



JANUARY 31, 2022

PERFORMANCE REPORT

NATIONAL INDIGENOUS KIDNEY TRANSPLANTATION TASKFORCE

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Executive Summary

In June 2019, the Commonwealth, represented by the Department of Health, committed \$2.3 million to establish the National Indigenous Kidney Transplantation Taskforce (NIKTT). It followed a report from an Expert Panel of the Transplantation Society of Australia and New Zealand which made 36 recommendations to improve access to and outcomes of kidney transplantation among Aboriginal and Torres Strait Islander people. The NIKTT comprises of a secretariat that is housed within the South Australian Health and Medical Research Institute, a steering committee, a national consumer board, and several working groups. The steering committee includes members from the clinical, academic, government and non-government sectors. The NIKTT will be responsible for implementing and evaluating the following key objectives:

- Establish the National Indigenous Kidney Transplantation Taskforce (NIKTT),
- Enhance data collection and reporting,
- Pilot initiatives to improve patient equity and access, and
- Evaluate cultural bias interventions.

This Performance Report outlines progress made by the NIKTT against each of these objectives from execution of the agreement to 31 January 2022.

Duration of the Activity

Due to the impact of the COVID-19 pandemic, the NIKTT received a further 12-month extension to 30 June 2022. TSANZ and SAHMRI have executed a contract to resource the NIKTT project and Secretariat for the extended period.

All NIKTT activities have now been completed, and the remaining period of the funding will be used to evaluate and report on the findings.

Progress Update

Objective 1: Continued collaboration with the NIKTT and Reference Groups

Overall Taskforce

The NIKTT remains well established, 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 [Attachment A](#).

The NIKTT held a cultural bias workshop in late November 2021, where all members of the Taskforce were invited to attend. A further Taskforce-wide update and future planning session will be held towards the end of March 2022.

Operations Committee

The NIKTT is supported by an Operations Committee comprising members from the TSANZ Council, the Organ and Tissue Authority, the Aboriginal and Torres Strait Islander kidney community, as well as the NIKTT Senior Project Officer, NIKTT Deputy Chair, and NIKTT Chair (full membership at [Attachment B](#)).

There have been recent changes in NIKTT Operations Committee membership with the recent departure of Amanda Bell (Organ and Tissue Authority representative) and Matilda D'Antoine (NIKTT Administrative Officer). Recruitment for the position of NIKTT Senior Project Officer was completed in August and Katie Cundale has taken on the role. The National Consumer Engagement Coordinator (Kelli Owen) reduced her commitment to NIKTT to 0.6 FTE to take advantage of a complementary position at the Central Adelaide Local Health Network. A second National Consumer Engagement Coordinator, Rhanee Lester, began work for the NIKTT in early January 2022, in order to backfill the role to a full 1.0 FTE position.

The Committee meets monthly and is responsible for managing the budget, associated contracts, and administering the delivery of NIKTT objectives and strategies, in accordance with the Taskforce's advice. The Operations Committee report to the NIKTT and TSANZ Council on finances, risks, and the status of strategy implementation. Most recently, the Chair and Senior Project Officer presented the NIKTT's progress and findings to date to the TSANZ Council at the beginning of December 2021.

On the 31st of January, 2022, the Chair, Deputy Chair, and Senior Project Officer will meet with representatives from the Department of Health, Indigenous Health Division, to discuss Activity 4: the Cultural Bias Review.

Indigenous Reference Groups

There are five Indigenous Reference Groups (IRGs) across Australia: two in New South Wales and one each in Western Australia, Queensland, and South Australia. The aim of the IRGs is to bring about change within transplant units by bringing together patients, carers, and families to discuss their kidney journeys, needs, and supports through to transplant and beyond.

Establishment of IRGs in Victoria and Tasmania has been unable to progress due to travel restrictions and the necessity of in-person meetings for the beginning stages of the Groups.

Table 1 outlines the details of the IRGs and their membership.

Table 1. Indigenous Reference Groups

| 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 from IRG participants has been overwhelmingly positive, with all jurisdictions interested in continuing the Groups after the initial NIKTT funding period is over. Work now will involve planning for, and procuring funding and space for, the continuation of the Groups.

National Community Panel

The National Community Panel comprises of 175 members who are 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 consists of family carers and Aboriginal and Torres Strait Islander health staff supporting kidney care. Members are contacted by the Community Engagement Coordinator (CEC) by telephone calls, emails, and face-to-face meetings. This multi-flexible approach allows for trust in holding the members' kidney journey. It is 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.

The National Panel is now under the purview of Rhanee Lester, who will be in regular contact with the Panel to share NIKTT updates, plan for the future of the Panel, and discuss how the Panel, IRGs, and renal units work together to integrate feedback and consumer voices going forwards.

Table 3 displays the total number of National Community Panel members by jurisdiction.

Table 2. National Community Panel Membership by Jurisdiction

| Jurisdiction | Members | |
|------------------------------|-------------|-----------------|
| | 2 July 2021 | 31 January 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 |

Educational Directory

TSANZ and the NIKTT CEC have been collaborating on co-creating an online Educational Directory displaying relevant and focused resources to share to community members, families, and clinicians. Content has been collected and is awaiting final upload to the newly built platform on the TSANZ site. This website will be publicly available by the end of February 2022.

Objective 2: Enhancing data collection and reporting

The NIKTT is finalising data collection on the extended pilot project involving tertiary renal health services. This project aimed to establish a consistent framework for collecting and reporting data on access to transplantation, which will improve our understanding of the inequities that affect Aboriginal and Torres Strait Islander patients throughout the pre-transplant journey. Data collection finalisation, cleaning, and analysis will be completed within the next few months.

Descriptive Data, 2020

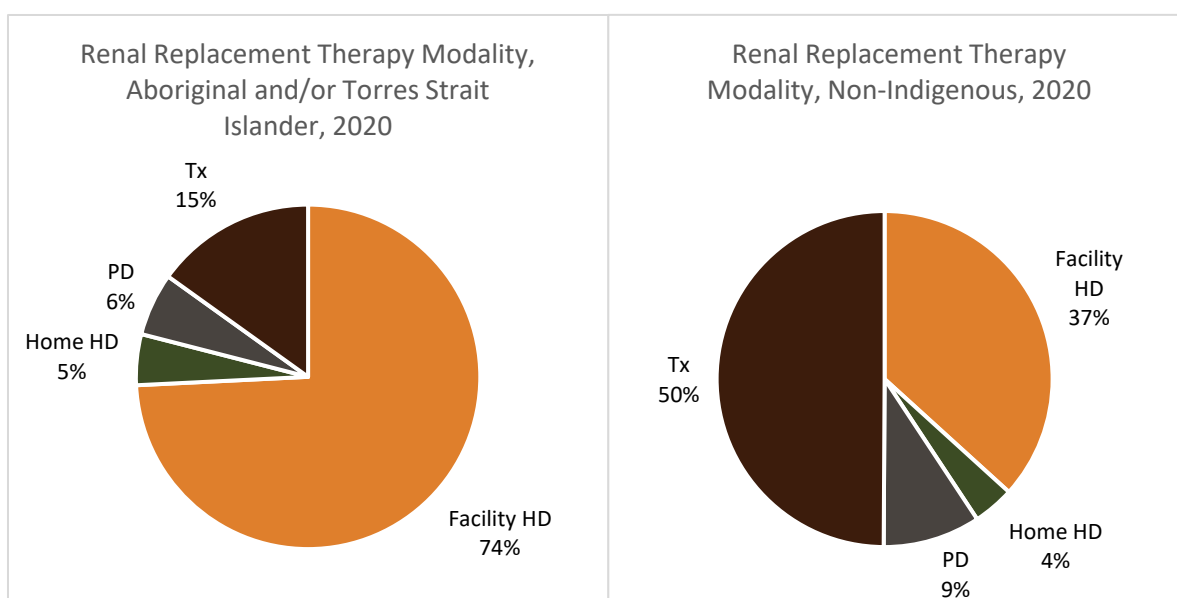
Data from the 44th Annual ANZDATA Report (2021) includes analyses of data to 31st December 2020. For the survey period ending 31-December-2020, all renal units across Australia and New Zealand contributed data to the Registry. The report produces a wide range of statistics relating to incidence, prevalence, and outcomes of treatment, of those with end stage kidney failure.

For 2020, there were 28,031 patients in Australia with end stage kidney disease on renal replacement therapy listed within the ANZDATA Registry. Of these, 2,471 patients identified as Aboriginal and/or Torres Strait Islander (8.8%).

For those 2,471 Aboriginal and/or Torres Strait Islander patients, 118 patients were on home haemodialysis for 2020 (4.7%), 1,834 patients were on facility-based haemodialysis (74.2%), and 373 patients had received a transplant from either a living or deceased donor (15.1%).

Figure 1 highlights the disparity in modality for Aboriginal and Torres Strait Islander patients compared to non-Indigenous Australian patients. Most Aboriginal and Torres Strait Islander patients were maintained on facility-based haemodialysis in 2020 (74%), compared to 37% for non-Indigenous patients. While 50% of non-Indigenous patients had received a kidney transplantation in 2020, just 15% of Aboriginal and Torres Strait Islander patients had received a transplant.

Figure 1. Difference in treatment modality for end stage kidney disease between Aboriginal and Torres Strait Islander patients in Australia compared to non-Indigenous patients, 2020



Source: [ANZDATA, 2021](#)

Initial Waitlisting Analysis, 2019

As part of the NIKTT data pilot project, renal units around Australia began listing whether prevalent dialysis patients 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. For the 2019 data, there were 2,243 Aboriginal and Torres Strait Islander patients recorded in the ANZDATA Registry (Table 1), 875 of which were listed as not eligible for waitlisting (39%).

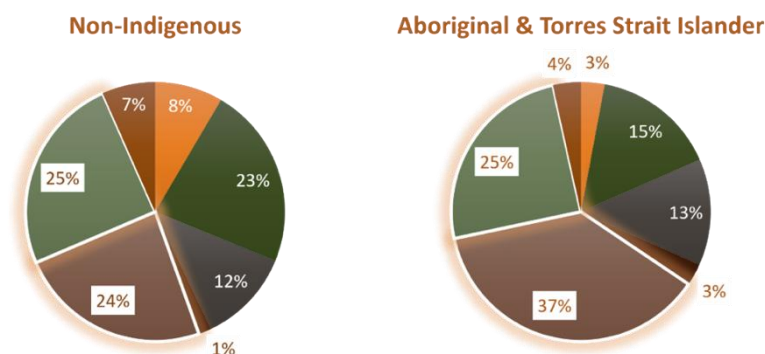
Table 3. Status of all patients, by Indigenous status, 2019

| Status | Aboriginal & Torres Strait Islander | non-Indigenous | Grand Total |
|--|-------------------------------------|----------------|--------------|
| Eligibility assessment not yet conducted | 226 | 502 | 728 |
| Eligible: workup commenced but not completed | 274 | 585 | 859 |
| Live donor pathway | | 17 | 17 |
| Missing | 205 | 1880 | 2085 |
| NA - not applicable | 507 | 8348 | 8855 |
| Not eligible: permanent contraindications | 560 | 2177 | 2737 |
| Not eligible: temporary contraindications | 315 | 647 | 962 |
| Not ready to pursue a transplant | 67 | 215 | 282 |
| On waitlist | 65 | 690 | 755 |
| Workup completed, awaiting assessment | 24 | 65 | 89 |
| Grand Total | 2243 | 15126 | 17369 |

Source: ANZDATA, 2020

The reasons listed for ineligibility for waitlisting were largely similar between Aboriginal and Torres Strait Islander and non-Indigenous patients, however for both groups, most of the reasons selected for ineligibility were classified only as “other” (Figure 2). To address this uncertain data point, the NIKTT data project collected free-text answers for why “other” was selected as a reason patients were listed as not eligible.

Figure 2. Reasons for not being waitlisted, by Indigenous status, 2019



Source: ANZDATA, 2020



When renal units completed the non-routine data collection form for the NIKTT, they were encouraged to list the reasons patients were not eligible for transplant workup or assessment. Because this data collection was free text, the responses were subsequently re-coded into broad categories by the NIKTT team. These categories, and the distribution of patients within each, are shown in Table 4.

Table 4. “Other” reasons for being listed Not Eligible, 2019

| | <i>Aboriginal Torres Strait Islander</i> | <i>& non- Indigenous</i> | <i>Grand Total</i> |
|---|--|----------------------------------|------------------------|
| <i>Age/Frailty</i> | 94 | 648 | 742 |
| <i>Medical</i> | 156 | 232 | 388 |
| <i>On hold/Awaiting more treatment/reason not specified</i> | 13 | 71 | 84 |
| <i>Psychosocial</i> | 155 | 141 | 296 |
| <i>Grand Total</i> | 418 | 1092 | 1510 |

Source: ANZDATA, 2020

Data cleaning, analysis, and write up for the complete data pilot project, including data from 2020, is currently underway.

Objective 3: Piloting initiatives to improve patient equity and access

Equity and Access Sponsorships

The NIKTT's Equity & Access Sponsorships were awarded to eight projects, totalling \$1,040,381. Funded initiatives are located in Western Australia, the Northern Territory, South Australia, and Queensland. The projects include 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. All projects are in the final stages of implementation and evaluation has begun.

All projects were significantly impacted by COVID-19-associated delays. Extension requests were approved for all sponsorship recipients, and all but one project has now completed their funded activity period. The NIKTT team, in conjunction with the sponsorship recipients and local communities, is now evaluating the projects and completing the final impact and evaluation report.

Cairns and Hinterland Hospital and Health Service

Cairns and Hinterland Hospital and Health Service received \$107,940.00 (GST excl) to employ patient mentors. Due to significant delays with project personnel, this project is still ongoing and will finish in March 2022.

Fiona Stanley Hospital

Fiona Stanley Hospital received \$109,224 (GST excl) to provide outreach assessment services to the Pilbara and Goldfields regions of Western Australia. This project has been completed and evaluation is underway.

Pika Wiya Health Service Aboriginal Corporation

Pika Wiya Health Service Aboriginal Corporation received \$148,000.00 (GST excl) to employ an Aboriginal Health Practitioner to bridge service delivery gaps. This project worked in partnership with the Port Augusta project to deliver education to kidney patients in the South Australia region of Port Augusta. This project has been completed and evaluation is underway.

Port Augusta Hospital and Regional Health Service

Port Augusta Hospital and Regional Health Service received \$84,667.00 (GST excl) to employ patient navigators to 'walk alongside' kidney transplant patients. This project worked with Pika Wiya to deliver education sessions to patients in the Port Augusta community. This project has been completed and evaluation is underway.

Princess Alexandra Hospital

Princess Alexandra Hospital received \$40,250.00 (GST excl) to provide kidney transplant education services to Townsville, Mount Isa, Cairns, and Thursday Island. This project has been completed and evaluation is underway.

Purple House – Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation

Purple House received \$200,000.00 (GST excl) to support an existing team of patient mentors to create a program targeted at supporting people looking for a kidney transplant in a culturally safe and respectful way. This project has been completed and evaluation is underway.

Royal Perth Hospital

Royal Perth Hospital received \$150,300.00 (GST excl) to work in collaboration with Sir Charles Gairdner Hospital in Western Australia to provide an outreach kidney transplant assessment service to the northern Kimberley region. This project has been completed and evaluation is underway.

Top End Health Service

Top End Health Service received \$200,000.00 (GST excl) to employ two Aboriginal and/or Torres Strait Islander health professionals to bridge cultural gaps between patients and mainstream health services. Although there were significant delays to the project due to recruitment, this project was completed by the end of 2021 and evaluation is underway.

Objective 4: Evaluating cultural bias initiatives

Cultural Bias in Indigenous Kidney Care and Kidney Transplantation

Cultural bias is a particular priority of the Taskforce. A Cultural Bias Workshop was held on the 22nd of November 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 that was completed by the Lowitja Institute. 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.

The NIKTT has sent the final Report and the NIKTT's response of 5 priority recommendations back to the Commonwealth Government. 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.

Financial and Budget Update

In relation to the project, a financial summary against each objective is provided monthly to the Operations Committee and as a standing agenda item at each NIKTT meeting. Provided below is the financial position of the NIKTT as of 31 December 2021.

Income and Expenditure as at 31 December 2021

| | | |
|---------------------------------|----|-------------------|
| Opening balance (1/7/21) | \$ | 239,386.54 |
| INCOME | | |
| Interest | \$ | 11.89 |
| Sponsorship refund | \$ | 13,200.00 |
| BAS Refund | \$ | 945.90 |
| Total Income | \$ | 14,157.79 |
| EXPENSES | | |
| Audit expenses | \$ | 1,524.60 |
| Meeting expenses | \$ | 1,118.70 |
| Sponsorship | \$ | 20,961.60 |
| SAHMRI Resources | \$ | 220,000.00 |
| Total Expenses | \$ | 243,604.90 |
| BALANCE | \$ | 9,939.43 |

Attachment A: NIKTT Membership

| 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 (<i>Deputy Chair</i>) | 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 |

Attachment B: Operations Committee Membership

| Name | Jurisdiction | Role |
|------------------|--------------|---|
| 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 |
| Alison Hodak | ACT | Organ and Tissue Authority representative |
| Angela Webster | NSW | TSANZ Council representative |
| Kelli Owen | SA | Indigenous Kidney Community Representative and Community Engagement Coordinator, NIKTT |
| Rhane Lester | SA | Patient Navigator and Community Engagement Coordinator, NIKTT |
| Katie Cundale | SA | Senior Project Officer, NIKTT |
| Kim Rawson | NSW | Senior Project Officer, TSANZ |