

NIKTT Final Report

Background

The Kimberley region of Western Australia (WA) with an estimated population of around 34,364 (2016 census) is more than 2000 kilometres from Perth. Aboriginal Australians are estimated to make up a third of the population with over 100 Aboriginal communities spread across its land mass of over 400,000 square kilometres.

Kidney transplantation is the treatment of choice for patients with kidney failure. In addition to improvements in life expectancy, quality of life and productivity, it has been shown to be more cost-effective than dialysis treatment. There is inequity in access to kidney transplantation for Indigenous Australians with kidney transplantation occurring in only 14% of with kidney failure compared with 50% amongst non-Indigenous patients [ANZDATA registry 2020]. There is also imbalance in deceased donor waitlisting with only 5.3% of Indigenous Australians active on the transplant waitlist despite representing 12% of all prevalent patients with kidney failure. Transplant outcomes in West Australian Aboriginal patients is poorer with a registry study showing significantly higher rates of biopsy proven acute rejection, especially antibody-mediated rejection and higher risk of death with a functioning graft compared with non-Aboriginal kidney transplant recipients. [Howson et al].

At the end of 2019, the Royal Perth Hospital Renal Service provided tertiary service for around 570 patients with stage 3-5 chronic kidney disease (CKD) with a further 170 patients on kidney replacement therapy (both haemodialysis and peritoneal dialysis). Since 2016, the Sir Charles Gairdner Hospital Transplant Team has established a collaborative and robust partnership with the RPH Renal Service to provide Kidney Transplant Services. By the end of 2019, of the Kimberley patients on dialysis, only 4 patients were active on the transplant waitlist.

There are a multitude of patient-related, institutional, health provider and socio-economic barriers to access to kidney transplantation and poor outcomes in Indigenous Australians which have been identified and highlighted in the report by the Transplant Society of Australia and New Zealand Report titled Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia.

The Royal Perth Hospital (RPH), in collaboration with the Kimberley Aboriginal Medical Service (KAMS) and Sir Charles Gairdner Hospital (SCGH) are privileged to be recipients of the National Indigenous Kidney Transplantation Taskforce Equity and Access Sponsorship Program. To address some of the inequities to access to kidney transplantation and improve outcomes for Aboriginal Australians with kidney disease in the Kimberley region, this project aimed:

Activities that were undertaken aimed at and to

1. Facilitate and deliver outreach clinics with transplant teams comprising of physicians, surgeon, transplant coordinators and Aboriginal Liaison workers /AHCC).
2. Support to increase the existing KRS transplant coordinator FTE.
3. Conduct community forums to establish an IRG.
4. Develop Culturally appropriate education materials and education program for patients and Health Professionals --- Train the Trainer Model.

Project Outcomes:

1. Multi-disciplinary Transplant Outreach Clinic

Prior to the initiative the transplant workup process did not have outreach assessment by the transplant team needing the patient to travel into metro areas after completing the work up with considerable impact on processing times.

Considering COVID-19 and border restrictions, three, week-long multi-disciplinary renal transplant clinics were conducted in the West and East Kimberley (March, June and October 2021). The team comprised of the visiting transplant physician, transplant surgeon and transplant nurses along with the usual visiting renal physician, local renal GPs and local transplant co-ordinator. Ms Kelli Owen, the National Community Engagement Coordinator for NIKTT also attended the visits in June (East Kimberley) and October (West Kimberley).

The Outreach clinics allowed for rapid assessment of patients suitable for work-up or waitlisting, provided an opportunity to advice on how to progress with work-up, perform physical assessment of patients for transplant suitability, identify potential barriers to transplantation and liaise with the local medical and nursing teams to help mitigate the barriers.

A total of 71 assessments were conducted during the three visits with some patients seen for reassessment, on the second visit to the West Kimberley. Of these, 23 patients were deemed to be suitable to commence work-up, while several other patients were noted to have modifiable barriers to commencing work-up. During the program, 10 patients were activated on the deceased donor transplant waitlist. During the project, 4 more patients from the region received a kidney transplant (see table below).

	Pre NIKTT project	NIKTT (Allowed complete existing review assessments)
Transplant assessments	10	71
Commence workup testing of suitable patients		23
Active on Transplant Waitlist	4	11
Patients transplanted	3	5

2. Support to increase Transplant coordinator FTE and generate Clinical Champions amongst local Nurses, Aboriginal Health Care Workers, and allied Health staff

We were able to support the Transplant coordinator role in part which was invaluable in terms of FTE available to dedicate to the portfolio . This led to streamlining of existing pathways and assist in coordination of visits.

We were able to demonstrate the importance and impact of involving Aboriginal Health Care workers (AHCC) in the process of first learning and then guiding the patients and their caregivers in the journey of assessment pathways.

Similarly, we noticed an increased level of participation from the Nursing and allied health professionals

3. Establishing a Kimberley Renal Indigenous Reference Group

This activity is ongoing and achieved momentum as the project activities progressed as there was team bonding amongst all stakeholders. The role of Ms Kelli Owen was invaluable in conceptualising and shaping the program.

The project allowed to identify 16 participants from the East Kimberley and another 23 from the west Kimberley who were keen to be part of the two Kimberley IRGs. Further plans for a face-to-face state-wide IRG meeting to occur in the first half of 2022 in close collaboration with the SCGH & RPH Aboriginal liaison team in partnership with the Derbarl Yerrigan Health Service.



4. Development of culturally appropriate kidney transplant education materials

For patients

The following kidney transplant education modules were developed for kidney patients in the Kimberley region:

- a) How do kidneys work and what happened when they fail?
- b) What is Kidney Transplantation?
- c) Journey towards getting a New Kidney: what patients need to know
- d) Long term care after kidney transplantation: what patients need to know

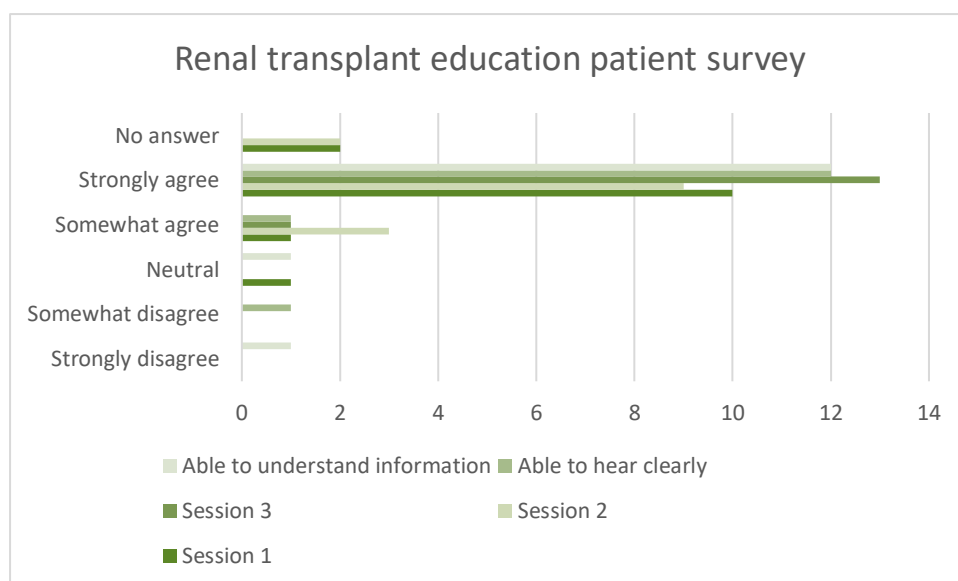
To ensure that these were culturally appropriate, we consulted reviewed education materials and consulted the team from the Menzies Institute, Northern Territory. Small group education sessions were conducted during the visit and involved the renal transplant nurses, local transplant coordinators and renal GPs (we had ~20 sessions across the three visits). One-on-one yarning sessions with the patients and renal transplant nursing staff gave patients an opportunity to ask questions and provide feedback on education sessions and the transplant work-up process. Attendees were encouraged to complete a patient satisfaction survey of the transplant educational material. Further refinements to the materials were made during the small group education sessions and informal yarning circles held in the East and West Kimberley Transplant Outreach Clinics. For example, patients were keen to know about the surgical procedure, length of stay in hospital, pain management, etc., and these were then incorporated into the educational materials.

Aboriginal kidney transplant recipients were also invited to attend the patient education sessions. They were very keen to participate and shared their transplant journey and experiences with the rest of the group as part of the education sessions. Patients were very perceptive to this and expressed their satisfaction at getting to hear a firsthand story of the transplant process from a local Aboriginal transplant recipient.

We have enlisted the assistance of the East Metropolitan Audio-visual departments and North Metropolitan Public Relations department to assist with creating flipbooks other materials which patients can access and utilise in their communities. This was one of the suggestions received from the patients in the region, during the small group teaching sessions.

We have commissioned a local interpreter to translate the key education materials to Kriol language.

Patient satisfaction survey: 14 patients completed the survey during the second visit to the West Kimberley region.



For health professionals

The following kidney transplant education modules were developed for health professionals:

- a) What is kidney transplantation? For health professionals
- b) Journey towards a new kidney: what health professionals need to know
- c) Caring for the Kidney Transplant Recipient: what health professionals need to know

To ensure that these were culturally appropriate, we presented the initial draft of the education slides to the SCGH Aboriginal liaison officers and Derbal Yerrigan Health Service and Kimberley Renal Services.

A total of 5 education sessions utilising the education slides were delivered for regional satellite dialysis unit staff (6-10 staff per session) and 3 education sessions were delivered to regional hospitals (3-15 staff per session) in the West and East Kimberley during the Multi-disciplinary Outreach Clinic visits where feedback was also sought.

Work is also underway in collaboration with the North Metropolitan Education eLearning Department to create an online module to increase the accessibility of these education material for a broader audience involved in the care of potential kidney transplant recipients.

Learnings and Recommendations

1. Inequalities and complexities of remote and regional healthcare specifically to Aboriginal patients were micro-discussed. This gave all participants and caregivers insights into factors affecting including cultural bias, resource and facility inequity and its implications of health care. This has assisted in generating champions who will be able to educate others on their learning to leave a positive impact.

2. 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 to facilitate this would need to train and recruit to form local Aboriginal teams of Medical, Nursing, allied and social Health

3. Providing resources to employ a full-time trained transplant coordinator and at visits by the appropriate transplant outreach team at regular interval to overcome the barriers of remoteness.