



TSANZ

The Transplantation Society of Australia and New Zealand



FEBRUARY 20, 2020

PERFORMANCE REPORT

NATIONAL INDIGENOUS KIDNEY TRANSPLANTATION TASKFORCE

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Performance Report – National Indigenous Kidney Transplantation Taskforce

Executive Summary

In June 2019, the Commonwealth, represented by the Department of Health, varied its existing agreement with the Transplantation Society of Australia and New Zealand (TSANZ) to include the new activity, “National Indigenous Kidney Transplantation Taskforce”. The Commonwealth has committed \$2.3 million to facilitate this activity, which comprises four 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 will outline progress made by the NIKTT against each of these objectives from execution of the agreement to 31 December 2019.

Figure 1: NIKTT members meeting at the National Indigenous Dialysis and Transplantation Conference – Alice Springs, 20 October 2019.



Progress Update

Objective 1: Establishing the NIKTT

The membership of the NIKTT was finalised in July 2019, comprising 26 stakeholders from a variety of disciplines including Indigenous kidney community members, nephrologists, nurses, policymakers, researchers, primary care and allied health professionals. The full NIKTT membership can be found at [Attachment A](#).

NIKTT members support and guide NIKTT initiatives, 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 wait-listing and transplantation pathways.

The NIKTT meets on a quarterly basis; previous meetings occurred on 6 August 2019, 20 October 2019 and 20 February 2020. Key clinical resources and access to subject matter experts have been contracted through the South Australian Health and Medical Research Institute (SAHMRI) to ensure that the NIKTT and associated deliverables are adequately resourced. In addition, the NIKTT is supported by an Operations Committee and five working groups.

Operations Committee

The Operations Committee comprises representatives from TSANZ Council, the Organ and Tissue Authority and the Indigenous kidney community, as well as the NIKTT Executive Officer, Senior Project Officer, Deputy Chair and Chair (full membership at [Attachment B](#)). The Committee's responsibilities include managing the budget, associated contracts and administering the delivery of NIKTT objectives and strategies, in accordance with the NIKTT's advice. The Operations Committee will report to the NIKTT and TSANZ Council on finances, risks and the status of strategy implementation at the quarterly Taskforce meetings, TSANZ Council meetings or out-of-session as required.

Working Groups

NIKTT working groups provide more granular input on the design, implementation and evaluation of specific NIKTT initiatives.

Five NIKTT working groups were established in August 2019:

1. Data
2. Community Engagement
3. Patient Mentors

4. Pre-Transplant Care Coordination
5. Review of Cultural Bias Initiatives

Objective 2: Enhancing data collection and reporting

The NIKTT has commissioned the ANZDATA registry to deliver a 12-month pilot project involving tertiary renal health services, which will enable the collection and analysis of additional pre-transplant data points. This is an important first step in establishing a consistent framework for collecting and reporting data on access to transplantation, which will significantly improve our understanding of the inequities that affect Indigenous patients throughout the pre-transplant journey.

Facility selection

All renal health services in Australia were invited to participate in the voluntary 12-month trial of an enhanced and expanded ANZDATA data collection protocol, which requires units to capture a number of additional pre-transplant data points. The 20 units who treat 90% of prevalent Indigenous dialysis patients were financially incentivised to participate, and will receive pro-rata payments based on prevalent dialysis patient numbers.

Patient selection

Participating units will capture and report data on all Indigenous and non-Indigenous patients receiving RRT who are covered under existing ANZDATA consent arrangements.

Funding details

The value of the ANZDATA registry contract to deliver the project is \$350,000. Of this funding, \$200,000 supports contract for services, including data management and reporting, while the remaining \$150,000 will be provided to participating renal units to incentivise the additional data collection.

Timeline

- August 2019 – scoping requirements finalised.
- September 2019 – contract executed between TSANZ and ANZDATA.
- November 2019 – participating units identified.
- January 2020 – commencement of data collection.
- March 2021 – first full year of data collection and reporting completed.
- December 2021 – findings to be published in the ANZDATA annual report.

Objective 3: Piloting initiatives to improve patient equity and access

On 26 November 2019 the NIKTT opened a competitive sponsorship process seeking proposals from the renal community for 12-month pilot projects that will improve access to and outcomes of kidney transplantation for Indigenous Australians. The sponsorships comprise two streams:

- Increasing FTE or creating new positions within health services for various roles where there is a demonstrated shortage, such as:
 - Transplant coordinators
 - Clinical champions
 - Indigenous Health Workers
 - Interpreters
 - Dietitians
- Targeted projects that improve equity and access to kidney transplantation for Aboriginal and Torres Strait Islander patients, such as:

- Programs that deliver tailored social/emotional support to patients navigating the transplant system, such as patient mentors/buddies.
- Establishment of community/patient/carer support groups.
- Purchase of assets, resources and tools, such as tailored educational materials or IT infrastructure.
- Other initiatives that improve access to kidney transplantation for Aboriginal and Torres Strait Islander patients.

Funding details

The NIKTT has offered eight sponsorships totaling \$1.04 million. These initiatives span across four jurisdictions and include: delivery of outreach kidney transplant education and assessment in rural and remote areas; establishment of transplant-focussed patient mentor pilot projects and Indigenous reference groups; and strengthening the Aboriginal and Torres Strait Islander health workforce in kidney transplant settings. As at 20 February 2020, seven funding agreements have been executed:

- Top End Health Service, Northern Territory (\$200,000)
- Purple House – Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation, Northern Territory (\$200,000)
- Royal Perth Hospital (in collaboration with Kimberley Aboriginal Medical Service and Sir Charles Gairdner Hospital), Western Australia (\$150,300)
- Pika Wiya Health Service Aboriginal Corporation, South Australia (\$148,000)
- Fiona Stanley Hospital, Western Australia (\$109,224)
- Cairns and Hinterland Hospital and Health Service, Queensland (\$107,940)
- Flinders and Upper North Local Health Network, South Australia (\$84,667)

Timeline

- 10 January 2020 - applications for equity and access sponsorships close.
- 24 January 2020 – successful applicants selected and offered funding agreement.
- 21 February 2020 – execution of funding agreements; unsuccessful applicants notified.
- 30 June 2020 – interim progress reports, capturing evaluation findings, to be submitted by sponsorship recipients to the NIKTT.
- Between 31 December 2020 and 30 June 2021 – final reports, capturing evaluation findings, to be submitted by sponsorship recipients to the NIKTT.

Objective 4: Evaluating cultural bias initiatives

The NIKTT has commissioned The Lowitja Institute to deliver a scoping review, which will address 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?

The review will draw upon Australian and international approaches to describe where cultural bias fits in relation to other cultural and bias models from an Indigenous perspective. Australian studies and examples will then form the basis of a comprehensive analysis of cultural bias interventions designed to address equity, access and health outcomes for Aboriginal and Torres Strait Islander Australians.

The search strategy and methodology will be developed in collaboration with the NIKTT's cultural bias working group.

Funding details

The NIKTT has committed \$50,628.75 to the Lowitja Institute to deliver the review.

Timeline

It is expected the scoping review will be completed by 30 June 2020, after which time a process of primary data collection may be undertaken to further investigate efforts made by health services to eradicate cultural biases from their policies and practices.

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 (<i>Chair</i>)	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 (Chair)	SA	Director of Dialysis; Central and Northern Adelaide Renal and Transplantation Service
Jaquelyne Hughes (Deputy Chair)	NT	Nephrologist; Royal Darwin Hospital
Judy Harrison	ACT	Chief Financial Officer; Organ and Tissue Authority
Natasha Rogers	NSW	Nephrologist; Westmead Hospital
Kelli Owen	SA	Indigenous Kidney Community Representative; NIKTT
Eleanor Garrard	SA	Executive Officer; NIKTT
Kim Rawson	NSW	Senior Project Officer; TSANZ