MJA
The Medical Journal of Australia

SUPPLEMENT

Towards kidney health equity: Insights from the National Indigenous Kidney Transplantation Taskforce

16 October 2023 Volume 219 No 8

www.mja.com.au

AMA Journal of the Australian Medical Association

AMPCo.
Australasian Medical Publishing Company

Towards kidney health equity: Insights from the National Indigenous Kidney Transplantation Taskforce

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This supplement was sponsored by

NIKTT
NATIONAL INDIGENOUS
KIDNEY TRANSPLANTATION
TASKFORCE

TSANZ
The Transplantation Society of Australia and New Zealand

Cover image: The focus of the National Indigenous Kidney Transplant Taskforce (NIKTT) was to drive equity in kidney transplantation for Aboriginal and Torres Strait Islander people in Australia. The NIKTT intentionally incorporated the voices and recommendations of Aboriginal and Torres Strait Islander people into all aspects of its work by consulting communities around the country. The cover of this *MJA* supplement reflects this collaboration: it is a message from the NIKTT to peers and the wider public on the objectives and outcomes of the Taskforce; but more importantly, it is a message from Aboriginal and Torres Strait Islander people and communities living with kidney disease and transplantation about the importance of this work and the need to continue to improve access and outcomes through the provision of culturally safe care.

The two message sticks in the foreground of the cover image were created for the NIKTT Indigenous Reference Groups by Kokatha artist Micky Barlow. Message sticks have traditionally been used by Aboriginal peoples as a means of delivering vital information between communities, providing both a symbolic and tangible graphic communication that commanded respect and acknowledgement. These message sticks represent the many strong voices uniting for change at renal and transplantation units around the country, carrying with them messages to our health system that change must occur to ensure better kidney health outcomes for Aboriginal and Torres Strait Islander people.

The *warup* (drum) was made by Thursday Island Elder Aunty Betty Mabo Tekahika. The *warup* is made from the waru tree; when played it makes the “buru buru” sound that carries over long distances. The *warup* communicates the voice of Zenadh, tellling listeners of the stories and messages of Islanders through song. (This information was provided by Mr Patrick Whap, Wagadagam Elder and linguist.) The *warup* here conveys the voices of kidney communities from the Torres Strait, celebrating the diversity of nations with which the NIKTT has worked alongside in the prevailing call for improvements in transplantation equity.

The kangaroo skin cloak on which these messages lie was created by the NIKTT’s Community Engagement Coordinator, Kelli Owen, a Kaurna, Narungga, and Ngarrindjeri woman. The cloak represents her (continuing) journey through life as she navigates her education, family, work, and life while living with kidney disease and transplantation. Kelli’s dedication to transplantation and health equity for Aboriginal and Torres Strait Islander people is evident throughout the work of the NIKTT; the inclusion of her kangaroo skin cloak in this cover image brings together the messages she gathered from communities with the recommendations and call for action borne out through the NIKTT and described within this supplement.

The National Indigenous Kidney Transplantation Taskforce: changing systems to achieve equitable access to kidney transplantation

Jaquelyne T Hughes[1,2,*], Katie Cundale[3,4], Kelli J Owen[3,5,†], Stephen P McDonald[4,6]

Aboriginal and Torres Strait Islander people with chronic kidney disease seek good health, good kidney health, and good experiences of health care at all stages of their kidney journeys.[1-3] Kidney replacement therapy is crucial for people with kidney failure, so needs to be accessed regularly, safely and sustainably alongside high quality cultural and clinical support. However, access to kidney transplantation, often the best kidney replacement therapy option, is not equally available to Aboriginal and Torres Strait Islander people in Australia.[4]

Racism — whether direct or indirect, institutional or personal — continues to impact the lives, wellbeing and health outcomes of Aboriginal and Torres Strait Islander people living in Australia.[5] This inherent racism plays out in part through the persistent and prolonged lack of access to transplantation experienced by many Aboriginal and Torres Strait Islander people with kidney disease — as well as through inequities in how people access dialysis, experience the impacts of the social determinants of health, and receive culturally (un)safe care.[6] Aboriginal and Torres Strait Islander people have told us time and again of their interest in the option of transplantation; consultations have also told us about people's desires to have dialysis on Country and to prevent young people from progressing to kidney failure.[2-3,7] Yet despite these express desires for change, there continue to be delays in referring Aboriginal and Torres Strait Islander patients for transplantation assessment, delays throughout the workup process, and continuous, often insurmountable barriers to reaching the waitlist, especially for older people and for those living in rural and remote areas.[8-10]

Up until 2018, distinct clusters of dedicated people worked hard to change the reality of kidney failure for Aboriginal and Torres Strait Islander people, yet little coordinated or national action had occurred within our health system to improve differential access to kidney transplantation or address the racism inherent within kidney services. The formation of the National Indigenous Kidney Transplantation Taskforce (NIKTT) — including a secretariat guided by the leadership of a Torres Strait woman (also a nephrologist) and a Kaurna, Narungga and Ngarrindjeri woman (also a kidney transplant recipient) — was a pivotal step in changing Australian transplantation access.

As clinicians, researchers, policy makers, and health experts, we must all be drivers for change in how care is delivered so that it best serves the health gains of Aboriginal and Torres Strait Islander people. Racism, identity, culture, language and beliefs cannot be disregarded in deference to non-Indigenous models of health and care. Aboriginal and Torres Strait Islander people must be given support to exercise their rights to sovereignty, through leadership, workforce, and community involvement, to enable effective design and delivery of kidney services.

The supplement that accompanies this issue of the *MJA* begins with an overview of the NIKTT, explaining how creating such a dedicated group of people — focused on transplantation — was an essential step in progressing transplantation equity in Australia.[11] Cundale and colleagues then explore which features of pilot initiatives help (and hinder) access to the kidney transplant waitlist, highlighting the need for an increased Aboriginal and Torres Strait Islander kidney health workforce, specific service delivery changes, and context-specific educational resource development.[12] Hughes and colleagues provide commentary on a review of cultural bias initiatives to elucidate what can, and should, be done to ensure kidney services are providing equitable care.[13] Owen and colleagues discuss the intricacies of creating Indigenous reference groups in transplantation units, and showcase what it takes to build an effective change-enabling structure to improve the delivery of culturally safe care.[14] Finally, Hughes and colleagues outline what it will take to maintain change in transplantation equity, summarising the NIKTT recommendations and outlining the key principles for next steps in continuing to improve access to transplantation for Aboriginal and Torres Strait Islander people.[15]

While this work showcases what is possible to change inequity, we acknowledge the need for continued research and dedicated effort throughout all aspects of kidney health services and culturally safe care delivery in general. Much remains to be done to improve critical elements of kidney journeys, such as post-transplant outcomes, donation rates, and live donor pathways. Nevertheless, the NIKTT has established a foundation. The challenge for all of us is to build upon this if we are to succeed in achieving equity in access to kidney transplantation.

Acknowledgements: We acknowledge and thank the Australian Government, represented by the Department of Health and Aged Care, for their funding of the National Indigenous Kidney Transplantation Taskforce (NIKTT) through an Indigenous Australians' Health Programme grant. This funding enabled the work described here to be undertaken, as well as the publication of the supplement that accompanies this issue of the *MJA*. We thank the Aboriginal and Torres Strait Islander people living with kidney disease and transplantation who have worked with the NIKTT. We acknowledge that Aboriginal and Torres Strait Islander people in Australia face inequities in accessing transplantation because of the barriers that exist within our health care system due to the lasting and ongoing impacts of colonisation. We thank everyone who has helped us to work towards improving access to transplantation. We thank and acknowledge the dedicated members of the NIKTT who have walked

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with us for the past few years, as well as the partner organisations and societies with whom we work on advancing access to kidney transplantation.

Competing interests: No relevant disclosures.

Provenance: Commissioned; not externally peer reviewed. ■

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Contents

Advancing accessible kidney transplantation for Aboriginal and Torres Strait Islander people: the National Indigenous Kidney Transplantation Taskforce

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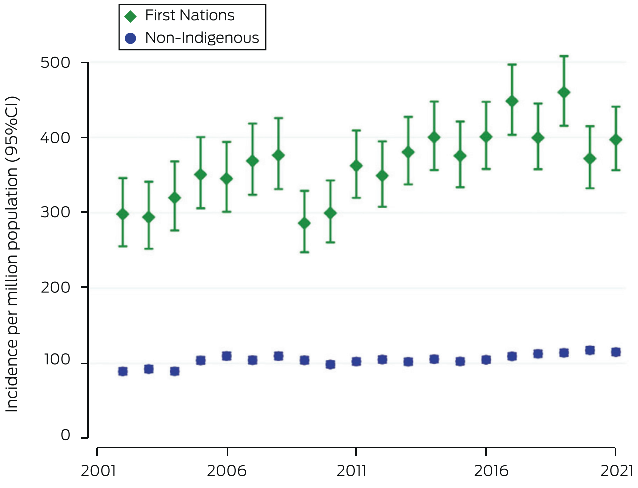
doi: 10.5694/mja2.52112

For tens of thousands of years, Aboriginal and Torres Strait Islander people have operated and thrived within sovereign societies. The sustained and systematic effects of colonisation — which enabled the combined denial of Aboriginal and Torres Strait Islander people's self-determination, autonomy, leadership, and capability to mobilise health-benefiting resources — have created the situation in which we find ourselves today of poor health and systemic differences in health care access and outcomes.[1] For kidney health in Aboriginal and Torres Strait Islander people, this situation is illustrated through the persistent inequities in kidney failure incidence rates, health system access, and treatment outcomes.[2]

Recorded rates of kidney failure requiring dialysis or transplantation among Aboriginal and Torres Strait Islander Australians have risen progressively over the past 40 years, remaining consistently higher than rates for non-Indigenous Australians (Box 1). This difference is even more marked for Aboriginal and Torres Strait Islander people living in rural and remote areas.[2] Aboriginal and Torres Strait Islander people have age-adjusted incidence rates of kidney replacement therapy (KRT) — dialysis or transplantation — eight to nine times higher than those of non-Indigenous Australians, with the median age of Aboriginal and Torres Strait Islander people who experience kidney failure being nearly 30 years younger than non-Indigenous people.[3] Furthermore, for Aboriginal and Torres Strait Islander people receiving KRT, incidence rates vary considerably between location and age (Box 2), as well as sex (Box 3), with people in the Northern Territory, Western Australia, South Australia, and Queensland experiencing higher rates.[2]

1 Unadjusted incidence rate of kidney replacement therapy in Australia[2]



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Finally, the modality with which KRT is delivered differs, with Aboriginal and Torres Strait Islander people predominantly accessing dialysis through facility-based haemodialysis, with lower rates of home-based therapies (peritoneal and home haemodialysis).[2] Access to kidney transplantation is substantially lower, reflecting lower waitlisting rates.[2]

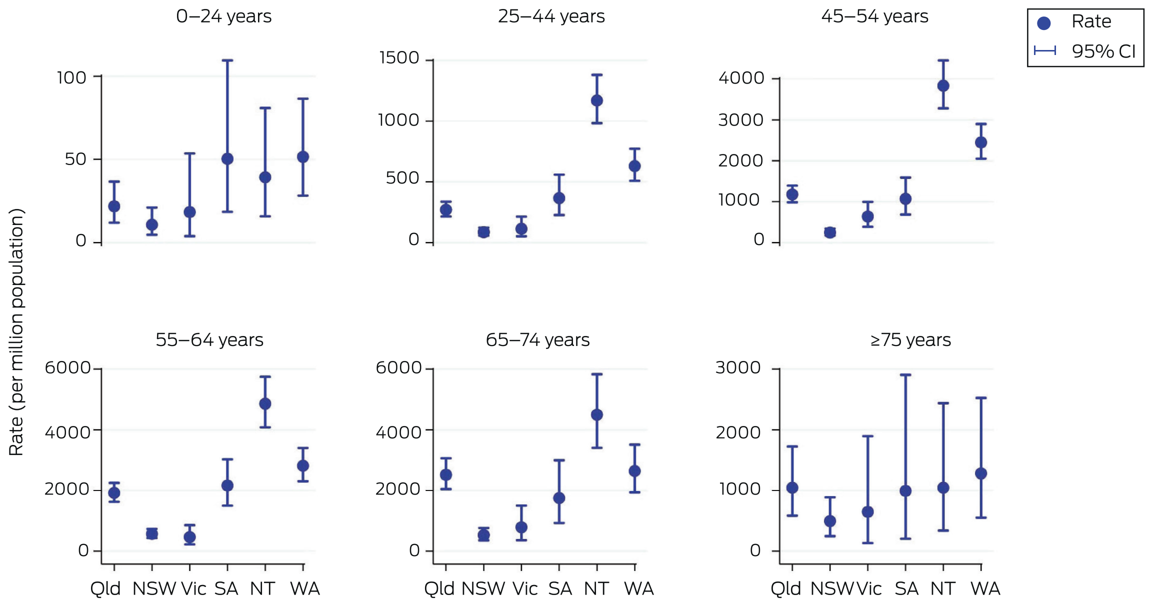
Combined, these disparities mean that Aboriginal and Torres Strait Islander people with kidney failure are likely to spend substantially longer (typically years longer) on facility-based dialysis, away from Country, community, and supportive networks. This dislocation serves to prolong and compound the disconnection, disempowerment and disruption felt by Aboriginal and Torres Strait Islander people when seeking kidney care in Australia.[4]

Why transplantation matters

For people with kidney failure, kidney transplantation is the preferred treatment option where possible. Not only is transplantation associated with lower mortality, and a substantial improvement in quality of life,[5] it is also less expensive in the long term, particularly when considering the cost of dialysis for rural or remote patients.[6] Transplantation therefore provides direct clinical benefits to patients and financial benefits to health systems. Aboriginal and Torres Strait Islander kidney transplant recipients and family members — like nearly all other transplant recipients — also affirm the many health and wellbeing benefits of transplantation,[7,8] and numerous community consultations have shown that Aboriginal and Torres Strait Islander people want a better understanding of, and access to, transplantation.[9-12]

Disparity in access to transplantation has been recognised for many years.[13-18] Although absolute rates of waitlisting and transplantation have increased among Aboriginal and Torres Strait Islander peoples, substantial inequity remains in rates of waitlisting and transplantation compared with non-Indigenous populations, as well as age at diagnosis, pre-transplant treatment modality, and transplantation outcomes.[2]

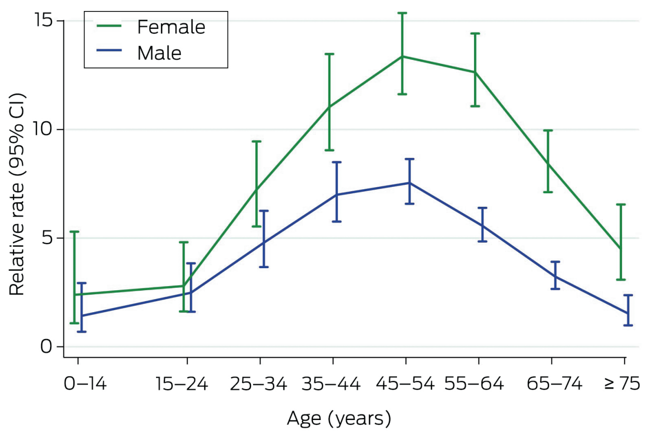
2 Age-specific incidence rates of treated kidney failure among Aboriginal and Torres Strait Islander Australians, by state and age at kidney replacement therapy start, 2016–2021[2]



NSW = New South Wales; NT = Northern Territory; Qld = Queensland; SA = South Australia; Vic = Victoria; WA = Western Australia. Note the y-axis scales vary between panels. Figure reproduced with permission of the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry. ◆

Furthermore, the reasons behind the inequity remain. Studies have consistently shown that inequity in access to transplantation cannot be explained by patient- or disease-related factors,[14-15] and that the principal block is on getting onto the waiting list, rather than receiving a kidney once on the list.[15] Receiving a kidney transplant requires patients to not just meet specific medical requirements, but also to navigate a complex process that includes multiple investigations, appointments, and ongoing reviews (Box 4). Each stage of this pathway can become a barrier to both waitlisting and transplantation.

3 Relative incidence rate of treated kidney failure for Aboriginal and Torres Strait Islander Australians, by sex, compared with non-Indigenous Australians, 2016–2021[2]



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The difference in waitlisting highlights an important need to focus on the gaps in processes and the barriers within the health system, or more specifically, within clinical services caring for people with kidney disease. To better understand these systemic gaps, in 2018 the Australian Government funded an Expert Panel, through the Transplantation Society of Australia and New Zealand (TSANZ), to undertake a comprehensive review into the hurdles, service gaps, and practical challenges faced by Aboriginal and Torres Strait Islander people receiving treatment for kidney disease. The report recommended 35 high priority actions and mapped responsible agencies, identifying where the federal government could strategically enable cross-jurisdictional consumer- and health service-partnered approaches.[19] From there, in March 2019, the then-federal Minister for Health and the Minister for Indigenous Australians accepted the report, announcing a $2.3 million award for TSANZ to oversee a two-year project to coordinate cross-jurisdictional activity.[20] This award established a national Taskforce whose overarching aim was to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people.

Establishing the Taskforce

The National Indigenous Kidney Transplantation Taskforce (NIKTT) was created to drive the development and implementation of initiatives that targeted knowledge and service delivery gaps identified by the TSANZ report, facilitating

4 Generalised pathway to kidney transplantation, including key clinical milestones, for an Australian adult[19]

Adapted with permission from Garrard and McDonald.[19] ◆

improved access to the kidney transplant waitlist and better post-transplant outcomes for Aboriginal and Torres Strait Islander patients. As this supplement will go on to describe, the Taskforce set out to accomplish this through key objectives around:

- designing and implementing enhanced data collection and reporting processes on pre- and post-transplant outcomes;
- improving the equity and accessibility of transplantation for Aboriginal and Torres Strait Islander patients by trialling a range of multidisciplinary service models and protocols; and
- reviewing existing initiatives that target cultural bias in health services to facilitate best practice care and support.

To best inform Taskforce action on these objectives, the NIKTT also created a national network of Aboriginal and Torres Strait Islander consumers and established Indigenous Reference Groups at transplant units around the country.

The development of a national Taskforce was critical to provide a focal point. Although many clinicians, researchers, patients and advocates have worked over the years to improve kidney health outcomes for Aboriginal and Torres Strait Islander people, there has not been a cohesive or coordinated approach to these challenges, nor has there been an opportunity to share and collaborate around service development.

Led by an appointed Chair and Deputy Chair, the Taskforce was comprised of 24 other expert members including nephrologists, nurses, policy makers, researchers and, crucially, Aboriginal and Torres Strait Islander people with a lived experience of kidney transplantation and dialysis, as well as Aboriginal and/or Torres Strait Islander health workers. Although originally scheduled to be completed within two years, the onset of the coronavirus disease 2019 (COVID-19) pandemic predictably altered the timeline of project implementation and the NIKTT was granted an extension until June 2023.

A strategic focus of the Taskforce was embedding Aboriginal and Torres Strait Islander people's self-determination and authority into designing models of care that aimed to improve access to kidney transplantation. The NIKTT set out to intentionally consolidate collaboration, partnership and leadership of Aboriginal and Torres Strait Islander people, as before the onset of the NIKTT, there was extremely limited systematic input of Aboriginal and Torres Strait Islander consumers into the processes of care in renal units and none in kidney transplant units.

This supplement outlines the recommendations of the Taskforce through describing the outcomes and findings of each objective. We highlight the need for Aboriginal and Torres Strait Islander patient engagement and leadership, the importance of co-designing models of care unique to local circumstances, and the challenges we still face as a community and health care system seeking to overcome cultural bias and institutional racism. We end this supplement with an overview of the Taskforce's recommendations for next steps and suggest direct actions that systems and services can take to build on the momentum established.

The members of the Taskforce are privileged to be part of this foundational work with health communities and Aboriginal and Torres Strait Islander communities across Australia. As we progress equity from here, we look forward to working in partnership with patients, communities, health professionals, governments, health organisations, and research institutions to continue to improve access to kidney transplantation.

We begin this supplement with a call to action for readers to join us in improving transplantation equity for all Aboriginal and Torres Strait Islander people with kidney disease.

> We, as Aboriginal and Torres Strait Islander people, know what is best for our health and wellbeing. While our people and cultures are strong and resilient, we continue to see harmful policies and practices implemented by government. While this can be difficult to hear, true change exists within discomfort, and progress is made when all parties are open to listening and responding. (Donna Murray, National Aboriginal and Torres Strait Islander Health Plan 2021–2031[21])

Acknowledgements: We acknowledge and thank the Australian Government, represented by the Department of Health and Aged Care, for their funding of the National Indigenous Kidney Transplantation Taskforce (NIKTT) through an Indigenous Australians' Health Programme grant (IHD-208-4-BIA3J8Y). This funding supported the salaries of two of the authors (Kelli Owen and Katie Cundale) and covered the publication fees of this *MJA* supplement.

We thank the Aboriginal and Torres Strait Islander people living with kidney disease and transplantation who have worked with the NIKTT. We acknowledge that Aboriginal and Torres Strait Islander people in Australia face inequities in accessing transplantation due to the systemic barriers that exist within our health care system. We thank everyone for helping us to work towards improving access to transplantation. In addition, we thank all members and supporters of the NIKTT. This supplement, outlining the work of the NIKTT, would not be possible without their dedication, expertise, and sustained commitment to transplantation equity.

Open access: Open access publishing facilitated by The University of Adelaide, as part of the Wiley – The University of Adelaide agreement via the Council of Australian University Librarians.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

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Improving equity in access to kidney transplantation: implementing targeted models of care focused on improving timely access to waitlisting

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doi: 10.5694/mja2.52099

Kidney transplantation provides better quality and quantity of life for people with kidney failure.[1] However, of the 14% of all prevalent dialysis patients who identify as Aboriginal and Torres Strait Islander within the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, only 2% were waitlisted in 2021, compared with 8% of non-Indigenous patients who were waitlisted.[2] Equitably addressing this waitlisting gap was a significant priority of the National Indigenous Kidney Transplant Taskforce (NIKTT).[3] Many barriers impede Aboriginal and Torres Strait Islander people who live with dialysis from accessing waitlisting, including slow or delayed assessments and referrals, cultural bias, misinformation, and the difficulties of distance (Box).[4-9]

The Commonwealth Department of Health and Aged Care awarded $1.3 million to the NIKTT to enable competitive project sponsorships for health care providers to develop models of care that promoted waitlisting attainment. All funded projects extended previously successful models of care to address context-specific barriers to waitlisting and transplantation.

These sponsorship projects were pilots of local care delivery that aimed to overcome context-specific barriers to kidney transplantation waitlisting. A more detailed evaluation of each of these projects will be available in the NIKTT's final report.[10] Here, we provide a commentary on elements of each project that acted as enablers or challenges, to better understand what could be scaled or used to improve services in the future. We outline the strategies used to overcome barriers, what was learned from the projects, and the implications for further practice change.

Outreach assessment clinics

A substantial barrier to waitlisting in Western Australia is the travel burden required to attend workup appointments, as transplantation assessments typically occur in Perth. Sponsorship was provided for two projects to initiate outreach assessment clinics — found to be culturally sensitive models of care[11-12] that increase equity of service delivery[13-14] — into regional WA.

Led by clinicians at Royal Perth Hospital and Sir Charles Gairdner Hospital and at Fiona Stanley Hospital, these projects were designed to increase the identification, assessment and waitlisting of suitable patients. Multidisciplinary teams, including transplant surgeons, nephrologists, transplant coordinators and renal nurses, attended eight to 15 days of clinics across three to five outreach visits. Alongside these outreach clinics, projects ran transplant education sessions for patients, communities, and health staff.

Outreach assessment clinics led to increased numbers of patients activated and transplanted. Outreach clinics increased the number of patients commencing workup, the number of patients waitlisted (while decreasing the time to listing), and the number successfully transplanted (Supporting Information). Communities found the education sessions empowering, with groups in East and West Kimberley now working to form Indigenous Reference Groups.[15]

Key enablers of these outreach clinics included: (i) a full-time transplant coordinator role, based locally or in Perth, who aided patient and clinic management; (ii) working closely with local Aboriginal medical services; (iii) patient, community and staff education sessions; and (iv) creating transplantation champions,

Barriers to kidney transplantation for Aboriginal and Torres Strait Islander peoples in Australia[5]

Sociocultural	• Communication divides between patients and clinical staff • Institutional racism experienced throughout the health care system, including a lack of understanding about the cultural elements of decision making, family commitments, and community obligations • Culturally inappropriate educational materials • Limited availability of appropriate interpreters • Misinformed or culturally unaware health professionals
Geographic	• Living in rural and remote communities not regularly serviced by transplant assessment teams • Living in communities where access to dialysis facilities is poor • The need to travel large distances to tertiary hospitals for follow-up appointments • Numerous trips off Country to attend workup tests • Logistic and time-consuming problems that arise from having to complete multiple trips to urban areas, including arranging transport, accommodation and bookings
Biomedical	• A high burden of comorbidities such as diabetes, smoking and alcohol-related illnesses, high body mass index, and cerebrovascular and cardiovascular diseases • Frailty • Persistent infection and malignancy

both patients and staff, who understood regional barriers to transplantation and could motivate others. Key challenges, outside of coronavirus disease 2019 (COVID-19) travel restrictions, involved the sustained funding of the outreach visits and transplant coordinator roles, as well as regional workforce vacancies.

Patient navigators

Institutional racism, and its impact on how cultural differences (including language, communication and protocols) influence service delivery, inhibits access to transplantation care.[5-6,9] Funding was granted to groups in the Northern Territory, South Australia and Queensland to assist in the employment of patient navigators (or mentors; PNs) — roles that have been found to improve waitlisting through bridging cultural differences and providing otherwise unavailable support.[16-20]

PNs in this context are Aboriginal and/or Torres Strait Islander people with a lived experience of kidney failure and transplantation. PNs at Purple House (Panuku) in Alice Springs, Port Augusta Hospital Renal Unit, and Cairns and Hinterland Hospital and Health Service were employed to help patients by advocating for their needs, translating health knowledge, and providing culturally safe support.

The projects found that PNs helped to increase the number of patients being assessed for eligibility, commencing workup, and being activated on the waitlist (Supporting Information). Navigators were able to develop a level of trust, understanding, effective two-way communication, and enhanced informed decision making that was previously unseen in these contexts, because of their unique position as brokers of culturally appropriate knowledge and practice alongside lived clinical experience.

PNs enabled better access to the waitlist through: (i) identifying and helping more patients undergo assessment; (ii) increasing awareness of transplantation through their presence in renal units and communities; (iii) providing culturally safe support through knowledge and guidance; and (iv) developing more suitable educational materials with renal teams based on patient feedback.

Challenges included integrating PN roles into the health system, sustainable funding, and the potential for navigators to burn out without established support mechanisms. A key takeaway from the projects was the concept of the "invisible work" undertaken by PNs — such as late-night phone calls or talking to patients and doctors about others' issues when seeking care for themselves. This work is reflective of the holistic role that the navigators fulfil, but which cannot be easily translated into Western metrics. Further examination of this invisible work is ongoing.

Educational resources

A significant barrier to waitlisting involves the pervasive poor communication from health systems to patients, leading to missed opportunities and culturally unsafe care.[6,8-9,21,22] The projects proposed the development of educational sessions and resources to educate patients and care providers on transplantation in local settings.

Projects in the NT (Top End Health Service), WA (Royal Perth Hospital and Sir Charles Gairdner Hospital, Fiona Stanley Hospital), SA (Port Augusta Hospital Renal Unit and Pika Wiya Health Service Aboriginal Corporation), and Queensland (Princess Alexandra Hospital) developed patient and staff education sessions to improve understanding of waitlisting and transplantation. Educational sessions included topics such as workup process, remaining on the waitlist, medications, and post-transplant care.

Educational resources were tailored to local contexts by using place-specific pictures and terms, translating documents into local languages, and consulting communities about the materials produced. Providing local, culturally relevant education to potential transplant patients led to better understanding of the complicated workup and transplant process, creating the opportunity for more patients to engage with workup while enhancing understanding of local processes. Education for health staff improved cultural awareness and understanding of local barriers (Supporting Information).

A crucial element of both printed resources and in-person educational sessions was that patients and communities participated in the development of shared content. The educational sessions especially benefitted from this structure, as they were able to adapt to changing circumstances (such as COVID-19). Another important aspect of the educational sessions was that many were held on Country. By hosting sessions on the patients' traditional lands, the projects promoted cultural safety for communities and also improved the cultural awareness and understanding of the visiting clinicians.

Areas for development

Recruiting, hiring and retaining Aboriginal and/or Torres Strait Islander staff proved challenging from both a workforce and institutional perspective.[23-25] Two projects experienced workforce difficulties and did not achieve their outcomes. For one project, limitations on team members' time and the inability to recruit suitable candidates meant the intended implementation of the project was not realised. For another project, significant staff turnover rendered assessment of activities impossible. In other circumstances, Aboriginal and Torres Strait Islander staff were employed but faced challenges within institutions, whether around their role, receiving renumeration, or encountering racism. It is critical that renal services — and the Australian health system generally — learn from these projects. Further development of Aboriginal and Torres Strait Islander roles and how they work with, and are supported by, health systems is essential.[26]

Most projects also suffered from workforce time pressures, with some finding assessment and reporting burdensome in addition to normal work.

This is a common issue to all project-based work in the health care system, where administrative support is often lacking.[27-29] As further models are implemented, developing support teams around the delivery and evaluation of care would be beneficial.

NIKTT projects found that local management and local answers to complex difficulties were vital to maintain transplant accessibility and project growth.[30] A common element to all projects was delivery of the intervention closer to home, especially in regional areas. It is a priority, therefore, that we continue to develop and resource regional centres that can consistently deliver local innovations.[31]

Conclusion

Achieving equity in kidney transplantation is a complex problem that continues to require distinctive solutions across multiple levels of service delivery. Providing workup assessments on Country, employing Aboriginal and Torres Strait Islander people as PNs, and investing in the transplant workforce are key enablers to improving waitlisting, as is the development of culturally and locally relevant education. The sustained resourcing of such models of care, alongside workforce support and integration, could substantially change disparities in waitlisting Australia-wide.

Acknowledgements: We acknowledge and thank the Aboriginal and Torres Strait Islander people living with kidney disease and transplantation, and their families, carers and communities, who have worked with us throughout these projects, and the project leads for their dedicated work and commitment to bettering transplantation access and outcomes. We also thank the members of the NIKTT working groups, and all members of the Taskforce, for their contributions to this work and transplantation equity. We acknowledge and thank the Australian Government, represented by the Department of Health and Aged Care, for their funding of the National Indigenous Kidney Transplantation Taskforce (NIKTT) through an Indigenous Australians' Health Programme grant. This funding supported the salaries of three of the authors (Katie Cundale, Matilda D'Antoine and Kelli Owen) and covered the publication fees of the *MJA* supplement that includes this article. Jacquelyne Hughes was supported by a National Health and Medical Research Council Fellowship 1174758.

Open access: Open access publishing facilitated by The University of Adelaide, as part of the Wiley – The University of Adelaide agreement via the Council of Australian University Librarians.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

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Supporting Information

Additional Supporting Information is included with the online version of this article.

Cultural bias in kidney care and transplantation: review and recommendations to improve kidney care for Aboriginal and Torres Strait Islander people

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doi: 10.5694/mja2.52110

Inequities persist for Aboriginal and Torres Strait Islander people accessing health services in Australia, as evidenced by kidney health outcomes and the consistently lower rate of access to kidney transplantation experienced by Aboriginal and Torres Strait Islander people.[1] The Australian Government has endeavoured to address this persisting inequity in access to kidney transplantation by establishing the National Indigenous Kidney Transplantation Taskforce (NIKTT), and tasking them to evaluate cultural bias interventions in Australia, with a focus on kidney services. The NIKTT's objective was to develop recommendations for best practice care and support that would enable health services to provide more culturally safe care for Aboriginal and Torres Strait Islander people. In this article, we highlight the main findings and recommendations from the *Cultural bias Indigenous kidney care and kidney transplantation report*.[2] We reflect on the resulting recommendations and highlight key elements that the NIKTT anticipates could substantially improve the cultural safety of kidney care for Aboriginal and Torres Strait Islander people across Australia.

Background to the report

Racism continues to act as a barrier to accessing and receiving appropriate health care for Aboriginal and Torres Strait Islander people in Australia.[3-6] Consumers accessing kidney services have continually stressed the importance of improving the cultural safety of care.[7-10] The Australian Health Practitioner Regulatory Authority released its cultural safety definition and strategy in 2022, defining culturally safe practice as the "ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism".[11] For the purposes of this work, cultural bias is therefore defined as any mechanism, action or inaction — from health professionals, organisations and systems – that contributes to disparate treatment, treatment outcomes, or an unsafe experience of health care for Aboriginal and Torres Strait Islander people.

To identify and evaluate what works best in addressing cultural bias in Australia, an NIKTT cultural bias working group was established. This group defined the scope and parameters of the review and evaluation, and approved the final recommendations. Based on advice from this working group, the NIKTT commissioned the Lowitja Institute, a renowned Aboriginal Community Controlled Research Organisation, to undertake the review in recognition of the need for it to be guided by Aboriginal and/or Torres Strait Islander researchers and include perspectives outside of nephrology.

The objective of the review was to understand which interventions have been utilised to address cultural bias in Australian kidney care settings. Early literature searches identified severely limited available publications. The working group and review authors therefore co-designed a three-part approach that included: an assessment of initiatives that had been formally evaluated across kidney health and wider health care settings, which were published in the peer-reviewed literature; a review of kidney health-specific grey literature; and the inclusion of perspectives of Aboriginal and Torres Strait patients and kidney health care professionals through national consultations being undertaken by the NIKTT at the same time.

The Cultural Bias Report was submitted to and approved by the Commonwealth Government in early 2022, and has since been disseminated and made public by the NIKTT.[2] This work, developed during 2019–2021, also informed the *Recommendations for culturally safe kidney care in First Nations Australians*.[12] The Cultural Bias Report, as well as a policy brief and translations of the recommendations into language more suitable for patients and communities, can be found on the NIKTT website.[13] Further details of the report planning process can also be found in the NIKTT final report.[14]

Report findings

The Cultural Bias Report identified that there were limited formally evaluated and published initiatives that specifically addressed cultural bias in kidney transplantation or dialysis settings. A range of evaluated initiatives were identified across other health care settings, and a number of small scale initiatives were identified within kidney care settings that were not published in peer-reviewed journals. The report authors grouped the evidence, and consequent recommendations, into four domains for action (Box 1). These domains provide a framework through which services, organisations, and governments could address cultural bias by ensuring culturally safe and equitable care is made available to Aboriginal and Torres Strait Islander people.

The first domain — Inclusion of Aboriginal and Torres Strait Islander people — identifies the necessity of privileging[15] the voices and experiences of Aboriginal and Torres Strait Islander people as fundamental to effective, culturally safe interventions. Evidence found that reference groups, peer navigators, and Aboriginal and Torres Strait Islander health professionals were

1 The Cultural Bias Report framework of four domains and their sub-domains[2]

Domain	Sub-domains
Inclusion of Aboriginal and Torres Strait Islander people	• Inclusion of family in care and decision making • Indigenous governance, community consultations, reference groups • Patient perspectives and feedback
Workforce	• Indigenous workforce • Knowledge and skills of all workforce • Two-way learning
Service delivery and models of care	• Advocacy • Case management, referral and follow-up • Collaboration • Communication, understanding, trust and transparency • Continuity of care and carer • Cultural safety and responsiveness • Flexibility • Health promotion, education, prevention • Responding to holistic health, wellbeing and socio-economic needs
Structures and policies	• Organisational governance, commitment, leadership and management • Policies, guidelines and standards • Physical environment • Resources and funding

safe channels through which patients could provide feedback, without fear of reprisal.

The second domain — Workforce — emphasises the need to focus on the roles, support, abilities and training of both the Aboriginal and Torres Strait Islander and the non-Indigenous workforce. Evidence in this domain found that successful initiatives valued the mastery of cultural skills, knowledge and relational networks of Aboriginal and Torres Strait Islander staff who are health professionals and bring a specific scope of practice through their specialised perspectives.

Domain three — Kidney health and kidney transplantation service delivery and models of care — highlights the importance of holistic continuity of care for clients and families to improve safety and outcomes. Addressing overall wellbeing and the specific socio-economic situation and needs of Aboriginal and Torres Strait Islander clients, particularly transport and accommodation, were seen as critical.

Domain four — Structures and policies — outlines the importance of institutional commitment and how national guidelines, policies and strategies are necessary to ensure that change is implemented, monitored, and followed through upon. Embedded evaluation, as well as continuous quality improvement through ongoing cycles of reflection and feedback from patients, were identified as important for improving service delivery and cultural safety.

The report's domains and recommendations are listed in Box 2, mapped against the relevant National Safety and Quality Health Service (NSQHS) Standard that each relates to and addresses.[16] Applying these recommendations to the NSQHS Standards illustrates how integrating the framework can create and monitor better and safer services.

Recommendations for applying culturally safe (and unbiased) practice in nephrology

The NIKTT convened a half-day Cultural Bias Workshop in late 2021 to discuss the review's findings, the report, and its implications. Consumers, carers and members of the taskforce were invited to attend in person or online. Over 25 attendees joined, including Aboriginal and Torres Strait Islander people who were kidney transplant patients and health professionals, as well as non-First Nations people who identified as transplantation coordinators, nephrologists, researchers, and other clinical and policy professionals. When reviewing the 14 recommendations listed within the report, the NIKTT and the workshop participants specifically recommended that five should be enacted immediately as essential steps towards effectively addressing cultural bias in kidney health settings. These actions are tangible, realistic steps that renal and transplantation units should implement to better ensure the cultural safety of services:

- Establish Indigenous Reference Groups in every transplantation unit.
- Support and increase the Aboriginal and Torres Strait Islander kidney health workforce.
- Establish and fund sustainable kidney patient navigator/peer support roles.
- Implement and evaluate comprehensive and ongoing cultural safety training programs.
- Fund, design, implement and evaluate tailored models of care.

Moving forward with culturally safe care

For clinicians and services, a comprehensive and standardised way to identify and track cultural safety, or the lack of cultural bias, is an essential step in progressing this work, but it needs well understood measurements. The report's four domains for action could be used by renal and transplant units to undertake an initial needs analysis of services, which could then be followed by specific resources to support the health unit and patient community to move towards equitable health care practice — as guided by specific recommendations. To best support kidney clinical services to apply this approach, the domains for action have been reframed in the form of sample questions that can be used by health services to prospectively evaluate the intent and commitment of delivered care. Box 3 provides an example of questions that have been informed by the work of the taskforce to provide unbiased care.

The dearth of published research focusing on cultural safety or cultural bias in kidney health settings illustrates a gap in prioritisation within both research and practice. Health care services that work with Aboriginal and Torres Strait Islander people with kidney failure need to promote implementation and reporting of programs and research that address cultural bias and institutional

2 Domains and recommendations from the Cultural Bias Report,[2] mapped to corresponding National Safety and Quality Health Service (NSQHS) Standards[16]

		NSQHS Standard			
Domain	**Recommendation**	**Clinical governance**	**Partnering with consumers**	**Comprehensive care**	**Communicating for safety**
Inclusion of Aboriginal and Torres Strait Islander people	Establish Indigenous Reference Groups in transplantation units across Australia to co-design culturally safe models of care and feedback mechanisms	✓	✓	✓	✓
	Increase the number of Aboriginal and Torres Strait Islander patients, families and health professionals on kidney health advisory boards and steering groups, especially in transplantation units	✓	✓		
Workforce	Increase and support Aboriginal and Torres Strait Islander people to work as clinicians, transplant coordinators, and case managers in kidney health	✓	✓	✓	✓
	Employ Aboriginal and Torres Strait Islander people with lived experience of kidney disease in patient navigator and peer-support roles, and ensure these are funded long term	✓	✓	✓	✓
	Deliver cultural safety training for all staff in transplantation and kidney health services	✓		✓	✓
Service delivery and models of care	Co-design new, holistic, culturally safe, and responsive models of kidney care and transplantation that actively involve patients and families in decision making; address inequalities and access issues; respect cultural priorities and obligations; and include traditional healers and a wider range of health professionals, healing, and support services	✓	✓	✓	✓
	Increase the use of telemedicine and videoconferencing, with Aboriginal health professional and interpreter support	✓	✓	✓	✓
	Improve access to, support of, and payment for interpreters	✓	✓		✓
	Involve Aboriginal and Torres Strait Islander people in co-developing new health promotion and health education resources and approaches to kidney transplantation	✓	✓		✓
Structures and policies	Review and update quality improvement and feedback processes, policies, protocols, and guidelines in transplant units and kidney health services	✓	✓		
	Use an institutional racism audit tool to assess levels of racism in transplantation units and kidney health services	✓		✓	
	Develop and implement new clinical guidelines for Aboriginal and Torres Strait Islander kidney care and transplantation, and evaluate how effective they are in increasing access to kidney transplantation	✓	✓	✓	✓
	Adequately fund the implementation and evaluation of cultural bias recommendations	✓	✓		
	Fund the National Indigenous Kidney Transplantation Taskforce to assess how each transplant unit scores in relation to cultural bias, and monitor improvements over time if/when recommendations are implemented	✓	✓		

racism. The creation of an archive of intervention outcomes that improve access to, and outcomes from, kidney transplantation would be an important advancement for patients.

The NIKTT believes that further studies must concentrate on research and initiatives that identify and demonstrate best practices to reduce cultural bias, so that government, service and stakeholder

3 Sample questions for applying the Cultural Bias Report[2] domains for action

Domain	Questions for service delivery
Inclusion of Aboriginal and Torres Strait Islander people	• Is there evidence of Aboriginal and Torres Strait Islander people being included in the governance, decision making, feedback loops, and leadership of clinical practice and health service delivery when services work with Aboriginal and Torres Strait Islander people? • How are services confirming that these representatives are full and effective in their contribution to culturally safe delivery of health care?
Workforce	• Are Aboriginal and Torres Strait Islander people represented throughout the health workforce? • What is the evidence of worker support to practice in a health care system free of racism? • How are they supported and resourced to provide adequate cultural safety for Aboriginal and Torres Strait Islander patients?
Service delivery and models of care	• Which indicators demonstrate service delivery has been specifically created, or modified from existing practices, to ensure cultural safety for Aboriginal and Torres Strait Islander people who are at work or are recipients of care? • What is the selection and review process and how is the service enabling implementation of recommendations? • What are the timeframe, review, complaints and resolution processes that alert the service to successful implementation or persisting issues?
Structures and policies	• Which structures, policies and processes are in place to ensure that auditing, accountability and responsibility are applied to providing culturally safe kidney care for Aboriginal and Torres Strait Islander people?

investment can systematically implement evidence-based recommendations and actions.

Consumer and community engagement, tailored models of care (including patient support roles), improved workforce access to cultural safety training, and an empowered kidney workforce are tangible actions that federal, state and local organisations can implement now. By affirming the recommendations and domains for action discussed here, bodies such as the Australian Health Practitioner Regulatory Authority and the Australian Commission on Safety and Quality in Health Care could drive practice change throughout both nephrology and other health fields by setting standards and exemplifying conduct against which equitable service delivery could be measured.

Acknowledgements: We acknowledge and thank the Aboriginal and Torres Strait Islander people living with kidney disease and transplantation who shared their invaluable thoughts and contributions to this work. We would also like to acknowledge the combined work and dedication of the cultural bias working group members, as well as all members of the National Indigenous Kidney Transplantation Taskforce (NIKTT). We acknowledge and thank the Australian Government, represented by the Department of Health and Aged Care, for their funding of the NIKTT through an Indigenous Australians' Health Programme grant. This funding supported the salaries of three of the authors (Katie Cundale, Matilda D'Antoine and Kelli Owen) and covered the publication fees of the *MJA* supplement that includes this article. Jacqui Hughes was supported by National Health and Medical Research Council Fellowship 1174758.

Open access: Open access publishing facilitated by The University of Adelaide, as part of the Wiley – The University of Adelaide agreement via the Council of Australian University Librarians.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

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From talk to action: Indigenous Reference Groups drive practice change in kidney transplantation care

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doi: 10.5694/mja2.52102

Consumer engagement is invaluable for informing, and thus supporting, improvements in the quality of health care delivery by services. Indeed, consumer engagement in health care has become an essential paradigm for Australian policy over the past 20 years, with one of the eight National Safety and Quality Health Service Standards focusing entirely on partnering with consumers.[1]

For Aboriginal and Torres Strait Islander peoples living with kidney disease, several consumer engagement activities were enabled by support from the National Indigenous Kidney Transplantation Taskforce (NIKTT) and other partners in recent years.[2-5] These consultations allowed communities around the country to provide feedback, opinions, and solutions to kidney care challenges.

Partnering with patients to overcome complex transplantation challenges is crucial and must be done with recognition and acknowledgement of the ways of knowing, being and doing that exist for Aboriginal and Torres Strait Islander peoples.[6] For Aboriginal and Torres Strait Islander peoples living with kidney disease and after transplantation, the health system must embed true partnership, engagement and, most importantly, real change from existing verbal feedback that is backed by evidence. Our health systems need to be empowered to embrace, accept and work with (and not against) Indigenous knowledges.[7-9]

The barriers that Aboriginal and Torres Strait Islander peoples face when contending with renal services are numerous, as discussed elsewhere in this supplement. The kidney transplant pathway has aptly been described by one Aboriginal patient as "fragmented, confusing, isolating, and burdensome".[10] In order to address some of these barriers, through authentic engagement with consumers, the NIKTT catalysed the establishment of Indigenous Reference Groups (IRGs) within transplantation units around Australia. Five transplantation units were initially selected to host these IRGs — these represented the hospitals that serve the largest proportion of Aboriginal and Torres Strait Islander peoples on kidney replacement therapy: the Royal Adelaide Hospital (RAH) in South Australia, Princess Alexandra Hospital in Queensland, Westmead Hospital and the Royal Prince Alfred Hospital in New South Wales, and Sir Charles Gairdner Hospital in Western Australia.

In this Perspective article, we describe the establishment of the RAH IRG to demonstrate how consumer engagement can deliver effective, culturally safe change.

Doing it right: establishing an effective Indigenous Reference Group in Adelaide

At the RAH, Aboriginal and Torres Strait Islander patients come from South Australia, the Northern Territory and western New South Wales to receive kidney transplantation care. This unit therefore provides care to people from many different Nations, each with their own languages, practices and ceremonies, and each with a distinct history of colonisation and health care experiences. These patients and their families travel enormous distances to receive care in a system that was created by, and predominantly for, an English-speaking, Western-orientated population. Although located on Kaurna Country, an out-of-the-way wall is the only welcome in Language that consumers coming to the RAH experience.

Due to the complexity of care for patients on kidney replacement therapies, especially those undertaking or having received a transplantation, a specific IRG was established to help patients' voices systematically report on barriers to care from within the hospital system. To best achieve this, the NIKTT first established a Consumer and Community Engagement (CCE) working group and a dedicated CCE officer role to guarantee consumers were not only consulted but, more importantly, were leading the process of improving access to transplantation. The RAH IRG originally consisted of 20 patients, but as members unfortunately died, membership was subsequently opened to carers and family members.

Seven key design elements (Box 1) for the IRG were developed throughout the establishment of the RAH group. Reflective practices[11] were used so that what worked, and what did not work, was continuously discussed and allowed to guide future meetings and partnership growth.

From the experience of establishing this reference group at the RAH, the CCE working group found that specific enablers paved the way for the IRG's successful engagement, integration and activism.

Creating a Blak space

Aboriginal and Torres Strait Islander voices were privileged by the creation of a safe, decolonised space through which the IRG could communicate with the clinical world. As no non-Aboriginal people attended the IRG meetings, the space was seen as a wholly "Blak space",[12] where only Aboriginal and/or Torres Strait Islander people were invited to participate, lead and govern meetings. The IRG was positioned as a catalyst to forming trusting relationships between the patients and the hospital staff, as two-way communication and

1 Essential design elements for the creation of a successful Indigenous Reference Group (IRG)

- Transplantation unit directors and heads of units were consulted before the establishment of the IRG and asked to clearly commit, in writing, to engaging with IRG suggestions on an ongoing basis. This was essential for engaging patients so they could trust that their voices would lead to meaningful change, rather than be sought, collated, and then ignored.
- The Consumer and Community Engagement (CCE) officer identified local clinical leaders and staff in the transplant unit that would be involved with the delivery of care and system change suggested by the IRG, to distinguish advocates and allies.
- The CCE officer used relational networks, clinical patient contacts, and community connections to identify potential IRG members.
- A "Blak space" was created wherein IRG meetings were only led by, and involved only, Aboriginal and Torres Strait Islander peoples. This space was deliberately set up to exist both physically and strategically within the transplantation hospital.
- Crucially, a terms of reference document was created that outlined the way in which the IRG worked together and in partnership with the hospital. The IRG then created a list of priorities that provided a positive framework for the unit specifically, and the hospital generally, to improve the cultural safety. These priorities were presented to the head of unit and the transplantation team in the form of a report and a specially commissioned message stick. Meeting minutes were made available to the transplantation team after each meeting.
- All IRG members were compensated for their time and the expertise that they shared.
- Finally, the IRG was brought together every three months using the considerations of time, deep listening, and reflection.

Aboriginal and Torres Strait Islander-led change were actively embraced at a local level.

Reflective practices were employed to ensure meetings were examined and improved upon, a practice that reflects Aboriginal ways of knowing, being and doing by valuing the acts of deep listening and reflection.[12] Questions such as "have the communities' needs been heard and met?", "what worked for us and what did not?", and "how can we do it better next time?" were asked after each IRG meeting. This reflection and real-time feedback allowed for each meeting to advance and develop based on feedback from within the Blak space.

Engaging clinicians

Clinical support and renal unit "buy-in" were instrumental in helping to gain traction within the hospital system, specifically formalised first through a letter of support from the head of unit and then through another letter committing to undertake change based on the IRG recommendations. The CCE officer and another member of the IRG formally presented these recommendations to the transplant management meeting in the form of a message stick and a written letter. Without the support of doctors, nurses, coordinators and administrators, the success of the IRG would have been limited: non-Aboriginal allies throughout the hospital system allowed for doors to be metaphorically opened and lines of communication begun. Box 2 illustrates this process for change and integration.

Leading from within

Aboriginal leads, and strong community connections, allowed for a resilient network to be built and maintained. Having Aboriginal kidney patients drive meeting times, agendas and outputs allowed for powerful momentum within the group to carry its message forward. In addition, having an Aboriginal person lead from within the renal unit was seen as vital to drive the project and maintain momentum.

Early outcomes from the Adelaide Indigenous Reference Group

Real practice change has occurred within the first year of the RAH IRG's existence, due to the strong relationships and trust built between IRG members and clinical staff. These changes include:

- Smoking (organ cleansing) Ceremonies are available on hospital grounds. In June 2022, the first kidney transplant Smoking Ceremony was held to pay respect to the organ donor and their family, while connecting the recipient and organ to the present. By facilitating such ceremonies, the RAH has enabled a holistic view of healing, delivering a more culturally sensitive system of care.[13]
- A new cultural safety training course is being developed by Aboriginal kidney patients.
- More Aboriginal health practitioners are being employed in the renal unit.
- Non-Aboriginal staff have expressed gratitude for the opportunity to better understand cultural protocols to facilitate culturally sensitive, and therefore safer, care.

A formal evaluation of this group, and the impact and outcomes it has on the transplantation and renal unit, has been recommended by the CCE and IRG members.

What could hold us back

Although the establishment of the RAH IRG has been successful and provided learnings for NIKTT, there are general challenges for establishing and sustaining IRGs.

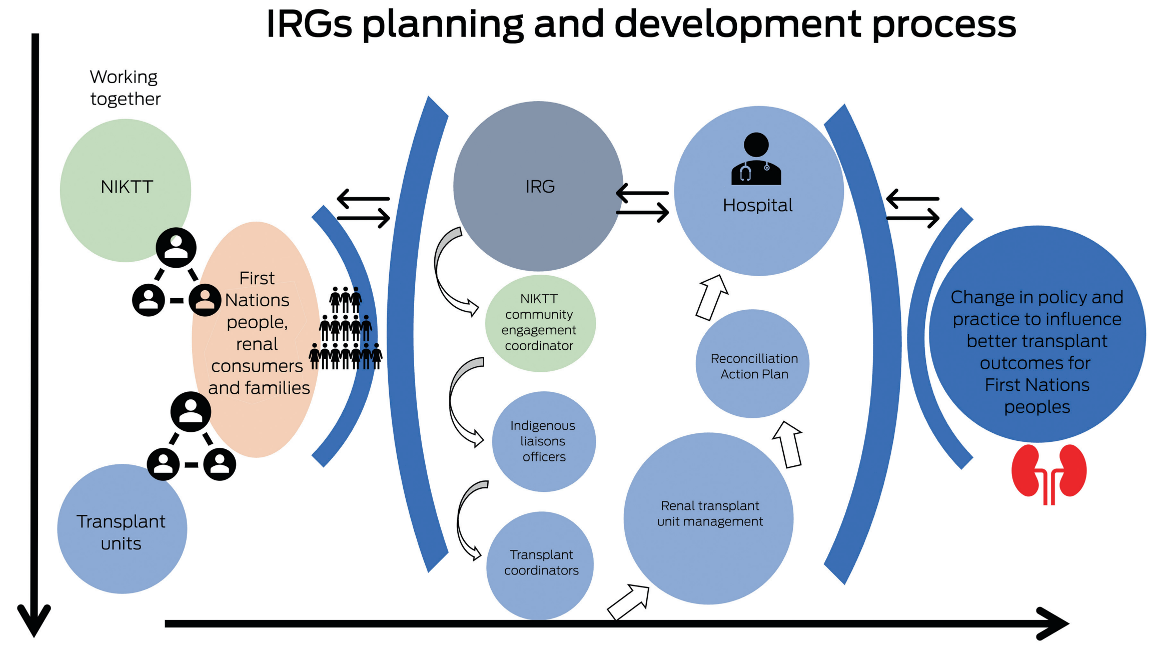
Funding

IRGs need financial support for both establishment and continued engagement. Costs are as low as $500 per meeting to cover sitting fees, catering and venue. Secured funding for the sustained support of IRGs is an easy obstacle to overcome once the benefits are considered. As units create new Aboriginal and/or Torres Strait Islander staff positions within kidney teams, more facilitators become available to ensure the cultural safety and continuity of each group.

Powerful partnerships

Although fundamentally enablers, trusting partnerships can also be obstacles if not continuously considered and acted upon. Aboriginal and Torres Strait Islander peoples have experienced innumerable broken promises over the hundreds of years of colonial

2 The design and process of the Royal Adelaide Hospital's Indigenous Reference Group (IRG)*



NIKTT = National Indigenous Kidney Transplantation Taskforce. * This workflow illustrates the ongoing flow of consultation and knowledge exchange allowed both for patients to feel more heard and for clinicians to gain a better understanding of cultural practices and protocols. ◆

subjugation. It therefore comes as no surprise that further broken promises or commitments unhonoured lead to frustration, mistrust and, ultimately, lack of engagement from Aboriginal patients.

Taking time

Finally, an important consideration for both the creation of and continued engagement with patient reference groups is time. It takes time to develop the trust and relationships that must occur for IRGs to be effective, and it takes time to implement the cultural considerations of deep listening and reflection. Follow-up is crucial to this process: anything raised in a meeting, reflected upon after a meeting, or brought up outside of a meeting by members or hospital staff must be recorded and revisited until everyone feels the issue has been managed. These ways of working take up dedicated physical and mental time — a notion that may be antithetical to some hospital processes.

Talking to take action

The benefits of establishing IRGs, from ensuring voices are heard to creating trusting relationships, far outweigh the challenges to implementation. Transplantation units around Australia must prioritise and ensure the sustainable funding of IRGs for them to become embedded within the system. While we continue to grapple with an inequitable health system, new models of care are needed that best serve disparate consumers. Establishing IRGs within hospitals is one important way to enact positive, meaningful and active consumer-led change.

Acknowledgements: Jaqui Hughes was supported by a National Health and Medical Research Council Fellowship (1174758). The Australian Government, represented by the Department of Health and Aged Care, funded the National Indigenous Kidney Transplantation Taskforce (NIKTT) through an Indigenous Australians' Health Programme grant. This funding supported the salaries of three of the authors (Kelli Owen, Katie Cundale, and Matilda D'Antoine) and covered the publication fees of this *MJA* supplement.

We thank the Aboriginal and Torres Strait Islander people living with kidney disease and transplantation who were involved in the establishment of Indigenous Reference Groups around Australia, as well as their families, carers and communities. We appreciate your dedication to change and your openness to sharing your experiences and visions for the future with us. We acknowledge and appreciate the work and dedication of the consumer engagement working group members, as well as all members of the NIKTT, who contributed to the development and implementation of this work.

Open access: Open access publishing facilitated by The University of Adelaide, as part of the Wiley – The University of Adelaide agreement via the Council of Australian University Librarians.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

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Towards equity in kidney transplantation: the next steps

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doi: 10.5694/mja2.52111

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.

Acknowledgements: We acknowledge and thank the Australian Government, represented by the Department of Health and Aged Care, which funded the National Indigenous Kidney Transplantation Taskforce (NIKTT) through an Indigenous Australians' Health Programme grant (IHD-208-4-BIA3J8Y). This funding supported the salaries of two of the authors (Kelli Owen and Katie Cundale) and covered the publication fees of this *MJA* supplement.

We thank the Aboriginal and Torres Strait Islander people living with kidney disease and transplantation who have worked with the NIKTT. We acknowledge that Aboriginal and Torres Strait Islander people in Australia face inequities in accessing transplantation due to the systemic barriers that exist within our health care system. We thank everyone for helping us to work towards improving access to transplantation.

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.

Open access: Open access publishing facilitated by The University of Adelaide, as part of the Wiley – The University of Adelaide agreement via the Council of Australian University Librarians.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

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This supplement was sponsored by

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