

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

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 care¹¹⁻¹² that increase equity of service delivery¹³⁻¹⁴ — 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 Australia⁵

Sociocultural	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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

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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 remuneration, 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.

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Supporting Information

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