

Report  
prepared for:



by:



POLICY BRIEF • DECEMBER 2020

# CULTURAL BIAS INITIATIVES TO IMPROVE KIDNEY TRANSPLANTATION FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

## THE ISSUE

Kidney disease is a serious and increasing health problem among Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander people are more likely to experience kidney failure compared to other Australians, be diagnosed at an earlier age, and have a higher prevalence of other health conditions. Despite this, Aboriginal and Torres Strait Islander people are four times less likely to receive a kidney transplant when they need it.

Various forms of racism and cultural bias have been identified as barriers to Aboriginal and Torres Strait Islander people receiving equitable access to kidney transplantation. The National Indigenous Kidney Transplantation Taskforce (NIKTT) was established in 2019 to improve access to, and post-transplant outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander people.

## THIS PROJECT

This project is the first step under the NIKTT to review existing health service cultural bias initiatives. It makes recommendations to inform future activities that can address cultural bias in service delivery for kidney transplantation for Aboriginal and Torres Strait Islander Australians.

The project examined grey and peer reviewed literature from Australian cultural bias initiatives across kidney healthcare and other tertiary healthcare settings. It also included Aboriginal and Torres Strait Islander patients, families and community members and health professional perspectives from community consultations across Australia. Patients are recognised as experts of their own lived experience of kidney disease and of how care is provided. They are in a unique position to identify barriers and gaps as well as propose possible solutions. Their voices must be privileged in this and wider discussions to achieve real change moving forward.

“ *Every which way you look at renal disease in Aboriginal people, the only solutions that will work in the long term are those that are Aboriginal-led, culturally responsive, located in Aboriginal organisations and evaluated through an Aboriginal lens.* ”

– Pat Turner CEO NACCHO, National Indigenous Dialysis and Transplantation Conference, October 2019



## RACISM AND CULTURAL BIAS IN HEALTHCARE

This project aims to bring understanding to the term cultural bias, how it is founded in racism and colonisation, and how racism occurs across the Australian healthcare system.

Although the causes of the health disparities between non-Indigenous and Aboriginal and Torres Strait Islander people are complex, multiple sources of evidence suggest that racism is a significant factor. Racism in the health system manifests in various ways through institutional and organisational systems and implicit and explicit bias from health professionals. Data on the experiences of Aboriginal and Torres Strait Islander healthcare users in Australia in regard to racism and cultural safety is limited<sup>i</sup>. This information is critical to reducing racism and the harm it causes.

One national survey found that 32.4 per cent of Aboriginal and Torres Strait Islander patients reported racial discrimination in medical settings most or all of the time<sup>ii</sup> and, in 2012–13, 20 per cent of Aboriginal and Torres Strait Islander Australians reported being treated unfairly by healthcare staff in the last 12 months<sup>iii</sup>.

Culturally safe health care systems are needed to address racism. Cultural safety, unlike cultural awareness, focuses on equity, systemic and individual change through critical reflection, and acknowledges the impact of colonisation and power differentials between healthcare providers and patients. Importantly, cultural safety is defined by recipients of care, not the care provider.

For the purposes of this work, cultural bias refers to the various mechanisms through which health professionals, organisations and systems perpetuate or deliver inequitable healthcare access and outcomes for Aboriginal and Torres Strait Islander peoples. These mechanisms include, but are not limited to, attitudes, beliefs, behaviours, policies, resourcing, governance and accountability and encompasses both institutional and interpersonal racism.

i. Australian Institute of Health and Welfare (AIHW) 2019, *Cultural Safety in Healthcare for Indigenous Australians: Monitoring framework*, Cat.no. IHW 222, AIHW, Canberra.

ii. Cunningham, J. & Paradies, Y.C. 2013, Patterns and Correlates of Self-reported Racial Discrimination among Australian Aboriginal and Torres Strait Islander Adults, 2008–09: Analysis of national survey data, *International Journal of Equity in Health*, vol. 12(47), DOI: <https://doi.org/10.1186/1475-9276-12-47>

iii. AIHW 2019, op. cit..

## WHAT CAN BE DONE?

Based on the review, we found four key domains of action that can address cultural bias in kidney transplantation for Aboriginal and Torres Strait Islander peoples.

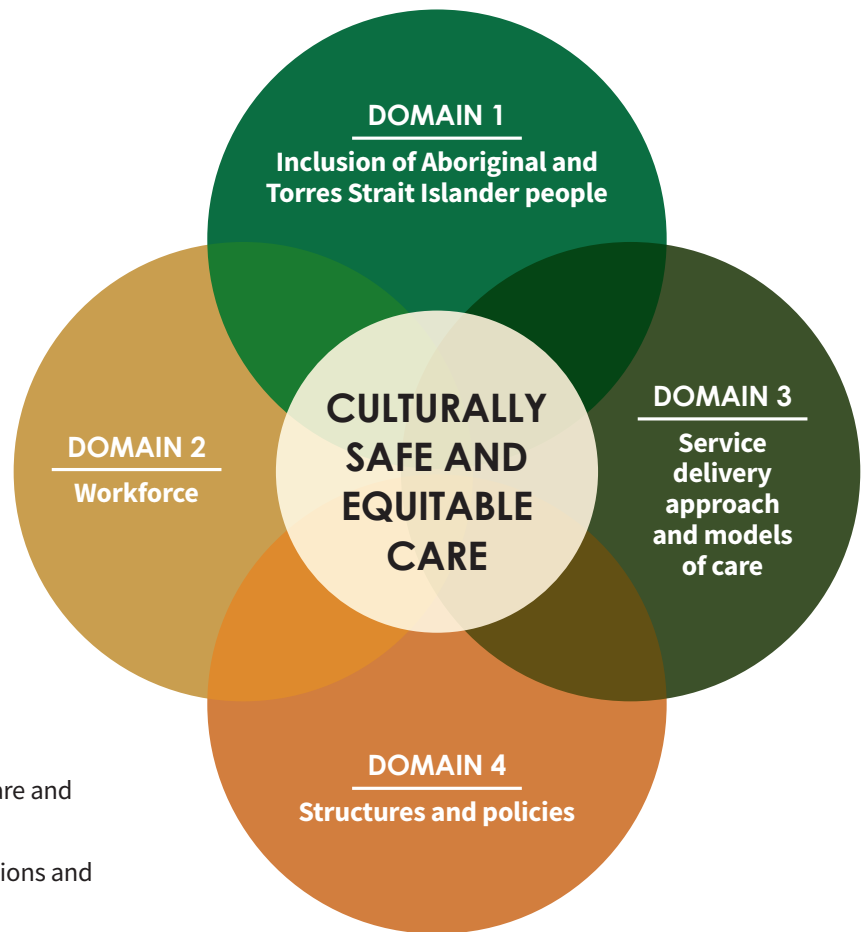
### DOMAIN 1: Inclusion of Aboriginal and Torres Strait Islander people

#### SUB-DOMAINS:



- Inclusion of patients and family members in care and decision making.
- Inclusion in governance, community consultations and reference groups.
- Patients' perspectives and feedback are welcomed and valued.

Privileging the voices of Aboriginal and Torres Strait Islander peoples through patient and family centred care, cultural governance models, Aboriginal and Torres Strait Islander representation on steering groups, committees and boards and strong engagement and partnerships with Aboriginal Community Controlled Organisations (ACCHOs) were identified as fundamental in effective culture bias initiatives.

Reference groups, peer navigators and Aboriginal and Torres Strait Islander health professionals are safe channels for patients to provide feedback, without fear of reprisal, and are an important aspect of enhancing cultural safety.



## RECOMMENDATIONS

-  **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 Islander transplant recipients and candidates.
-  **2** Increase Indigenous representation on relevant kidney health advisory boards and steering groups, especially within boards and management of transplant units.

“ One area of patient feedback that requires specific cultural bias attention is the creation of safe processes to enable patients to provide constructive feedback regarding gaps and barriers in care without experiencing negative impacts on the quality of care they receive in return. Disturbingly, some patients have reported that after they have lodged a complaint, they are labelled as a trouble maker and experience ‘pay back’ behaviours from some staff, such as getting needled and put on the machine last when they attend dialysis, regardless of what time they arrive.

Kelli Owen, NIKTT Community Engagement Coordinator and transplant recipient

## DOMAIN 2: Workforce

### SUB-DOMAINS:

- Increasing and supporting the Aboriginal and Torres Strait Islander workforce.
- Increasing cultural safety knowledge, skills, practice and training of all workforce.
- Two-way learning to enhance clinical-cultural abilities.

Initiatives that successfully address cultural bias focus on the roles, support, abilities and training of both Aboriginal and Torres Strait Islander and the non-Indigenous workforce. They often include the development of new roles for Aboriginal and Torres Strait Islander people in peer support and healthcare coordination where necessary. The most effective initiatives value the well-developed cultural skills, knowledge and relational networks of Aboriginal and Torres Strait Islander staff and the unique perspective and understanding they offer Aboriginal and Torres Strait Islander patients. Those initiatives also ensure that non-Indigenous staff were highly skilled in cultural safety and had a positive and respectful attitude toward two-way learning, enabling the combination of clinical and cultural skills.

## RECOMMENDATIONS

-  **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 Practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).
-  **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.
-  **5** Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.

“ On my kidney journey I had a Close the Gap case manager who helped me through my complex walk. Linking appointments, staying on top of workup tests, dental and ongoing appointments. A few tests were able to be done locally in my regional town due to the knowledge of the case managers (nurse knowledge).

Kelli Owen, NIKTT Community Engagement Coordinator and transplant recipient

## DOMAIN 3: Service delivery and models of care

### SUB-DOMAINS:

- Advocacy
- Case management & follow up
- Collaboration
- Communication, understanding, trust
- Continuity of care and carer
- Cultural safety and responsiveness
- Flexibility
- Health promotion and health education
- Improving access through holistic care
- Peer support
- Quality, safety and evaluation.

Many studies identified the importance of holistic continuity of care for clients and families to improve outcomes and enhance cultural safety. This included built-in flexibility to enable patients to access care in ways that met their needs and life situation. In the case of kidney care, flexibility extended to changing guidelines to better reflect how Aboriginal and Torres Strait Islander patients are impacted by kidney disease, to respond to the benefits of holistic outreach services, and to be flexible as to the location of care to enable patients to stay or reconnect with family, community and Country.

Responding to the holistic health, wellbeing and socioeconomic situation and needs of Aboriginal and Torres Strait Islander clients, particularly transport and accommodation, were seen as critical. Many studies highlighted the importance of family being involved in care and decision making.

Case management and coordinating care across services and through the different stages of the kidney journey is complex but has been shown to improve outcomes, referral and follow up for renal patients. Coordination with other services, especially ACCHOs, is an important aspect of successful programs, particularly in kidney care.

Effective communication underpinned all initiatives and was identified repeatedly, especially in a range of kidney care studies. Communication is not just about getting important clinical messages across, through effective health education, but also about building relationships and trust. This was identified as necessary to counter judgemental and discriminatory attitudes received by Aboriginal and Torres Strait Islander patients and clients. One concerning theme that emerged is that Aboriginal

and Torres Strait Islander patients often feel unsafe when providing critical feedback, or highlighting gaps in care, and their experience is that lodging a complaint often leads to negative care responses by staff and is inherently unsafe. This situation counters effective quality and safety, and feedback mechanisms, and can lead to patient anxiety and disengagement.

Some initiatives showed that effective communication and rapport could be established using tele-and video-health options involving specialists, and that additional training could assist with this process. The use of telehealth/ video health was also identified as a means for increasing the involvement of family members in care. The use of interpreters has also been shown to strengthen relationships, understanding and trust between patients and health professionals.

**“ Follow up on our people is needed as we do everything at a hospital level prior to their release but our people need local and personal follow up to stay on top of their health needs. Having a model of care between the hospitals and GPs/ACCHOs within community is necessary.**

**Darren Quartermaine, Aboriginal Hospital Liaison Officer, Sir Charles Gairdner Hospital**

## RECOMMENDATIONS

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



- are patient/client and family centred, and include continuity of care;
- are based on the feedback and perspectives of patients and consistently involve family in healthcare discussions, decision making and health education;
- are responsive to holistic health, and wellbeing and the socioeconomic and cultural needs of Aboriginal and Torres Strait Islander peoples, including specific needs around transport, accommodation, social and emotional wellbeing and involvement of traditional healers.

- are based on partnerships and collaboration between services, especially with Aboriginal Community Controlled Health Organisations
- recognise, value and include the role of the Aboriginal and Torres Strait Islander workforce, including establishing new roles such as Aboriginal Transplant Coordinators and Patient/Peer navigators
- include multidisciplinary pre- and post-transplant teams in urban areas and outreach services in regional, rural and remote areas.

These models of care should be co-developed to address the needs of local communities and may vary across the country. They should be a means of addressing inequities in access to and outcomes from kidney transplantation and will require long term funding.

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**7** Expand and embed the use of telehealth and videoconferencing services for kidney transplant recipients and candidates and ensure the inclusion of Aboriginal and Torres Strait Islander health workers/practitioners (and interpreters when required) in these consultations.

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**8** Support and fund the further use of interpreters.

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**9** Co-develop specific health promotion and health education resources and approaches on kidney transplantation with Aboriginal and Torres Strait Islander people.

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## DOMAIN 4: Structures and policies

### SUB-DOMAINS:

- Organisational governance, commitment, leadership and management
- Physical environment welcoming and accommodating
- Policies, guidelines and standards to guide improvements.

Organisational commitment and leadership from management, executives and boards were consistently identified as a factor in determining whether a program was able to successfully implement cultural bias initiatives.

Policies, guidelines and standards were also identified as important for supporting new initiatives or as key barriers that required reform. Embedded evaluation, continuous quality improvement through ongoing cycles of reflection and feedback from patients were identified as important for improving service delivery and cultural safety. The peer reviewed literature highlights the importance of reviewing and embedding supportive policies at unit, service and health system levels.

A series of policies, standards and guidelines have been developed nationally to guide and direct kidney and transplantation care in Australia, some of which focus specifically on the needs of Aboriginal and Torres Strait Islander peoples. There is an increasing trend to include and respond to the voices, perspectives and priorities of Aboriginal and Torres Strait Islander patients and community members, health professionals and services in these documents.

The need for system change to reduce racism and address healthcare disparities was also identified in a number of studies. Institutional racism audit tools provide a means for transplant units and kidney health service providers to begin to assess the levels of institutional racism within their organisations. There are significant opportunities to address institutional racism and to more effectively de-colonise our healthcare system, thereby enabling more equitable access and outcomes.

Wider healthcare standards have the potential to help address cultural bias that are not kidney health specific. These include the National Safety and Quality Health Service (NSQHS) Standards six specific actions for Aboriginal and Torres Strait Islander health and the Australian Health Practitioner Regulation Agency cultural safety strategy. The analysis of the literature has identified



that while these standards exist, their impact is not being felt or perceived consistently and reliably by Aboriginal and Torres Strait Islander patients and clients. Australia's major healthcare settings are not yet being perceived as a uniformly safe place for care by Aboriginal and Torres Strait Islander people.

Resources and funding ultimately determine the scope and extent of practice, responsiveness of services, functionality and how frequently services can operate. Funding was identified as critical to rolling out and sustaining any cultural bias initiatives.

## RECOMMENDATIONS

**10** Review existing CQI processes, policies, protocols and guidelines in transplant units and kidney health services to ensure equity of access and safe feedback channels for Aboriginal and Torres Strait Islander people.



**11** Assess institutional racism within transplant units and kidney health services using an institutional racism audit tool.



**12** Develop and implement specific clinical guidelines for Aboriginal and Torres Strait Islander kidney care and evaluate their effectiveness in increasing equity of access to kidney transplantation.



**13** That the Australian Government Department of Health allocate a dedicated funding stream to implement and evaluate the recommendations in this report across multiple jurisdictions to increase equity of access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander Australians.



**14** That the NIKTT undertake further work to assess the baseline status of these recommendations within transplant units and further develop an evaluation framework and supporting data development to monitor the implementation of the recommendations and provide public reporting.



## WHAT NEXT?

Multiple studies conducted over the last 20 years have clearly identified gaps in kidney care for Aboriginal and Torres Strait Islander peoples.

Many of these studies propose specific strategies for improvement, consistent with the recommendations from this review. In order to effect change and improve kidney transplantation rates and kidney health outcomes, future needs to focus on funding effective implementation and evaluation of initiatives from the perspective of patients, families, communities and healthcare professionals, and on healthcare services and systems' models of care, quality improvement, guidelines and standards.

Co-designed and co-created participative approaches to research, implementation and evaluation offer the greatest opportunities for the development of new models of transplantation care that meet the complex clinical and cultural care needs of Aboriginal and Torres Strait Islander people living with kidney disease.



## RECOMMENDATION MAPPING

### (WHO IS RESPONSIBLE?)



#### **For transplant units and kidney health services:**

Recommendations 1, 2, 3, 4, 5, 6, 7, 8, 10, 11



#### **National peak bodies and organisations (NIKTT):**

Recommendations 2, 6, 9, 12, 14



#### **For governments and funders:**

Recommendations 3, 4, 6, 7, 8, 13

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## ABOUT THIS POLICY BRIEF

This brief, and corresponding report, were prepared by staff from the University of Adelaide, Lowitja Institute and the National Indigenous Kidney Transplantation Taskforce.

The full report will be available from December 2020 from the Lowitja Institute website:  
[www.lowitja.org.au](http://www.lowitja.org.au).

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Published by the Lowitja Institute,  
Melbourne, Australia

ISBN: 978-1-921889-74-5

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Australia's National Institute for Aboriginal and  
Torres Strait Islander Health Research

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