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Supporting Information

Supplementary table

This appendix was part of the submitted manuscript and has been peer reviewed.
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Appendix to: Cundale K, McDonald SP, Irish A, et al. Improving equity in access to kidney transplantation: implementing targeted models of care focused on improving timely access to waitlisting. *Med J Aust* 2023; doi: 10.5694/mja2.52099.

Overall objectives, findings and recommendations from National Indigenous Kidney Transplantation Taskforce (NIKTT)-sponsored equity and access projects, 2020-2022

Project type	Project team	State/territory	Design and objectives	Activities and implementation	Quantitative findings	Qualitative findings	Recommendations
Outreach assessment clinic	Fiona Stanley Hospital	Western Australia	■ Employ a dedicated 0.4 FTE transplant coordinator for regional/Aboriginal patients ■ Deliver two outreach visits per region (Pilbara and Goldfields) utilising a nurse, surgeon, physician, pharmacist, and Aboriginal liaison officer. The visiting team, in conjunction with established local Aboriginal medical services, community health centres, hospitals and regional dialysis units, will identify, educate and assess patients suitable for renal transplantation and prioritise for further assessment to expedite transplant waitlisting	■ 8 full-day clinics held in Port Hedland, Karratha and Kalgoorlie across 5 outreach visits ■ Distance to Perth for these communities ranged from around 600 km to 1700 km ■ 4 patient and family education sessions held, 2 education workshops for health professionals held	■ Number of patients assessed: 28 ■ Number who commenced workup: 26 ■ Number of Aboriginal patients entering the transplant waitlist: 13 ■ Number of Aboriginal transplants performed: 12 ■ Average time from first NIKTT clinic to waitlisting: 7.2 months (3–15 months) ■ Average time from waitlisting to transplantation: 3 months (2 days to 12 months) ■ Number of education sessions and attendees: 6 education sessions	■ Having a dedicated transplant coordinator for regional areas is effective ■ Visiting regional teams conducting yarning — transplant education in a non-hospital setting, with family members attending, is effective ■ Patients who have received a successful transplant and visiting the dialysis units to encourage and motivate the patients is effective ■ Initial assessments done by the visiting multidisciplinary team and completing the final assessment in Perth, in one co-ordinated visit, is helpful for patients and lessens the time taken to workup ■ Overall, a dedicated transplant coordinator for regions and regular visits by multidisciplinary team working in conjunction with the regional teams expedites the transplant assessment process and reduces the time to waitlisting ■ Each region has its own unique challenges. Staff retention is an issue especially in the Pilbara. Since late 2021, a regional chronic kidney disease nurse position in the Pilbara has been vacant	■ A fully funded permanent transplant coordinator role, based in Perth, who works in closely with regional teams and visits regional centres regularly ■ Regularly funded multidisciplinary team visits to rural and remote regions to conduct patient discussions/education (formal and informal) as well as clinic reviews ■ Regional staff vacancies must be filled ■ Work must be undertaken in close partnership with local Aboriginal corporations and Aboriginal health services to provide culturally appropriate services

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Outreach assessment clinic	Royal Perth Hospital/Sir Charles Gairdner Hospital	Western Australia	■ Deliver 1-week outreach visits to the Kimberley utilising a transplant coordinator, Aboriginal liaison officer, transplant nephrologist, and transplant surgeon. The visiting team will undertake transplant assessments, commence workup testing of suitable patients, and provide transplant education ■ Increase the FTE of the existing Kimberley transplant coordinator from 0.5 FTE to 1.0 FTE ■ Conduct community forums to establish an Indigenous reference group ■ In collaboration with the Indigenous reference group, develop a comprehensive suite of culturally appropriate kidney transplant education materials and an education program for patients and health professionals involved in the care of renal patients utilising a train-the-trainer model	■ 3 week-long multidisciplinary renal transplant clinics conducted in East and West Kimberley (March, June, October 2021) ■ Distance to Perth from these communities ranged from around 2000 km to nearly 3000 km ■ 20 education sessions held across the 3 visits with patients and community ■ 5 education sessions held with regional satellite dialysis staff (6–10 staff per session) and 3 education sessions with regional hospital staff (3–15 staff per session)	■ Number of patients assessed: 71 ■ Number who commenced workup: 23 ■ Number entered onto waitlist: 10 ■ Number transplanted: 4	■ Allowed for the rapid assessment of patients suitable for workup and waitlisting ■ Provided an opportunity for the team to advise patients on how to progress with workup ■ Allowed for physical assessments of patients to be performed for transplant suitability ■ Identified potential barriers to transplantation ■ Helped mitigate potential barriers by coordinating local and metropolitan team efforts ■ During the project, the existing transplant coordinator role, employed through Kimberley Renal Services, was increased from 0.5 FTE to 1.0 FTE. Because of this increase in time dedicated to the portfolio, pathways were able to be streamlined and visits were much better coordinated ■ The project additionally aimed to generate clinical champions among local nurses, Aboriginal health care workers, and allied health staff	■ Inequalities and complexities of remote and regional health care specifically to Aboriginal patients should be micro-discussed by transplant teams. This gives all participants and caregivers insights into factors affecting including cultural bias, resource and facility inequity, and their implications for health care, and has assisted in generating champions who will be able to educate others to leave a positive impact ■ The involvement of local Aboriginal patients, caregivers and volunteers is an invaluable resource to keep moving forward and this must be addressed as a priority. Providing health care with cultural appropriateness must be an aim, and facilitating this would require training and recruitment to form local Aboriginal teams of medical, nursing, allied, and social health workers ■ Resources should be provided to employ a full-time trained transplant coordinator and visits by the appropriate transplant outreach team at regular intervals to overcome the barriers of remoteness

Patient navigator	Purple House (Panuku)	Northern Territory	▪ Identify and employ four patient mentors with connections to Lajamanu, Kalkarindji, Yirrkala or Groote Eylandt to “walk alongside” and provide support to kidney transplant candidates from targeted communities. The patient mentors will assist kidney transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling patients to efficiently complete pre-transplant workup and assessment requirements. The hunting transplant team will adhere to the workup schedule and recommendations specified by the primary nephrologist and transplant unit staff ▪ Employ a renal transplant coordinator (0.6 FTE) to oversee the management of the hunting transplant team and provide support to the patient mentors ▪ Collaborate with key stakeholders, including transplant staff at Royal Adelaide Hospital, the Renal Advocacy Advisory Committee, and the Central Australian Renal Voice to establish a kidney transplant support network and facilitate further opportunities for	▪ The program was modelled on the framework of hunting. Hunting involves acknowledgement that a particular process must be undertaken and that certain things are required to achieve success. Elements of a successful hunt include: ‣ Knowledge about the target and its environment: understanding how to navigate health services and pre/post-transplant care; mentors to provide targeted education and support that complements and enhances mainstream service delivery ‣ Planning the process: determining how the target will be captured (undertaking workup and maintaining transplant fitness and motivation); mentors assist with motivational support and assistance to meet workup requirements ‣ Determining resources: transport and tools, including support, transport to appointments (plus a companion when required), maintaining good communication lines with mainstream transplant coordination team ‣ Follow through: maintaining commitment in the pre/post-transplant phase ‣ Outcome: hit the mark or miss, retry, or target an alternative hunt ▪ The role and activities of the mentors have been central to the hunting transplant project	▪ 109 patients assessed/mentored ▪ 12% of all patients transplanted ▪ Active workup increased from 14% to 16% of patient population seen by Panuku ▪ People interested in transplantation increased from 3% to 19% ▪ Not assessed reduced from 32% to 0	▪ Access to NT government mainstream health service clinical information is an ongoing challenge as it creates a data gap for the performance metrics identified in the scholarship application ▪ The team’s commitment to working within an Indigenous designed evaluation framework is a work in progress ▪ The mentors’ wellbeing and physical health is always a priority and at times will naturally have an impact on their work commitments. The group is committed to collaborative decision making and consequently, when important decisions are required, they will wait until everyone is able to participate in the process	▪ Embed mentor roles in renal services ▪ Ensure there is formal acknowledgement of the mentor role ▪ Recruit more mentors to balance gender, age, and community representation

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			education and information sharing ■ Partner with the Menzies School of Health Research and the NIKTT Patient Mentor Working Group to develop a culturally appropriate evaluation framework that will assess the efficacy of the original patient mentor program and the new hunting transplant team from both community and health care provider perspectives	and focused on: introducing patients to the transplant system and clinical team; building confidence and trust in the process; sharing information; providing emotional support; empowering patients with knowledge; and connecting patients with relevant services before and after transplant			

Patient navigator	Port Augusta Hospital Renal Unit	South Australia	■ Identify and employ four patient navigators to “walk alongside” and provide support to kidney transplant candidates in Port Augusta and surrounding communities. The patient navigators assist kidney transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling more patients to commence the kidney transplant assessment and workup process ■ Oversee the management of the patient navigator project, including development of education programs and provision of training and support to the navigators, by committing time of a Transplant Coordinator – Level 2 Associate Nurse Unit Manager (0.4 FTE) ■ Deliver fortnightly information sessions, in partnership with Pika Wiya Health Service Aboriginal Corporation, covering issues such as: healthy behaviours (quitting smoking, good diet, active lifestyle), self-management (cooking classes, medication management), pre-transplant requirements and the journey to kidney transplantation, organ	■ 3 patient navigators recruited, who all commenced in February 2021: 2 navigators based in Port Augusta, and 1 in Adelaide who attends meetings by linking up via an iPad. The Adelaide-based navigator was also able to attend appointments in person at the Royal Adelaide Hospital (RAH) with patients when available ■ Initially the patient navigators were asked to visit the unit regularly to become familiar with staff and patients, to build on the relationships with patients and be accessible for conversation. Patient navigators progressed to helping in meeting preparations, including inviting patients, setting up resources and room, arranging transport, and completion of the satisfaction surveys ■ To establish the role in Port Augusta, the transplant coordinator attended the RAH to meet the kidney transplant team. This helped to foster better communication between Adelaide and Port Augusta and an understanding of the roles. Education was also arranged by the RAH transplant team on kidney transplant workup process, transplant surgery, and post-transplant care. The visit also included a day in operating suite to observe live donor and recipient kidney transplant ■ A “My track to kidney transplant” booklet was created by the transplant coordinator, project manager and Pika Wiya Aboriginal health practitioner; it	■ Number of attendees at fortnightly information sessions (30 meetings held across 11 different topics): 32 patients attended an average of 5.3 topics each (range 1–11). The most attended topic was healthy eating (29/32), and the least attended was healthy habits (11/32) ■ Patients on active transplant list increased from 0 to 1 (all dates September 2020 to October 2021) ■ Number suitable for workup decreased from 23 to 12 ■ Number referred for workup increased from 0 to 11 ■ Number not for transplant decreased from 6 to 5 ■ Number removed from project: 3	■ Preliminary evaluations with patients about the patient navigator role showed it was a welcome addition to the team, and something clinicians in the area had heard patients requesting for many years to provide support, particularly at appointments and trips to Adelaide ■ Adding activities within the meetings that were of interest to the target group was a useful tool to engage patients. Painting and cooking and campfire days proved particularly popular and uplifted spirits in general in the dialysis unit ■ Being able to spend time with the patients in a relaxed non-clinical environment has helped the staff to understand how to engage on a different level to exchange information and education ■ The patient navigator role is still in development phase. The role has grown and as a result, demands have increased, and utilisation has expanded. As activity increases with more patients going through the workup process, so too will the activity of the patient navigator	■ Continued funding of the patient navigator role ■ Financial resources to target education and transplant workup services in country areas ■ The expansion of the patient navigator role to support the patient through the spectrum of chronic renal failure ■ Greater support for lifestyle transition post-transplant ■ Development and evaluation of educational material for spiritual cleansing of the transplant organs ■ Development and evaluation of a “transplant journey folder” in an electronic application for smartphones and iPads ■ Support and resources to evaluate the full project from a First Nations perspective ■ Support and resources for consumer groups lead by patient navigators ■ Support and resources to link consumers journey with clinicians via electronic devices ■ Recreational therapy for patients on dialysis to support social and emotional wellbeing and consumer networks

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			donation, and staying healthy post-transplant	included all meetings and workup tests in a visual format ■ Fortnightly meetings were held whereby culturally appropriate education was provided on topics such as transplant workup story, healthy eating/behaviours, quitting smoking, medication self-management, diabetes, advance care directives, and staying healthy after transplant			

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Patient navigator	Cairns and Hinterland Health Service	Queensland	■ Identify and employ 2 patient mentors (based in Cooktown and Thursday Island) to walk alongside and provide support to kidney transplant candidates in their community. The patient mentors will assist transplant candidates to overcome language, knowledge and cultural barriers posed by the mainstream health system, enabling patients to efficiently complete pre-transplant workup and assessment requirements ■ Oversee the management of the patient mentor project and provide support to the mentors by committing time of a renal transplant clinical nurse consultant (0.1 FTE) and Indigenous liaison officer (0.2 FTE). ■ Deliver education sessions in Cooktown and Thursday Island, utilising tailored resources (such as pamphlets/information sheets) ■ Undertake an audit of the dialysis population at Cairns Hospital to determine the barriers and delays in the pre-transplant workup process that prevent successful completion of transplant workup and assessment	■ Mentor meetings and education sessions were held throughout 2021 ■ 0.2 FTE Aboriginal and Torres Strait Islander liaison officer seconded to the project ■ 5 mentors were inducted through the Far North Queensland Health Foundation as volunteers ■ Mentor for Thursday Island identified in August 2021 and initial patient/mentor sessions were conducted at Cairns Hospital	■ Number of patients undergoing workup increased from 5 to 10 following intervention ■ Number of patients on waiting list remained stable at 4 ■ Number of patients not undergoing workup decreased from 14 to 1 ■ Number of patients transplanted increased from 0 to 2 ■ Number of face-to-face patient–mentor interactions: 84 ■ Number of patient–mentor phone interactions: 27	■ The project provided a culturally safe approach to patient education that was well received by patients and their families ■ The project identified that most pre-transplant patients wanted to know about post-transplant medications, what happens at the transplanting hospital, and what is required to get on the list ■ Increased collaboration with other sites (Port Augusta and Panuku) was important ■ Mentor visits to units created greater awareness of transplantation ■ The current pay structure at the organisation made it difficult to employ mentors ■ Fewer mentors were found; many Aboriginal and Torres Strait Islander transplant patients did not have time to give to the project due to current employment or family duties ■ COVID-19 significantly impacted mentors' ability to arrange group activities; 4 were organised but all were affected by lockdowns or restrictions on group meetings ■ Such a program needs a dedicated transplant nurse to work with mentors if project is to be upscaled ■ Ongoing funding is needed for mentors and support staff	■ Ongoing funding for Aboriginal and/or Torres Strait Islander mentors ■ Expansion of the mentor program for all units with a significant proportion of Aboriginal and/or Torres Strait Islander patients ■ The ability to pay for mentors through a Queensland Health pay classification system that recognises their expertise ■ Mentors must be involved across the continuum of kidney health including in primary health. Kidney stories can be impactful across generations ■ Establishment of mentor-led consumer groups at local dialysis unit level ■ An education package for mentors about dialysis and transplant options ■ Increased culturally appropriate education material for pre-transplant patients, especially on the journey to transplant, transplant medications, and what to expect after transplant. This would be best produced at a state level to reflect state-based processes

Workforce and education	Top End Health Service	Northern Territory	■ Recruit 2 Aboriginal and Torres Strait Islander health practitioners and/or Aboriginal liaison officers (1.0 FTE responsible for servicing the Darwin region and 0.6 FTE responsible for servicing the Katherine region) ■ Train the them to deliver transplant education and have them shadow transplant nurses to increase their knowledge of the transplant workup and assessment process ■ Support them to deliver transplant education, coordinate workup appointments, review education materials, and support Indigenous patients being referred to multidisciplinary health care teams, including Adelaide clinics	■ An Aboriginal liaison officer was employed full time from July 2021, with the remaining funding to support an Aboriginal and Torres Strait Islander health practitioner. The liaison officer was working in the renal home therapies service, so recruitment happened relatively quickly ■ Together, the health practitioner and liaison officer organised a NIKTT Indigenous patient reference group with 6 patients identified as members and 4 meetings organised between July and November 2021 ■ Following the resignation of the health practitioner, the liaison officer was the sole Indigenous Australian on the project and went on to lead the reference group meetings, organise a meeting with Panuku group members, and support the existing renal transplant nurses	■ 89 patients were assessed for transplant suitability ■ 34 commenced workup ■ 9 were no longer suitable for workup ■ 70 received targeted culturally appropriate transplant education ■ 12 out of 107 patients did not attend appointments from November 2020 to May 2021; 18 out of 26 missed appointments were dental. There were only 2 missed appointments from June to Dec 2021 (1 dental and 1 cardiac)	■ COVID-19 had a profound impact on the outcome of the sponsorship activities due to access to care and specialist services either not being allowed, not available, or limited	■ Recruitment of Aboriginal and Torres Strait Islander health practitioners into the transplant team workforce, as the skills, qualification and cultural expertise that they bring to the team is invaluable in bridging the cultural gap and gaining learnings/stories that Indigenous Australians may not share with health professionals from different cultures ■ Recruitment of an Aboriginal liaison officer into the transplant team workforce, as the skills and qualifications this role brings has a different focus to that of the health practitioner and is more focused on everyday needs, the ability to access health care, and social needs aspects of care (eg, helping patients to obtain ID, documents required to obtain ID, dealing with Centrelink and Medicare, housing, and adjusting to living in town if new to kidney replacement therapy) ■ Recruitment of patient navigators/mentors into the transplant team workforce as this role provides support and lived experience of the transplant process and pathway to help make the journey a smoother and less stressful process while offering expert patient knowledge and guidance ■ Development of culturally appropriate educational resources with videos of patients telling their own stories in multiple languages ■ Education and training for health professionals on how to

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							deliver culturally appropriate education and how to interact and communicate with patients in a private consultation to overcome cultural barriers ■ Alternative ability to assess patients for transplant suitability when specialists are unable to visit remote sites, to avoid creating a further barrier to accessing transplantation. For example, telehealth consultation, with primary nephrologist referring the patient and transplant nephrologist and transplant surgeon giving guidance on any physical assessment required. If a surgeon is required to provide physical assessment, then liaison with the referring hospital surgical team to see if a joint surgical consultation can be undertaken which would meet the criteria for assessment

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Workforce and education	Princess Alexandra Hospital	Queensland	■ Deliver outreach education on kidney transplantation to regional and remote centres more than 250 km from Brisbane. Education seminars tailored to address the needs of the target community, harnessing local knowledge ■ Develop culturally appropriate resources for dissemination at outreach education sessions ■ Deliver face-to-face yarning circles, improving rapport between Aboriginal and Torres Strait Islander communities and the Princess Alexandra transplant team. This will also facilitate the sharing of cultures, constituting a two-way learning experience	■ Yarning session, Townsville, 2 November 2020 ■ Yarning session, Mount Isa, 3 November 2020 ■ Yarning session, Cherbourg, 14–15 June 2021 ■ Yarning session, Toowoomba, 16 June 2021 ■ Yarning session, Woorabinda, 28–29 June 2021	■ Number of education sessions: 7 ■ Number of visits: 6 ■ Number of patients commencing workup: 9 ■ Number of patients activated on the waiting list: 4 ■ Number of patients transplanted: 2	■ The project helped to strengthen life experience through “living in the shoes” of others ■ Project found that it is important to have an understanding of where people come from physically, mentally, spiritually and culturally ■ Sharing of life experiences builds rapport, trust and integrity between patients and clinicians ■ Utilising Indigenous staff and letting them have freedom to apply their cultural skills is crucial	■ An initial pre-assessment is needed before conducting educational sessions on Country — making contact initially, and then going onto Country, meeting the appropriate stakeholders, sharing the concept, and gaining permission to enter Country to deliver culturally appropriate care ■ Co-design education with Aboriginal and Torres Strait people as cultural resources, appropriate to that specific part of Australia ■ Indigenous clinicians must lead the programs ■ Deliver education on Country, and keep it personable, simple and relatable

FTE = full-time equivalent.