

## ARTICLE

# National Indigenous Kidney Transplantation Taskforce (NIKTT): an update

*Matilda D'Antoine, Kelli Owen and Stephen McDonald on behalf of the NIKTT*

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The National Indigenous Kidney Transplantation Taskforce (NIKTT) was established in 2019 by the Commonwealth Department of Health to improve access to kidney transplantation for Aboriginal and Torres Strait Islander people. 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 a steering committee, a national consumer board, several working groups and a secretariat which is based in Adelaide at the SA Health and Medical Research Institute. The steering committee includes members from the clinical, academic, government and non-government sectors.

## Main objectives

The NIKTT has three funded objectives which aim to improve access to kidney transplantation for Aboriginal and Torres Strait Islander people. These include:

- Enhanced data collection and reporting around access metrics and pre-transplant workup processes;
- Pilot initiatives to improve patient equity and access to kidney transplantation; and
- Evaluation of cultural bias interventions and development of Indigenous Reference Groups (IRGs).

## Enhanced data collection and reporting processes

The NIKTT commissioned the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) to deliver a pilot project to capture several additional pre-transplant data points. All renal units in Australia were invited and 26 participated. This data comprises two components. The first involves an end of year survey – the Transplant Assessment Stage – which is collected as an extension of the normal ANZDATA Annual Survey for 2019, 2020 and 2021. This asks whether dialysis patients are yet to be assessed for transplantation, are in workup for transplantation, are on the waiting list, or are ineligible for transplantation, and outlines the reasons why. The second component involves the 'real time' reporting of incident dialysis patients during 2020 and 2021. Sites are required to report on a patient's progress towards achieving kidney transplant waitlisting, including their history of undertaking eligibility assessment, workup, and transplant assessment. ANZDATA will also be

incorporating a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander people.

## Pilot initiatives to improve equity and access

Following a call for submissions, the NIKTT awarded eight sponsorships, totalling \$1.04 million, to support initiatives that improve equity and access to kidney transplantation for Aboriginal and Torres Strait Islander patients. The projects range from peer navigator programs, outreach transplant assessment clinics, transplant educational sessions, and the formation of IRGs. These projects are currently underway. Analysis, reporting and feedback from these will be crucial to inform the development of next steps.

## Development of IRGs

A key deliverable of the NIKTT is to catalyse the establishment of IRGs in transplant units to help design pathways and models of care that are culturally appropriate. A community engagement coordinator (Kelli Owen) was recruited to coordinate this. The aim for each IRG is to bring together patients, carers and families to discuss their kidney journey, needs and supports through to transplant and beyond. The aim is to bring about change within the transplant unit, and build relationships, trust and rapport with the IRG members and the transplant units.

## Stakeholders

Initially five tertiary renal units were selected based on the number of Indigenous people receiving kidney transplants at those units. All these units have supported the project and have committed to establish and fund the IRGs for sustainability.

The Royal Adelaide Hospital (RAH) NIKTT IRG has had two official group meetings with their first response received from the RAH executive transplant management unit. The transplant unit accepted the members' brief and outline of eight themes – cultural awareness training for health staff, cultural cleansing of donated organs, the establishment of safe spaces, increasing and supporting Aboriginal and Torres Strait Islander workforce, assistance with transportation and accommodation that is culturally appropriate, raise awareness

and improve education around organ donation for Aboriginal and Torres Strait Islander families and communities, support and dialysis/transplantation education, and continuity of care and improved communication between services.

Both key stakeholders are now committed to co-creating changes over the next 3–5 years. The RAH NIKTT IRG members are a collective of representatives from Adelaide, Darwin, Alice Springs, Broken Hill, Port Augusta, Port Pirie, Mount Gambier, Whyalla, Ceduna and Port Lincoln. The meetings are held via virtual screen and face-to-face meetings every 3 months. The consumer engagement policy within the Central Adelaide Health Local Network (CAHLN) has supported our members to meet and discuss issues that need addressing for First Nations People in a safe space and under Indigenous governance principles with our terms of reference.

In addition, Sir Charles Gairdner Hospital in Perth and Princess Alexandra Hospital in Brisbane are well positioned to hold their first meeting with members and report to their own executive transplant units. Both hospitals have staff that are empowered and supported to lead the projects; these are kidney health professionals who are open and eager to start the process of sharing dialogues.

The staff at Royal Prince Alfred and Westmead Hospital in Sydney have been on board and ready to start since 2020. However, due to COVID-19 and staffing commitments, there have been delays. However, this has not immobilised the approach, with both hospital patients and potential members engaged; transplant unit staff are supporting the project and encouraging the identification of a First Nations person within the hospital to lead the project. The NIKTT community engagement coordinator is also consulting with local Elders, community and key stakeholders to drive the project from a grass roots level with lived experience.

## Other initiatives

Truth telling and building trust between both groups is critical to share local issues, challenges, concerns and celebrations; these all ultimately take time. To rush this important process is to anticipate disappointing outcomes. It is crucial to empower the lead in operating, respectfully consulting, and translating the knowledge shared between both groups.

## Listening to communities

Visiting local communities and listening to the stories shared is an important role of the community engagement coordinator. Face-to-face meetings and listening time have taken place in Darwin, Katherine, Ballina, Perth, Adelaide, Alice Springs, Brisbane, Townsville, Mount Isa and Torres Strait Islands. Amid lockdowns, COVID-19 restrictions and well-timed travel, the consultation process is continual. Holding the space to retell stories that are impacting our communities and inform the NIKTT of critical situations allows for the kidney community to share ideas and solutions,

and allows the people living and caring with kidney disease to have a much-needed voice.

## Establishing a National Indigenous Kidney Community Panel

The National Indigenous Kidney Community Panel has now reached approximately 100 members located across all jurisdictions. All members are either living with chronic kidney disease, undergoing dialysis treatment, are on the active waitlist for a transplant, are post-transplant, or are family carers. Members are contacted frequently by the NIKTT community engagement coordinator by telephone calls, emails, and face-to-face meetings to listen and talk over issues concerning kidney care in their respective regions and to support them in being proactive in possible solutions at the local level. Main topics are then fed back to the NIKTT Taskforce and the Operations Committee for further discussion and unpacking ways to move forward.

## Developing a directory of education resources

The TSANZ and NIKTT have been collaborating on an online educational directory displaying relevant and focused resources to share to Aboriginal and Torres Strait Islander patients with end-stage kidney disease, their families, and clinicians. It is anticipated that the directory will be completed by December 2021.

## Evaluating cultural bias initiatives

The NIKTT commissioned the Lowitja Institute to deliver a policy report and literature review on cultural bias interventions and models of care in health services designed to address equity, access and health outcomes for Aboriginal and Torres Strait Islander Australians. The policy report and literature review analysed peer reviewed publications, grey literature and reports in order to answer the following key questions:

- What health service cultural bias interventions currently exist in healthcare settings?
- What is the potential effectiveness of these interventions in relation to outcomes such as (but not limited to) waitlisting for kidney transplantation?
- What do patient, carer/support person and provider experiences and outcomes of these interventions reveal about the acceptability and effectiveness of existing interventions, as well as barriers and facilitators of implementation?

A total of 14 recommendations were devised and the NIKTT is currently engaging and consulting national community members, health professionals and First Nations advocacy groups to prioritise the recommendations, and strategise projected resources and the next steps in actioning. The official release of both documents will be taking place in the next few months.