



INPUT FOR THE NATIONAL STRATEGY FOR ORGAN DONATION, RETRIEVAL AND TRANSPLANTATION

In consultation with the Secretariat for the Organ and Tissue Policy and Programs Section

*Prepared by the Secretariat of the National Indigenous Kidney Transplantation
Taskforce on behalf of Taskforce members*

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EXECUTIVE SUMMARY

Kidney transplantation rates and outcomes are inequitable for Aboriginal and Torres Strait Islander peoples in Australia. Historical and contemporary research have shown these significant gaps in access and outcomes continue to persist.

The NIKTT strongly recommends that a dedicated line of work continue to investigate and oversee transplantation access and outcomes for Aboriginal and Torres Strait Islander peoples with kidney failure.

Collaborative networks and directed effort have made progress in recent years to address both kidney transplantation and kidney health more generally in Aboriginal and Torres Strait Islander peoples around Australia. Work to date has shown that progress is achievable and sustainable when designed and implemented with the recipients of care. However, further work, including the implementation of culturally acceptable models of care at State and Territory levels, and continued directed investment into discovering additional barriers to waitlisting, challenges post-transplant, and increasing community education around transplantation and donation, is needed to maintain progress and advance improvements in closing the gap.

This continued work necessitates:

- (1) the implementation of particular models of care at State/Territory levels;
- (2) the resourcing of a Secretariat to maintain momentum and collaborative networks, that will:
 - a. Help guide the creation of a National Body for Kidney Health and Transplantation; and
 - b. Further research and implement projects for further equity and access.

BACKGROUND

The *National Indigenous Kidney Transplantation Taskforce* (NIKTT) was established in 2019 in response to recommendations from the Transplantation Society of Australia and New Zealand (TSANZ) expert panel *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia Performance Report* (Performance Report). As noted in the EY's *Review of the Australian organ donation and transplantation system Final Report* (Final Report), the Performance Report highlighted the disparities and barriers that exist within Australia when it comes to kidney transplantation for Aboriginal and Torres Strait Islander peoples. The NIKTT was formed to bring together a multidisciplinary team to address some of the numerous barriers.

The initial remit of the Taskforce included four objectives:

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

As of 30 June 2022, the NIKTT has completed all four objectives and is compiling findings and recommendations for submission back to the Commonwealth and community. As part of the NIKTT's work, the *Cultural Bias in Indigenous Kidney Care and Kidney Transplantation Report* (Cultural Bias Report) was completed by the Lowitja Institute. This report listed an additional 14 recommendations for the improvement of health service delivery that would impact the care received by Aboriginal and Torres Strait Islander people with kidney disease and transplantation.

This input into the Strategy is therefore based upon both the work of the NIKTT and the recommendations listed within the TSANZ Performance Report, the EY Final Report, and the Lowitja Cultural Bias Report. Several key themes have arisen from the NIKTT's initial work that build on the Performance Report, the Final Report, and the Draft National Strategy. These are integral to the development of the *National Strategy for Organ Donation, Retrieval and Transplantation* (the Strategy). The NIKTT's input into the Strategy focuses on two essential criteria:

1. Aboriginal and Torres Strait Islander people assert their right to make decisions and control what happens to their communities in terms of kidney health care, kidney transplantation, and health system change.
2. Any national body that oversees the implementation of the Strategy, or any changes made to health service delivery due to the Strategy, that impacts the care given to Aboriginal and Torres Strait Islander people, must regularly consult, involve, and feed back to Aboriginal and Torres Strait Islander patients and their communities, ideally coordinated through a national body or Secretariat.

Due to the complicated nature of kidney transplantation and the importance of sovereignty and cultural safety, the NIKTT strongly recommends that within the national Strategy, Aboriginal and Torres Strait Islander people are represented by Aboriginal and Torres Strait Islander people. This

includes meaningful representation throughout all aspects of the planning, implementation, evaluation, and subsequent monitoring and reporting that comes about due to the Strategy.

RECOMMENDATIONS AND PROPOSED INITIATIVES

PRIORITY ONE: A NATIONAL APPROACH TO OPTIMISE ORGAN DONATION, RETRIEVAL, AND TRANSPLANTATION

Goal: National governance and funding arrangements effectively support Australia's organ donation, retrieval, and transplantation system

Recommendation: *National bodies, such as the NIKTT – or more ideally, a peak body that the NIKTT will help to form in the coming year – are funded to represent Aboriginal and Torres Strait Islander peoples in need of, and benefiting from, transplantation. These must be governed by Aboriginal and Torres Strait Islander people and work closely with OTA, TSANZ, health systems, Aboriginal and Torres Strait Islander-controlled health services, and the public.*

Goal: More Australians consent to donation

Recommendation: *For Aboriginal and Torres Strait Islander people, it is important that future initiatives or campaigns to increase Aboriginal and Torres Strait Islander donation consent are co-created, co-designed, and co-executed with Aboriginal and Torres Strait Islander people. Due to differing cultural beliefs around organ donation, it is very important that many different communities are consulted for campaigns to be effectively realised.*

Implementation: Priority 1, Goal 1. For kidney transplantation, we specifically recommend that the NIKTT is funded, through the TSANZ, to continue to drive the momentum and change already established, building on existing networks and trust. This will allow for oversight, continuity, and governance that works within the structure but represents Aboriginal and Torres Strait Islander peoples. A specific task of this continued work will be to help form a national peak body of Aboriginal and Torres Strait Islander kidney health representatives – this prospective group will be able to provide advice, consultation, networking, and governance to specific projects and strategies in the future.

Implementation: Priority 1, Goal 2. A specific remit of this continued NIKTT work should be to work closely with campaign designers to ensure Aboriginal and Torres Strait Islander people are consulted and help co-design campaigns aimed at improving the rates of Aboriginal and Torres Strait Islander people consenting to donation. Aboriginal and Torres Strait Islander-focused campaigns are needed if more of this population are going to consent to donation, and these *must* be created with consultation and co-design of differing groups and nations. Consultation meetings, campaign co-design, and campaign feedback needs to be coordinated between different regions in Australia.

- A specific solution is to offer a grant/funding to an Aboriginal and Torres Strait Islander-led team or person to initiate consultations and co-design campaigns in

conjunction with Donate Life. Notably, for this to be effective and culturally sensitive, the NIKTT strongly recommends that different Aboriginal and Torres Strait Islander groups, in different parts of Australia, are consulted over the course of the campaign pre-design, design, implementation and rollout, and importantly, monitoring, evaluation, and learning.

PRIORITY TWO: EQUITABLE ACCESS FOR AUSTRALIANS WHO WOULD BENEFIT FROM ORGAN TRANSPLANTATION WITH A FOCUS ON ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE AND THOSE LIVING IN RURAL, REGIONAL AND REMOTE AREAS

Goal: Policy and programs break down barriers and improve access to transplantation

Recommendation: The NIKTT has shown that perceived barriers to transplantation wait listing is a function of health system design, not of design by Aboriginal and Torres Strait Islander people. The NIKTT has demonstrated that certain models of care – including Indigenous Reference Groups, Patient Navigator programs, outreach clinics, and Aboriginal and Torres Strait Islander-led educational programs – are effective in enabling health care clinicians to provide equitable access to the transplantation waiting list for Aboriginal and Torres Strait Islander people. However, further barriers need to be researched, assessed, and nationally coordinated, in collaboration with Aboriginal and Torres Strait Islander people and communities, in order to deconstruct further barriers. These barriers include ongoing problems such as transportation issues, cultural safety within hospitals and renal units, and a lack of Aboriginal and Torres Strait Islander renal health workers, health practitioners, nurses, transplantation coordinators, allied health professionals, and transplantation Physicians and Surgeons. These additional barriers were raised in the TSANZ Performance Report, the EY Final Report, the Lowitja Cultural Bias Report, and have been again highlighted throughout the work of the NIKTT. Further barriers to care must be investigated and illustrated by Aboriginal and Torres Strait Islander patients, as highlighted by previous consultation work such as the *Catching Some Air* project.

Goal: Nationally consistent, equitable, transplant wait list, organ allocation, offer and acceptance processes

Recommendation: Changes to processes that involve Aboriginal and Torres Strait Islander patients must be made in consultation with Aboriginal and Torres Strait Islander people. Directed investigation into these processes across state and territory lines, and in relation to vulnerable and minoritised groups with a focus on Aboriginal and Torres Strait Islander communities, should be conducted as a first priority, creating a transparent and clear overview of each system in order to elucidate gaps and opportunities for improvement.

Implementation: Priority 2, Goal 1. Please see the *attached proposal* that outlines specific implementation strategies for this goal. Overall, we believe that a national group, such as the NIKTT, needs to provide oversight and guidance to Government and other key

stakeholders on the remaining challenges facing Aboriginal and Torres Strait Islander peoples' equitable access to transplantation.

There are 3 specific recommendations for action from the NIKTT, the first of which rely on the resourcing of a Secretariat or Taskforce to coordinate and maintain work and progress in this area:

1. The resourcing of further research and implementation strategies, including pre- and post-transplant challenges; and
2. The coordinated creation of a national body and targeted roadmap for Aboriginal and Torres Strait Islander peoples' kidney health and transplantation equity.

Additionally, the NIKTT recommends that State and Territory governments resource, through local renal units and ACCHOs:

3. The implementation of particular models of care at State/Territory levels.

See the detailed proposal [here](#).

PRIORITY THREE: ENHANCED ORGAN RETRIEVAL AND TRANSPLANTATION CAPABILITY AND CAPACITY TO OPTIMISE TRANSPLANT OUTCOMES

Goal: Capability and capacity within the health system delivers optimal organ retrieval and transplantation services

Recommendation: Increased Aboriginal and Torres Strait Islander representation within the health system is crucial for the safety of patients and improvements in health outcomes. Aboriginal and Torres Strait Islander (Identified) positions within renal teams, including Identified transplant coordinators, nurses, nephrologists, surgeons, and health practitioners, allow for Aboriginal and Torres Strait Islander patients to feel more comfortable and have better access to cultural translation. Findings from throughout the work of the NIKTT have highlighted the importance of increasing the Aboriginal and Torres Strait Islander renal health workforce.

Goal: Australian transplant recipients have access to high quality post-transplantation programs and services

Recommendation: The TSANZ Performance Report, and the work of the NIKTT, have emphasised the importance of better post-transplant care for Aboriginal and Torres Strait Islander patients, especially those that live in rural or remote parts of the country. More investigation is required to understand what these programs and services look like and how they work best for Aboriginal and Torres Strait Islander patients and communities. The NIKTT recommends that directed funding for research into best practices is supported by the

government, either through a body such as the NIKTT or in collaboration with a funding stream such as the Medical Research Futures Fund.

Implementation: Priority 3, Goal 1. A recurring recommendation from the work of the NIKTT, the TSANZ Performance Report, the Lowitja Cultural Bias Report, and community consultations is the requirement of an increased Aboriginal and Torres Strait Islander renal health workforce, representing all roles and levels within the health system. These positions should be implemented through State, Territory, and ACCHO systems.

Implementation: Priority 3, Goal 2. Work of the NIKTT to date has not examined the challenges and opportunities surrounding post-transplant care for Aboriginal and Torres Strait Islander kidney patients. It is imperative that Aboriginal and Torres Strait Islander people-specific challenges post-transplant are investigated, and better systems implemented to improve transplantation success.

- The NIKTT recommends coordinated funding for consultation, research, and implementation of post-transplant challenges and preferred models of care is implemented.

PRIORITY FOUR: ENHANCED SYSTEMS AND DATA COLLECTION AND REPORTING TO DRIVE CLINICAL BEST PRACTICE

Goal: Data is accessible and reported to drive best practice

Recommendation: The NIKTT has found that data collection, metrics, and reporting around Aboriginal and Torres Strait Islander kidney transplantation, wait listing, and dialysis incidence needs further investigation, infrastructure, and people-support investments. This research would reveal barriers to care around assessment, determination of best measurements (including in cultural safety), modifiable risk factors, and data collection techniques in order for all units around Australia to better understand the enablers and barriers to care and directed needs of Aboriginal and Torres Strait Islander patients within their health service.

Implementation: Priority Four, Goal 1. The NIKTT recommends that any data collection or registry work consults an Aboriginal and Torres Strait Islander advisory group at all possible stages or employs an Aboriginal and/or Torres Strait Islander person to oversee data collection and reporting.

SUMMARY

The NIKTT recommends that for these goals to be achieved, and priority areas improved upon, the Strategy must include:

- (1) further research into pre- and post-transplant enablers and barriers to care, donation, and better health outcomes for Aboriginal and Torres Strait Islander peoples;
- (2) the formation or continuation of a national body that is governed by Aboriginal and Torres Strait Islander people that drives the continued improvement of increased access to transplantation; and
- (3) the immediate implementation of models of care that have found to be culturally safe, effective, and adaptable, such as an increased Aboriginal and Torres Strait Islander renal workforce, Indigenous Reference Groups, Patient Navigator programs, and Outreach Assessment Clinics to rural and remote communities.

PROPOSAL FOR DIRECTED EQUITY

There are 3 specific recommendations for action from the NIKTT, which we believe rely on the resourcing of a Secretariat or Taskforce to coordinate and maintain work and progress in this area:

1. **The resourcing of further research and implementation projects, including:**
 - a. **Expanded investigation into additional barriers to waitlisting, such as:**
 - i. Culturally tailored education around transplantation, medication, immunosuppression, donation, and workup
 - ii. Continuity of CKD primary care and integration with RRT care and transplantation options
 - iii. Culturally tailored weight loss strategies and bariatric surgery
 - iv. Availability of safe and affordable housing and transportation options
 - v. Development of multidisciplinary pre-and post-transplant clinic that integrates services needed for workup and post-transplant care, such as dental and cardiac services, as well as accommodation and travel support
 - b. **Research into post-transplant challenges and outcome improvement, such as:**
 - i. Point-of-care testing availability and development of post-transplant-care POCT program
 - ii. Culturally tailored education on medications and follow-up care
 - iii. Development and evaluation of novel immunosuppressive regimens
 - iv. Identification of further challenges and reasons for graft loss or suboptimal outcomes
 - c. **Evaluation of cost-effectiveness of integrated workup teams, transplantation, and post-transplant care**
 - d. **Investigation into what is needed in terms of data collection and feedback**
 - e. **Development and implementation of accreditation courses for Aboriginal and Torres Strait Islander health practitioners in renal care and dialysis**
 - f. **Development and implementation of cultural safety training programs for renal workforce**
2. **The coordinated creation of a national body that represents Aboriginal and Torres Strait Islander kidney patients from pre-diagnosis through to post-transplant care.**
3. **The implementation of particular models of care at State/Territory levels, including:**
 - a. Indigenous Reference Groups at all major transplantation units
 - b. Outreach Transplantation Assessment Clinics for remote communities
 - c. Increased renal Aboriginal and Torres Strait Islander health workforce
 - d. Patient Navigator programs integrated into hospital and renal unit systems

These models of care need to be implemented by State and Territory governments, ideally through ACCHOs and/or local renal units, so they can be integrated into health systems as business as usual.

We specifically propose that a resourced Secretariat be employed for the next 12 to 18 months to coordinate and develop an implementation plan for this work.

- This would include salary support for up to 3 full-time staff, travel, meeting, and consultation expenses, as well education material development and dissemination costs.

TIMELINE

DECEMBER 2022: NIKTT

- NIKTT Gathering and community feedback and endorsement of proposal

MARCH 2023: NIKTT

- Final NIKTT project report due

JUNE – DEC 2023: NIKTT 2 OR SECRETARIAT

- Continued network maintenance and growth
 - Including collaboration with groups such as CARI guidelines on implementation best practices; continued collaboration with OTA and TSANZ on Strategy finalisation and implementation.
 - Coordination and synchronisation of current and proposed research and projects involving Aboriginal and Torres Strait Islander people with kidney failure or transplantation.
- Identification of pathways and specific projects for future research
 - Including application for grants; collaboration with Strategy and funding bodies such as MRFF to support research; identification of project teams to undertake work; consultation with community and stakeholders on priority projects; detailed plans for priority projects.
- Creation of national body
 - Coordinated buy-in from kidney consumers, health organisations, ACCHOs, etc
 - Detailed governance framework and implementation plan finalised
 - Nominated/elected governance board identified, and stream-specific groups identified, such as research advocacy, patient engagement, network coordination, etc.
- Expansion of current resource availability and support for groups working on transplantation equity
 - Including creation of national database for patient- and clinical-focused educational resources; research, grant writing, and advocacy support for projects currently underway or working in transplantation equity now.

JAN 2024 – DEC 2028: IMPLEMENTATION OF STRATEGY AND TRANSPLANTATION / KIDNEY HEALTH ROADMAP

- Further research projects identified and commenced
- National body formed and work commenced