

TRACKS TO TRANSPLANT

Sponsored by National Indigenous Kidney Transplant Taskforce (NIKTT)

Cairns and Hinterland Hospital and Health Service (CHHHS) and Torres and Cape Hospital and Health Service (TCHHS)

FINAL REPORT JUNE 2022





ACKNOWLEDGMENT OF COUNTRY

“We acknowledge Aboriginal people and Torres Strait Islanders as this country’s First Nations people. We recognise First Nation people and communities as traditional and cultural custodians of the lands on which we work to provide safe and quality health services. We pay our respect to Elders past, present and emerging.”

BACKGROUND

In late 2019, the NIKTT announced that applications for equity and access sponsorship was available to provide funding for resources and projects that improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people. Examples of targeted projects included programs that deliver tailored social/emotional support to patients navigating the transplant system, such as patients mentors/buddies, establishment of community/patient/carer support groups.

Cairns and Hinterland Hospital and Health Service applied for sponsorship to initiate a patient mentoring program. The patient mentor project would identify Aboriginal and Torres Strait Islander patients who could mentor pre transplant Aboriginal and Torres Strait Islander patients towards transplant. The role of the patient mentor is to provide CKD patients and staff with a cultural conduit/expert to assist patients and families to navigate their renal journey to transplantation in a culturally safe and supported environment. The aim is to increase the number of Aboriginal and Torres Strait Islander patients being referred and receiving a transplant in a supportive manner. The anticipated start date for the project was 1 April 2020 and ending 1 April 2021. The amount applied for was \$87,940 to enable mentors to be paid for, catering at meetings and travel to the project sites of Cooktown and Thursday Island and the temporary recruitment of an Aboriginal and Torres Strait liaison officer at 0.2FTE to assist in the coordination of the project and funding to backfill the transplant CNC position 0.2 FTE.

The CHHHS project was sponsored \$118,734 (including GST)

PROJECT PARTNERSHIPS

To enable the project to commence, partnerships were established with the Torres and Cape Hospital and Health Service and the Far North Queensland Hospital Foundation.

PROJECT TIMELINE

- 14 Nov 2019 – Applications opened for NIKTT equity and access sponsorships
- 10 Jan 2020 – Application lodged with NIKTT
- 23 Jan 2020 – Notification of the outcome of the application
- 10 Feb 2020 – Sponsorship agreement signed
- 26 Mar 2020 – Notification to NIKTT (E Gerrard) that start date of project would be delayed due to COVID-19. Cape York/Torres Strait Island communities quarantined, hospital visitations not allowed, Transplant CNC focussing on supporting transplant patients during COVID-19 outbreak, transplant activity in Queensland (including transplant assessment clinic) ceased till 11 May 2020. Attempts continuing to establish legal employment contracts for mentors.
- 28 May 2020 – Email to NIKTT to move project sites from Thursday Island and Cooktown to Cairns and Atherton Tablelands due to lack of identified mentors in those areas available to participate in the project (due to employment)
- 6 Jun 2020 – Notification of extension of projects to the end of 2021 due to COVID interruptions
- 4 Jul 2020 – Biosecurity restrictions lifted for Cape York/Torres Strait area
- 9 Jul 2020 – Project lead (B Hayes) on sick leave for 1 month



- 18 Aug 2020 – Project lead (B Hayes) on extended emergent bereavement/family leave till 25 Jan 2021. Email sent from Dr Murty Mantha to Dr Stephen McDonald informing him of project leads extended leave
- 27 Jan 2021 – Project lead returns to work and catches up on transplant referrals not done for past six months
- 17 Feb 2021 – Meeting with Far North Queensland Hospital Foundation (FNQHF) asking for assistance in employing patient mentors as attempts to get mentors paid through Queensland Health had failed due to pay structures. They were going to discuss with their employment lawyer
- 14 Apr 2021 – Mentor meeting
- 3 May 2021 – Mentor meeting and education
- 18 May 2021 – Mentor meeting and education – Still waiting to hear from FNQHF regarding employment contract
- 1 Jun 2021 – Mentor meeting and education
- 7 Jun 2021 – 0.2 FTE Aboriginal and Torres Strait Islander Liaison officer seconded to the project. End date 31/4/22
- 22 June 2021 – Five mentors inducted through the FNQHF as volunteers – still trying to sort employment contracts
- 13 Jul 2021 – Project launch with BBQ on Esplanade – cancelled to due rise in COVID cases in Cairns area
- 17 Jul 2021 – Mentor for Thursday Island identified (recently returned to Cairns having had a transplant early 2021)
- 3 Aug 2021 – First patient/mentor sessions conducted at Cairns Private (Public) unit
- 8 Oct 2021 – Progress report submitted to NIKTT
- 30 Apr 2022 – Project finish
- 16 Jun 2022 – Poster presentation at Renal Society of Australasia conference in Darwin
- 20 Jun 2022 – Poster presentation at Transplant Society of Australia and New Zealand conference in Adelaide
- 27 Jun 2022 – Submission of final report

ESTABLISHING THE NAVIGATOR ROLE

Four Aboriginal and Torres Strait Islander transplant patients and one pre-transplant patient were invited to be patient mentors. Three were located in Cairns, one on the Atherton Tablelands and one on Thursday Island.

Thanks to the work previously completed by the Purple House in developing the patient mentor role and three of the patient mentors in Cairns having met with Purple House mentors at the NIKTT meeting in Alice Springs in 2019, the mentors had a good understanding of the mentor role. The mentors also had catch ups with the NT mentors via zoom during May and June of 2020.

Initially it was thought that the mentors could be paid via Queensland Health but after talking to HR there was no identifiable classification or employment contract that would suit the mentor role. The Far North Queensland Hospital Foundation came onboard mid 2021 initially thinking that they could employ them but it was in conflict with the purpose of the Foundation so mentors were remunerated through regular honorariums for the hours they volunteered to the project.

The mentors gave time as able rather than on a regular basis due to work and family commitments as well as COVID-19 fear or transmission. They did not want to be committed to fixed hours/week.



The mentors and transplant CNC met for regular meetings and educations sessions in May and June 2021. During the same time the mentors were inducted into the FNQHF and given guidelines on confidentiality and work place health and safety.

A project launch was planned for the 13 July 2021 but Cairns had new COVID-19 cases on the 12 July so the launch was cancelled. Restrictions on group meetings were heavily restricted in Queensland until February 2022. It was decided by the mentors to commence one-on-one mentor sessions in early August 2021.

The mentors were often accompanied by the project liaison officer and the transplant CN but discussions were held only between the patient and mentor with the transplant CN there to answer any difficult questions if they arose

PROJECT ARTWORK

One of the mentors created artwork for the project that was used for the mentors and transplant staff polo shirts



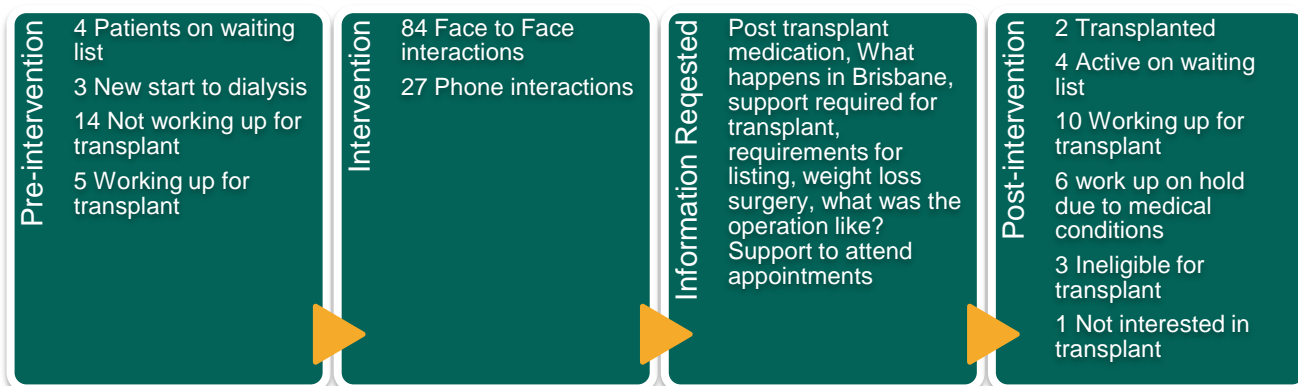
Project artwork by Glenis Hastie (Mentor)

The four outer circles represent the meeting places of Aboriginal and Torres Strait Islander people and where they have dialysis. The footprints on white represents the journey to dialysis and back. The inner circles with three lines represent the healing place, the transplant hospital. The footprints on black represent the journey from the community to the transplant hospital and back. The green represents new beginnings. The yellow represents happiness.



PROJECT PERFORMANCE METRICS

1. *Health literacy and knowledge of the transplant process*
 - a. *KPI 1: Improved health literacy scores post-intervention*
 - i. KPI not achieved due to limited time and COVID-19 restrictions on staff travelling between dialysis units
2. *Attendance at appointments*
 - a. *KPI 1: Improved attendance rates post-intervention*
 - i. Not measured due to closure of clinics during 2020-2022. Patients were seen by nephrologist in their dialysis unit. Attendance to work up appointment remained high with only three appointments being missed due to communication errors from the service providers
3. *Access to transplantation*
 - a. *KPI 1: Increased number of patients undergoing work-up post-intervention*
 - b. *KPI 2: Increased number of patients on the transplant waitlist post-intervention*
 - i. 26 patients were involved in the project. Outcomes are as followed:



4. Identification of the barriers to kidney transplantation in Far North Queensland

a. No KPI stated

i. Audit conducted 3 Jan 2022 – Raw data sent to Ross Francis 4 Jan 2022

CASE EXAMPLE

One pre-dialysis patient was connected to the mentors during a rural dialysis visit. Mary was a 52 year old Aboriginal lady who lived 30 minutes away from her nearest dialysis unit. It had been noted by renal unit staff that Mary had attended one clinic appointment and then failed to attend any more appointments that had been booked for her. The mentor team were going to visit the dialysis unit and Mary was invited to meet with them which she was keen to do. Under a tree, the mentor, liaison officer and patient sat and yarned about having a fistula formed, dialysis treatments and transplant. She was of the understanding that if she had a fistula formed she would have to start dialysis the next day and she wasn't ready for that and therefore had avoided coming to Cairns for appointments. She also said that the doctor used big words that she did not understand and was scared. Mary also identified travel issues getting to Cairns, 90 minutes away and was scared to stay in Cairns overnight. For the next two hours Mary and the mentor team yarned and answered Mary's questions leading to Mary successfully transitioning to dialysis and now being worked up for transplantation.

FINANCIAL

Two mentors did not want remuneration via an honorarium at their request. One mentor on the Atherton Tablelands had limited contact with pre-transplant patients because there were not many eligible for transplant in her area.

Credit	
From NIKTT	\$118,734.00
Debit	
QH staff remuneration	\$35,842.00
Mentor honorarium	\$2,905.00
Travel to Thursday Island	\$1,974.72
Catering	\$405.30
Artwork	\$681.71
Office supplies	\$3,113.98
Project polo shirts	\$1,050.00
Debit Total	\$45,972.71
Remaining Balance	\$72,761.29



SWOT ANALYSIS



RECOMMENDATIONS

1. Ongoing funding for Aboriginal and/or Torres Strait Islander mentors
2. Expansion of the mentor program for all units with significant proportion of Aboriginal and/or Torres Strait Islander patients
3. The ability to pay for mentors through Queensland Health pay classification system that recognises the expertise that expert patients have. There are existing positions in Queensland Health that do not require formal qualifications e.g. Liaison officers
4. That mentors be involved across the continuum of CKD including in primary health. Kidney stories can be impactful across generations
5. Establishment of mentor led consumer groups at local dialysis unit level
6. An education package for mentors about dialysis and transplant options. Mentors were only experts in the modalities they had experienced
7. Increased culturally appropriate education material for pre-transplant patients about transplant especially 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



Healing Spirit Hands

This unique Cairns and Hinterland HHS artwork by local artist Jedess Hudson depicts our five hubs as health and healing circles with lines connecting places and people.

The artwork is named Healing Spirit Hands (Gubi-Wawu-Murra - Language: Ewamian/Badun). Jedess's artwork inscription reads: *"May the warm winds of spirit blow gently on us, and may the great spirits bless all who enter our sacred healing space. May your feet make happy tracks on country, and may the colours of the land always touch your soul"*