



RESPONSE TO THE NATIONAL STRATEGY FOR ORGAN DONATION, RETRIEVAL AND TRANSPLANTATION CONSULTATION

In response to the Review of the Australian organ donation, retrieval and transplantation system and progressed in conjunction with the Progressing Australian organ and tissue donation and transplantation to 2025 Strategic Plan

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

13th of July 2022

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 *Performance Report* (*Performance Report*). As noted in the Consultation overview and the *Review of the Australian organ donation and transplantation system Final Report* (*Final Report*), the *Performance Report* highlighted the disparities that exist within Australia when it comes to kidney transplantation for Aboriginal and Torres Strait Islander peoples. Numerous barriers, including pre- and post-transplant, exist for Aboriginal and Torres Strait Islander people and the NIKTT was formed to bring together a multidisciplinary team to address some of these barriers.

Managed by a Secretariat based at the South Australian Health and Medical Research Institute (SAHMRI), the NIKTT is comprised of Aboriginal and Torres Strait Islander kidney transplant recipients, members of the Aboriginal and Torres Strait Islander health workforce, including nephrologists and nurses, as well as non-Indigenous clinical, research, and professional advocates.

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, 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.

A number of key themes have arisen from the NIKTT's initial work that build on the *Performance Report* and the *Final Report*. These are integral to the development of the *National Strategy for Organ Donation, Retrieval and Transplantation* (the *Strategy*).

Below, we outline themes of importance we believe must be taken into consideration when finalising the *Strategy* and policy documents. We have responded to each key priority area and goals.

RESPONSE

The NIKTT's response to 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 renal 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.

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 change that comes about due to the Strategy.

Specifically, we recommend that the following points are included in the Strategy:

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, 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, health systems, Aboriginal and Torres Strait Islander-controlled health services, and the public.

For kidney transplantation, we specifically recommend that the NIKTT is funded for another five years to continue to drive the momentum and change already established, building on existing networks and trust.

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.

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 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.

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.

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 and 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.

SUMMARY

The NIKTT recommends that for these goals to be achieved, and priority areas improved upon, the Strategy must include: (1) 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; (2) further research into pre- and post-transplant enablers and barriers to care, donation, and better health outcomes for Aboriginal and Torres Strait Islander peoples; and (3) increased Aboriginal and Torres Strait Islander health workforce participation and leadership at all levels, to implement Strategy changes.

(1) The national body would:

- Advocate, research, and translate findings, as well as advise, guide, consult, and support others
- Be a forum for continuous consultation – for ongoing feedback to the healthcare system on changes seen and changes needed
- Be a medium through which findings, policies, and changes are shared and guided by a patient-expert and Aboriginal/Torres Strait Islander perspective.

(2) Further investigation is needed into:

- Barriers to pre-transplant care: including transport, cultural safety, health literacy, weight co-morbidities, and earlier detection
- Post-transplant barriers: including medication adherence/understanding, cultural safety, education, and availability of information
- Organ Donation: Aboriginal and Torres Strait Islander-designed campaigns for donation, community consultation, and clearer guidelines
- Costing: updated costing of dialysis and transplantation, especially for Aboriginal and Torres Strait Islander people and rural and remote people.

(3) The importance of a larger Aboriginal and Torres Strait Islander health workforce is needed to:

- Support patients to stay strong and healthy on the transplantation waiting list
- Be immediate providers of culturally safe practice, and provide cultural safety guidance in the health care system
- Advocate and facilitate Aboriginal and Torres Strait Islander views and perspectives when unit-level changes are considered and implemented.