



## **Position Statement:**

# Transplantation Equity for Aboriginal and Torres Strait Islander Peoples with Kidney Disease

**Endorsed by the delegates of the National Indigenous Kidney Transplantation Taskforce Gathering, December 5 and 6, 2022 in Adelaide, South Australia.**

Delegates attending the NIKTT Gathering support the continued strategic efforts by Aboriginal and Torres Strait Islander peoples, in partnership with advocates, to advance Aboriginal and Torres Strait Islander peoples' rights to optimal health and wellbeing through equitable and accessible kidney transplantation.

### **The delegation endorses the following recommendations to improve care before and after kidney transplantation:**

- Establishment of a peak body that coordinates national efforts to improve care, including the development of resources, leading advocacy efforts, contributing to knowledge creation and exchange, and supporting accountability through monitoring and reporting on research and service delivery;
- Continued development, support, and succession pathways for the Aboriginal and Torres Strait Islander kidney health workforce across all levels, including nurses, doctors, allied health professionals, patient navigators, transplantation coordinators, Aboriginal liaison officers, and Aboriginal health practitioners;
- Wrap-around support services implemented and expanded, including support groups and patient reference groups;
- Aboriginal and Torres Strait Islander people experience healthcare free of racism, through ongoing cultural awareness, training, safety, and accountability;
- Relevant education and sharing resources created that are designed by and delivered by Aboriginal and Torres Strait Islander people;
- Transparency of information established and support provided for family decision making for live kidney donation and transplantation;
- Young peoples' kidney health and wellbeing, improved through transplantation, prioritised in the next phase of strategic transplantation equity work;
- Identify and address the unmet needs of carers, adult patients, children and young adults, and elders navigating transplant access and care.



The delegation endorses the rights of self-determination and leadership by Aboriginal and Torres Strait Islander peoples who are best positioned to understand the needs of their own community.

The delegates find it crucial that efforts to improve outcomes of kidney failure through transplantation must partner effectively with existing health services. Delegates endorse the safety of all workforce members, including the right to work without oppression and racism (overt and covert), as important partnership foundations of continued shared aspirations.

Delegates recognise that kidney health, and health during kidney replacement therapy (including transplantation), is but one part of optimal health care amongst a diverse and multi-disciplinary structure that must support health and wellbeing as a whole. We recognise that to work together to address improved health, individual efforts require their own funding and governance, controlled under the agency of Aboriginal and Torres Strait Islander leadership. We recognise the limitations of others to partner in this effort when this is not appropriately resourced. The NIKTT has learned, through equity and access sponsorship projects, that work needed to improve transplantation equity requires funding that is not costed by current service procedures.

**The delegation therefore endorses the following actions for the next phase of the work to improve transplantation equity:**

1. Establishing a peak body to represent Aboriginal and Torres Strait Islander peoples living with kidney disease and transplantation, which will oversee and support networks, resources, reporting, monitoring, and accountability;
2. Ongoing development of programs to facilitate better access to transplantation with a particular focus on improving the health of people with CKD so they can be waitlisted;
3. Monitoring, recording, and reporting (e.g. through an annual score-card) on improvements in workforce, program delivery, and transplant waitlisting and achieved transplantation;
4. Working with workforce partners to grow an experienced and culturally safe and resourced Aboriginal and Torres Strait Islander regional workforce across all levels of transplant access and post-transplant care;
5. Promoting transparency and accountability of funding of kidney health services so that we can know how decisions are made, by whom, and what has been achieved;
6. Enabling awareness raising and capabilities of national networks through sustaining an annual Gathering Meeting.



**The Position Statement is endorsed by:**

<b>Name</b>	<b>Role at Gathering</b>
Stephen McDonald	Chair, NIKTT
Jaquelyne Hughes	Deputy Chair, NIKTT
Katie Cundale	NIKTT
Kelli Owen	NIKTT
Julius Tabua	Patient Expert
Rochelle Pitt	NIKTT
Breanna Solomon	NIKTT
Edna Sambo	Patient Expert
Gina Tabua	Carer
Azaria Gebadi	Patient Expert
Annie Reis	Patient Expert
Kiris Reis	Carer
Kate Tyrell	SA Health
Rhanee Lester	Patient Expert
Nari Sinclair	Patient Expert
Sam Bateman	SA Health
Matilda D'Antoine	NIKTT
Kim Rawson	NIKTT
Shilpa Jesudason	NIKTT
Dean Whyman	Patient Expert
Monica Kerwin	Carer
Helen Pilmore	NIKTT
Kate Wyburn	TSANZ
Nic Corsair	KAMS
Dunba Nunju	Patient Expert
Bernadette Nunju	Carer
Yomei Jones	Menzies
Michael Brown	Patient Expert
Debra Brown	Carer
Lee-Anne Taylor	Patient Expert
Noel Taylor	Carer
Kerry Dole	NIKTT
Kim O'Donnell	AKction2
Colleen Raven-Strangeways	Community
Isaac Brown	NIKTT
Zoe Harker	ANZDATA
Gary Torrens	NIKTT
Christine Russell	NIKTT
Sam Crafter	SA Health
Khalil Patankar	NIKTT
Jasmin Mazis	ANZDATA
Heather Hall	NIKTT
Michelle Misener	NIKTT