



Addressing Cultural Bias in Kidney Transplantation

Response to the *Cultural Bias in Indigenous Kidney Care and Kidney Transplantation Report*

Aboriginal and Torres Strait Islander people in Australia seek high-quality care for kidney health, including access to kidney transplantation, improved outcomes of kidney transplantation, and the ability to experience respectful and culturally safe health systems. Yet, there is a substantial and increasing burden of kidney failure amongst Aboriginal and Torres Strait Islander people in Australia, coupled with a considerably lower chance that those in need will receive kidney transplantation. In part, this is because alongside physical and geographical obstacles to transplantation, Aboriginal and Torres Strait Islander people experience cultural bias as a barrier to care as well.

There are multiple and additive mechanisms through which cultural bias acts as a barrier to kidney care and transplantation for Aboriginal and Torres Strait Islander people. The Australian health system has been built to a Western model of health without reference to Aboriginal knowledges of health. Therefore, processes have not been systematically embedded in usual care that equitably support Aboriginal and Torres Strait Islander people to fully access and benefit from transplantation. A crucial component of the National Indigenous Kidney Transplantation Taskforce (NIKTT) is to explore the best ways to evaluate and leverage interventions that address cultural bias in kidney transplantation settings to ensure that cultural bias no longer acts as a barrier to care.

The NIKTT commissioned the Lowitja Institute to produce the *Cultural Bias in Indigenous Kidney Care and Kidney Transplantation Report* (the Report), with the aim to explore cultural bias interventions in renal transplantation services throughout Australia. Based on the available published and grey literature, the Report identified 14 individual recommendations to address cultural bias by renal health services, national organisations, and funding bodies. The Report identified only two peer-reviewed publications from Australian renal settings which addressed the specific research question, along with a few publications from other health care fields such as maternal health and oncology. This dearth of published research reveals a lack of coordinated reflection and action using cultural bias as a lens through which interventions can improve health care delivery and outcomes. This gap therefore embodies the most significant implication of the Report for the NIKTT: health care services need to prioritise reporting of programs and research that identify and address cultural bias.

Cultural Bias defined: any action or inaction that contributes to disparate treatment or treatment outcomes for Aboriginal and Torres Strait Islander people.

The creation of an archive of intervention outcomes that improve access to, and outcomes from, kidney transplantation is essential. Multiple stakeholders need this information: (1) health services need this to review practices and innovate as necessary; (2) the Aboriginal and Torres Strait Islander community (who live with sustained kidney transplant inequity) need confidence through transparency in health care decision making and evidence that systems are co-designed and co-evaluated; (3) health system policy makers and accreditation bodies need this to demonstrate effective partnerships with consumers (Standard 2 of the National Safety and Quality Health Service Standards) and to address patient-important outcomes of care; and finally (4) government and other funding bodies throughout national, state, and Territory levels can use findings to demonstrate how public obligations are best met, drawing on an evidence base that includes patient-centred outcomes, effective consumer partnerships, and culturally safe delivery of care.

Cultural bias is a modifiable barrier to care, and particularly transplantation, for Aboriginal and Torres Strait Islander people. The NIKTT recommends the following priority areas as immediate opportunities that the government and communities can work together on to improve the lives of Aboriginal and Torres Strait Islander kidney patients.

NIKTT's Priorities

The NIKTT convened a Cultural Bias Workshop in late November 2021 to discuss the Report and its implications, with representatives present from Aboriginal and Torres Strait Islander kidney transplant patients, Aboriginal and Torres Strait Islander health professionals, transplantation coordinators, nephrologists, researchers, and other clinical and policy professionals. The Workshop allowed both Aboriginal and Torres Strait Islander patient and health worker voices to be privileged in order to guide the NIKTT's response to the Report and our priorities moving forwards.

Overall, we strongly recommend that further examination into what works, in which contexts, is undertaken throughout renal health care settings in Australia. In terms of the recommendations listed within the Report, the highest priority recommendations for the NIKTT are as follows:

- Recommendation 1: Establish Indigenous reference groups in every transplantation unit to co-design culturally appropriate models of care and safe feedback channels that are tailored to the needs of Aboriginal and Torres Strait Islander transplant recipients and candidates.

The NIKTT established Indigenous Reference Groups (IRGs) in five jurisdictions across Australia, together with an overarching national group. Their sustained existence and expansion are essential components of ongoing kidney transplantation care, as the role of the patient voice is integral to improving models of care and addressing cultural bias. The ongoing funding of IRGs is an immediate and critical need.

- Recommendation 3: Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, including the development of specialised clinical roles such as Aboriginal Regional Transplant Care Coordinators, Case Managers, Health and Practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).

Increasing the Aboriginal and Torres Strait Islander health workforce is essential to allow for the value of cultural skills, understandings, and ways of doing to improve the experience of kidney patients around the country. Patients have consistently raised the importance of – at a minimum – having Aboriginal Liaison Officers or Aboriginal Health Practitioners present in renal units to help translate cultural customs, advocate for patients, and help patients and their families feel more comfortable.

- Recommendation 4: Establish and fund sustainable kidney patient navigator/peer support roles in transplant units and kidney health services. These roles involve peer support from an Aboriginal and Torres Strait Islander person with lived experience of kidney disease and require long-term funding.

Peer and patient support roles have been established through the NIKTT in several locations as pilot programs and initial evaluations are underway. Early findings include 1) important gains, including community acceptance, in facilitating access through the complex process of transplant workup and 2) a keen interest from other jurisdictions to implement similar programs.

- Recommendation 5: Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.

While cultural safety training has been implemented at a health-service level in settings throughout Australia, there are no kidney-specific cultural safety trainings. The nature of care for dialysis patients is unique within the hospital system, with ongoing contact multiple times a week for years. Content- and context-specific trainings therefore need to be co-designed and co-created for a renal-specific audience. Most importantly, these trainings must be evaluated and adjusted so that health professional recipients of training are held accountable to the learnings and are not just a cursory introduction.

- Recommendation 6: Fund, design, implement and evaluate tailored models of care for Aboriginal and Torres Strait Islander kidney transplant recipients and candidates.

The NIKTT's Equity and Access Sponsorships were designed to pilot models of care to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people. These projects are currently being evaluated and the findings will inform future directions, including scale up and expansion, to ensure care is tailored to Aboriginal and Torres Strait Islander people.

Each of these recommendations is critical to improving access and outcomes and need to be initiated concurrently rather than sequentially. This creates collaboration, partnership, transparency, accountability, and trust.

Next Steps

Embedded within the recommendations to address cultural bias is the need for continuous improvement and evaluation. As the Report demonstrates, there is limited published evidence for cultural bias interventions within renal medicine in Australia and in kidney transplantation units in particular. Findings from all aspects of the NIKTT's work will contribute to this existing evidence gap, however continued evaluation of cultural bias is an essential part of ongoing work towards health equity for Aboriginal and Torres Strait Islander peoples. While there are several immediate next steps needed based on the Report, lasting change will require a long-term commitment and oversight from a national body that can amalgamate research and recommend best practices.

Next steps for action based on the recommendations from this Report

- Creation and piloting of a core set of cultural bias interventions as well as a core set of outcome measures for kidney transplantation settings that are generalisable to different health care sectors (including state, Territory, and community-controlled services). These must be co-designed and led by Aboriginal and Torres Strait Islander peoples.
- Establishment of a Working Group to oversee this future work.
- Ongoing funding for IRGs and Aboriginal and Torres Strait Islander health professional positions and community mentors and navigators as a part of core business.

The implicit and explicit effects of racism, discrimination, and colonisation (cultural bias) are entrenched within the Australian community. Thus, we recognise that improving care so that Aboriginal and Torres Strait Islander people have intergenerational kidney health and individual wellbeing – instead of intergenerational kidney disease and poor wellbeing – is challenging and multi-faceted for the kidney transplant community. Given this, the recommendations listed within the Report reflect these complex, interdependent challenges, and offer ways forward to improve access to transplantation and outcomes for transplantation that are equitably available to Aboriginal and Torres Strait Islander patients. As such, a number of these recommendations will need to be addressed by renal units and other state- and federal-level interventions. Most require meaningful community engagement and buy-in from clinical and professional staff.

Continued evaluation of interventions to improve kidney transplantation services will ensure actions taken to mitigate cultural bias are appropriate and realised. Sustained coordination of local, state, and national efforts to address both cultural bias and other barriers to care for Aboriginal and Torres Strait Islander people will allow for these recommendations to be most effective across all settings.

We therefore recommend that implementation and evaluation is funded and coordinated across renal and kidney transplantation settings around Australia to ensure that knowledge exchange, best practices, and evidence-based interventions are capitalised upon. While addressing cultural bias is just one part of the transplantation pathway, it is fundamental to improving access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people.

This recommendation is endorsed the Aboriginal and Torres Strait Islander members and non-Indigenous members of the community, clinical, and research network of the National Indigenous Kidney Transplantation Taskforce.

National Indigenous Kidney Transplantation Taskforce

