Towards equity in kidney transplantation: the next steps

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Lasting improvement in access to, and outcomes of, kidney transplantation will take sustained focus and coordinated effort. Further gains in transplantation access and outcomes are immediately available with directed attention on racism, cultural safety, equity and Aboriginal and Torres Strait Islander-led change by our kidney communities and change makers. Transforming our entrenched systems will not be easy, but it must be done.

In this Perspective article, we focus not on re-expressing the trauma of exclusion and racism experienced by Aboriginal and Torres Strait Islander people in renal care, but instead focus the discussion on what must be done to systemically change care delivery going forwards. We reflect on some of the underlying principles that will ensure true equity and health sovereignty are realised as we continue to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people. These changes, supported by the generosity and commitment of Aboriginal and Torres Strait Islander people, allied partners and many others, must be grounded in Aboriginal and Torres Strait Islander sovereignty and leadership. Although there have been early improvements in access to waitlisting and transplantation, we look at which next steps are needed for continued and sustained change.

Change through focus

A focused, coordinated national effort to increase access to kidney transplantation for Aboriginal and Torres Strait Islander people has been intentionally resourced by the Australian Government over the past five years: first, with the funding of an expert panel to review extant barriers to transplantation,[1] and then by the establishment of the National Indigenous Kidney Transplantation Taskforce (NIKTT) to address specific barriers.[2] The timing of the review and the action of the national Taskforce coincide with an improvement in the rates of both transplantation and active waitlisting for Aboriginal and Torres Strait Islander people around Australia.[3]

Alongside quantitative evidence for improvements in transplantation and waitlisting rates,[4,5] the NIKTT has found qualitative evidence around the various enablers and barriers to transplantation access for Aboriginal and Torres Strait Islander people in Australia, detailed throughout this supplement. Combining these findings, as well as a position statement on transplantation equity[6] that was endorsed by many community and clinical members of the Taskforce and larger network, the NIKTT identified three key areas for action, and associated recommendations, to continue to improve access to kidney transplantation (Box). In this final Perspective article, we discuss how we, as a health care community, can continue to improve access to waitlisting and transplantation.

Service redesign

The complexity of changing service delivery within the current Australian health care system cannot be understated. Among renal units, staffing pressures and a lack of available dialysis chairs have created situations where delivery of even basic renal care is difficult in some situations. The challenge (and its opportunity) for the Australian health system lies in addressing multiple aims: improving access to kidney transplantation and dealing with limited haemodialysis capacity and the need to implement prevention programs, all while working within a resource-limited system.[7] These aims cannot be mutually exclusive priorities if we are to provide care to all who need it.

Dealing with issues around transplantation access will involve sustained institutional and unit-level practice changes. Increasing the Aboriginal and Torres Strait Islander kidney health workforce (discussed below) is a first step. Other changes, such as the establishment and maintenance of Indigenous Reference Groups or Patient Navigator programs, are tangible steps renal and transplantation units can take to directly involve patients and their families in the creation of safe care pathways. The benefits to patients and services are considerably higher than the modest resourcing required to sustain these activities once initiated, so they must be included in renal unit budget planning. Similarly, although coordination of care requires complex interactions between many health care actors, the benefits and value-added of collaboration across and within institutional boundaries strengthen continuity of care and coordinated practice. These directly speak to what Aboriginal and Torres Strait Islander patients have called for and are integral facets of chronic and complex care pathways. As recommended by the NIKTT, outreach assessment clinics in rural and remote Australia are illustrative of how collaborative working arrangements between transplantation units and local primary health teams can achieve a greater magnitude of benefit when they are able to access, integrate and capitalise on ground-level knowledge and coordination capabilities.[8]

Australia is presently struggling to deliver health care, particularly with nursing staff shortages[9] and especially within renal services in regional and remote areas.[10] Increasing the Aboriginal and Torres Strait Islander health workforce at all levels will be a fundamental part of the solution to this, as well as transplantation accessibility more generally. Strategies for immediate action include creating bespoke roles for Aboriginal Health Practitioners, exploring alternatives to dialysis nursing from within the community, and investing in culturally relevant positions such as interpreters or patient navigators. The NIKTT consistently found across pilot projects that Aboriginal Health Workers or Practitioners

Key areas for action, and their associated recommendations, identified by the National Indigenous Kidney Transplantation Taskforce

Key area for action	Detailed recommendations
Service redesign	Jurisdictions must sustainably fund the following: • **Outreach assessment clinics:** clinics should be resourced to provide multidisciplinary team visits to rural and remote locations. Funding should include the provision of a full-time transplant coordinator role and clinics should include educational sessions for staff and patients alongside clinic visits. • **Indigenous Reference Groups (IRGs):** all transplant hospitals should resource and implement unit-based IRGs alongside mechanisms for reporting and workflow integration. Groups should be led by Aboriginal and Torres Strait Islander kidney patients and/or Aboriginal and Torres Strait Islander renal health workers. • **Increased Aboriginal and Torres Strait Islander renal health workforce:** identified renal health roles at all levels, including (but not limited to) patient navigators and transplant coordinators, should be developed and sustainably resourced at renal units and transplant hospitals that serve Aboriginal and Torres Strait Islander patients. These roles must be embedded and supported within renal and transplantation units.
Maintained leadership, coordination, and governance led by Aboriginal and Torres Strait Islander people	• Coordinated efforts are essential to identify issues, catalyse activity, and maintain profile and focus on transplantation. A national Secretariat, guided by Aboriginal and Torres Strait Islander people, would provide leadership, collaboration, monitoring and reporting and should be resourced to continue national coordination of transplantation equity work. This group should be responsible for the implementation of the following: ▸ **Ongoing monitoring:** progress on improving waitlisting numbers, kidneys transplanted, and post-transplant outcomes should be consistently monitored through the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry. This monitoring should include the development and implementation of an annual scorecard for renal units. ▸ **Maintaining focus and engagement:** a coordinated network should be maintained to ensure attention remains on transplantation access and outcomes until significantly improved. Such maintenance of a network should include an annual gathering, consistent community engagement, sustained online resource portal, and conference attendance. ▸ **Developing a proposal for a National Aboriginal and Torres Strait Islander Body:** a coordinated, collaborative approach should be implemented to develop a proposal for a sustainable national body that represents the holistic journey of Aboriginal and Torres Strait Islander people with kidney disease, inclusive of all modalities including transplantation. Secretariat support should include the development of partnerships, governance, terms of reference, and key objectives and deliverables.
Research and evaluation	• Funding should be offered to support the investigation of solutions for further drivers of inequity. Research into, and implementation and evaluation of, initiatives that address additional drivers of inequity should be nationally resourced and coordinated to understand best practices. • **Additional barriers:** further barriers to transplantation equity, including overweight/obesity, treatment uptake, and reversible health issues, should be researched and best practices identified to address these barriers across rural and remote regions. • **Design initiatives across the transplantation pathway:** research into and implementation of solutions to additional transplantation pathway aspects, with Aboriginal and Torres Strait Islander people, should be resourced, including post-transplant care, paediatric transplantation, culturally tailored transplant education, and donation.

offered immeasurable benefits to renal services by leading culturally safe access to, and provision of, care and a crucial interdisciplinary team approach to care. Implementing this at a jurisdictional level will require a coordinated approach that includes design of appropriate scope of roles, role delegation, integration within models of care, creation and accreditation of appropriate training courses, and, ideally, a national framework that recognises expertise and training in this area.

Maintained leadership, coordination and governance led by Aboriginal and Torres Strait Islander people

A fundamental tenet of high quality care is a patient-centred approach,[11] yet, until recently, there have been very few mechanisms for patient engagement in service design, especially in renal services caring for Aboriginal and Torres Strait Islander people. Over the past two decades, activity-based funding, and thus economic efficiency, have driven health care service models. These centre the needs of care providers rather than outcomes-based models, which centre the needs, wants or particularities of patient-users of services. In kidney transplantation settings that serve Aboriginal and Torres Strait Islander people, the opportunities for patient voices to influence the design of services and care models have been minimal.[12,13] Shared responsibility for leadership and governance by health care users and health care providers was an important priority of the NIKTT community network, as evidenced through Indigenous Reference Groups.[14] Even though the NIKTT has catalysed the formation of these bodies in several regions, ongoing support must come from the jurisdictions and health services involved.

Although individual kidney transplant services are provided by state- and territory-run hospitals, substantial elements of policy and practice are driven at a national level. Issues such as the acceptance criteria for waitlisting and the algorithms for kidney allocation are determined by national bodies, which have often lacked representation from Aboriginal and Torres Strait Islander communities. These processes that provide care for Aboriginal and Torres Strait Islander people, yet exclude Aboriginal and Torres Strait Islander people from making decisions or providing input, recolonise, subjugate and must be avoided.[15] Similarly, we must continue to question processes around data collection and reporting. How are data sovereignty[16] and governance maintained? Are we underestimating the number of Aboriginal and Torres Strait Islander people within registry datasets without self-identification being the norm?[17] At both national and local levels, we must ensure that Aboriginal and Torres Strait Islander leadership guides discussions about how we maintain, develop and use data going forward.

The NIKTT strongly recommends that a national network or body be established, representing Aboriginal and Torres Strait Islander people living with kidney disease, failure and transplantation. Consumers, community members, and clinical advocates have called for such a body[6] that centralises and coordinates efforts to improve the lives of people with kidney problems — from prevention through to post-transplant care — allowing us to reduce duplicated efforts, build on the strength of networks, and share resources and knowledge for the betterment of communities across Australia. Health sovereignty will not be established within Australia unless Aboriginal and Torres Strait Islander people lead health system change.

Research and evaluation to investigate additional barriers and alternative approaches to care

Despite the many challenges to ongoing equity and change, it is broadly recognised that there is a strong and growing momentum for lasting improvement. This reflects the strength of actors calling for change, the political and clinical will to improve health outcomes for Aboriginal and Torres Strait Islander people, and the demonstration of effective interventions. The recommendations here are just the next steps. Undoubtedly, there will be other barriers and issues identified that need to be managed, alongside modifications to programs. Learnings from both successful and less-than-successful projects are critical. Ideally, current systems will evolve into learning-health systems that are driven by Aboriginal and Torres Strait Islander people's priorities; this is likely to be an iterative process, creating the need for national coordination and facilitation of discussions and advocacy.

As revealed throughout the work of the NIKTT, barriers such as obesity, treatment uptake, and systemic miscommunication and racism continue to reduce access to waitlisting. Initiatives that are led and designed by and with Aboriginal and Torres Strait Islander communities should be evaluated across Australia. Additional aspects of the transplantation pathway, such as post-transplant care and paediatric transplantation, that were not within the scope of this iteration of the NIKTT's work must also be researched and initiatives evaluated.

Next steps

In March 2023, the NIKTT Secretariat submitted a funding proposal for $4.8 million over four years to the Commonwealth Department of Health and Aged Care. This proposal addressed the three key areas for action and the recommendations therein, asking for funding to support:

- the resourcing of a continued Secretariat to maintain collaborations;
- the development of a data dashboard to support monitoring and reporting on equity progress;
- the development of a national body that represents Aboriginal and Torres Strait Islander people living with all stages of kidney disease, failure and transplantation; and
- the resourcing of additional sponsorship opportunities for local service delivery change based on outstanding barriers and additional aspects of the transplant pathway.

How inequalities are addressed and actioned in the kidney transplant sector is very relevant for the broader health system. The type of complex care pathways — involving multiple care providers in different institutions with different governance and funding streams — is an inevitable part of the multidisciplinary management of chronic diseases. There will be many lessons from the transplant sector that can be taken up throughout services that care for people with chronic kidney disease, other chronic health conditions, and, more broadly, for Aboriginal and Torres Strait Islander people across Australia.

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We thank the members of the NIKTT for their dedication and commitment to transplantation equity and for their time and effort on Taskforce activities, and we look forward to continuing to change our health systems for the better.

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