

Equitable access to kidney transplants for Aboriginal and Torres Strait Islander people in Australia

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First Nations peoples in Australia face systemic inequities in access to kidney transplantation. The National Indigenous Kidney Transplant Taskforce was established to address these. It has provided support to clinicians to implement and evaluate innovative practices and developed strategies to address biases in the structures and models of care that create barriers to wait-listing.

In Australia, a marked excess of kidney failure is seen among Aboriginal and Torres Strait Islander people. This differential is particularly evident among those aged 40–60 years, among females, and among those living remote from highly served areas¹. Systemic differences also exist in the way Aboriginal and Torres Strait Islander people receive kidney replacement therapy relative to their treatment and care needs. Far fewer Aboriginal and Torres Strait Islander people than non-Indigenous people have functioning kidney transplants, fewer receive home dialysis, and many more receive facility-based dialysis away from their homes¹.

As a wealthy nation with universal healthcare, Australia should make transplantation readily and equitably available to all people who need it. However, the availability of kidneys for transplantation – from both living and deceased donors – is critically limited. The lower rates of kidney transplantation among Aboriginal and Torres Strait Islander people arise from differences in the rates of both living and deceased donor transplantations. In 2021, 1 in 1,000 Aboriginal and Torres Strait Islander people on dialysis received a living donor transplant as compared with 15 per 1,000 non-Indigenous people. Similarly, 23 in 1,000 Aboriginal and Torres Strait Islander people on dialysis received a deceased donor transplant in 2021 as compared with 46 per 1,000 for non-Indigenous people¹.

These differences are not new, nor are they unique to Australia. Similar differential access to kidney transplantation was noted over 10 years ago for First Nations peoples in New Zealand, Canada and the United States^{1,2}.

The drivers of these inequities are complex. Transplantation is keenly desired by Aboriginal and Torres Strait Islander people, yet education for patients is often notably inadequate³. Historical studies among clinicians show systematic beliefs and biases about 'poor compliance' as a predictor of poor outcomes after transplantation⁴. However, Aboriginal and Torres Strait Islander people must navigate healthcare systems that are ill-suited to their needs⁵ and where poor communication is pervasive⁶. Pathways to transplantation are complex, requiring series of investigations before wait-listing that are usually

conducted at metropolitan hospitals (Fig. 1). The net result is a system of institutions and structures that do not offer equitable access to a crucial treatment modality.

“Aboriginal and Torres Strait Islander people must navigate healthcare systems that are ill-suited to their needs”

Detailed examination of the pathway to transplantation in Australia has shown that the substantive barriers are at the wait-listing stage rather than allocations⁷. These barriers are greater for older people and for those living remote from hubs of services and the decision makers who provide the investigations necessary for treatment optimization.

These differences in access to transplantation are not isolated. They sit within a health system and society that continues to be inequitable as a consequence of institutional racism⁸. *Closing the Gap* is a long-standing National Agreement that covers a broad variety of Australian Government targets across health, education, economic and social outcomes. Unfortunately, progress towards most of these goals has been minimal, and indicators specific to kidney disease have not been part of *Closing the Gap* reporting⁹.

To address the disparities in access to kidney transplantation, the National Indigenous Kidney Transplant Taskforce (NIKTT) was formed under the auspices of the Transplantation Society of Australia and New Zealand with funding from the Australian Government Department of Health. The aims of the Taskforce were to obtain more granular data on barriers to transplantation in conjunction with existing registry data, improve the equity and accessibility of transplantation for Aboriginal and Torres Strait Islander patients by trialling a range of multidisciplinary service models and protocols and through the creation and support of Indigenous Reference Groups, and review existing initiatives that target cultural bias in health services to facilitate best practice care and support¹⁰.

To date, the NIKTT has funded eight proposals that aim to improve equity and accessibility in transplantation, including outreach clinics of transplantation assessment teams to remote locations; patient navigator programs; and context-specific models of transplant education.

Work of the NIKTT has also yielded a number of important lessons. First is the burden of reporting. Primary health care for Aboriginal and Torres Strait Islander people in Australia is delivered through a large number of clinics – both community controlled and government

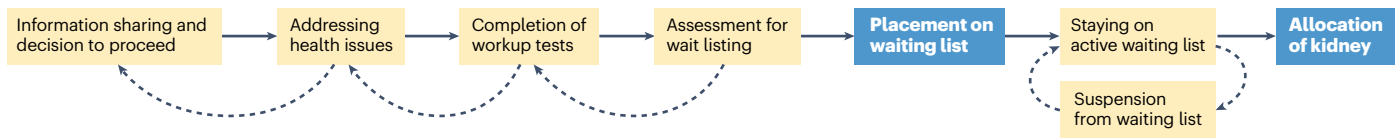


Fig. 1 | Notional steps to receipt of a deceased donor kidney transplant.

This is a simplified depiction of a complex process; within each box there may be multiple elements. For example, the workup tests for kidney transplantation are often extensive and often not available in regional or remote areas. There are often situations where progress is not linear: workup tests may disclose health

issues that need to be addressed before potential transplantation; at the point of assessment further tests may be requested. After initial placement, people may also be suspended from the active waiting list on a temporary or permanent basis if intercurrent health issues arise.

operated. The services these clinics provide are crucial to the overall health and wellbeing of dialysis and transplant patients. However, small clinics, which are often located in rural or remote areas, typically lack the administrative resources to support the reporting burdens associated with research or service delivery programs.

“We need to be honest about our past, hold ourselves accountable for and learn from our mistakes”

Second, transplant services, like other highly specialized and resource-intensive services, tend to be organized for the financial and time efficiency of hospitals and staff. The creation of services that prioritize patient access and engagement can be seen as inconsistent with this ‘efficiency’ approach. However, indifference to the needs and priorities of Aboriginal and Torres Strait Islander patients creates culturally unsafe environments, perpetuates institutional racism and will directly impact the care and health outcomes experienced by Aboriginal and Torres Strait Islander people.

Third, the central role of the consumer voice is paramount to achieving culturally safe health services. The design, creation and implementation of structures and services that meet the needs of consumers requires input from and engagement with those very consumers. Without Indigenous Reference Groups and similar structures to support meaningful and ongoing engagement, health services cannot design culturally safe services nor adequately respond to the needs of consumers. The expansion of such Indigenous Reference Groups will need sustainable ongoing funding and resources, as well as leadership by a First Nations member from within the hospital.

Recommendations from the NIKTT include immediate improvements to access and services, through implementation of Outreach Assessment Clinics and Indigenous Reference Groups and by increasing the Aboriginal and Torres Strait Islander renal workforce; the institution of ongoing and specific monitoring of access to and outcomes of transplantation for Aboriginal and Torres Strait Islander people; and investigation of initiatives to address identified barriers to wait-listing and post-transplantation care.

A clear mandate exists from Aboriginal and Torres Strait Islander kidney health consumers, carers and communities for change. The Australian Government’s draft *National Strategy for Organ Donation Retrieval and Transplantation* explicitly identifies equitable access to transplantation as a Priority Area, with an express focus placed on making transplantation accessible to Aboriginal and Torres Strait Islander people¹¹. We anticipate that the findings and recommendations from the NIKTT will inform the implementation of this policy at a national and regional level.

The need is now for governments, health systems and individual service providers to implement change. As individuals working as

health-care workers, we need to be honest about our past, hold ourselves accountable for and learn from our mistakes, and create brave spaces for change to occur. Transplantation equity for Aboriginal and Torres Strait Islander people living in Australia is still a work in progress, but it is essential and achievable work that requires persistent support from all of us.

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Competing interests

The authors declare no competing interests.