



JUNE 30, 2022

PERFORMANCE REPORT

NATIONAL INDIGENOUS KIDNEY TRANSPLANTATION TASKFORCE

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Executive Summary

The National Indigenous Kidney Transplantation Taskforce (NIKTT) was established in 2019 by the Commonwealth Department of Health to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people. Over the past three years, the NIKTT has created a national network of consumers and clinicians, alongside community and research advocates, who share in the mission of enhancing the cultural safety of renal services and improving their accessibility to Aboriginal and Torres Strait Islander peoples, thus improving kidney transplantation waitlisting numbers and increasing the rate of kidney transplantation.

The NIKTT comprises of a Secretariat that is housed within the South Australian Health and Medical Research Institute (SAHMRI), as well as a steering committee, a national consumer board, and several working groups. The steering committee includes members from the clinical, academic, government, and non-government sectors. The NIKTT was tasked with implementing and evaluating the following key objectives:

1. Establishing the National Indigenous Kidney Transplantation Taskforce (NIKTT),
2. Enhancing data collection and reporting,
3. Piloting initiatives to improve patient equity and access, and
4. Evaluating cultural bias interventions.

This Performance Report outlines progress made by the NIKTT against each of these objectives from execution of the agreement to 30 June 2022.

Duration of the Activity

The impact of the COVID-19 pandemic was felt most acutely in the delivery of Objective 3: piloting initiatives to improve equity and access. Due to staff shortages, operational delays, and travel restrictions relating to the pandemic, a number of pilot projects required adjustment to their original activity plans and three projects ended up with significant project underspend.

On the 21st April 2022, the Department of Health approved that these funds be repurposed to extend the NIKTT secretariat operations until the end of the year. The Financial Acquittal Report is now due by the 31 October 2023, with the overall Final Report due on 31 March 2023.

The NIKTT secretariat will use the funds to consult with community on the findings and recommendations from the initial work of the NIKTT and plan for the future, including the creation of a national strategy for improving access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander peoples.

Progress Update

Objective 1: Continued collaboration with the NIKTT and Reference Groups

Overall Taskforce

The NIKTT remains well established, with membership comprising of 26 stakeholders from a variety of disciplines including Aboriginal and Torres Strait Islander kidney community members, nephrologists, nurses, policymakers, researchers, and primary care and allied health professionals. The full NIKTT membership is listed in [Attachment A](#).

The NIKTT held a Taskforce-wide update and future planning session in March 2022. The NIKTT also attended and had informational booths at two key conferences:

1. [Renal Society of Australasia Annual Conference](#), Darwin, 16-18 June
2. [Transplantation Society of Australia and New Zealand Annual Scientific Meeting](#), Adelaide, 19-21 June

Attendance at these conferences was highly beneficial for re-connecting face-to-face with NIKTT members and other key stakeholders, as well as meeting new supporters of the NIKTT and spreading awareness about the progress and future of the work.



Three members of the NIKTT Secretariat: Katie Cundale (left), Senior Project Officer; Professor Stephen McDonald, Chair; and Professor Jaquelyne Hughes, Deputy Chair. RSA Conference, Darwin, June 2022

Operations Committee

The NIKTT is supported by an Operations Committee comprising members from the TSANZ Council, the Organ and Tissue Authority, the Aboriginal and Torres Strait Islander kidney community, as well as the NIKTT Senior Project Officer, NIKTT Deputy Chair, and NIKTT Chair (full membership at [Attachment B](#)). A second National Consumer Engagement Coordinator, Rhanee Lester, began work for the NIKTT in early January until March 2022.

The Committee meets monthly and is responsible for managing the budget, associated contracts, and administering the delivery of NIKTT objectives and strategies, in accordance with the Taskforce's advice. The Operations Committee report to the NIKTT and TSANZ Council on finances, risks, and the status of strategy implementation.

On the 31st of January, the Chair, Deputy Chair, and Senior Project Officer met with representatives from the Department of Health, Indigenous Health Division, to discuss Objective 4: the Cultural Bias Review. Furthermore, the Chair, Deputy Chair, and Senior Project Officer met with the CEO of OTA, Lucinda Barry, in Adelaide during the TSANZ conference, as well as with TSANZ Council President Helen Pilmore, President Elect Kate Wyburn, and Secretary Fiona Mackie.

Indigenous Reference Groups

The five established Indigenous Reference Groups (IRGs) in New South Wales, Western Australia, Queensland, and South Australia remain active and engaged. Establishment of further IRGs in Perth and Far North Queensland are also underway and should be completed by the end of the year.

Feedback from IRG participants has been overwhelmingly positive, with all jurisdictions interested in continuing the Groups after the initial NIKTT funding period is over. Work now will involve planning for, and procuring funding and space for, the continuation of the Groups.

One significant milestone for the established IRGs occurred at the Royal Adelaide Hospital (RAH) in June 2022. One of the main issues that the IRG raised with the RAH around cultural safety was the idea of organ smoking ceremonies for new transplant patients. For the Kurna people, and other nations around South Australia and Australia, organ cleansing through a smoking ceremony is an important step in paying respect to the donor. According to a news article by the [Central Adelaide Local Health Network](#), "Family members spoke about the importance of the ceremony in helping to dispel negativity and trauma from the donated organ, to connect the organ through smoke to the present, and to say thank you to the donor and family."

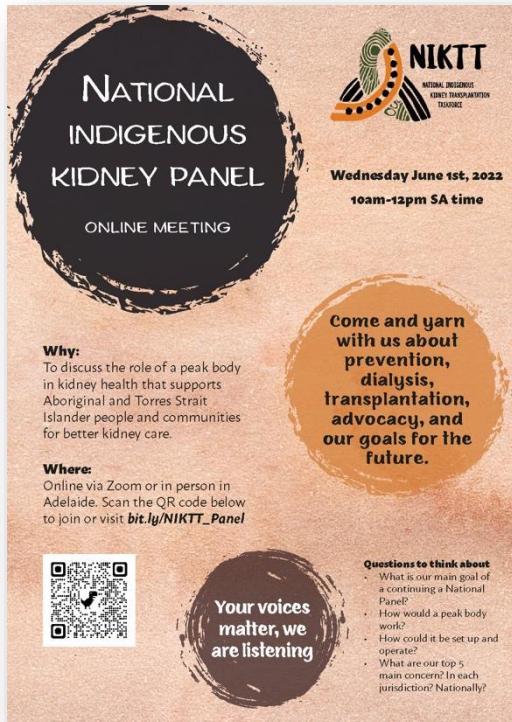


Kuranye Owen with his mum, Kelli Owen, and Toby Coates AO, Director of Kidney and Islet Transplantation at the RAH

What was particularly special about this smoking ceremony was that the NIKTT's Kelli Owen, National Consumer Engagement Coordinator and leading advocate for the creation of IRGs around the nation, was there to celebrate the ceremony with her son: 18 year-old Kurange Owen was the RAH's first transplant patient to benefit from the inclusion of smoking ceremonies on the grounds of the hospital.

National Community Panel

The National Community Panel comprises of 175 members who are Aboriginal and/or Torres Strait Islander people living with chronic kidney disease, undergoing dialysis treatment, on the active wait list for a transplant, and post-transplant. The panel also consists of family carers and Aboriginal and Torres Strait Islander health staff supporting kidney care.



NATIONAL INDIGENOUS KIDNEY PANEL
ONLINE MEETING

NIKTT
NATIONAL INDIGENOUS KIDNEY TRANSPLANTATION TRUST

Wednesday June 1st, 2022
10am-12pm SA time

Why:
To discuss the role of a peak body in kidney health that supports Aboriginal and Torres Strait Islander people and communities for better kidney care.

Where:
Online via Zoom or in person in Adelaide. Scan the QR code below to join or visit bit.ly/NIKTT_Panel

QR Code

Come and yarn with us about prevention, dialysis, transplantation, advocacy, and our goals for the future.

Your voices matter, we are listening

Questions to think about

- What is our main goal of a continuing a National Panel?
- How would a peak body work?
- How could it be set up and operate?
- What are our top 5 main concerns? In each jurisdiction? Nationally?

The NIKTT hosted a special National Panel open consultation online in June to gather feedback from the Panel and other key stakeholders on the future of the NIKTT. The goal was to share progress to date and hear from members around the country on what they believed was the best format for a Panel going forwards, including what the aims, goals, and mission of such a group would be.

Feedback from the consultation was very encouraging, with members and other stakeholders voicing the importance of having a dedicated organisation working towards improving kidney health and transplantation for Aboriginal and Torres Strait Islander people. The idea of a 'Peak Body' was pitched and endorsed with considerable support, although the parameters and function of this organisation is still being worked out by the NIKTT with partners such as the Organ and Tissue Authority and the Transplantation Society of Australia and New Zealand.

The NIKTT is hosting an ongoing feedback form online to collect further suggestions and thoughts from patients, clinicians, and other advocates.

Objective 2: Enhancing data collection and reporting

The NIKTT has finalised data collection on the extended pilot project involving tertiary renal health services. This project aimed to establish a consistent framework for collecting and reporting data on access to transplantation, which will improve our understanding of the inequities that affect Aboriginal and Torres Strait Islander patients throughout the pre-transplant journey. The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) was commissioned to provide new data collection forms for renal services: the first was an extension of normal ANZDATA annual survey, including details on whether patients had been assessed, or were in workup, on the waitlist, or ineligible for transplant; the second form involved 'real time' reporting of progress towards transplantation. 26 units across Australia collected this data for 2019 and 2020, as shown below.

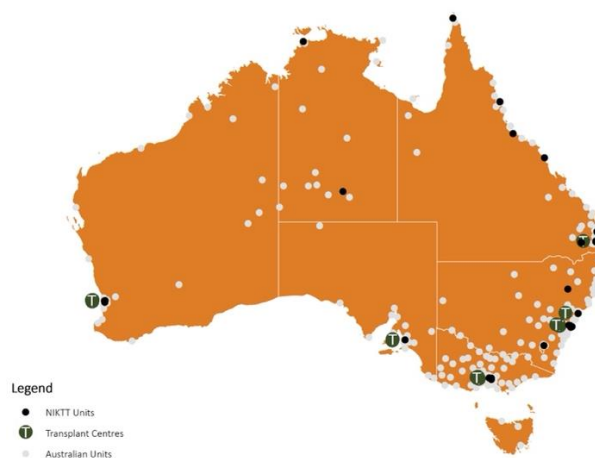


Figure 1. Map of renal units in Australia that collected data for the NIKTT Enhanced Data Collection project

Data is now being cleaned, analysed, and interpreted before manuscripts are prepared for publication and the NIKTT identifies key recommendations from this important aspect of the work.

Initial Waitlisting Analysis

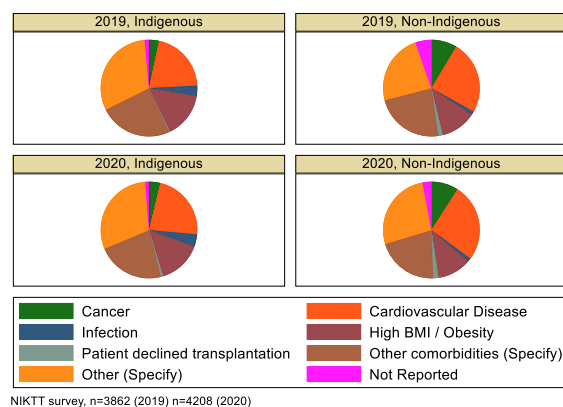


Figure 2. Reasons for not being eligible to be placed on the transplantation waitlist, 2019-2020. ANZDATA, 2021

From 2019 and 2020 Registry data, Figure 2 describes the reasons listed for why Aboriginal and Torres Strait Islander (Indigenous) patients and non-Indigenous patients were not eligible for being listed on

the transplantation waitlist. As shown in Figure 2, a sizable proportion of reasons, for both Aboriginal and Torres Strait Islander patients and non-Indigenous patients, are classified as either “Other” or “Other comorbidities”. Below, Tables 1 and 2 illustrate initial data analysis by the NIKTT pulled out some reasons listed for the large proportion of “other” reasons above.

Table 1. Simple overview of “other” reasons for ineligibility for waitlisting that included descriptors related to obesity (ANZDATA, 2021).

	Age under or over 50y and Ethnicity			
	<50y		50y+	
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous
any obesity				
No mention of obesity	170	167	670	2049
	75.89	75.23	83.02	87.08
Any mention of obesity	54	55	137	304
	24.11	24.77	16.98	12.92

Table 2. Simple overview of “other” reasons for ineligibility for waitlisting that included descriptors related to compliance (ANZDATA, 2021).

	Age under or over 50y and Ethnicity			
	<50y		50y+	
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous
any compliance				
No mention of non-compliance/social	168	177	735	2309
	75.00	79.73	91.08	98.13
Any mention of non-compliance/social	56	45	72	44
	25.00	20.27	8.92	1.87

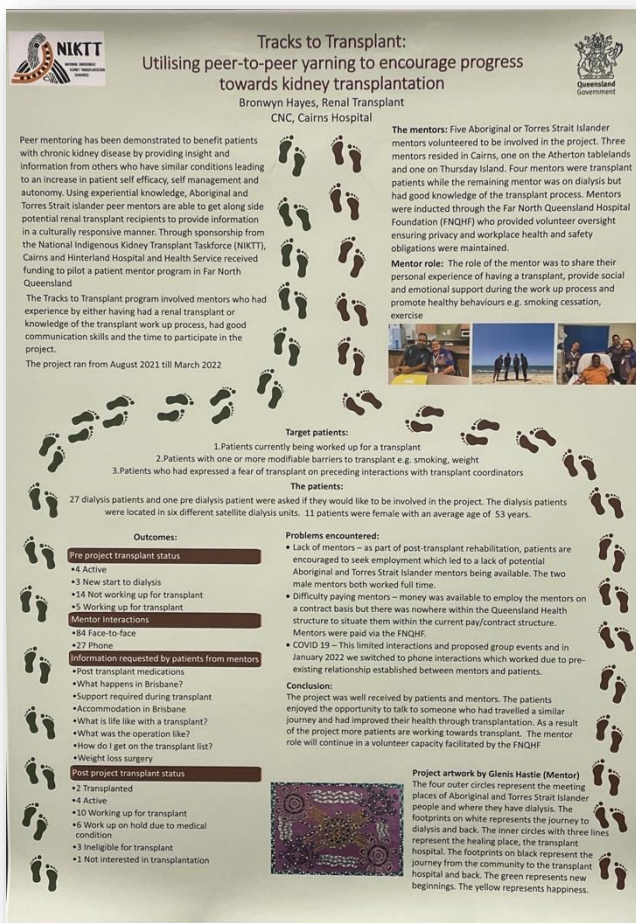
Objective 3: Piloting initiatives to improve patient equity and access

Equity and Access Sponsorships

The NIKTT's Equity & Access Sponsorships were awarded to eight projects, totalling \$1,040,381. Funded initiatives are in located Western Australia, the Northern Territory, South Australia, and Queensland. The projects include activities such as: delivery of outreach kidney transplant education and assessment in rural and remote areas; establishment of transplant-focused patient mentor projects and Indigenous Reference Groups; and strengthening the Aboriginal and Torres Strait Islander health workforce in kidney transplant settings. All projects are in the final stages of implementation and evaluation has begun.

All projects were significantly impacted by COVID-19-associated delays. Extension requests were approved for all sponsorship recipients, and all but one project has now completed their funded activity period. The NIKTT team, in conjunction with the sponsorship recipients and local communities, is now evaluating the projects and completing the final impact and evaluation report.

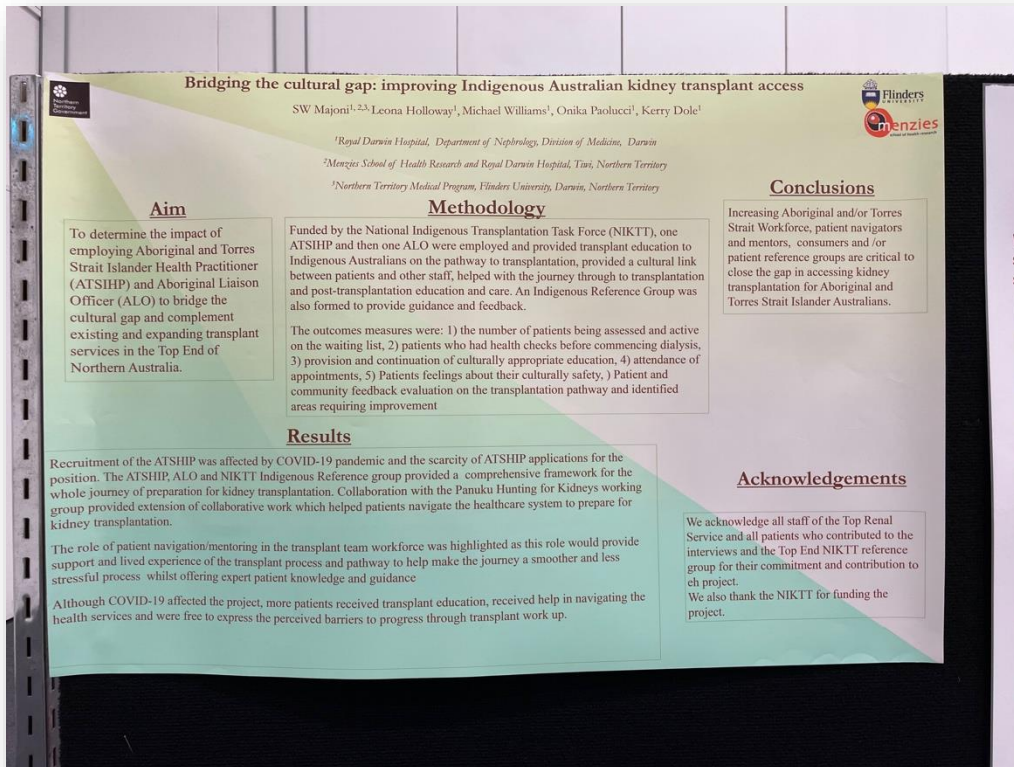
Recently, four of these projects had the opportunity to present initial findings from their work at the TSANZ Annual Scientific Meeting in Adelaide. Below are copies of three poster-presentations and an image of one sponsorship project reporting their results during a live oral presentation.



Poster by Bronwyn Hayes for the Cairns and Hinterland "Tracks to Transplant" Project



Poster by Dr Suda Swaminathan for the Fiona Stanley Hospital Outreach Project



Poster by Dr William Majoni for the Top End Renal Services Project



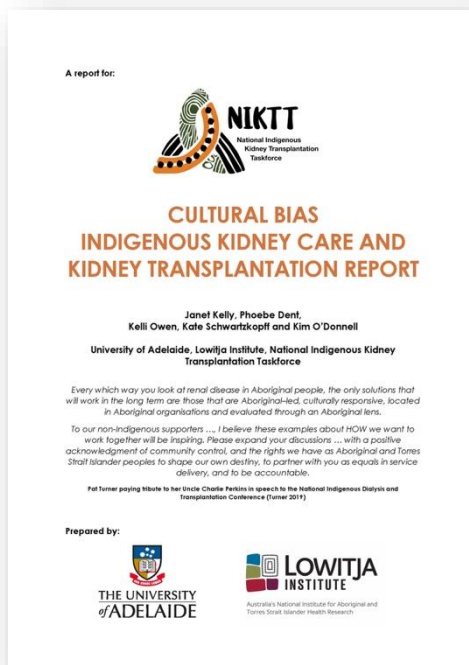
Presentation by Dr Doris Chan for the Royal Perth Hospital and Sir Charles Gairdner Hospital Outreach Project

Objective 4: Evaluating cultural bias initiatives

Cultural Bias in Indigenous Kidney Care and Kidney Transplantation

Cultural bias was a particular priority of the Taskforce. The NIKTT has sent the final Report and the NIKTT's response of 5 priority recommendations back to the Commonwealth Government. The outcomes from this piece of work show us that more evidence is needed from renal settings, with a systematic tool implemented to measure cultural bias and safety at both system and patient levels.

Both the Cultural Bias Report and Policy Brief are now available online and have been shared widely with relevant networks.



Financial and Budget Update

Please see the Income and Expenditure Report from 1st January 2022 to 30 June 2022 as per item E below. All Equity and Access Sponsorship projects were significantly impacted by COVID-19-associated delays and each project was evaluated with the final impact resulting in two Sponsorship projects returning an underspend. They were;

- The Cairns and Hinterland Hospital and Health Service project returned sponsorship funds to the amount of \$72,761.26 (inc. GST); and
- The Top End Health Service project returned sponsorship funds to the amount of \$77,039.60 (inc. GST).

Provided below is the financial position of the NIKTT as of 30 June 2022.

Income and Expenditure as at 30 June 2022

Opening balance (1/1/22)	\$	9,939.43
INCOME		
Interest	\$	-
Sponsorship refund	\$	149,800.89
BAS Refund	\$	20,000.00
Total Income	\$	169,800.89
EXPENSES		
Merchandise	\$	1,660.70
Meeting expenses	\$	1,694.97
Website	\$	115.80
SAHMRI Resources	\$	-
Total Expenses	\$	3,471.47
BALANCE	\$	176,268.85

As per the Deed of Variation to the Standard Grant Agreement, 4-87T1QOR, the balance of the funds are being utilised to extend the Secretariat function of the NIKTT until 31 December 2022, which is the Activity's new completion date.

Attachment A: NIKTT Membership

Name	Jurisdiction	Role	Working Group (if applicable)
Lucinda Barry	ACT	CEO; Organ & Tissue Authority	N/A
Peter Boan	WA	Infectious Diseases Physician, Microbiologist; Fiona Stanley Hospital	Data
John Boffa	NT	Chief Medical Officer, Public Health; Central Australian Aboriginal Congress	Cultural Bias
Alan Cass	NT	Director; Menzies School of Health Research	Cultural Bias
Sajiv Cherian	NT	Head of Unit; Central Australian Renal Services & Top End Renal Services	Data
Su Crail	SA	Nephrologist; Central and Northern Adelaide Renal and Transplantation Service	Patient Mentors
Jenny Cutter	WA	Manager; Kimberley Renal Services	Pre-transplant coordination
Anuja Daniel	NT	Renal psychologist; Top End Renal Service	Community Engagement
Kerry Dole	NT	Renal transplant clinical nurse consultant; Top End Renal Service	Data & Pre-transplant coordination
Ross Francis	QLD	Nephrologist; Princess Alexandra Hospital	Pre-transplant coordination
David Goodman	VIC	Nephrologist; St Vincent's Private Hospital Melbourne	Community Engagement
Heather Hall	NT	Manager; Purple House "Panuku" Darwin	Patient Mentors
Bronwyn Hayes	QLD	Renal Transplant CNC; Cairns and Hinterland Hospital and Health Service	Patient Mentors
Jaquelyne Hughes (<i>Deputy Chair</i>)	NT	Nephrologist; Royal Darwin Hospital	Cultural Bias

Ashley Irish	WA	Nephrologist; Fiona Stanley Hospital	Pre-transplant coordination
Shilpa Jesudason	SA	Nephrologist; Central and Northern Adelaide Renal and Transplantation Service	Community Engagement
Paul Lawton	NT	Nephrologist & Senior Research Fellow; Menzies School of Health Research	Cultural Bias
Wai Lim	WA	Nephrologist; Sir Charles Gairdner Hospital	Data
Sandawana William Majoni	NT	Nephrologist; Royal Darwin Hospital	Cultural Bias
Stephen McDonald (Chair)	SA	Director of Dialysis; Central and Northern Adelaide Renal and Transplantation Service	Data
Kelli Owen	SA	Transplant recipient and community representative	Community Engagement
Rochelle Pitt	QLD	Aboriginal and Torres Strait Islander Nurse Navigator; Metro South Health	Community Engagement
Christine Russell	SA	Consultant transplant and vascular access surgeon; Royal Adelaide Hospital	Patient Mentors
Ray Sambo	QLD	Peritoneal dialysis recipient and community representative	Patient Mentors
Paul Snelling	NSW	Nephrologist; Royal Prince Alfred Hospital	Data
James Stacey	WA	General Practitioner; Broome Renal Health Centre	Pre-transplant coordination

Attachment B: Operations Committee Membership

Name	Jurisdiction	Role
Stephen McDonald	SA	Chair, NIKTT; Director of Dialysis, Central and Northern Adelaide Renal and Transplantation Service
Jaquelyne Hughes	NT	Deputy Chair, NIKTT; Nephrologist, Royal Darwin Hospital
Alison Hodak	ACT	Organ and Tissue Authority representative
Angela Webster	NSW	TSANZ Council representative
Kelli Owen	SA	Indigenous Kidney Community Representative and Community Engagement Coordinator, NIKTT
Rhane Lester	SA	Patient Navigator and Community Engagement Coordinator, NIKTT
Katie Cundale	SA	Senior Project Officer, NIKTT
Kim Rawson	NSW	Senior Project Officer, TSANZ