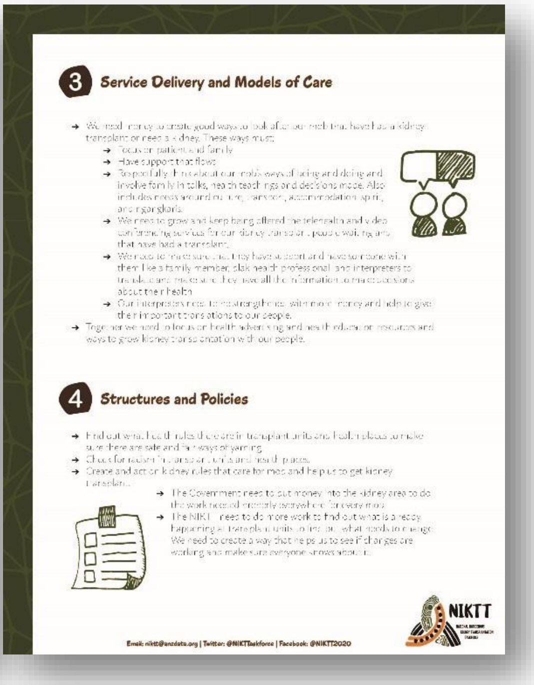

3 Service Delivery and Models of Care

- → We need money to create good ways to look after our mob that have had a kidney transplant or need a kidney. These ways must:
  - → Focus on patient and family
  - → Have support that flows
  - → Respectfully think about our mob's ways of being and doing and involve family in talks, health teachings and decisions made. Also includes needs around culture, transport, accommodation, spirit, and ngangkaris.
  - → We need to grow and keep being offered the telehealth and video conferencing services for our kidney transplant people waiting and that have had a transplant.
  - → We need to make sure that they have support and have someone with them like a family member, blak health professional and interpreters to translate and make sure they have all the information to make decisions about their health.
  - → Our interpreters need to be strengthened with more money and help to give their important translations to our people.
- → Together we need to focus on health advertising and health education resources and ways to grow kidney transplantation with our people.

4 Structures and Policies

- → Find out what health rules there are in transplant units and health places to make sure there are safe and fair ways of yarning.
- → Check for racism in transplant units and health places.
- → Create and act on kidney rules that care for mob and help us to get kidney transplants.
  - → The Government need to put money into the kidney area to do the work needed properly everywhere for every mob.
  - → The NIKTT needs to do more work to find out what is already happening in transplant units to find out what needs to change. We need to create a way that helps us to see if changes are working and make sure everyone knows about it.

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3. Collaborations

To best achieve each objective covered above, the NIKTT has placed a strong emphasis on collaboration and partnerships across Australia. These collaborations have been instrumental in coordinating, advancing, and promoting national and regional efforts to improve access to transplantation and waitlisting.

First and foremost, our work has been able to succeed due to guidance and input from Aboriginal and Torres Strait Islander people and Communities. Aboriginal and Torres Strait Islander individuals living with kidney disease and transplantation, their families, carers, and communities have been integral to the efforts and outcomes of the NIKTT. Consumer voices have shaped the way in which the NIKTT undertook activities, made decisions, and reported back to stakeholders.

Collaboration with clinical kidney specialists, including nephrologists, transplant nurses and surgeons, Aboriginal and Torres Strait Islander Health Practitioners, and other allied health workers has been fundamental to ensuring all NIKTT activities were progressed with best clinical practices considered, and these collaborations have established a foundational network upon which we can build to further progress transplantation equity. Similarly, the support of organisations such as the Transplantation Society of Australia and New Zealand have allowed the work of the NIKTT to progress and advance equity.

The NIKTT's partnerships with Aboriginal and Torres Strait Islander health and community organisations across the country have been essential in ensuring our work reflects the reality of local circumstances and effectively addresses the needs and wants of Communities. Similarly, the NIKTT's work could not have been completed without the support and partnership of renal and transplantation units throughout each State and the Territory.

Lastly, the NIKTT's collaboration with Australian Government agencies and Committees has provided the NIKTT, and our funding partners, the opportunity to influence future outcomes for Aboriginal and Torres Strait Islander people seeking kidney care and transplantation through advocacy, representation, and guidance on key national policies and documents such as the *National Strategy for Organ Donation, Retrieval and Transplantation*.

The NIKTT sincerely thanks each of our partners, collaborators, and stakeholders. These include, but are not limited to:

Funding and Governance Organisations:

- Commonwealth Government of Australia
- Department of Health and Aged Care / Indigenous Australians' Health Programme
- Organ and Tissue Authority
- Jurisdictional Organ Tissue Steering Committee

Registry and Research Institutes:

- Australia and New Zealand Dialysis and Transplant Registry
- South Australian Health and Medical Research Institute

Medical and Professional Associations:

- Transplantation Society of Australia and New Zealand
- Australian and New Zealand Society of Nephrology
- Renal Society of Australasia

Aboriginal and Torres Strait Islander Health and Research Organisations:

- Lowitja Institute

- University of Adelaide
- Purple House – Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation
- Kanggawodli Caring House
- Kimberley Aboriginal Medical Service
- Pika Wiya Health Service Aboriginal Corporation

Hospitals and Healthcare Providers:

- Royal Perth Hospital
- Royal Adelaide Hospital
- Central and Northern Adelaide Renal and Transplantation Service
- Fiona Stanley Hospital
- Princess Alexandra Hospital
- Cairns and Hinterland Hospital and Health Service
- Flinders and Upper North Local Health Network
- Port Augusta Renal Unit
- Top End Health Service

4. Taskforce Recommendations

This Final Report documents the findings that have emerged from the three years of NIKTT work. These findings underscore the pressing need to address systemic disparities in access to transplantation for Aboriginal and Torres Strait Islander people in Australia. In this section of the Report, we provide an overview of the findings and recommendations that were informed by all objectives.

There are several broad learnings that have arisen from the activities and objectives of the National Indigenous Kidney Transplantation Taskforce, including:

- An understanding that disparity in kidney transplantation waitlisting continues to be experienced by Aboriginal and Torres Strait Islander peoples in Australia, despite recent improvements in the rates of waitlisting and transplantation;
- Continued focus and engagement must be resourced if we are to progress transplantation equity;
- Kidney services need to ensure they are providing culturally safe care, through engagement with consumers, to address the inequitable treatment that arises from systemic racism and bias;
- Models of care that target Aboriginal and Torres Strait Islander communities need to consider local contexts and work closely with consumers and communities to ensure their voices are integrated into the design and implementation of kidney services;
- Aboriginal and Torres Strait Islander people must be involved in the design, delivery, and evaluation of care and services, including being supported across all levels of the health service; and
- With a coordinated network and continued data collection and reporting, further research and evaluation should be undertaken to address the remaining barriers to transplantation for Aboriginal and Torres Strait Islander people.

Our recommendations encompass immediate improvements, ongoing commitments, and further solutions:

- Immediate improvements to access and services: Sustainable funding for outreach assessment clinics, Indigenous Reference Groups, and an expanded Aboriginal and Torres Strait Islander renal health workforce.
- Ongoing Secretariat for coordination: Continued monitoring, maintenance of focus, and engagement to ensure progress and accountability.
- Investigating additional measures: Research and implementation of initiatives targeting ongoing barriers to transplantation equity.

Below, we summarise and then detail the proposed measures to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people in Australia.

4.1 Summary

A focused, coordinated national effort to increase access to kidney transplantation for Aboriginal and Torres Strait Islander people has been intentionally resourced by Australian federal governments over the last five years: firstly, with the funding of an expert panel to review barriers to transplantation and then by the establishment of the National Indigenous Kidney Transplantation Taskforce (NIKTT) to address specific barriers. The timing of the review and the action of the national Taskforce coincide with an improvement in the rates of both transplantation and active waitlisting for Aboriginal and Torres Strait Islander people around Australia.

Alongside quantitative evidence for improvements in transplantation and waitlisting rates, the NIKTT has found qualitative evidence around the various enablers and barriers to transplantation access for Aboriginal and Torres Strait Islander people in Australia. Combining these findings, as well as a Position Statement on Transplantation Equity, the NIKTT Final Recommendations identified three Key Actions to continue to improve access to kidney transplantation. The following actions and associated recommendations were derived from this work and reflect clinical, consumer, and community priorities.

Key action 1: Immediate improvements to access and services

Jurisdictions must sustainably fund the following:

- Outreach Assessment Clinics: clinics should be resourced to provide multidisciplinary team visits to rural and remote locations. Funding should include the provision of a full-time Transplant Coordinator role and clinics should include educational sessions for staff and patients alongside clinic visits.
- Indigenous Reference Groups (IRGs): all transplant hospitals should resource and implement IRGs alongside mechanisms for reporting and workflow integration. Groups should be led by Aboriginal and Torres Strait Islander kidney patients and/or Aboriginal and Torres Strait Islander renal health workers. A NIKTT Secretariat could support the establishment of IRGs alongside coordination of groups across sites to facilitate effective development and activity.
- Increased Aboriginal and Torres Strait Islander renal health workforce: Identified renal health roles, including, but not limited to, patient navigators, transplant coordinators, nurses, physicians, health practitioners, and liaison officers should be developed and sustainably resourced at renal units and transplant hospitals that serve Aboriginal and Torres Strait Islander patients. These roles must be embedded and supported within renal and transplantation units.

Key action 2: Resource ongoing Secretariat to monitor and progress transplantation equity

Coordinated efforts are essential to identify issues, catalyse activity, and maintain profile and focus on transplantation. A national Secretariat would provide leadership, collaboration, monitoring, and reporting and should be resourced for a minimum of three years to continue national coordination of transplantation equity work. This group should be responsible for the implementation of the following:

- Ongoing Monitoring: through the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, progress on improving waitlisting numbers, kidneys transplanted, and post-transplant outcomes should be consistently monitored. This monitoring should include the development and implementation of an annual scorecard for renal units.
- Maintaining Focus and Engagement: a coordinated network should be maintained to ensure attention remains on transplantation access and outcomes until significantly improved. Such maintenance of a network should include an annual gathering, consistent community engagement, sustained online resource portal, and conference attendance.

- Providing Additional Organ Support: through ANZDATA expertise, the Secretariat should explore and support the development of pathways to better transplantation access and outcomes for non-kidney organs in Aboriginal and Torres Strait Islander populations.
- Developing a Proposal for a National Aboriginal and Torres Strait Islander Body: a coordinated, collaborative approach should be implemented to develop a proposal for a sustainable national body that represents the holistic journey of Aboriginal and Torres Strait Islander peoples with kidney disease, inclusive of all modalities including transplantation. Secretariat support should include the development of partnerships, governance, terms of reference, and key objectives and deliverables.

Key action 3: Investigate additional measures to address to drivers of inequity

Funding should be offered to support the investigation of solutions for further drivers of inequity. Research into, and implementation of, initiatives that address additional drivers of inequity should be nationally resourced and coordinated to understand best practices.

- Additional Barriers: further barriers to transplantation equity, including overweight/obesity, treatment uptake, and reversible health issues, should be researched and best practices identified to address these barriers across rural and remote regions.
- Design Initiatives Across the Transplantation Pathway: research into and implementation of solutions to additional transplantation pathway aspects, with Aboriginal and Torres Strait Islander peoples, should be resourced, including post-transplant care, paediatric transplantation, culturally tailored transplant education, and donation.

4.2 Key Actions and Recommendations

Key action 1: Immediate improvements to access and services

Locally driven models of care should be implemented by state and territory hospitals and renal units in conjunction with primary health services and/or Aboriginal and Torres Strait Islander medical services where applicable.

Rationale

Findings from NIKTT objectives 3 and 4 strongly support the recommendation that particular changes to service delivery implemented at local, state/territory, and federal levels could substantially increase access to the transplantation waitlist for Aboriginal and Torres Strait Islander peoples as well as provide more culturally safe care. Implementation of the following service delivery changes should be aligned with the National Strategy for Organ Donation, Retrieval and Transplantation, and driven by jurisdictions.

Scope

The NIKTT recommends the following service delivery changes, or models of care, based on findings from pilot initiatives, the Cultural Bias Report, community consultations, and evidence noted in previous reports such as the TSANZ Performance Report and the EY Review. The NIKTT recommends that jurisdictions, in consultation with renal and transplantation units, implement the following models of care when providing services to Aboriginal and Torres Strait Islander peoples living with kidney disease and kidney failure.

While the NIKTT foresees that the following service changes could improve waitlisting, cultural safety, and ultimately transplantation, there will be local variation in implementation given the variability in service delivery models.

Methods

Outreach Assessment Clinics

NIKTT pilot projects found that multidisciplinary Outreach Assessment Clinics were beneficial in evaluating more patients, progressing more patients through workup assessment, placing more patients onto the transplant waitlist, and ultimately transplanting more patients. Key enablers from these Clinics included the coordination afforded to regional and metro teams through the role of a full- time transplant coordinator as well as the support and continuity of care provided by partnering with local Aboriginal medical services. Additional benefits to both patients and providers were the provision of locally tailored education on the transplantation process. This culturally relevant information aided patients in understanding and undertaking workup, and clinician-focused education aided providers in understanding local circumstances to better provide culturally safe care.

Based on these findings, the NIKTT strongly recommends that Outreach Assessment Clinics should be resourced to provide quarterly multidisciplinary team visits to rural and remote Australia. Funding must include the provision of a full-time Transplant Coordinator role and clinics should be co-run with local primary health care services. Educational sessions for staff and patients should be utilised alongside clinic visits to improve locally relevant transplantation knowledge.

While the makeup of each Outreach Assessment Clinic will vary based on location, in general, the NIKTT recommends that they incorporate:

- The provision of a specific transplant coordinator role, ideally an Aboriginal and/or Torres Strait Islander person, to coordinate clinic visits. This person(s), based locally or in metro areas, would be responsible for identifying patients eligible for workup, monitoring those already undergoing workup and ensuring they complete processes, arranging clinic visits with locally based medical teams, aiding in the development of educational materials, and maintaining contact and follow up with patients after each clinic.
- The creation of a multidisciplinary transplant assessment team that includes; nephrologist, transplant surgeon, transplant nurse, Aboriginal Health Practitioner and/or ALO, transplant coordinator, and other specialists as needed.
- Development of educational materials relevant to the local area that outlines regional processes to transplantation, including workup, staying on the list, transplantation, and post-transplant care. Resources need to be fit for purpose in the local area, and will benefit from local piloting to ensure relevance, understanding, and meaningfulness.

Outreach Assessment Clinics should be resourced by and directed from renal and transplantation hospitals throughout each state and territory.

Indigenous Reference Groups (IRGs)

Based on findings from the NIKTT pilot projects and extensive community engagement, the NIKTT strongly recommends that Indigenous Reference Groups (IRGs) are established at all hospitals that provide renal and transplantation services for Aboriginal and Torres Strait Islander peoples with kidney failure. We also recommend the establishment of a mechanism for support and coordination of IRGs across sites to facilitate effective development and activity.

Overall, NIKTT findings emphasise the importance of IRGs as a means of supporting culturally safe practice from within the hospital system. NIKTT suggests that each IRG considers the following elements for success:

- The NIKTT recommends that IRG success will be enabled by strong support from hospital executive, transplantation unit clinical directors, and renal unit heads of unit. These executives should commit in writing to ongoing engagement and support of IRG recommendations.
- A nominated Consumer and Community Engagement Officer is crucial to identify, engage, and maintain relationships with both clinical advocates and consumer representatives.
- A culturally safe physical meeting space must be provided wherein consumers and Aboriginal and Torres Strait Islander health staff can meet regularly.
- A Terms of Reference document must be created to outline how the IRG works in partnership with the

unit.
- A list of priorities and actions should be agreed to first within the IRG and then in collaboration with the hospital.
- All IRG members should be compensated for their time and expertise.
- Quarterly or bi-annual reports should be completed by units to report on engagement and partnership with the IRG.

Increased Aboriginal and Torres Strait Islander renal health workforce

Findings from the NIKTT projects, the Cultural Bias Report, and the Gathering Position Statement strongly support the increased employment of Aboriginal and Torres Strait Islander peoples in renal health service delivery. Increased numbers of Identified roles within renal and transplantation units, and renal support services, would provide for professional service delivery whilst simultaneously enhancing communication, representation, cultural safety, and community engagement.

The NIKTT recommends that governments provide resources for the continued development, support, and implementation of permanent roles and succession pathways for the Aboriginal and Torres Strait Islander kidney health workforce across all levels, including nurses, doctors, allied health professionals, patient navigators, transplantation coordinators, Aboriginal liaison officers, Aboriginal health practitioners, unit managers, department leads, and executive roles. Managers and executive leadership are crucial to supporting the growth, retention, and capability development of the Aboriginal and Torres Strait Islander health professional workforce. Managers and executive leadership should have training and regular reviews to ensure provision of culturally informed workforce leadership. These roles must be embedded and supported within the system.

Deliverables

Key deliverables from these recommendations include:

1. Ongoing funding secured for Outreach Assessment Clinics currently extant in Western Australia.
2. Establishment of Outreach Assessment Clinics and multidisciplinary teams for clinic visits at each major transplantation unit Australia-wide.
3. Establishment and maintenance of IRGs at each renal and transplantation hospital in Australia.
4. Creation of a national network of transplantation-focused consumer groups supported by a national Secretariat.
5. Commitment and action plan from jurisdictions and/or transplantation units to employ Aboriginal and Torres Strait Islander peoples in transplantation-focused health service roles.

Key action 2: Resource ongoing Secretariat to monitor and progress transplantation equity

A national Secretariat should be resourced for another three years to continue coordination of transplantation equity work.

Rationale

The formation of the original National Indigenous Kidney Transplantation Taskforce (NIKTT) was crucial to provide a focal point for improving access and outcomes related to kidney transplantation in Aboriginal and Torres Strait Islander peoples. Work over the previous few decades has improved transplant, waitlisting, and dialysis numbers, however considerable inequity in access and outcomes remain. The coordination of transplantation equity efforts – across jurisdictions, with community, and between disciplines – has enabled better directed attention and efforts, which has led to an improved rate of waitlisting and transplantation, although hindered by COVID-19.

Through sustained and targeted national community consultation, the NIKTT has learnt that there is compelling interest in the continuation of a group that works to coordinate, administer, and explore equity programs that improve access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander peoples. This Secretariat would work closely with TSANZ and AOTA to monitor transplantation access and outcomes, continue to collaborate, network, and educate stakeholders on issues fundamental to the improvement of access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait peoples, and develop the strategy and implementation plan for a national body representing Aboriginal and Torres Strait Islander kidney health and transplantation. The Secretariat would act as the bridge between community and the finalisation of the National ODRT Strategy and its implementation plan.

Scope

Because transplantation involves a vast array of services and specialists, a national approach is needed to ensure best practices are shared and duplicated efforts are minimised. Due to the complexity of transplantation, a transplant-focused network is necessary to ensure challenges and opportunities unique to transplantation are identified and addressed.

The proposed Secretariat would focus on:

- The continued barriers to waitlisting, staying on waitlist, transplantation support, and post- transplant support and outcomes.
- Improving the cultural safety of all transplantation-related services.
- Developing and maintaining national networks of both consumers and service providers.
- Providing support, development, and guidance for national strategy and long-term action plans.

Methods/Implementation

Governance: The structure of a continued Secretariat would build on the existing strength of networks and foundations that the NIKTT has created. For accountability and clinical oversight, we recommend that the Secretariat resourcing is provided through the Transplantation Society of Australia and New Zealand (TSANZ). To implement recommendations, this Secretariat would:

- Employ a salaried Secretariat team, including community engagement, administration, project management, and research positions. This team would regularly report to an oversight committee, TSANZ, and funding partners.
- Form an oversight committee (6-8 members) to achieve the goals of the NIKTT, through initial expressions of interest and referrals, with the majority being Aboriginal and/or Torres Strait Islander peoples. Chairs or co-chairs should include at least one community member.
  - Appointments would be made to address complementary skills with the requirement of culturally respectful conduct. This committee will provide clinical and community leadership and advice to the Secretariat on a regular and ongoing basis.
  - A community observer should be resourced to provide transparency and support good conduct.
  - Some members of the oversight committee would draw stipend if not otherwise funded to undertake this role. This would be compensated for at Commonwealth- recommended sitting fees, for four to six meetings per year.
  - Committee members would be supported to work as a team, with training in cultural safety, reflective practice, intercultural teamwork, corporate governance, and Indigenous governance. Meetings should be hosted wherever possible on Country and/or with a local IRG.
- The Secretariat will help the committee to facilitate time-limited working groups to action boutique needs such as youth and paediatric transplant access, or post-transplant care, non-kidney organ transplant, and low-immunogenicity transplants, or who give additional oversight to some functions of the NIKTT (such as functions of IRGS, or resource development).

Data monitoring: Through the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, the Secretariat would collect, analyse, and report on metrics relating to transplantation in Aboriginal and Torres Strait Islander populations. This would include the continued production of specific chapters in the ANZDATA annual reports on metrics relating to Aboriginal and Torres Strait Islander peoples, as well as the creation and sharing of infographics for community and clinical stakeholders.

Scorecard development: Through ANZDATA, and in collaboration with stakeholders such as TSANZ and ANZSN, the Secretariat would work to develop an annual scorecard that monitors, records, and reports on improvements in waitlisting, transplantation, workforce, and program delivery. This would include:

- Development of metrics to measure unit-level cultural safety.
- Development of identification and tracking system to monitor and evaluate transplant- related initiatives and outcomes.
- Development of reporting system so renal units can assess their progress towards better.
- transplantation access and outcomes.
- Develop, monitor, and evaluate publication methods of transplantation-related data, for knowledge exchange with differing actors including community.

Network: The Secretariat would capitalise on the well-established partnerships and engagement created over the last three years of NIKTT work. The Secretariat would continue to foster this network through:

- Developing partnerships with key stakeholders, such as AOTA, TSANZ, ANZSN, KHA, and NACCHO, to share, discuss, and learn from current work.
- Hosting an annual Gathering that includes both clinicians and community members.
- Sharing resources and promote knowledge exchange through communities of practice, participation in conferences, online resource portal development, and regular meetings.

Consumer coordination: The Secretariat would help to coordinate and develop a national consumer network, building on existing relationships and communities of practice. Through this, the Secretariat would help to bring together Indigenous Reference Groups from around the country, in order to link up, support, and amplify consumer voices in transplantation.

Additional support: through ANZDATA expertise, the Secretariat would explore and support the development of pathways to better transplantation access and outcomes for non-kidney organs in Aboriginal and Torres Strait Islander populations, such as liver and lung transplantation.

National body proposal: Through the work of the NIKTT, community, consumers, and clinical advocates have strongly supported the ambition to develop a national body that represents Aboriginal and Torres Strait Islander peoples undergoing kidney transplantation and living with kidney failure. Such a body will take time and dedicated collaboration to develop, and the Secretariat would be best placed to begin this groundwork. The Secretariat would:

- Conduct community consultations to best understand patient/carer/community perspectives on what a national body should look like.
- Cultivate partnerships and commitments with all relevant stakeholders, including clinicians, organisations (TSANZ, KHA, etc.), state/territory health departments, hospitals/HOUs, renal units.
- Determine the structure, workflow, and deliverables of such a body.
- Determine the governance, budget, accountability, outcomes, and evaluation of such a body.
- Create an action plan for implementation, monitoring, and evaluation.

Deliverables

Key deliverables of the continued NIKTT Secretariat would include:

1. An integrated report and scorecard deployed within the ANZDATA system that tracks renal unit- level metrics on waitlisting, transplantation, and cultural safety.
2. A cohesive network maintained, through consistent online meetings and one in-person Gathering per year.
3. The establishment of a connected consumer voice through the coordination and development of Indigenous Reference Groups at renal and transplantation units.

4. A fully developed framework and implementation proposal for a national Aboriginal and Torres Strait Islander body that represents people living with kidney disease, failure, and transplantation.

Key action 3: Additional drivers of inequity investigated

Community-prioritised investigation into, and implementation of, initiatives that address additional drivers of inequity should be nationally resourced and coordinated to understand best practices. Development of research themes and support in monitoring and evaluation could be supported by a NIKTT Secretariat.

Rationale

The work of the NIKTT was based on the recommendations of a Performance Report published by the Transplantation Society of Australia and New Zealand (TSANZ) in 2018. This Report, Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander Peoples in Australia, laid out 35 evidence-based recommendations for funding and immediate action. The three key areas of focus from the report, namely (1) establishing a resourced National Indigenous Kidney Transplantation Taskforce, (2) enhancing data collection and reporting; and (3) improving the equity and accessibility of transplantation, formed the basis of the first iteration of NIKTT work, alongside the Commonwealth-recommended focus on cultural bias initiatives.

There were many recommendations from this report, and the subsequently published EY Report, that were not covered within the first iteration of NIKTT work. These additional recommendations, mapped to Taskforce, State/Territory, and Commonwealth responsibilities, still remain. Priority areas from community consultation have also identified additional areas of need.

Additional drivers of inequity include weight and/or obesity; treatment uptake; reversible health conditions; post-transplant care; paediatric transplantation; and support services such as transportation, housing, and wraparound services.

Investigation into these additional barriers to transplantation should be resourced through a nationally coordinated body, as informed by Indigenous Reference Groups, community consultations, and the Secretariat governance board.

A gap exists within the Australian health care system whereby community-driven priority initiatives may not have access to implementation funding either due to project scale, organisational structure, or research capacity. The NIKTT recommends that another round of sponsorship grants are offered to community, renal units, and other stakeholders working in kidney transplantation to address the remaining drivers of inequity. The NIKTT Secretariat would oversee the development, coordination, implementation, monitoring, and evaluation of projects.

Scope

Investigative projects should be funded to address:

- Further barriers, drivers, and opportunities surrounding transplantation access and outcomes for Aboriginal and Torres Strait Islander peoples that were not addressed through the work of the NIKTT.
- System-level processes and policies that impact access to waitlisting and transplantation.
- Post-transplantation outcomes, education, and care pathways.
- Implementation, evaluation, and monitoring of culturally safe models of care.
- National, jurisdictional, and regional -specific projects.

Methods

Analysis and review of previous recommendations and progress to date should be first undertaken to best evaluate future research needs. A NIKTT Secretariat could work with research funders to determine themes and priorities for grant opportunities.

Research into additional drivers of inequity, and the translation of research findings into practice, should be coordinated nationally to facilitate knowledge exchange. The NIKTT recommends that projects are funded for two-to-four years due to the complexity and time needed to progress patients through the transplantation pathway.

All research must have oversight from a board of Aboriginal and Torres Strait Islander peoples to ensure principles of cultural safety, accountability, strength-based approaches, and sovereignty are maintained.

Deliverables

1. Five to ten projects funded to explore additional drivers of inequity within kidney transplantation for Aboriginal and Torres Strait Islander peoples.
2. Culturally safe models of care identified that improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander peoples.

4.3 Next Steps

Lasting improvement in access to, and outcomes of, kidney transplantation will take sustained focus and coordinated effort. Further gains in transplantation access and outcomes are immediately available with directed attention on racism, cultural safety, equity, and Aboriginal and Torres Strait Islander-led change by our kidney communities and change makers. Transforming our entrenched systems will not be easy, but it must be done. Lasting change will take a sustained investment in the coordination and focus through which the NIKTT has worked thus far. Changing systems, policy, and bias will require Aboriginal and Torres Strait Islander leadership, consumer engagement, and continued advocacy.

The NIKTT submitted a funding proposal for $4.8m to the Department of Health and Aged Care in March 2023, outlining the recommendations listed above alongside a plan for the next three years. The NIKTT Secretariat team is now working with the First Nations Health Division of the Department of Health and Aged Care to determine actions going forward.

Below, we once more summarise the themes and priorities for the next steps toward transplantation equity.

Engagement and Representation:

- Establish IRGs at all transplantation units.
- Increase the Aboriginal and Torres Strait Islander kidney health workforce.
- Prioritise Aboriginal and Torres Strait Islander leadership and governance across kidney health services and programs.

Data Collection and Monitoring:

- Enhance data collection and reporting mechanisms to capture pre- and post-transplant access and outcomes.
- Develop measurable and modifiable targets for improving transplant outcomes.
- Establish metrics to systematically measure and report on cultural bias within renal unit and transplantation hospitals.
- Collaborate with units across Australia to establish a consistent scorecard for all renal units to track progress towards equity.

Equitable Access:

- Establish sustainable and resourced outreach assessment clinics.
- Develop patient navigator programs to facilitate access to transplant waitlists.
- Provide culturally sensitive, locally adapted educational resources to increase awareness and health literacy.
- Trial and evaluate further models of care that increase access to the transplant waitlist.

Cultural Bias:

- Create institutional commitment and implement national and regional guidelines to ensure change is enacted, monitored, and improved upon.

- Implement and evaluate comprehensive cultural safety training programs.
- Promote partnerships with Aboriginal Community Controlled Organisations (ACCHOs) for culturally safe care.

Innovation and Policy Change:

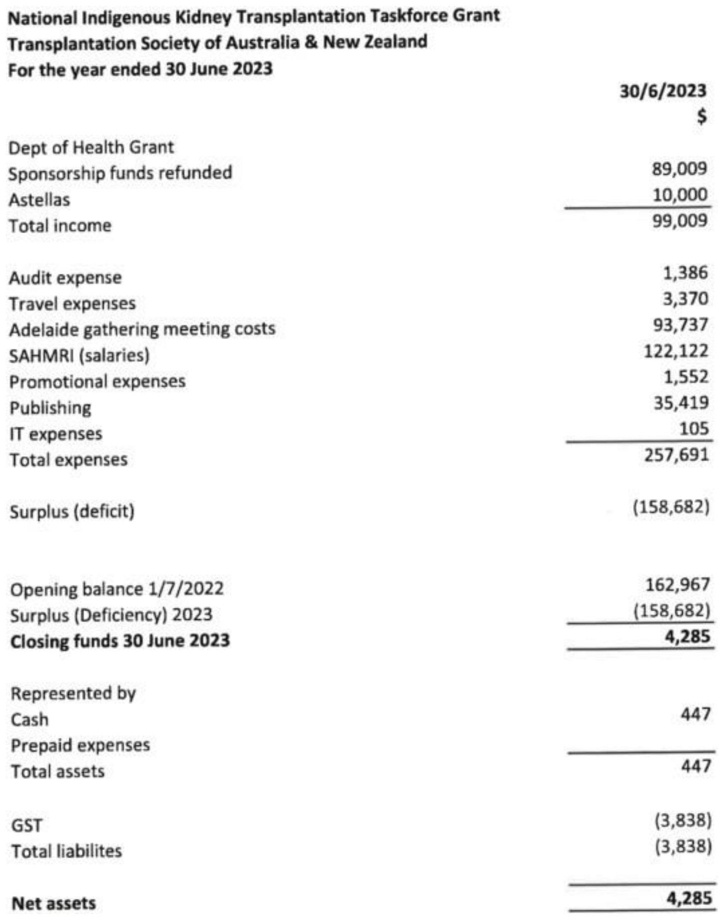
- Identify and investigate additional barriers to waitlisting and transplantation.
- Implement national strategies in partnership with consumers and communities.
- Advocate for policy changes at local, state, and federal levels to ensure equitable access and culturally safe care.

5. Financial and Budget Update

Please see the Income and Expenditure Report from 1 July 2022 to 30 June 2023 as per item E, below. The Top End Health Service and the Cairns and Hinterland Hospital and Health Service received sponsorship funding for their pilot project initiatives to improve equity and access to transplantation and they were unable to complete their activities in full due to staff shortages, operations delays, and travel restrictions related to the pandemic.

In addition to these two sponsorships, the Royal Perth Hospital has advised that they had to adjust their original activity plans and have ended up with an underspend. This has been due to resourcing issues, operational delays as well as logistical matters. The original number of scheduled outreach clinics was not able to be realized due to staffing limitations and community shutdowns. The underspent funds were utilised to cover the salaries and the NIKTT Gathering, as provided in the previous unspent fund's proposal. Details will be provided in the final financial acquittal, due October 31, 2023.

Provided below is the financial position of the NIKTT as of June 30, 2023.



National Indigenous Kidney Transplantation Taskforce Grant
Transplantation Society of Australia & New Zealand
For the year ended 30 June 2023

	30/6/2023 **$**
Dept of Health Grant	
Sponsorship funds refunded	89,009
Astellas	10,000
Total income	99,009
Audit expense	1,386
Travel expenses	3,370
Adelaide gathering meeting costs	93,737
SAHMRI (salaries)	122,122
Promotional expenses	1,552
Publishing	35,419
IT expenses	105
Total expenses	257,691
Surplus (deficit)	(158,682)
Opening balance 1/7/2022	162,967
Surplus (Deficiency) 2023	(158,682)
Closing funds 30 June 2023	**4,285**
Represented by	
Cash	447
Prepaid expenses	
Total assets	447
GST	(3,838)
Total liabilites	(3,838)
Net assets	**4,285**

As per the Standard Grant Agreement, 4-87CKFUZ, the final Financial Acquittal Report will be provided by the due date of 31 October 2023.

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7. Appendices

Appendix A: *Recommendations from the 2019 TSANZ Improving access to and outcomes of kidney transplantation for Indigenous and Torres Strait Islander people in Australia – Performance Report*

Domain / Theme	Recommendation
Establishment of a National Indigenous Kidney Transplantation Taskforce	1. Establish a resourced National Indigenous Kidney Transplantation Taskforce, with representations from DoH, TSANZ, ANZDATA, ANZSN, OTA and invited subject experts, to drive the implementation of the report's recommendations, consult the Indigenous and health care communities on all relevant initiatives, and advocate for equitable access to transplantation for Indigenous patients.
Data	2. Implement a 12-month pilot project to capture additional pre- and post-kidney transplant data points in an expanded ANZDATA data collection protocol.
	3. Incorporate a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander peoples.
	4. Undertake additional data linkage and research projects that target Indigenous patients' post-transplant outcomes, enabling identification of best practice immunosuppression, infective prophylaxis and vascular complication protocols.
Consumer engagement and education	5. Deliver education programs to Indigenous communities about the value of organ donation and how it links to transplantation, ideally in partnership with local transplant recipients and donor families.
	6. Undertake consumer engagement projects that specifically explore Indigenous transplant candidates' and recipients' preferred models of care.
	7. Establish an Indigenous reference group in every transplant unit to help design pathways and models of care that are culturally appropriate.
	8. Trial and evaluate the adoption of patient navigator programs and yarning circles in pre-transplant protocols.
	9. Pilot culturally informed transplant education interventions, including remote language centres and culturally tailored immunosuppression adherence education videos.
Improving equity and access to transplant services	10. Evaluate and leverage existing initiatives that target cultural bias in health services to facilitate the rollout of best practice pre-transplant care and support interventions for Indigenous transplant candidates.
	11. Ensure Indigenous transplant candidates are connected with primary care services earlier in the ESKD treatment continuum, to enable health issues to be addressed prior to workup.
	12. Trial and evaluate weight loss strategies for Indigenous kidney transplant candidates including conservative, culturally tailored weight loss programs and bariatric surgery.
	13. If an empirical evidence base supports the use of bariatric surgery for Indigenous kidney transplant candidates, increase funding for bariatric surgery procedures in public hospitals.
	14. Trial a multidisciplinary pre- and post-transplant clinic in one major regional centre for 12 months, prioritising the availability of dental and cardiac services, as well as travel and accommodation support for rural and remote patients.
	15. Fund relevant medical and allied health services and positions in regional centres to facilitate the delivery of specialist transplant support outreach services, complementing pre- and post-transplant clinics and improving coordination of appointments and services.
	16. Conduct a study on transplant models of care to quantify the costs for rural and remote Indigenous patients to inform the development of a needs-based funding model.
	17. Undertake a systematic review of Australian POCT models to guide the development of a post-transplant care POCT program, comprising new POCT measures that enable the monitoring of renal function and immunosuppressive drug levels in kidney transplant recipients.
	18. Subsidise POCT tests that have been validated by empirical evidence.
	19. Investigate the value of telenephrology and telepharmacy programs for kidney transplant recipients living in rural and regional areas.
	20. Design and implement a remote community pharmacist trial to facilitate improved awareness and knowledge of transplant related maintenance requirements among Indigenous kidney transplant candidates and recipients.
	21. Subsidise clinical pharmacy outpatient consults for Indigenous transplant recipients.
	22. Broaden the list of eligible prescribers for the Closing the Gap PBS Co-payment Measure to include transplant centres.

Researching, developing, and implementing clinical guidelines and protocols	23. Systematically review the evidence on the outcomes of kidney transplantation with a live donor in the Indigenous patient population to inform health service protocols.
	24. Evaluate the impact of immunological matching at the epitope (eplet) level for allocation of deceased donor kidneys.
	25. Establish a national dose administration aid protocol and a consistent format for drug information.
	26. Implement and evaluate novel, long-acting immunosuppressive agents in Indigenous transplant recipients.
	27. Adopt prolonged-release tacrolimus-based regimens in immunosuppressive protocols.
	28. Revise immunosuppressive protocols based on relevant findings from the pharmacokinetic study of immunosuppressives in Indigenous transplant recipients.
	29. Design and undertake research projects to identify the antecedents to infective episodes.
	30. Test and evaluate novel infective prophylaxis interventions for Indigenous transplant recipients.
	31. Adopt coordinated, nationally consistent clinical data collection, analysis and reporting protocols of infective complications across renal units.
	32. Implement a tailored prophylactic protocol for Indigenous transplant recipients.
Workforce training and development	33. Deliver consumer engagement training to renal unit and transplant centre staff.
	34. Implement recruitment and training strategies for the renal workforce, particularly in remote areas, to improve the delivery of culturally appropriate pre-transplant care.
	35. Implement transplant-specific ‘train the trainer’ workshops for Indigenous health workers.

Appendix B: *Recommendations from the 2018 EY Review of the organ donation, retrieval and transplantation system – Final report*

Overarching Element: System Governance	1. The Australian Government working in collaboration with states and territories use this report to guide the development of a future national strategy for the retrieval and transplantation sector to optimise every deceased donation opportunity for maximum transplantation outcomes.
	2. The Australian Government working in partnership with states and territories, develop a long-term national workforce strategy for the organ donation, retrieval and transplantation sectors.
	3. All Australian Governments resolve that the OTA should take a national strategic or coordination role under its existing legislation in regard to the following organ donation retrieval and transplantation issues: o National planning and service development o National standards and guidelines development o Advocacy for the donation, retrieval, and transplantation system o Provision of advice to national research funding bodies based on advice obtained from the Transplantation Society of Australia and New Zealand (TSANZ) and other clinical advisers o Data collection, analysis and reporting to drive change and clinical best practice o National planning for the adoption of new evidence-based practice including new tissue typing and ex vivo organ perfusion technologies.
	4. The OTA should provide advice, based on guidance obtained from the TSANZ and other clinical advisers, to research funding organisations on the priorities for research in organ donation and transplantation.
Element 1: Initial assessment and wait listing management of potential transplant recipients	5. All transplantation programs work with the continuing medical education pathways to improve the understanding of eligibility of patients for transplantation and the referral pathways among clinicians.
	6. The OTA, through the TSANZ, oversee a clinical review of waiting list practices and management across all non-renal transplantation units in Australia, including the application of the Clinical Guidelines for Organ Transplantation from Deceased Donors ('the Clinical Guidelines') for non-renal transplantation and data management. The findings from the clinical review should be used to identify best practice in waiting list practices and management, as well as better enabling benchmarking to drive performance improvement across transplantation units.
	7. All Australian governments consider strategies to improve access to non- renal outreach clinics for assessment for transplantation, including an emphasis on work up for transplantation as close as possible to the potential recipient's place of residence.
	8. The OTA, through the TSANZ, commission a clinical review of the application of the Clinical Guidelines for kidney transplantation across all kidney transplantation units in Australia to assess the extent of variability in the use of these guidelines.
	9. Based on findings from the above-mentioned clinical review, a national policy for the management of kidney transplantation waiting lists is to be agreed. It should seek to improve inequities in access to waiting lists and implement best practice waiting list management.
	10. The OTA, through collaboration with transplantation units, should publish the performance parameters for the management of kidney transplantation waiting lists annually in a clearly accessible form for the public. This includes the number of people and the proportion of Aboriginal and Torres Strait Islander and culturally and linguistically diverse people on dialysis on waiting lists to enable assessment of access to kidney transplantation for these groups.
	11. All patients on long-term dialysis programs should be informed by their treating medical specialist of the possibility of transplantation and their compliance with the waiting list acceptance criteria.
	12. All kidney transplantation programs should implement formal outreach arrangements with rural dialysis units as a condition of funding within the state or territory. These rural outreach arrangements must include a clearly defined pathway to kidney transplantation for rural residents, including specifically designed pathways for Aboriginal and Torres Strait Islander peoples, as well as a commitment to 'work up' a potential kidney transplantation recipient as close to their place of residence as possible.
	13. All kidney transplantation programs should implement formal arrangements with Aboriginal Community Controlled Health Organisations to increase the understanding of transplantation as a possibility for Aboriginal and Torres Strait Islander patients on dialysis.
	14. All dialysis units should have formal arrangements in place with a kidney transplantation program for the assessment of dialysis patients for possible kidney transplantation.
	15. All kidney transplantation programs should implement a formal process for the provision of a second opinion to potential transplant recipients who are determined to be ineligible for transplantation.
	16. The OTA through the TSANZ review the information provided to all potential recipients of organ transplantation to improve the understanding of the range of options that may arise if suitable donated organs are identified.
Element 2: Deceased donor organ donation	17. An epidemiological study into demand for organ transplantation in Australia to better understand the organ donation rates required to meet demand should be commissioned by the Australian Government.

	18. Based on the findings from the above study, the COAG Health Council should review the national organ donation target to ensure that donation strategies are designed to meet the expected demand for organ transplantation.
	19. The donation performance by each hospital with a total inpatient activity of over 20,000 National Weighted Activity Units (NWAU) per annum annually should be published on the DonateLife website in an easily accessible and user-friendly format to assist in identifying variability in performance and enabling benchmarking to manage hospital performance more effectively.
	20. As part of the development of the future national strategy for the retrieval and transplantation system, the Australian Government working in partnership with states and territories should develop a national Aboriginal and Torres Strait Islander and culturally and linguistically diverse population's organ donation strategy to improve donation rates in these groups. It should be based on the findings from this Review, and the work of the TSANZ (the Improving access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander peoples project). The strategy should be developed in collaboration with the National Aboriginal Community Controlled Health Organisation, its affiliates, and the states and territories.
	21. An advisory group of key stakeholders should be established as part of the strategy development to provide oversight and input into Aboriginal and Torres Strait Islander issues relating to organ donation.
	22. The OTA through the TSANZ, should undertake a review and revision of the national standards for donor organ assessment and medical suitability of donors.
	23. All key stakeholders should consider the Australian Organ Donor Register (AODR) as the primary focus for the registration of an individual's decision about becoming an organ donor for transplantation after death across Australia. The focus should shift from the AODR being a record of donor consent to a record of donor intent. In doing so, consideration should be given to previous arrangements, including the driver's license-based system, and the decision of the Australian Health Ministers' Conference regarding its purpose.
	24. The Australian Government should design and implement strategies to improve the number of registrations on the AODR, in particular for Aboriginal and Torres Strait Islander peoples and other groups of non-European heritage and data should be captured on the use of the AODR by different demographics in the Australian population in order to inform strategies to improve registration rates.
	25. The strategies to improve the AODR registrations should be broadened to include links to social media and other entry portals. This will enable greater visibility and accessibility of the AODR.
	26. States and territories establish a nationally uniform process for arrangements for donor families and recipients over the age of 18 to be identified to each other based on the principle of mutual informed consent.
Element 3: Organ allocation	27. The introduction of concomitant sharing of donor profiles with all transplantation programs once the matching process has progressed beyond the home state offer should be considered and implemented as part of the OrganMatch functionality. This should be considered as part of a review of the heart, lung and liver organ allocation process in order to improve the efficiency of the organ matching process in liver, heart and lung transplantation.
	28. The planned review of the kidney matching algorithm to be conducted by the TSANZ should include Aboriginal and Torres Strait Islander health expertise and community representation.
	29. The planned review to be conducted by the TSANZ of the kidney matching algorithm should take into account the latest science to ensure that the algorithm remains relevant to contemporary kidney transplantation best practice.
	30. The replacement of the NOMS to OrganMatch is a key opportunity to improve the organ allocation process and must be adequately resourced and managed at a national level. The Australian Government should consider what is required to effectively implement and optimise OrganMatch in the future.
	31. A national plan should be developed by all Australian Governments for the adoption of new tissue typing technologies.
	32. A system for national benchmarking of tissue typing service performance be implemented nationally by all Australian Governments.
	33. The OTA, through the TSANZ, undertake a review of the State Balancing System to determine the impact on the efficiency, effectiveness, and equity of the allocation process. Any proposed changes should then be modelled and reviewed to understand their impact.
Element 4: Organ offer	34. As per Recommendation 27, the introduction of concomitant sharing of donor profiles with all kidney transplantation programs in OrganMatch at the commencement of the matching process should be considered to improve the efficiency of the process of organ offer process for transplantation.
	35. The OTA to commence a process to plan arrangements for an extensive upgrade to the output of the Electronic Donor Record (EDR) (or an alternative platform, such as utilising the functionality of OrganMatch), in collaboration with donation and transplantation specialists, to improve its functionality. The upgrade should facilitate rapid time feedback to improve surveillance and safety. The plan should then be considered by the Australian Government for approval.
Element 5: Organ acceptance	36. The OTA, through the TSANZ, should develop a clinical review process and optimise the use of extended criteria donated organs.
	37. The OTA, through the TSANZ, should develop a process to monitor the incidence of organ offer decline decisions and a process to clinically review those decisions.

Element 6: Retrieval	38. The OTA should develop a national organ retrieval resource plan to more effectively manage and coordinate processes and training programs across Australia to meet the expected increase in organ retrieval demand.
	39. The current organ retrieval tasking system should be retained; however, its adequacy should be reviewed in two years' time by the OTA to ascertain whether a national tasking system is required as demand increases.
	40. Consideration should be given to the development of national sourcing of aviation services by the states and territories to support organ retrieval services in a more coordinated manner.
	41. All Australian governments consider developing a national plan to optimise the use of perfusion technologies and ensure that best practice technology is available to transplantation units.
Element 7: Transplantation	42. The OTA should provide a national oversight role to identify opportunities for practice improvement in relation to the operational management of transplantation procedures.
Element 8: Post transplantation care	43. The heart, lung and liver transplantation programs develop post transplantation models of care that includes shared care with an appropriate locally based clinical team after the initial period of post transplantation stabilisation, particularly in the case of rural and regional patients.
	44. Each paediatric organ transplantation program, and its affiliated adult transplantation program, develop explicit pathways for transition to adult care if these pathways are not already in place.
	45. Each transplantation unit should provide comprehensive rehabilitation for patients post transplantation with a focus on employment and social participation.
	46. Patient reported outcome measures be added to all organ transplant outcome registries.
Supporting element 1: Data and information management	47. The states and territories should facilitate access to and sharing of nationally agreed de-identified datasets among jurisdictions through continued support to the OTA to develop and implement its data governance framework.
	48. National patient outcome registries for heart and lung transplantation should be formally and comprehensively supported by the OTA and funded to reflect their purpose.
	49. Consideration should be given by the OTA to the consolidation of all registries into one central system.
	50. Consideration be given by the states and territories to the automation of data submission to the organ transplant outcome registries via the electronic medical records operating in most transplantation units.
	51. Measures of access to the kidney transplantation programs and data relating to the profile and numbers of patients on the kidney transplantation waiting list as well as outcomes from the use of organs from extended criteria organ donors should be considered by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) for inclusion in the data set that is collected and reported.
Supporting Element 2: Financing arrangements for the system	52. The Independent Hospital Pricing Authority (IHPA) conduct a costing study and classification review for the classification of organ donation, retrieval and transplantation to take into account the cost impact of the use of DCD donated organs and organs from extended criteria donors and to appropriately attribute retrieval costs.
	53. Consideration be given by the Australian Government to applying indexation to the Organ Donation Hospital Support Funding (ODHSF) at the same rate as the indexation of the National Efficient Price as determined by the IHPA annually.
	54. The IHPA conduct a costing study and classification review for the classification of non-admitted pre and post organ transplantation care.
	55. Consideration should be given by the Australian Government for the proscription of access to the Medicare Benefits Schedule (MBS) for the recipients of organ transplantation other than kidney transplantation be removed from the next version of the General Explanatory Notes 13.33 of the MBS.
	56. The funding allocated to the implementation of OrganMatch should be reviewed by the Australian Government to take into account the need to model the potential outcomes of any altered algorithms that will be utilised within the new system.
Supporting Element 3: Research for the organ donation, retrieval and transplantation system	57. The OTA should provide national oversight and coordination of research activities after consultation with the TSANZ and other clinical advisers and consider the following research opportunities and priorities: o The place of ex vivo perfusion technologies in kidney and liver transplantation. o Point of care testing for kidney transplant recipients in remote Australian communities. o The possible use of monthly administration of immunosuppressant medications in remote communities following organ transplantation. o Alternative donor matching technologies. o Organ donation patterns in minority and marginalised communities within Australia. o The reasons why families change their mind after agreeing to organ donation. o The overall demand for organ transplantation in Australia (see Recommendations 17 and 18).

Appendix C: NIKTT Activity Work Plan

Activity Work Plan

Purpose: To improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander peoples.

Objectives: Establish the National Indigenous Kidney Transplantation Taskforce (NIKTT) to oversee the implementation of the key objectives and provide an additional report to the Minister for Indigenous Health to inform the development of a National Indigenous Kidney Transplantation Strategy.

Key objectives:

1. Establish the NIKTT.
2. Enhance data collection and reporting.
3. Pilot initiatives to improve patient equity and access.
4. Evaluate cultural bias interventions.

Objective	Strategies	Performance Measures	Risks	Outcomes
1. Establish the NIKTT				
• NIKTT established • Regular meetings facilitated	a) Establish a consumer panel to inform the implementation of key objectives b) Implement key objectives c) Develop the National Indigenous Kidney Transplantation Strategy	• Consumer panel engagement • Key objectives implemented • National Indigenous Kidney Transplantation Strategy provided to the Commonwealth	• Delays in establishment of Taskforce • Inadequate representation of key sectors on the Taskforce • Inadequate consumer representation and engagement Mitigation: • High level of collaboration within the sector • Robust communication and engagement strategy • Consumer incidentals reimbursed for panel attendance • Shared social goal between clinical, policy and consumer sectors	• Membership of 26 established in 2019 • National Consumer Panel established with over 170 members • First annual NIKTT Gathering hosted in 2022 • Recommendations, advice, and feedback provided to the Jurisdictional Organ and Tissue Steering Committee (JOTSC) on the draft *National Strategy for Organ Donation, Retrieval and Transplantation* • NIKTT recommendations and future directions provided to Ministers McCarthy and Kearney in March 2023
2. Enhanced data collection and reporting				
• Data points and participating units identified • Collection of data completed	a) Identify data points b) Transplant units opt into data collection c) Data collection tool developed by ANZDATA	• Data capture commence January 2020 • First full year of data collection and reporting by 2020	• Lack of engagement by participating units Mitigation: • Close engagement between grantee and renal sector.	• Data collected from 26 units for 2019 and 2020 • Data analysed and results published in the Medical Journal of Australia

	d) Units collect and report to ANZDATA e) ANZDATA analyse and publish findings in annual report	• Separate chapter in ANZDATA annual report published by 2021	• Consideration of sector incentives	
3. Pilot initiatives to improve patient equity and access				
• Projects selected and funded • Evaluation reports completed	a) Indigenous reference groups b) Patient navigator pilots c) Enhance pre-transplant coordination of care pilot	• Projects funded and implemented • Evaluation reports completed	• Inability to recruit relevant subject matter experts • Availability of suitably qualified patient navigators • Engagement with Indigenous transplant candidates and recipients to partake in reference groups Mitigation: • Robust stakeholder engagement and communication strategies in place • Leverage existing initiatives and collaborate effectively with key stakeholders	• All projects received sponsorship money across 2020-2022 • 7/8 projects completed detail progress and final reports • Projects provided evidence of improved access to waitlisting, as well as barriers and recommendations for future models of care
4. Evaluate cultural bias interventions				
• Scoping review completed	a) Evaluate and leverage existing initiatives that target cultural bias in health services	• Completion of scoping review • Completion of recommendations	• Inexperienced contractor • Scoping review does not adequately address the key objective Mitigation: • Engagement of experienced and culturally aware contractor • Final payment dependent on acceptance of scoping review	• Review and subsequent report was completed in 2021 • Report provided to Commonwealth Government in 2022 • Recommendations from Report informed NIKTT recommendations and input for the draft *National Strategy*

Appendix D: List of NIKTT Members

Name	Jurisdiction	Role	Working Group (if applicable)
Lucinda Barry	ACT	CEO; Organ & Tissue Authority	N/A
Peter Boan	WA	Infectious Diseases Physician, Microbiologist; Fiona Stanley Hospital	Data
John Boffa	NT	Chief Medical Officer, Public Health; Central Australian Aboriginal Congress	Cultural Bias
Alan Cass	NT	Director; Menzies School of Health Research	Cultural Bias
Sajiv Cherian	NT	Head of Unit; Central Australian Renal Services & Top End Renal Services	Data
Su Crail	SA	Nephrologist; Central and Northern Adelaide Renal and Transplantation Service	Patient Mentors
Jenny Cutter	WA	Manager; Kimberley Renal Services	Pre-transplant coordination
Anuja Daniel	NT	Renal psychologist; Top End Renal Service	Community Engagement
Kerry Dole	NT	Renal transplant clinical nurse consultant; Top End Renal Service	Data & Pre-transplant coordination
Ross Francis	QLD	Nephrologist; Princess Alexandra Hospital	Pre-transplant coordination
David Goodman	VIC	Nephrologist; St Vincent's Private Hospital Melbourne	Community Engagement
Heather Hall	NT	Manager; Purple House "Panuku" Darwin	Patient Mentors
Bronwyn Hayes	QLD	Renal Transplant CNC; Cairns and Hinterland Hospital and Health Service	Patient Mentors
Jaquelyne Hughes (*Deputy Chair*)	NT	Nephrologist; Royal Darwin Hospital	Cultural Bias
Ashley Irish	WA	Nephrologist; Fiona Stanley Hospital	Pre-transplant coordination
Shilpa Jesudason	SA	Nephrologist; Central and Northern Adelaide Renal and Transplantation Service	Community Engagement
Paul Lawton	NT	Nephrologist & Senior Research Fellow; Menzies School of Health Research	Cultural Bias

Wai Lim	WA	Nephrologist; Sir Charles Gairdner Hospital	Data
Sandawana William Majoni	NT	Nephrologist; Royal Darwin Hospital	Cultural Bias
Stephen McDonald (*Chair*)	SA	Director of Dialysis; Central and Northern Adelaide Renal and Transplantation Service	Data
Kelli Owen	SA	Transplant recipient and community representative	Community Engagement
Rochelle Pitt	QLD	Aboriginal and Torres Strait Islander Nurse Navigator; Metro South Health	Community Engagement
Christine Russell	SA	Consultant transplant and vascular access surgeon; Royal Adelaide Hospital	Patient Mentors
Ray Sambo	QLD	Peritoneal dialysis recipient and community representative	Patient Mentors
Paul Snelling	NSW	Nephrologist; Royal Prince Alfred Hospital	Data
James Stacey	WA	General Practitioner; Broome Renal Health Centre	Pre-transplant coordination

Appendix E: *Expression of Interest for NIKTT Membership*

TSANZ
The Transplantation Society of Australia and New Zealand

Expression of Interest

National Indigenous Kidney Transplantation Taskforce

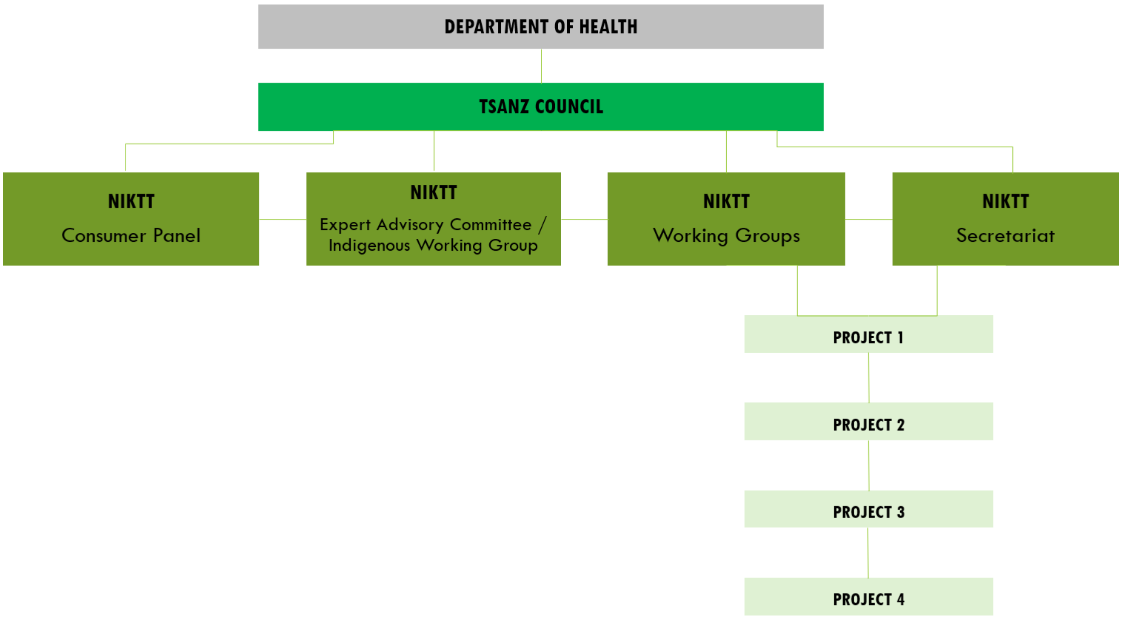
The National Indigenous Kidney Transplantation Taskforce (NIKTT) will comprise a **Secretariat**, **Expert Advisory Committee** and **Consumer Panel**. The NIKTT will report to the Commonwealth Department of Health via the Transplantation Society of Australia and New Zealand (TSANZ).

The **Secretariat** will be responsible for the coordination of the Expert Advisory Committee, Consumer Panel and NIKTT activities, including the management of priority projects across the realms of data, consumer engagement and improving access to transplantation. The Secretariat will also liaise with the Commonwealth and other key stakeholders on behalf of the NIKTT and will complete the necessary reporting requirements.

The **Expert Advisory Committee** will provide strategic guidance on the NIKTT's operations and will also function as the TSANZ's Indigenous Working Group. Expert Advisory Committee members may also nominate to serve on one or more of the NIKTT Working Groups, which will involve providing more granular input on the design, implementation and evaluation of specific NIKTT projects.

The **Consumer Panel** will comprise patients and carers who have lived experience of dialysis or transplantation. The Consumer Panel will provide advice on relevant consumer engagement activities and will also have the opportunity to influence the NIKTT's strategic direction and future funding priorities as part of a National Indigenous Kidney Transplantation Strategy.

Figure 1: NIKTT hierarchy and structure.



Membership

The TSANZ is seeking expressions of interest from the following stakeholders to serve as Expert Advisory Committee members:

people who have clinical/research expertise and experience working with Indigenous transplant candidates and recipients (i.e., nephrologists, nurses, allied health practitioners, primary care providers and health researchers);

people with relevant policy and advocacy experience, preferably through involvement with government and/or a peak body (i.e., Organ and Tissue Authority, Australian and New Zealand Society of Nephrology, Kidney Health Australia, National Aboriginal Community Controlled Health Organisation); and

Indigenous consumers and/or carers with lived experience of the pathways to waitlisting and kidney transplantation.

Behaviours

Expected behaviours of Expert Advisory Committee members include:

- All members exercise due diligence and act in good faith.
- Members are provided with timely access to information, and information is shared amongst members.
- Appropriate confidentiality is respected.
- Members review all papers in advance of meetings.
- Full and active participation in discussions by all members is promoted.
- Constructive questioning and vigorous debate is encouraged, with expressions of dissent undertaken in a harmonious and collegiate fashion.
- Members deal with each other with courtesy and respect.
- The right issues are considered, decisions documented and follow up conducted.
-

Performance

Members are expected to attend a minimum of 75 per cent of meetings, either in person or via video/teleconference. Meetings will be held on a quarterly basis over a 12-month period. It is anticipated that the first meeting will be held on **Tuesday 23 July in Adelaide**, with videoconferencing facilities available to those who cannot attend in person.

Applying

If you are interested in nominating for the NIKTT Expert Advisory Committee, please complete the application form on page 3 and return to projects@tsanz.com.au by **COB on Thursday 11 July 2019.**

If you require any further information about the NIKTT and the expression of interest process, please contact Kim Rawson, TSANZ Senior Project Officer, on 0451 380 757 or projects@tsanz.com.au.

Application for the NIKTT Expert Advisory Committee

Name:	
Address:	
Phone:	
Email:	
Position & Organisation (if relevant):	

1. **Please tick the relevant stakeholder groups that you have the expertise and/or experience to represent:**

☐ Consumers and their families and communities

☐ Renal care providers

☐ Primary/community care providers

☐ Allied health professionals

☐ Medical/health researchers

☐ Peak bodies, including ANZSN, KHA, OTA and NACCHO

☐ Other (please specify): ____

2. **Are you able to commit to four meetings, to be held either face to face or via video/teleconference, over a 12-month period?** ☐Yes ☐No

3. **Please indicate which working groups (if any) you'd be interested in serving on:**

☐ Data

☐ Consumer engagement

☐ Patient navigators (i.e. establishing patient mentorship systems)

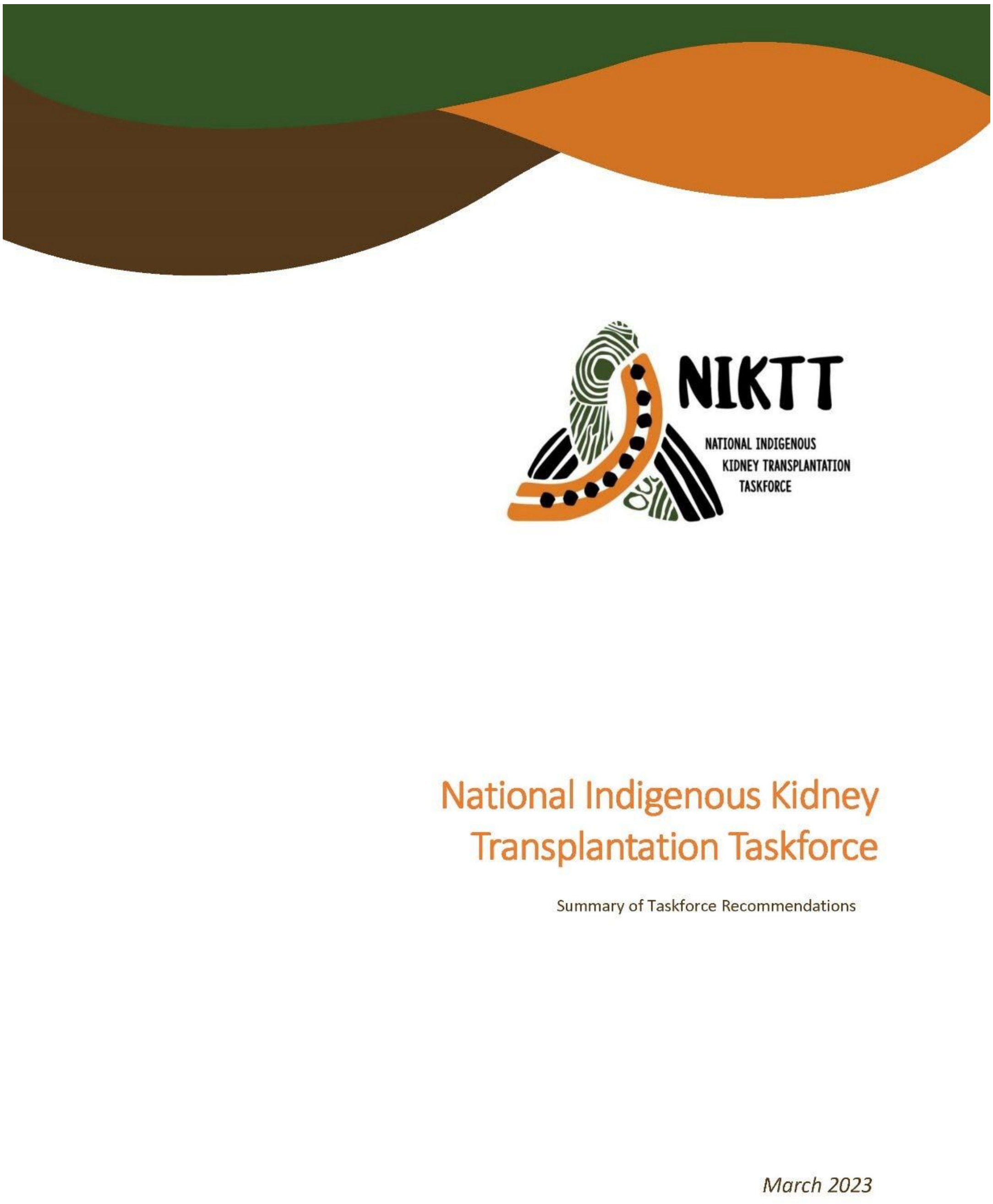
☐ Pre-Transplant care coordination

4. **If you would like to nominate to serve as the NIKTT Expert Advisory Committee Chairperson, please provide a brief statement (less than 200 words) outlining why you are a strong candidate for this role.**

Appendix F: *List of NIKTT Operations Committee Members, as of 2023*

Stephen McDonald	SA	Chair, NIKTT; Director of Dialysis, Central and Northern Adelaide Renal and Transplantation Service
Jaquelyne Hughes	NT	Deputy Chair, NIKTT; Nephrologist, Royal Darwin Hospital
Lucinda Barry	ACT	Organ and Tissue Authority representative
Angela Webster	NSW	TSANZ Council representative
Kelli Owen	SA	Indigenous Kidney Community Representative and Community Engagement Coordinator, NIKTT
Katie Cundale	SA	Senior Project Officer, NIKTT
Kim Rawson	NSW	Senior Project Officer, TSANZ

Appendix G: Summary of Taskforce Recommendations – Document Presented to Ministers in March 2023



NIKTT

NATIONAL INDIGENOUS
KIDNEY TRANSPLANTATION
TASKFORCE

National Indigenous Kidney Transplantation Taskforce

Summary of Taskforce Recommendations

March 2023

1 Overview

Disparities exist for Aboriginal and Torres Strait Islander people seeking and undergoing kidney transplantation in Australia. An examination of the barriers pre- and post-transplant that contribute to this disparity identified the need for a dedicated Taskforce to oversee improvements in transplantation access and outcomes. The National Indigenous Kidney Transplantation Taskforce (NIKTT) was established to undertake four main objectives between 2019-2022:

(1) Establish the National Indigenous Kidney Transplantation Taskforce and network;
(2) Enhance data collection and reporting;
(3) Pilot initiatives to improve patient equity and access; and
(4) Evaluate cultural bias interventions.

The Taskforce was comprised of 26 members. The Taskforce's work, findings, and recommendations have been guided by extensive engagement with and leadership from Aboriginal and Torres Strait Islander people with kidney disease and transplantation, alongside their families and carers. While work undertaken was divided between objectives, we present unified recommendations here as many findings were consistent across objectives.

As identified in the EY *Review of the Australian organ donation, retrieval and transplantation system Final Report* and the draft *National Strategy for Organ Donation, Retrieval, and Transplantation*, "a nationally driven approach to improve organ donation and transplantation rates among Aboriginal and Torres Strait Islander Australians" was, and continues to be, needed.

2 Recommendations

The following three key actions and associated recommendations were derived from the work of the NIKTT. These recommendations reflect clinical, consumer, and Community priorities.

Key action 1: Immediate improvements to access and services

Key action 2: Resource ongoing Secretariat to monitor and progress transplantation equity

Key action 3: Investigate additional measures to address drivers of inequity

Key action 1: Immediate improvements to access and services

Jurisdictions must sustainably fund the following:

1) Outreach Assessment Clinics: clinics should be resourced to provide multidisciplinary team visits to rural and remote locations. Funding should include the provision of a full-time Transplant Coordinator role and clinics should include educational sessions for staff and patients alongside clinic visits.
2) Indigenous Reference Groups (IRGs): all transplant hospitals should resource and implement IRGs alongside mechanisms for reporting and workflow integration. Groups should be led by Aboriginal and Torres Strait Islander kidney patients and/or Aboriginal and Torres Strait Islander renal health workers. A NIKTT Secretariat could support the establishment of IRGs alongside coordination of groups across sites to facilitate effective development and activity.
3) Increased Aboriginal and Torres Strait Islander renal health workforce: Identified renal health roles, including, but not limited to, Patient Navigators, transplant coordinators, nurses, physicians, health practitioners, and liaison officers should be developed and sustainably

resourced at renal units and transplant hospitals that serve Aboriginal and Torres Strait Islander patients. These roles must be embedded and supported within renal and transplantation units.

Key action 2: Resource ongoing Secretariat to monitor and progress transplantation equity

Coordinated efforts are essential to identify issues, catalyse activity, and maintain profile and focus on transplantation. A national Secretariat would provide leadership, collaboration, monitoring, and reporting and should be resourced for a minimum of three years to continue national coordination of transplantation equity work. This group should be responsible for the implementation of the following:

4) Ongoing Monitoring: through the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, progress on improving waitlisting numbers, kidneys transplanted, and post-transplant outcomes should be consistently monitored. This monitoring should include the development and implementation of an annual scorecard for renal units.
5) Maintaining Focus and Engagement: a coordinated network should be maintained to ensure attention remains on transplantation access and outcomes until significantly improved. Such maintenance of a network should include an annual Gathering, consistent community engagement, sustained online resource portal, and conference attendance.
6) Providing Additional Organ Support: through ANZDATA expertise, the Secretariat should explore and support the development of pathways to better transplantation access and outcomes for non-kidney organs in Aboriginal and Torres Strait Islander populations.
7) Developing a Proposal for a National Aboriginal and Torres Strait Islander Kidney Health Body: a coordinated, collaborative approach should be implemented to develop a proposal for a sustainable national body that represents the holistic journey of Aboriginal and Torres Strait Islander people with kidney disease, inclusive of all modalities including transplantation. Secretariat support should include the development of partnerships, governance, terms of reference, and key objectives and deliverables.

Key action 3: Investigate additional measures to address to drivers of inequity

Funding should be offered to support the investigation of solutions for further drivers of inequity. Research into, and implementation of, initiatives that address additional drivers of inequity should be nationally resourced and coordinated to understand best practices.

11) Additional Barriers: further barriers to transplantation equity, including overweight/obesity, treatment uptake, and reversible health issues, should be researched and best practices identified to address these barriers across rural and remote regions.
12) Design Initiatives Across the Transplantation Pathway: Research into and implementation of solutions to additional transplantation pathway aspects, with Aboriginal and Torres Strait Islander people, should be resourced, including post-transplant care, paediatric transplantation, culturally tailored transplant education, and donation.

Total over three years: $4.8 million (inclusive of investigation project funding)

3 Detailed Proposals

3.1 Key action 1: Immediate improvements to access and services

> Locally driven models of care should be implemented by state and territory hospitals and renal units in conjunction with primary health services and/or Aboriginal and Torres Strait Islander medical services where applicable.

Rationale

Findings from NIKTT objectives 3 and 4 strongly support the recommendation that particular changes to service delivery implemented at local, state/territory, and federal levels could substantially increase access to the transplantation waitlist for Aboriginal and Torres Strait Islander people as well as provide more culturally safe care. Implementation of the following service delivery changes should be aligned with the National Strategy for Organ Donation, Retrieval and Transplantation, and driven by jurisdictions.

Scope

The NIKTT recommends the following service delivery changes, or models of care, based on findings from pilot initiatives, the Cultural Bias Report, Community consultations, and evidence noted in previous reports such as the TSANZ Performance Report and the EY Review.

The NIKTT recommends that jurisdictions, in consultation with renal and transplantation units, implement the following models of care when providing services to Aboriginal and Torres Strait Islander people living with kidney disease and kidney failure.

While the NIKTT foresees that the following service changes could improve waitlisting, cultural safety, and ultimately transplantation, there will be local variation in implementation given the variability in service delivery models.

Methods

3.1.1 Outreach Assessment Clinics

NIKTT pilot projects found that multidisciplinary Outreach Assessment Clinics were beneficial in evaluating more patients, progressing more patients through workup assessment, placing more patients onto the transplant waitlist, and ultimately transplanting more patients. Key enablers from these Clinics included the coordination afforded to regional and metro teams through the role of a full-time transplant coordinator as well as the support and continuity of care provided by partnering with local Aboriginal medical services. Additional benefits to both patients and providers were the provision of locally tailored education on the transplantation process. This culturally relevant information aided patients in understanding and undertaking workup, and clinician-focused education aided providers in understanding local circumstances to better provide culturally safe care.

Based on these findings, the NIKTT strongly recommends that Outreach Assessment Clinics should be resourced to provide quarterly multidisciplinary team visits to rural and remote Australia. Funding must include the provision of a full-time Transplant Coordinator role and clinics should be co-run with local primary health care services. Educational sessions for staff and patients should be utilised alongside clinic visits to improve locally relevant transplantation knowledge.

While the makeup of each Outreach Assessment Clinic will vary based on location, in general, the NIKTT recommends that they incorporate:

- The provision of a **specific transplant coordinator role**, ideally an Aboriginal and/or Torres Strait Islander person, to coordinate clinic visits. This person(s), based locally or in metro areas, would be responsible for identifying patients eligible for workup, monitoring those already undergoing workup and ensuring they complete processes, arranging clinic visits with locally based medical teams, aiding in the development of educational materials, and maintaining contact and follow up with patients after each clinic.
- The creation of a **multidisciplinary transplant assessment team** that includes: nephrologist, transplant surgeon, transplant nurse, Aboriginal Health Practitioner and/or Aboriginal Liaison Officer, transplant coordinator, and other specialists as needed.
- Development of **educational materials** relevant to the local area that outlines regional processes to transplantation, including workup, staying on the list, transplantation, and post-transplant care. Resources need to be fit for purpose in the local area, and will benefit from local piloting to ensure relevance, understanding, and meaningfulness.

Outreach Assessment Clinics should be resourced by and directed from renal and transplantation hospitals throughout each state and territory.

3.1.2 Indigenous Reference Groups (IRGs)

Based on findings from the NIKTT pilot projects and extensive community engagement, the NIKTT strongly recommends that Indigenous Reference Groups (IRGs) are established at all hospitals that provide renal and transplantation services for Aboriginal and Torres Strait Islander peoples with kidney failure. We also recommend the establishment of a mechanism for support and coordination of IRGs across sites to facilitate effective development and activity.

Overall, NIKTT findings emphasise the importance of IRGs as a means of supporting culturally safe practice from within the hospital system. NIKTT suggests that each IRG considers the following elements for success:

- The NIKTT recommends that IRG success will be enabled by strong support from hospital executive, transplantation unit clinical directors, and renal unit heads of unit. These executives should commit in writing to ongoing engagement and support of IRG recommendations
- A nominated Consumer and Community Engagement Officer is crucial to identify, engage, and maintain relationships with both clinical advocates and consumer representatives
- A culturally safe physical meeting space must be provided wherein consumers and Aboriginal and Torres Strait Islander health staff can meet regularly
- A Terms of Reference document must be created to outline how the IRG works in partnership with the unit
- A list of priorities and actions should be agreed to first within the IRG and then in collaboration with the hospital
- All IRG members should be compensated for their time and expertise
- Quarterly or bi-annual reports should be completed by units to report on engagement and partnership with the IRG

3.1.3 Increased Aboriginal and Torres Strait Islander renal health workforce

Findings from the NIKTT projects, the Cultural Bias Report, and the Gathering Position Statement strongly support the increased employment of Aboriginal and Torres Strait Islander peoples in renal health service delivery. Increased numbers of Identified roles within renal and transplantation units, and renal support services, would provide for professional service delivery whilst simultaneously enhancing communication, representation, cultural safety, and Community engagement.

The NIKTT recommends that governments provide resources for the continued development, support, and implementation of permanent roles and succession pathways for the Aboriginal and Torres Strait Islander kidney health workforce across all levels, including nurses, doctors, allied health professionals, patient navigators, transplantation coordinators, Aboriginal liaison officers, Aboriginal health practitioners, unit managers, department leads, and executive roles. Managers and executive leadership are crucial to supporting the growth, retention, and capability development of Aboriginal and Torres Strait Islander health professional workforce. Managers and executive leadership should have training and regular reviews to ensure provision of culturally informed workforce leadership. These roles must be embedded and supported within the system.

Deliverables

Key deliverables from these recommendations include:

1. Ongoing funding secured for Outreach Assessment Clinics currently extant in Western Australia
2. Establishment of Outreach Assessment Clinics and multidisciplinary teams for clinic visits at each major transplantation unit Australia-wide
3. Establishment and maintenance of Indigenous Reference Groups at each renal and transplantation hospital in Australia
4. Creation of a national network of transplantation-focused consumer groups supported by a national Secretariat
5. Commitment and action plan from jurisdictions and/or transplantation units to employ Aboriginal and Torres Strait Islander people in transplantation-focused health service roles.

3.2 Key action 2: Resource ongoing Secretariat to monitor and progress transplantation equity

A national Secretariat should be resourced for another three years to continue coordination of transplantation equity work.

Rationale

The formation of the original National Indigenous Kidney Transplantation Taskforce (NIKTT) was crucial to provide a focal point for improving access and outcomes related to kidney transplantation in Aboriginal and Torres Strait Islander people. Work over the previous few decades has improved transplant, waitlisting, and dialysis numbers, however considerable inequity in access and outcomes remain. The coordination of transplantation equity efforts – across jurisdictions, with Community, and between disciplines – has enabled better directed attention and efforts, which has led to an improved rate of waitlisting and transplantation, although hindered by COVID-19.

Through sustained and targeted national community consultation, the NIKTT has learnt that there is compelling interest in the continuation of a group that works to coordinate, administer, and explore equity programs that improve access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander people. This Secretariat would work closely with TSANZ and AOTA to monitor transplantation access and outcomes, continue to collaborate, network, and educate stakeholders on issues fundamental to the improvement of access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander Australians, and develop the strategy and implementation plan for a national body representing Aboriginal and Torres Strait Islander kidney health and transplantation. The Secretariat would act as the bridge between Community and the finalisation of the National ODRT Strategy and its implementation plan.

Scope

Because transplantation involves a vast array of services and specialists, a national approach is needed to ensure best practices are shared and duplicated efforts are minimised. Due to the complexity of transplantation, a transplant-focused network is necessary to ensure challenges and opportunities unique to transplantation are identified and addressed.

The proposed Secretariat would focus on:

- The continued barriers to waitlisting, staying on waitlist, transplantation support, and post-transplant support and outcomes
- Improving the cultural safety of all transplantation-related services
- Developing and maintaining national networks of both consumers and service providers
- Providing support, development, and guidance for national strategy and long-term action plans

Methods/Implementation

- **Governance:** The structure of a continued Secretariat would build on the existing strength of networks and foundations that the NIKTT has created. For accountability and clinical oversight, we recommend that the Secretariat resourcing is provided through the Transplantation Society of Australia and New Zealand (TSANZ). To implement recommendations, this Secretariat would:

  - Employ a salaried Secretariat team, including Community Engagement, Administration, Project Management, and Research positions. This team would regularly report to an oversight committee, TSANZ, and funding partners.
  - Form an Oversight Committee (6-8 members) to achieve the goals of the NIKTT, through initial expressions of interest and referrals, with the majority being Aboriginal and/or Torres Strait Islander peoples. Chairs or co-chairs should include at least one Community member.
    - Appointments would be made to address complementary skills with the requirement of culturally respectful conduct. This Committee will provide clinical and Community leadership and advice to the Secretariat on a regular and ongoing basis
    - A Community Observer should be resourced to provide transparency and support good conduct
    - Some members of the Oversight Committee would draw stipend if not otherwise funded to undertake this role. This would be compensated at Commonwealth-recommended sitting fees, for four to six meetings per year
    - Committee members would be supported to work as a team, with training in cultural safety, reflective practice, intercultural teamwork, corporate governance, and Indigenous governance. Meetings should be hosted wherever possible on Country and/or with a local IRG.
  - The Secretariat will help the Committee to facilitate time-limited working groups to action boutique needs such as youth and paediatric transplant access, or post-transplant care, non-kidney organ transplant, and low-immunogenicity transplants, or who give additional oversight to some functions of the NIKTT (such as functions of IRGS, or resource development)
- **Data monitoring:** Through the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, the Secretariat would collect, analyse, and report on metrics relating to transplantation in Aboriginal and Torres Strait Islander populations. This would include the continued production of specific chapters in the ANZDATA annual reports on metrics relating to Aboriginal and Torres Strait Islander people, as well as the creation and sharing of infographics for Community and clinical stakeholders.
- **Scorecard development:** Through ANZDATA, and in collaboration with stakeholders such as TSANZ and ANZSN, the Secretariat would work to develop an annual scorecard that monitors, records, and reports on improvements in waitlisting, transplantation, workforce, and program delivery. This would include:
  - Development of metrics to measure unit-level cultural safety
  - Development of identification and tracking system to monitor and evaluate transplant-related initiatives and outcomes
  - Development of reporting system so renal units can assess their progress towards better transplantation access and outcomes
  - Develop, monitor, and evaluate publication methods of transplantation-related data, for knowledge exchange with differing actors including Community.

- **Network:** The Secretariat would capitalise on the well-established partnerships and engagement created over the last three years of NIKTT work. The Secretariat would continue to foster this network through:
    - Developing partnerships with key stakeholders, such as AOTA, TSANZ, ANZSN, KHA, and NACCHO, to share, discuss, and learn from current work
    - Hosting an annual Gathering that includes both clinicians and Community members
    - Sharing resources and promote knowledge exchange through communities of practice, participation in conferences, online resource portal development, and regular meetings.
- **Consumer coordination:** The Secretariat would help to coordinate and develop a national consumer network, building on existing relationships and communities of practice. Through this, the Secretariat would help to bring together Indigenous Reference Groups from around the country, in order to link up, support, and amplify consumer voices in transplantation.
- **Additional support:** through ANZDATA expertise, the Secretariat would explore and support the development of pathways to better transplantation access and outcomes for non-kidney organs in Aboriginal and Torres Strait Islander populations, such as liver and lung transplantation.
- **National body proposal:** Through the work of the NIKTT, Community, consumers, and clinical advocates have strongly supported the ambition to develop a national body that represents Aboriginal and Torres Strait Islander people undergoing kidney transplantation and living with kidney failure. Such a body will take time and dedicated collaboration to develop, and the Secretariat would be best placed to begin this groundwork. The Secretariat would:
    - Conduct Community consultations to best understand patient/carer/Community perspectives on what a national body should look like
    - Cultivate partnerships and commitments with all relevant stakeholders, including clinicians, organisations (TSANZ, KHA, etc), state/territory health departments, hospitals/HOUs, renal units
    - Determine the structure, workflow, and deliverables of such a body
    - Determine the governance, budget, accountability, outcomes, and evaluation of such a body
    - Create an action plan for implementation, monitoring, and evaluation.

Deliverables

Key deliverables of the continued NIKTT Secretariat would include:

- An integrated report and scorecard deployed within the ANZDATA system that tracks renal unit-level metrics on waitlisting, transplantation, and cultural safety
- A cohesive network maintained, through consistent online meetings and one in-person Gathering per year
- The establishment of a connected consumer voice through the coordination and development of Indigenous Reference Groups at renal and transplantation units
- A fully developed framework and implementation proposal for a national Aboriginal and Torres Strait Islander body that represents people living with kidney disease, failure, and transplantation.

Indicative Budget

Funding for a national Secretariat to carry out the above directives would include, per year:

Secretariat team (including oncosts) yearly

- 1.0 FTE Executive Officer: $160,000
- 1.0 FTE Community Engagement Coordinator: $150,000
- 1.0 FTE Research and Data Officer: $140,000
- 1.0 FTE Administration Support: $100,000

Oversight Committee

- Sitting fees: $100,000
- Oversight Committee member competency and training: $75,000
- Facilitation and meeting support: $25,000

Data Monitoring and Scorecard Development

- Salary support for ANZDATA project development team: $50,000
- Cultural bias metric development: $200,000

Network Maintenance

- Annual conference: $150,000
- Resource development, marketing, communications: $10,000

Proposed National Body Development

- Community consultations: $100,000
- Community education and resource development and dissemination: $10,000

Communication

- Resources, marketing support: $50,000

Total per year: $1,320,000

Total for three years: 3,960,000

3.3 Key action 3: Investigate additional measures to address drivers of inequity

Community-prioritised investigation into, and implementation of, initiatives that address additional drivers of inequity should be nationally resourced and coordinated to understand best practices. Development of research themes and support in monitoring and evaluation could be supported by a NIKTT Secretariat.

Rationale

The work of the NIKTT was based on the recommendations of a Performance Report published by the Transplantation Society of Australia and New Zealand (TSANZ) in 2018. This Report, *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia*, laid out 35 evidence-based recommendations for funding and immediate action. The three key areas of focus from the report, namely (1)establishing a resourced National Indigenous Kidney Transplantation Taskforce, (2) enhancing data collection and reporting; and (3) improving the equity and accessibility of transplantation, formed the basis of the first iteration of NIKTT work, alongside the Commonwealth-recommended focus on cultural bias initiatives.

There were many recommendations from this report, and the subsequently published EY Report, that were not covered within the first iteration of NIKTT work. These additional recommendations, mapped to Taskforce, State/Territory, and Commonwealth responsibilities, still remain. Priority areas from Community consultation have also identified additional areas of need.

Additional drivers of inequity include: weight and/or obesity; treatment uptake; reversible health conditions; post-transplant care; paediatric transplantation; and support services such as transportation, housing, and wraparound services.

Investigation into these additional barriers to transplantation should be resourced through a nationally coordinated body, as informed by Indigenous Reference Groups, Community consultations, and the Secretariat Oversight Committee.

A gap exists within the Australian health care system whereby Community-driven priority initiatives may not have access to implementation funding either due to project scale, organisational structure, or research capacity. The NIKTT recommends that another round of sponsorship grants are offered to Community, renal units, and other stakeholders working in kidney transplantation to address the remaining drivers of inequity. The NIKTT Secretariat would oversee the development, coordination, implementation, monitoring, and evaluation of projects.

Scope

Investigative projects should be funded to address:

- Further barriers, drivers, and opportunities surrounding transplantation access and outcomes for Aboriginal and Torres Strait Islander people that were not addressed through the work of the NIKTT
- System-level processes and policies that impact access to waitlisting and transplantation
- Post-transplantation outcomes, education, and care pathways
- Implementation, evaluation, and monitoring of culturally safe models of care
- National, jurisdictional, and regional -specific projects

Methods

Analysis and review of previous recommendations and progress to date should be first undertaken to best evaluate future research needs. A NIKTT Secretariat would work with Indigenous Reference Groups, the Oversight Committee, and other clinical and consumer stakeholders to determine themes and priorities for grant opportunities.

The investigation of additional measures to address drivers of inequity, and the translation of research findings into practice, should be coordinated nationally to facilitate knowledge exchange. The NIKTT recommends that projects are funded for one-to-three years due to the complexity and time needed to progress patients through the transplantation pathway.

All research must have oversight from a committee of Aboriginal and Torres Strait Islander people to ensure principles of cultural safety, accountability, strength-based approaches, and sovereignty are maintained.

Deliverables

- Five to ten projects funded to explore ways to address the additional drivers of inequity within kidney transplantation for Aboriginal and Torres Strait Islander people
- Culturally safe models of care identified that improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people

Budget

- Sponsorship opportunity per project: $50,000-120,000
- = $800,000 across 5-10 projects

Appendix H: Overview of NIKTT Working Groups

PURPOSE: To provide an overview of the purpose, roles and responsibilities of the NIKTT operations committee and working groups.

NIKTT working group members will be involved in providing more granular input on the design, implementation and evaluation of a specific NIKTT initiative.

Working group members are expected to:

- Have a detailed knowledge of the aim, strategy and intended outcomes of the relevant NIKTT initiative;
- Demonstrate an enthusiasm for the initiative and the intended outcomes; and
- Serve as an advocate for the initiative.

Specific responsibilities of working group chairs include:

- Ensuring that meetings run smoothly;
- Ensuring that key objectives and timelines, as per the Activity Work Plan, are met; and
- Ensuring that items stemming from working group meetings are actioned.

Specific responsibilities of working group members include:

- Ensuring the initiative's workplan aligns with, and is likely to achieve, the desired outcomes;
- Drawing upon their strong subject knowledge to guide the Secretariat on the management of the initiative to facilitate the attainment of identified milestones;
- Fostering positive engagement within the NIKTT and beyond with regard to the initiative's progress and outcomes;
- Actively promoting the outputs of the project to a broad spectrum of stakeholders; and
- Providing advice to the Operations Committee to inform the delivery of objectives and strategies as outlined in the Activity Work Plan; and
- Reporting to the NIKTT and involving the Indigenous Kidney Community Panel on an as- needed basis.

Appendix I: *Example Terms of Reference for an Indigenous Reference Group, as enacted through the Royal Adelaide Hospital*

Indigenous Reference Group Agreement

(The Way We Work Together)

Project Brief

The aim of this project is to provide opportunities for Aboriginal and Torres Strait Islander kidney patients and families, health professionals and health services to work together to improve renal care, and specifically access to kidney transplantation services, in South Australia and the Northern Territory at the Royal Adelaide Hospital. We aim to identify and respond to the needs of Aboriginal and Torres Strait Islander kidney patients and their families, and to work with the Royal Adelaide Hospital Renal & Transplantation Unit team to inform both local and national responses to the gaps in health care provision. The ultimate goal is to improve the coordination and delivery of renal care and services, increasing equity and access to the kidney transplant waitlist for Aboriginal and Torres Strait Islander patients.

Key issues, emerging themes, and health journey stories will be written up and reported back to the Transplantation Unit through the following methods:

- Focus groups involving Aboriginal and Torres Strait Islander renal patients, their families, support networks & health care staff
- Identification of barriers and enablers, and effective strategies for improvement
- Priority setting and knowledge translation workshops
- Aboriginal and Torres Strait Islander community consultations
- Education package development for staff and students
- Patient journey mapping, from the perspectives of renal patients, their families, support networks, staff and services

The IRG project is located at the Royal Adelaide Hospital. Patients from regional and metropolitan areas will be represented, including members from Adelaide, Darwin, Alice Springs, Broken Hill, Port Augusta, Port Lincoln, Whyalla, Port Pirie, Murray Bridge, Mount Gambier, Ceduna, and any other Aboriginal communities that the group may identify (within the funding scope). Virtual meetings via video camera and phone link ups will be arranged for members living outside the Adelaide Metro area. Representatives from the Royal Adelaide Hospital Renal Unit, dialysis sites and Aboriginal health services will also be invited to partake and partner in this important initiative.

This project is led by Royal Adelaide Hospital and supported by the National Indigenous Kidney Transplantation Taskforce (NIKTT).

The Reference Group

We are a Community Reference Group made up of Aboriginal and Torres Strait Islander renal patient experts guiding all aspects of this IRG project. Kelli Owen and Brenton Wilson have worked together to lead this group since March 2020.

The role of the IRG is to provide:

- Advice about cultural and community perspectives or considerations;
- Insights and guidance for Royal Adelaide Hospital and the NIKTT;
- Feedback and help to set identified priorities;
- Guidance to understand the findings and help develop the recommendations
- Assistance in translating themes using own local knowledge, and;
- Advise on ways to share findings and promote the recommendations to improve the coordination and delivery of transplantation services for all Aboriginal people.

Guiding Principles

The Royal Adelaide Hospital IRG project team (Community Engagement Coordinator, Aboriginal Health Practitioner, patient experts, their families and renal staff) agree to these principles of yarning:

- Be approachable, respectful, polite and non-judgemental
- Maintain confidentiality about personal journeys and any stories shared within the group
- Challenge assumptions respectfully
- Be open to learning from each other
- To enjoy ourselves and not forget to laugh
- To be flexible about how we meet (e.g., phoning sometimes, virtual with COVID)
- In the event that a member cannot attend, the member can nominate a proxy to speak on their behalf or contact Brenton or Kelli prior to the meeting to add to the agenda.

First Nations Space

As required, the Royal Adelaide Hospital NIKTT IRG can decide to discuss issues amongst ourselves (without health service representation/involvement), and such decisions will be respected by all present. An invite to Health professionals will be sent to join us when we need their input.

Meetings

The IRG project team will provide a project update before and at each IRG meeting. The IRG will meet every 3 months at a comfortable, easily accessible venue. Key decisions can be made providing there is a minimum of 5 members. Decisions are made by the members of the group in attendance. A light meal is provided each time we meet.

Members: The maximum number of members meeting at any given time is 20.

Support: Each time the meetings are held, members are paid $30 an hour as a sitting fee as per the CALHN (Central Adelaide Local Health Network) Consumer Partnering & Community Engagement Framework Policy. Preparation and reading time are also reimbursed under CALHN.

Travel: Cab vouchers are provided to cover travel from metro areas, or mileage reimbursement (85cents per KM- with the pay cycle of SA Health) is provided for regional travel in your private vehicle. Please provide bank account details if you choose this option. Tele- and videoconferencing will be made available to all members, particularly for those based in regional and remote areas, to optimise attendance.

Passing

On the media consent form there is a separate section that requires your signature. Your signature and approval give us consent to use photos after a person has passed. This option is offered to honour and respect the work members achieve in their lifetime to improve kidney care for Aboriginal and Torres Strait Islander peoples.

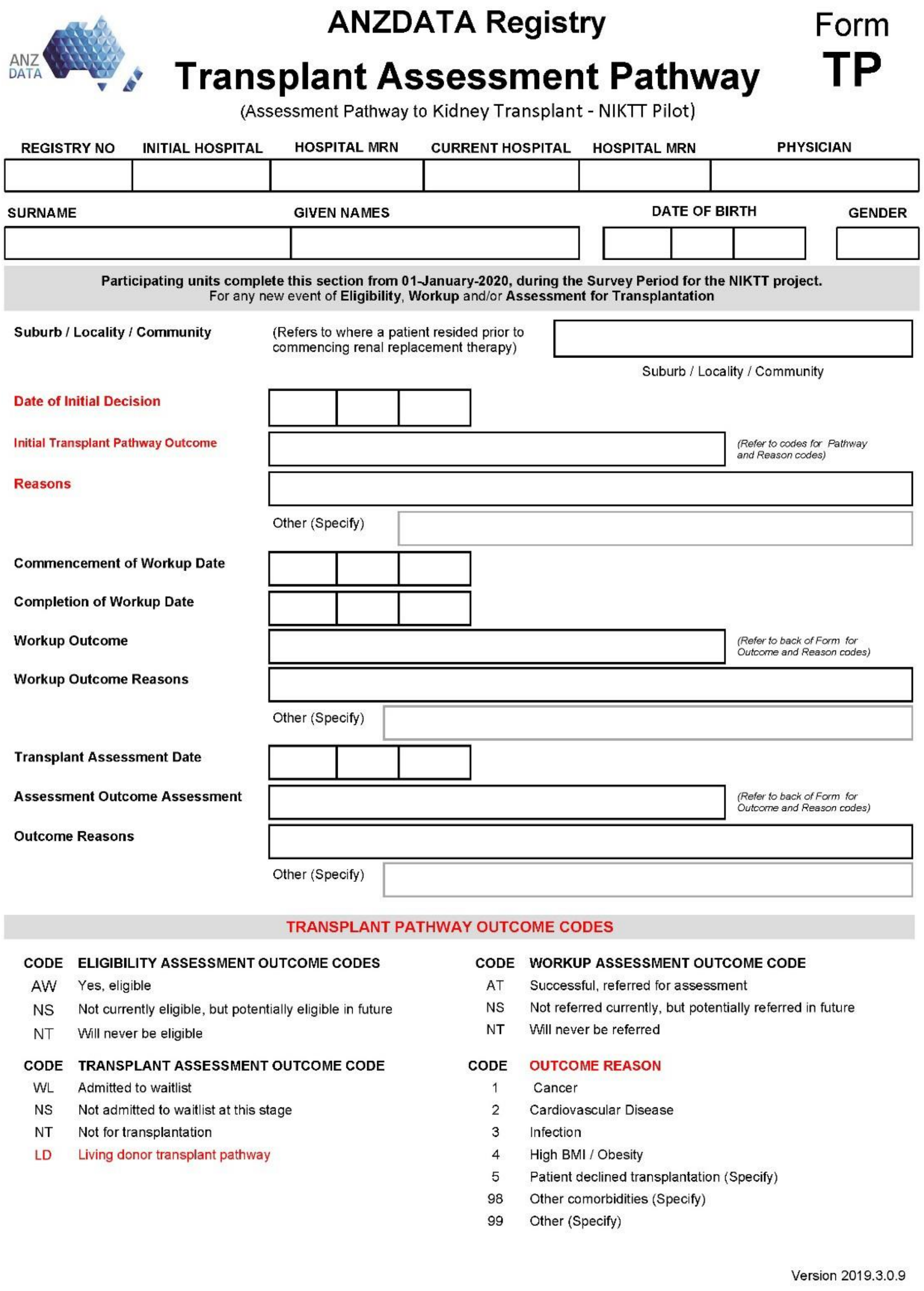
Publicity

The project team requires permission from each member to use their image or words of wisdom for all forms of media (including photos, videos, interviews, quotes, stories, artwork). Each member can decide whether they would like their photos to be used into the future.

Future Opportunities

We the Royal Adelaide Hospital Indigenous Reference Group have a goal that we will have a respected place with SA Health as an Advisory Group to renal and transplantation care and services into the future.

Appendix J: Transplant Assessment Pathway and Transplant Assessment Stage Forms



ANZ DATA

ANZDATA Registry

Transplant Assessment Pathway

(Assessment Pathway to Kidney Transplant - NIKTT Pilot)

Form
TP

REGISTRY NO	**INITIAL HOSPITAL**	**HOSPITAL MRN**	**CURRENT HOSPITAL**	**HOSPITAL MRN**	**PHYSICIAN**

SURNAME	**GIVEN NAMES**	**DATE OF BIRTH**	**GENDER**

Participating units complete this section from 01-January-2020, during the Survey Period for the NIKTT project.
For any new event of **Eligibility**, **Workup** and/or **Assessment for Transplantation**

Suburb / Locality / Community (Refers to where a patient resided prior to commencing renal replacement therapy)

Suburb / Locality / Community

Date of Initial Decision

Initial Transplant Pathway Outcome *(Refer to codes for Pathway and Reason codes)*

Reasons

Other (Specify)

Commencement of Workup Date

Completion of Workup Date

Workup Outcome *(Refer to back of Form for Outcome and Reason codes)*

Workup Outcome Reasons

Other (Specify)

Transplant Assessment Date

Assessment Outcome Assessment *(Refer to back of Form for Outcome and Reason codes)*

Outcome Reasons

Other (Specify)

TRANSPLANT PATHWAY OUTCOME CODES

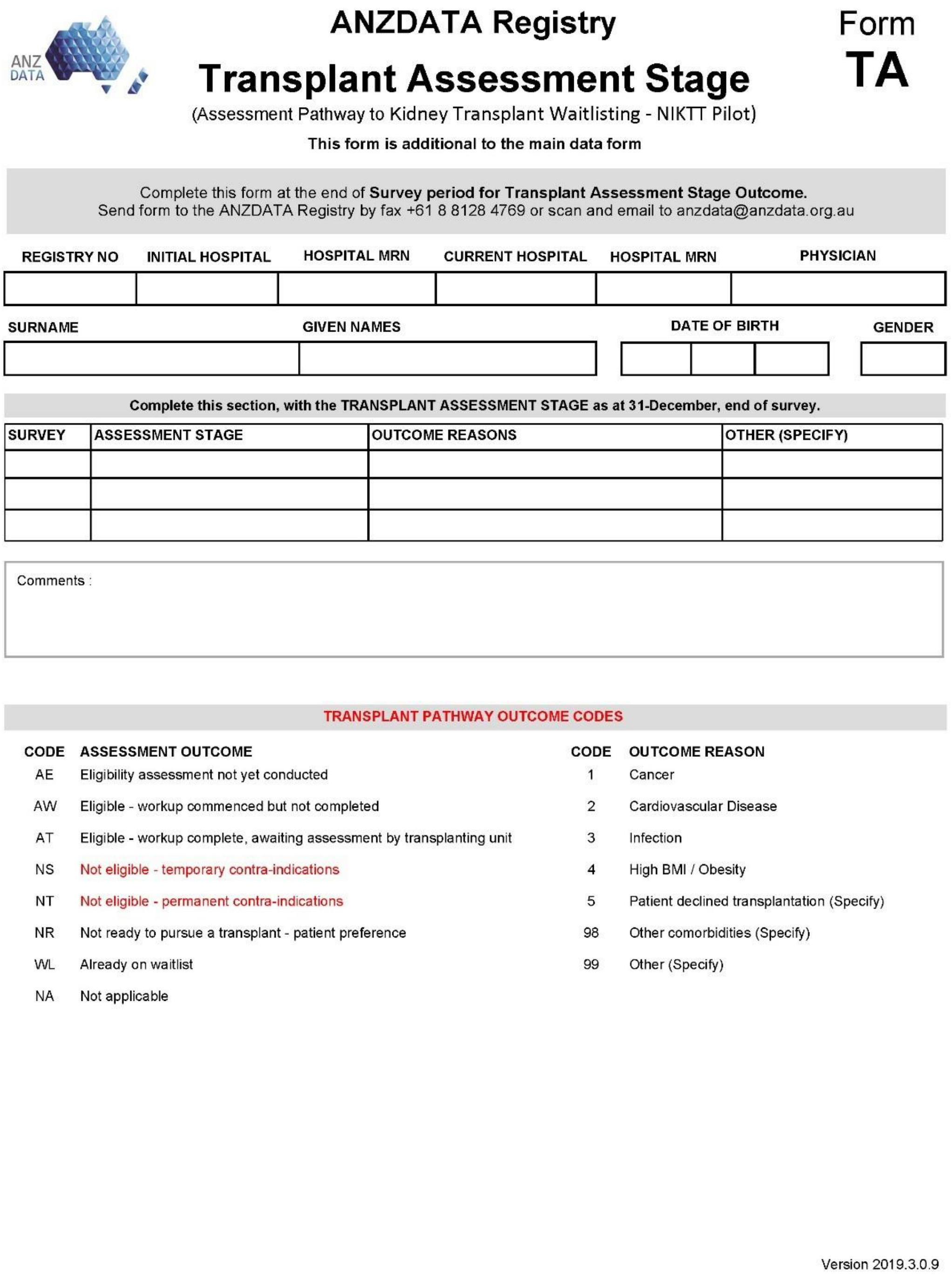
CODE	ELIGIBILITY ASSESSMENT OUTCOME CODES
AW	Yes, eligible
NS	Not currently eligible, but potentially eligible in future
NT	Will never be eligible

CODE	WORKUP ASSESSMENT OUTCOME CODE
AT	Successful, referred for assessment
NS	Not referred currently, but potentially referred in future
NT	Will never be referred

CODE	TRANSPLANT ASSESSMENT OUTCOME CODE
WL	Admitted to waitlist
NS	Not admitted to waitlist at this stage
NT	Not for transplantation
LD	Living donor transplant pathway

CODE	OUTCOME REASON
1	Cancer
2	Cardiovascular Disease
3	Infection
4	High BMI / Obesity
5	Patient declined transplantation (Specify)
98	Other comorbidities (Specify)
99	Other (Specify)

Version 2019.3.0.9



ANZDATA Registry

Form
TA

Transplant Assessment Stage

(Assessment Pathway to Kidney Transplant Waitlisting - NIKTT Pilot)

This form is additional to the main data form

Complete this form at the end of **Survey period for Transplant Assessment Stage Outcome.**
Send form to the ANZDATA Registry by fax +61 8 8128 4769 or scan and email to anzdata@anzdata.org.au

REGISTRY NO	INITIAL HOSPITAL	HOSPITAL MRN	CURRENT HOSPITAL	HOSPITAL MRN	PHYSICIAN

SURNAME	GIVEN NAMES	DATE OF BIRTH			GENDER

Complete this section, with the TRANSPLANT ASSESSMENT STAGE as at 31-December, end of survey.

SURVEY	ASSESSMENT STAGE	OUTCOME REASONS	OTHER (SPECIFY)

Comments :

TRANSPLANT PATHWAY OUTCOME CODES

CODE	ASSESSMENT OUTCOME	CODE	OUTCOME REASON
AE	Eligibility assessment not yet conducted	1	Cancer
AW	Eligible - workup commenced but not completed	2	Cardiovascular Disease
AT	Eligible - workup complete, awaiting assessment by transplanting unit	3	Infection
NS	Not eligible - temporary contra-indications	4	High BMI / Obesity
NT	Not eligible - permanent contra-indications	5	Patient declined transplantation (Specify)
NR	Not ready to pursue a transplant - patient preference	98	Other comorbidities (Specify)
WL	Already on waitlist	99	Other (Specify)
NA	Not applicable		

Version 2019.3.0.9

Appendix K: List of Participating Renal Units in NIKTT Extended Data Collection

Unit Code	Unit name	Funded
ALIC	Alice Springs	YES
CAIR	Cairns & Thursday Island	YES
CANB	Canberra	YES
CNAR	Central Northern Adelaide	YES
CONC	Concord	
EPWE	Epworth Eastern	
FSTH	Fiona Stanley	YES
HUNT	Hunter	YES
LISM	Lismore	YES
MACK	Mackay	
QMAT	Mater South Brisbane	
MMCP	Monash Children's	
PSAH	Princess Alexandra	YES
RBSH	Royal Brisbane	YES
DARW	Royal Darwin	YES
RMBH	Royal Melbourne	YES
RLPT	Royal Perth	YES
SCGH	Sir Charles Gairdner	YES
STGH	St George	
GSTA	St. Andrews	
SCUH	Sunshine Coast	
SCHL	Sydney Children's	
TAMW	Tamworth	YES
TWMB	Toowoomba	YES
TOWN	Townsville	YES
WEST	Westmead	YES
