



National Indigenous Kidney Transplantation Taskforce Top End Renal Service, Final Report 2022

Project Performance

Key Activities and timelines:

	Phase 1 6 Weeks	Phase 2 4 weeks	Phase 3 38 weeks	Phase 4 4 weeks
	Phase 1 Recruitment	Phase 2 Orientation to Service / Training / Education / Supernumery	Phase 3 Transplant coordination	Phase 4 Review
Activities	List of activities	List of activities	List of activities	List of activities
	Advertise	Orientation to service and systems	Provide transplant education	Review of KPIs
	Interview	Completion of Mandatory training	Coordinate Work up appointments	Review of project
	Referee Check	Shadow Transplant nurses	Review education materials	Submission of recommendations
	Commence	Competence in delivery of education	Refer as required to Multidisciplinary team	Review of challenges
		Confidence in coordination of work up	Prepare for Adelaide clinics Prepare and support patients going to and from Adelaide for transplant	

Summary of Activity (Table 1)

- Recruit two ATSIHPs (1.0 FTE responsible for servicing the Darwin region and 0.6 FTE responsible for servicing the Katherine region).

Outcome:

Phase 1, Recruitment of Aboriginal Torres Strait Islander Health Practitioner (ATSIHP) was delayed from March 2020 to Oct 2020 due to covid 19. Once commenced recruitment proved difficult with only 2 ATSIHP applying, 1 of whom was not qualified therefore leaving only 1 applicant. This applicant was employed to the project, commencing 14th Dec 2020 on a return to work program as after the recruitment process it came to light that the applicant had a current workers compensation claim in process. Human Resources (HR) approved the applicant to be employed at ATSIHP Level 2 top increment without consultation with the project team. Finance were asked to readjust the expected expenditure using the new figures of 1 ATSIHP at level 2 top increment leaving an under spend of \$53,884 (See table 4 below). The expectation at the time was for the ATSIHP to service the whole of the Top end with no ATSIHP recruited to the Katherine region due to no suitable applicants

- Train the ATSIHPs to deliver kidney transplant education and have them shadow transplant coordinators to increase their knowledge of the transplant workup and assessment process.



Outcome:

Phase 2, took approx 6 weeks due to ATSIHP being on a return to work program with reduced hours. The training and education relating to transplant (Tx) went well with the ATSIHP learning quickly. Tx CNC Kerry Dole provided articles, power points and education relating to the barriers to Tx and post Tx outcomes and problems. Tx RN provided education relating to the Tx work up process, appointments to be made and assessment by Royal Adelaide Hospital (RAH) team.

ATSIHP was planned to be involved in the RAH Tx assessment clinic to be able to learn what happens from the patients perspective and also to increase their own clinical knowledge , however due to ATSIHP sick leave this did not happen

- **Support the ATSIHPs to deliver kidney transplant education, coordinate workup appointments, review education materials, and support Indigenous patients being referred to multidisciplinary health care teams, including Adelaide clinics.**

Outcome:

In Phase 3 delays have been experienced due to ATSIHP being present at work for only 53% of the expected time due to health issues and the impact of Covid 19

- ATSIHP worked with the Chronic Kidney Disease (CKD) ATSIHP who had been delivering the Tx education to support the Tx nurses in delivering culturally safe education. CKD ATSIHP provided education on the current format of Tx educations session, resources used and the feedback form. ATSIHP was given a caseload of 30 patients to focus on regarding reviewing the suitability status of the patients for Tx from current Drs letters Tx and then liaising with the patients to assess if they were still interested in Tx. If patients were not interested then to ask patients why, and record the information on the database. 5 patients were identified as no longer suitable for Tx, with the remaining still being interested in Tx and either yet to commence work up or in varying stages of the work up process ATSIHP has delivered 2 education sessions to the end of June 2021 and attended a 2 day outreach clinic in Katherine to promote and deliver Tx education to the dialysis population in the Katherine region.
- Covid 19 has impacted every aspect of the activity , however 3 IPRG groups were able to happen with the final meeting cancelled due to CHO and hospital executive directions

Summary Outcome of Activity

Overall the activity outcomes were affected by 2 main issues these being recruitment to the ATSIHP position and the impact of Covid 19 on access to care and specialist services. The inability to recruit 2 ATSIHP was the first problem experienced with their then being HR issues. To help overcome this issue an Aboriginal Liaison Officer (ALO) was employed full time from July 2021 with the remaining funding to support ATSIHP. The ALO was currently working in



the Renal Home Therapies service so recruitment was able to happen relatively quickly. Together the ATSIHP and ALO organised the NIKTT Indigenous Patient Reference Group with 6 patients identified as members and 4 meetings organised for 28th July, 8th sept, 15th Oct and 19th Nov. July saw the resignation of the ATSIHP and so then the ALO was the sole Indigenous Australian working in the project whom went on to lead the IPRG meetings, organise a meeting with the Panuku group members and to support the existing renal transplant nurses who compromised of an N5 and N2 .The ALO collected data on her daily activities. See attachments for the afore mentioned

The impact of Covid 19 had a profound effect on the outcome of the sponsorship activities due to access to care and specialist services either not being allowed, not available or limited. Transplant work up testing was limited and sporadic depending on Chief Health Officer directions for travel in and out of remote communities .Transplant education sessions were cancelled as were 3 RAH Transplant assessment visits so no patients were assessed for their suitability for Tx listing resulting in no new listings from April - Dec 2021. However a lot of patient feedback and advice was sought via the ATSIHP, ALO, IPRG and the Panuku Hunting for Kidneys working group on matters relating to transplant education, the work up process and life post Tx and what staff should be part of the Transplant team and any other advise they felt was important (See meeting minutes attached for 3 IPRG meetings and 1 meeting with Panuku mentors). So although the sponsorship hasn't seen big changes in the number of patients in work up or being listed there has been a lot of valuable feedback information obtained and recommendations on how to improve Indigenous Australian access to kidney transplant (See Table 2 and 3)



TABLE 1: ACTIVITIES BY PROJECT MATRIX

PROJECT METRIC	MEASURED BY	KPI IF APPLICABLE	NUMBER OF PATIENTS BY MONTHS															
			Oct 20	Nov	Dec	Jan 21	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Dec
Access to clinical assessment	Number of patients assessed for transplant (Tx) suitability	Increase in number assessed (pre- vs post-intervention)	5	6	1	5	15	7	6	7	4	4	12	6	6	2	3	
	Number of patients who commenced transplant workup	Total patients commencing work up	4	1	3	1	6	3	0	2	1	2	1	2	3	0	2	3
	Total patients no longer suitable for work up	Total patients no longer suitable for work up	0	0	0	0	0	0	5	0	0	1	1	1	1			
	Total patients	Total patients	Oct 20	Nov	Dec	Jan 21	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	



86	89	90	96	103	98	100	86	96	98	95	100	101	98	101
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Attendance at appointments

Attendance rates at pre-transplant workup and assessment appointments

Improved attendance rates (pre- vs post-intervention)

Data collection shows 12 out of 107 patients did not attend (DNA) Appts from Nov 20-May 21 :18 out of 26 appts were missed dental Appts.
 Data collection shows there were only 2 missed apt from June to Dec 2021 these being 1 dental and 1 cardiac

Access to targeted transplant education

Number of patients who received tailored and culturally appropriate transplant education

Increase in number receiving tailored, culturally appropriate transplant education (pre- vs post-intervention)

Oct 20	Nov	Dec	Jan 21	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec
5	6	1	5	15	7	6	7	0	0	8	5	5	0	0

Patient satisfaction survey of transplant educational material

19 Patient satisfaction Surveys have been collected to date with the feedback highlighting that patient’s knowledge did increase following education and that all 19 patients would like a kidney transplant. Patients gave limited feedback on the delivery of the education session, cultural appropriateness, and suggested changes. The project team will review the feedback form re need for further changes.



Engagement with primary health care
 Number of visits to primary health care services by CKD patients (prior to commencement of renal replacement therapy)

Demonstrated increase in primary health care visits by pre-RRT patients (pre- vs post-intervention)
 Top End Renal Services (TERS) has long-standing collaborative and integrative relations in the provision of care with several stakeholder organisations across the Top End. TERS will continue to engage and collaborate with these current tertiary, primary health care services and non-governmental organisations to promote the pathway to transplant. CKD coordinators remain the main source for providing pre Tx education on outreach visits. Further outreach visits by the ATSIHP are planned to the Katherine region. All current patients in work up are on a renal replacement therapy. The project team are exploring ways of how to improve engagement and access to Tx work up for patients in the CKD stage. No specific visits done yet. Unable to achieve due to covid 19

Access to kidney transplantation
 Number and timing of Indigenous patients completing transplant workup
 Average reduction of time from initial assessment to completion of workup (pre- vs post-intervention)

Oct 20	Nov	Dec	Jan 21	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Dec
															0

Number and timing of Indigenous
 Increase in the number of Indigenous

Oct 20	Nov	Dec	Jan 21	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Dec
0	3	1	0	0	0	3	0	0	0	0	0	0	0	0	0



patients entering the transplant waitlist

s patients from the targeted areas on the transplant waitlist (pre- vs post-intervention)

	26m 30 42	28	n/a	n/a	n/a	13 20 21	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
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No of Pts entering Time in months to listing

Total number of patients	Jan 21	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec 21
	90	89	90	92	96	96	98	97	99	97	97	98



Recommendations and Learnings

- Recruitment of ATSIHP into the transplant team workforce as the skills , qualification and cultural expertise that they bring to the team is invaluable being able to bridge the cultural gap and gain learnings /stories that Indigenous Australians may not share with health professionals from different cultures
- Recruitment of ALO into the transplant team workforce as the skills and qualifications this role brings has a different focus to the ATSIHP and is more focused on the social , everyday needs , ability to access health care needs aspects of care eg helping patients to obtain ID, documents required to obtain ID, Centrelink , Medicare , housing etc and adjusting to living in town if new to RRT
- 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 whilst offering expert patient knowledge and guidance
- Development of culturally appropriate educational resources with videos of patients telling their own stories in multi languages
- Education and Training for health professionals on how to deliver culturally appropriate education and how to interact /communicate with patients in a private consult to overcome the cultural barrier
- Alternative ability to assess patients for Tx suitability when visiting specialists team are unable to visit remote sites so not to create a further barrier to accessing transplantation eg Telehealth consult with primary nephrologist referring the patient and Tx nephrologist and Tx surgeon giving guidance on any physical assessment required. If surgeon required to do physical assessment then to liaise with the referring hospitals surgical team to see if a joint surgical TH consult can be undertaken which would meet the criteria for assessment
- Learning from patients and health professionals perspectives relating to what are perceived barriers to transplant – see table 2 &3



Activity Material Produced

Please see attachments that include:

Pre and post patient feedback form

EOI for IPRG members

Power point presentation to the IPRG

Tx navigator stats

Income and Expenditure Statement

Please see attached excel spreadsheet showing the sponsorship has not been fully expended incurring an underspend of \$ 70,036 of which these funds are to be returned to the TSANZ. Can you please advise how to do this?

TOTAL EXPENSES	0	129,964
SURPLUS OR (DEFICIT)	0	70,036



TABLE 2: IDENTIFIED BARRIERS TO WORK UP FOR TRANSPLANTATION FROM PATIENTS' PERSPECTIVE

Barriers to Tx Identified from Patient Feedback	No of Patients
Navigating Complex Healthcare Systems	15
A lot of doctor in the surgery room in Adelaide	1
Don't like or want 'stress test' as it makes me feel no good	1
Eye test at casuarina , not sure where to go	1
Getting lost and confused-needs escort support (daughter) & (get lost & frustrated)	4
Not knowing where to go and getting frustrated not being able to find certain areas too attend eg, NTC, LFT etc. Navigating our complex systems	2
Not sure where to go DPH, RDH, dental & mammogram, need someone to take me	2
NT cardiac appt - not sure where to go	2
Work up testing is very clinical, try make list easier for me/us to understand	2



Fear, scared, disappointing, frighten of the unknown	20
Adelaide driver driving very rough with Tx client	1
Adelaide very big & busy, 1st time away from NT	2
Client & family involved with the renal journey	2
Frighten to use the elevator for the Breast screening appointment	2
Frighten to use the elevator for the Dental appointment	3
Infection after Tx while is hostel in Adelaide	1
Long time to wait 7-8 years	1
Mental Health issues & need help at times	1
Mentor/Navigator needs to be with client & doctor during appointment (client to understand the doctor)	1
Missed 2 Tx, but third time lucky	1
No strong alone, we need to stand together with services & clients	1
Scared of lift to the Dentist & Mammogram appointments	3
Scared of passing away while being in the operating room, not having family around to support one's passing away	1



Transport	8
Transport issues (not being able to utilise TEPTS-as don't service some areas) Therefore patient then needs to call and organise other means of transport	2
Driver in Adelaide driving very rough with Tx client	1
Lack of support ?? What that means	1
TEPTS not waiting around enough if someone is not waiting out the front of their premises (they may have just gone inside to toilet)	3
Traveling from Kalkarinji to Darwin & back for work ups	1
Too many appoints to attend	15
Being too tired to attend appts because of dialysing x 3 days per week and just wanting to rest on days off	2
Hard to do work up appointments & PD	2
Humbug from all the services requiring us to attend for workup appts	3
Long time to wait for appts and then forgetting	3
Too tired to listen to story today as just finished haemodialysis	2
Tried but took too long -"was doing it, appts but decided to give up, as too much humbug"	3
Cultural Beliefs	22



Blackfella magic,/curse/payback/jealously for cultural & ceremony, very strong, as some Aboriginal people cannot die of a medical problem	2
Funerals	3
Hesitant in receiving someone else's kidney	4
Receiving a kidney from the wrong person (wrong skin if extended family member has offered their kidney) possibly not knowing until after receiving kidney	2
Some Aboriginal people die from their own beliefs (curse/sung)	2
Sorry Business, also while in Adelaide	2
Times when cultural obligations take precedent over medical appts and other conflicting appts	5
Transplant appointment should not be with pregenant mother's on the 8th floor	2
Appt Notification	2
Simply missing appts - Because of forgetting, not being advised possibly the day before	2
Patient Decision Making	2
Being humbugged (Hi Michael, I have spoken to xxx and he would not like any further communication re transplant until he makes up his mind"	1
Family members are decision makers in the event that patinet cannot make his own decisions	1



Social and Emotional Wellbeing	12
DNA appt because of conflicting appts eg - "because involved in Money Management Church Group, "Very Urgent Meeting"	1
Heard bad news about own health put off from doing other tests until decision made	3
Look after family 1st and my health 2nd	2
Mental Health issues and needed help at times	2
Missed appt 26/02 was because he had family business, organising meetings and meeting his niece for the first time (conflicting family meetings)	1
Missing family due to being away from country in a long time	2
Too much grog	1
Communication Tool	10
Can't understand some staff because from different country (language barrier)	2
Communication misunderstanding, not a good partnership between clients, doctors & nurses	3
Help with weight loss	2
Not having communication tools eg mobile phones to organise support and transport	2



Communication is a big barrier	1
Co-morbidities	2
No good heart, breathing problem big mob other health problem	1
Heart operation required , no point in doing the tests	1
Education material/Resources	23
Education material/resources in both words & pictures, also books, DVD & posters	2
Education too long, do in blocks - 1st block workup tests, 2nd block transplant operation, 3rd block transplant medication	2
Larger print for people with reading difficulty (bigger than normal font, expanded words & bold?)	1
Medication education in blocks/parts/sessions - 1st what the medication looks like, 2nd what the medication do, 3rd if you don't take med what could happen	2
Men & women's education sessions separate (especially when removing stent, pap smear, mammogram & prostate test)	2
Ongoing transplant education, education before & after Tx	3
Remembering to drink a lot of water	1
Resources material in both words & pictures please	1



Tx education in the morning, as can be very tiring in the afternoon	2
Education in the community rural & remote area	2
Update education material	2
Education team ATSI Health Practitioner, ALO, Interpreter, Mentor & Navigator	3
Who could support patients to break down these above BARRIERS	36
Aboriginal Liaison Officers	2
ATSI Health Practitioners	4
Community Services (Panuka) & RHT working together	4
Interpreter	3
Involve family members, if client request	5
Mentors	4
Navigators from community, Panuka or hospital	5
Own bus services for Renal patients & escort	4
Working together	5



Other	3
Adelaide was very cold/freezing	3

TABLE 3: IDENTIFIED BARRIERS TO WORK UP FOR TRANSPLANTATION FROM ABORIGINAL LIAISON OFFICERS, ABORIGINAL HEALTH PRACTITIONERS AND OTHER HEALTH CARE PROFESSIONALS' PERSPECTIVE

Barriers to Tx from ALO/Health Professionals Feedback	No of HP
Cultural Beliefs	8
Attending funerals	3
Missing family due to being away for a long time	3
Worried that one's spirit of person deceased, being release away from their country	2



Too many appoints to attend	4
Simply missing appts - Because of forgetting, not being advised possibly the day before	2
Empower the clients by giving them a copy of the 'Transplant Recipient Workup' list in a simpler form	2
Social and Emotional Wellbeing	1
Too much grog (R/A while on outreach)	1
Transport	1
Transport issues (not being able to utilise TEPTS-as don't service some areas) Therefore patient then needs to call and organise other means of transport	2
Communication Tool	3
Misunderstanding between client & doctor	2
Not having communication tools eg mobile phones to organise support and transport	1
Comorbidities	1



Some chronic conditions will exclude one from RTx	1
Transient Lifestyle	1
Patients very transient	1
Patient Decision Making	4
Some Family are decision makers and then possibly not being able to decide as not informed enough about the RTx journey, complication, commitment needed etc	4
Patient Education	8
Information session too long-too much education	2
Inappropriate and none-targeted education resources	3
More medication education after Tx	3
ATSI Workforce	13
Not enough ATSI Staff	5



Encourage Interpreter involvement	4
Navigator	4
Accommodation in Darwin or Adelaide	5
Need own shower and toilet facilities to reduce infection	3
Need own renal accommodation for meals, hygiene, fluid, education in one area	2



