



National Indigenous Kidney Transplantation Taskforce

Final Report



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1. Executive Summary

In January 2024, the Commonwealth, represented by the Department of Health and Aged Care committed funding for the National Indigenous Kidney Transplantation Taskforce (NIKTT) through the **Bridging Extension of the National Indigenous Kidney Transplantation Taskforce to Maintain Progress Towards Transplantation Equity Agreement (NIKTT Bridging)**, Activity ID: 4-J1UOL4U. NIKTT along with the support of the Transplantation Society of Australia and New Zealand (TSANZ) continued its mission to improve access to kidney transplantation for Aboriginal and Torres Strait Islander peoples, ensuring culturally safe, equitable, and effective pathways to care. This Final Report covers the period from 1 February 2024 to 20 February 2025 for the NIKTT Bridging.

Despite initial delays due to staffing contracts, the Taskforce made significant strides in achieving its objectives. This report highlights the outcomes, impact, and key learnings from the bridging year, showcasing the progress made in strengthening Indigenous kidney transplantation services and reducing disparities.

Key Achievements:

1. Continued Operation of the NIKTT Secretariat

- Ensured sustained leadership and coordination of Indigenous kidney transplantation initiatives.
- Facilitated engagement with key stakeholders, including the Commonwealth, health services, and Indigenous communities.

2. Development of a National Data Dashboard

- Established a comprehensive, real-time data tool to track kidney transplantation access and outcomes for Aboriginal and Torres Strait Islander patients.
- Enhanced visibility of key metrics, supporting evidence-based policy and service improvements.

3. Successful Hosting of the Second NIKTT Gathering

- Brought together Indigenous patients, families, clinicians, policymakers, and researchers to discuss challenges and best practices in kidney transplantation.
- Strengthened national collaboration and knowledge-sharing to drive further advancements in Indigenous kidney health.

4. Progress Towards a National Indigenous Kidney Transplant Consumer Network

- Initiated planning and engagement for a consumer-led network to amplify the voices of Indigenous patients and families in transplant care.
- Established foundational structures to ensure sustainable consumer representation in policy and service design.

5. Expansion of Culturally Safe Transplant Pathways

- Strengthened support systems, including Indigenous patient navigators, to improve access and engagement with transplant services.

- Continued development of co-designed models of care that prioritise Indigenous perspectives and cultural needs.

6. Sustained Advocacy and Policy Influence

- Maintained strong engagement with the Commonwealth to highlight the need for continued investment in Indigenous kidney health.
- Contributed to national discussions on transplantation equity, influencing broader health reforms.

7. Capacity Building and Workforce Development

- Advanced training initiatives for healthcare providers to improve cultural safety in nephrology and transplant services.
- Encouraged Indigenous workforce participation in kidney health, fostering long-term systemic change.

8. Resilience in Overcoming Challenges

- Despite uncertainty around future funding, NIKTT successfully maintained momentum and stakeholder engagement.
- Adapted to structural barriers, ensuring ongoing progress toward key objectives.

Through these achievements, NIKTT has reinforced its role as a national leader in Indigenous kidney transplantation advocacy and reform. The collaboration with TSANZ has been instrumental in integrating Indigenous-led approaches into mainstream transplantation policy and practice, ensuring that Aboriginal and Torres Strait Islander patients receive equitable, culturally safe kidney transplant care.

The remainder of this report details progress on specific activities as outlined in the Activity Work Plan.

2. Evaluation of Performance, Benefits, and Outcomes

Performance regarding each Activity’s Tasks is detailed in [Appendix A: Activity Work Plan](#). A summary of each Activity is provided here.

2.1 Activity 1: National Indigenous Kidney Transplantation Taskforce Secretariat

Activity 1 Objective

To maintain oversight, governance, and activities relating to the NIKTT through the continuation of the NIKTT Secretariat.



NIKTT Secretariat team (L-R): Katie Cundale, Stephen McDonald, Jaquelyne Hughes, Kelli Owen

2.1.1 Performance and Benefits of Activity 1 Deliverables

Task: Appointment of Project Manager. Katie Cundale was successfully appointed as Program Manager. As Program Manager, Ms Cundale oversaw the operational and strategic implementation of NIKTT activities, ensuring that all deliverables were executed efficiently, within budget, and in alignment with the project’s overarching goals. Her leadership in work planning, reporting, financial oversight, and personnel management provided the structural backbone necessary for NIKTT to operate effectively. Ms Cundale ensured that project reporting requirements were met, maintained regular communication with Commonwealth stakeholders, and oversaw grant management to ensure financial compliance. Ms Cundale provided strategic support to governance structures, ensuring that NIKTT’s activities remained aligned with both clinical and cultural governance principles. She worked closely with the Community and Clinical Chairs, Commonwealth and transplantation stakeholders, reinforcing a collaborative approach to the Taskforce’s work. She ensured strategic objectives were translated into actionable plans so that all components of the project—from data governance to community engagement—were well-coordinated and implemented effectively. Her work ensured that NIKTT remained a well-structured, efficient, and accountable organisation, capable of delivering complex, high-impact activities. Her expertise in project management, governance, and stakeholder engagement provided the necessary leadership to sustain NIKTT’s work beyond the immediate grant period, reinforcing the importance of long-term systems change in transplantation equity.

Task: Appointment of Community Engagement Coordinator. Kelli Owen was employed as the National Community Engagement Coordinator. Ms Owen played a fundamental role in ensuring that NIKTT’s work was deeply connected to Aboriginal and Torres Strait Islander communities. As a Kaurua, Narungga, and Ngarrindjeri sovereign woman with lived experience of kidney transplantation, she brought not only professional expertise but also a deeply personal commitment to improving the

kidney care journey for Aboriginal and Torres Strait Islander people. Her cultural authority, strong Community connections, and advocacy skills were central to embedding cultural safety and Indigenous governance into every aspect of NIKTT’s work. Throughout the reporting period, Ms Owen worked tirelessly to ensure that cultural protocols were upheld and that Community priorities shaped the work of the Taskforce. She played a crucial role in ensuring that Community voices were not only included but actively led conversations about transplantation equity. She worked closely alongside Professor Jaquelyne Hughes to ensure that NIKTT’s activities were not just clinically sound but were also culturally appropriate and aligned with Indigenous self-determination in health care.

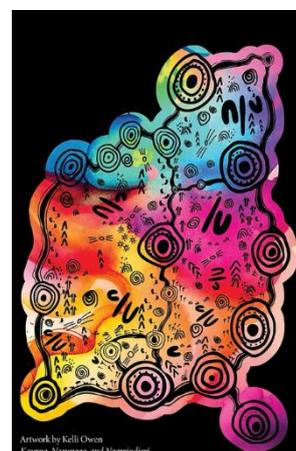


Ms Owen facilitated direct engagement between Community members and clinical stakeholders. Her approach to Community engagement was rooted in cultural respect and relationship-building, ensuring that discussions about transplantation were led by the needs and priorities of Aboriginal and Torres Strait Islander people. She travelled extensively to support Community visits, listen to patients and families, and advocate for improved pathways to transplantation. Her ability to connect with people at a deeply personal level made her an essential bridge between Community, clinicians, and policymakers.

Another key contribution was Ms Owen’s role in developing and delivering culturally appropriate resources and materials for NIKTT activities. She ensured that all communications, events, and engagement strategies were culturally safe, accessible, and relevant to Aboriginal and Torres

Strait Islander patients, families, and health workers. This included her work on NIKTT’s lanyards, picture below, which provided conversation prompts for clinicians on how to engage meaningfully with Aboriginal and Torres Strait Islander patients. Her work in this space demonstrates her ability to translate complex clinical information into practical, culturally grounded resources that could be used by both patients and healthcare providers.

Ms Owens’s lived experience as a kidney transplant recipient also positioned her as a powerful advocate and role model for Aboriginal and Torres Strait Islander patients navigating the transplantation journey. Her openness in sharing her experiences helped create safe spaces for Community members to voice their concerns, ask questions, and feel supported throughout their own health journeys. Her leadership ensured that NIKTT’s work was not just about policy and data but was fundamentally about people, families, and Community healing.



In addition to her direct engagement work, Kelli played a key role in shaping discussions about long-term systemic change in transplantation equity. She worked closely with government representatives, health services, and research teams to ensure that Aboriginal and Torres Strait Islander voices were central to all policy and service delivery reforms. Her leadership contributed to shifting the power dynamic within

nephrology and transplantation, reinforcing that Aboriginal and Torres Strait Islander communities must lead the way in shaping their own health outcomes.

Appointment of Community Project Officer. Though not an original work plan deliverable, the appointment of Matilda D’Antoine as the NIKTT Community Project Officer played an essential role in supporting Community engagement activities. As a Paakantyi woman from far western NSW, Ms D’Antoine provided operational and logistical support for Community trips, ensuring that Aboriginal and Torres Strait Islander patients and families were able to meaningfully participate in NIKTT’s work. She played a key role in assisting Kelli Owen with engagement activities, supporting direct interactions with consumers and Community members. Ms D’Antoine also contributed to the successful delivery of Activity 4: Transplantation Equity Gathering, providing on-the-ground support to ensure the event was accessible and inclusive for Aboriginal and Torres Strait Islander attendees. Her contributions were instrumental in building relationships, amplifying Community voices, and ensuring that the engagement work of the NIKTT remained deeply connected to culture and Community.

Task: Appointment of Community and Clinical Chair. Professor Jaquelyne Hughes was appointed as the Community and Clinical Chair of the NIKTT. Professor Hughes is a proud Goemulgal ipeka (woman) belonging to the Wagadagam community on Mabuiag Island. She is a physician, specialising in nephrology, and a Clinical Research Professor, Aboriginal and Torres Strait Islander Health Advancement within Rural and Remote Health, College of Medicine & Public Health at Flinders University. Professor Hughes is a member of Australian Indigenous Doctors Association and received the Australian Indigenous Doctor of the Year Award in 2019 and the Lowitja Institute Cranlana Award for Ethical Research Leadership in 2023.



NIKTT Co-Chairs
Stephen McDonald and Jaquelyne Hughes

Professor Hughes played a pivotal role in ensuring that NIKTT’s activities, recommendations, and strategic direction remained deeply rooted in both Community priorities and clinical best practices. Her leadership ensured that every aspect of the Taskforce’s work was guided by Indigenous governance, self-determination, and cultural integrity, making certain that Aboriginal and Torres Strait Islander people were not only the focus of transplantation equity efforts but were also recognised as the leaders and decision-makers driving systemic change.

Throughout the reporting period, Professor Hughes maintained strong relationships with Community leaders, clinical networks, and policymakers. Professor Hughes helped to ensure that the voices of Aboriginal and Torres Strait Islander people were at the forefront of NIKTT’s work, challenging existing structures that historically excluded Indigenous perspectives from transplantation decision-making. She consistently challenged and reshaped national conversations on equity, reinforcing that solutions must be

Indigenous-led, culturally appropriate, and grounded in the lived experiences of Aboriginal and Torres Strait Islander patients, families, and communities.

Her participation in national and international nephrology and transplantation conferences ensured that the equity conversation was amplified on a global stage, reinforcing the importance of Indigenous governance in health policy and service delivery. Through keynote speeches, panel discussions, and engagement with clinicians, researchers, and policymakers, she positioned NIKTT as a model for how Indigenous leadership can transform kidney transplantation systems.

Professor Hughes ensured that NIKTT’s governance structures upheld Indigenous leadership and decision-making at every level. Whether through strategic planning, policy development, or engagement with health services, her position on the NIKTT served to reinforced the agency of Aboriginal and Torres Strait Islander communities in shaping their own health outcomes. Her contributions were not just about improving transplant statistics but about driving long-term systemic reform that prioritised Community leadership, cultural safety, and equity.

Overall, Professor Hughes’ leadership as Community and Clinical Chair was instrumental in ensuring that NIKTT’s work was not just about equity in transplantation but about Indigenous self-determination in health care. Her advocacy, governance expertise, and commitment to centering Aboriginal and Torres Strait Islander voices, knowledge systems, and priorities drove change.

Task: Appointment of Clinical Chair. Professor Stephen McDonald, AM was appointed as the Clinical Chair of the NIKTT. Professor McDonald is a Senior Staff Nephrologist at the Central Northern Renal and Transplantation Service, Clinical Director of Renal Services for the Country Health SA Rural Support Service and chairs the South Australian Renal Community of Practice. He is the Executive Officer of the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry.



Professor McDonald ensured that NIKTT’s activities, recommendations, and strategic direction remained clinically relevant and feasible within the broader transplantation and nephrology landscape. His leadership guided discussions, proposals, and policy recommendations to be anchored in medical best practice, evidence-based nephrology, and the realities of the Australian healthcare system.

Throughout the reporting period, Professor McDonald maintained strong clinical engagement and stakeholder relationships, acting as a bridge between the NIKTT and key transplant units, nephrology networks, and professional medical bodies. Professor McDonald was instrumental in engaging with clinicians, hospital administrators, and policymakers to embed transplantation equity into broader clinical practice. He ensured that the perspectives of transplant physicians and nephrologists were aligned with NIKTT’s goals, fostering buy-in from clinical stakeholders.

His participation in national and international transplantation and nephrology conferences further amplified NIKTT’s impact. Through presentations and panel discussions, Professor McDonald brought the transplantation equity conversation to the forefront of nephrology and organ transplantation discourse, reinforcing the importance of Indigenous-led governance in clinical decision-making. His presence at these forums helped translate NIKTT’s findings and recommendations into actionable insights for clinicians and researchers, ensuring that the work of the Taskforce influenced both policy and clinical practice.

Beyond advocacy, Professor McDonald ensured that NIKTT’s proposals and recommendations were clinically sound, realistic, and implementable. By considering workforce constraints, hospital

processes, and system-wide operational challenges, he helped refine recommendations into practical, actionable steps that clinicians and policymakers could adopt. His expertise ensured that the proposed Equity Data Dashboard metrics were aligned with clinical key performance indicators, allowing for meaningful monitoring of transplantation outcomes.

Overall, Professor McDonald's leadership as Clinical Chair significantly contributed to the credibility, relevance, and impact of NIKTT's work. His efforts in stakeholder engagement, knowledge translation, and clinical advocacy strengthened the Taskforce's ability to drive real-world change in kidney transplantation equity for Aboriginal and Torres Strait Islander people.

2.1.2 Outcomes of Activity 1 Deliverables

The NIKTT Secretariat successfully maintained oversight, governance, and strategic coordination, ensuring sustained progress towards equity in kidney transplantation for Aboriginal and Torres Strait Islander people. The Secretariat provided a structured and accountable foundation for project activities, including Community engagement, policy development, and data-driven advocacy. The Secretariat maintained consistent and structured engagement with the Commonwealth Department of Health, facilitating regular discussions on transplantation equity and long-term planning. This engagement led to the development of a budget submission proposal, outlining financial requirements and implementation strategies to support the implementation of the National Strategy for Organ Donation, Retrieval and Transplantation. Overall, Activity 1 successfully maintained momentum and delivered key strategic outcomes, reinforcing the importance of sustained investment in Indigenous-led transplantation equity initiatives. The Secretariat's work has established a strong governance and operational foundation that can support ongoing systemic reforms in kidney transplantation policy and practice.

2.2 Activity 2: Indigenous Reference Groups



Activity 2 Objective

To establish and support Indigenous Reference Groups in key transplantation units across Australia.

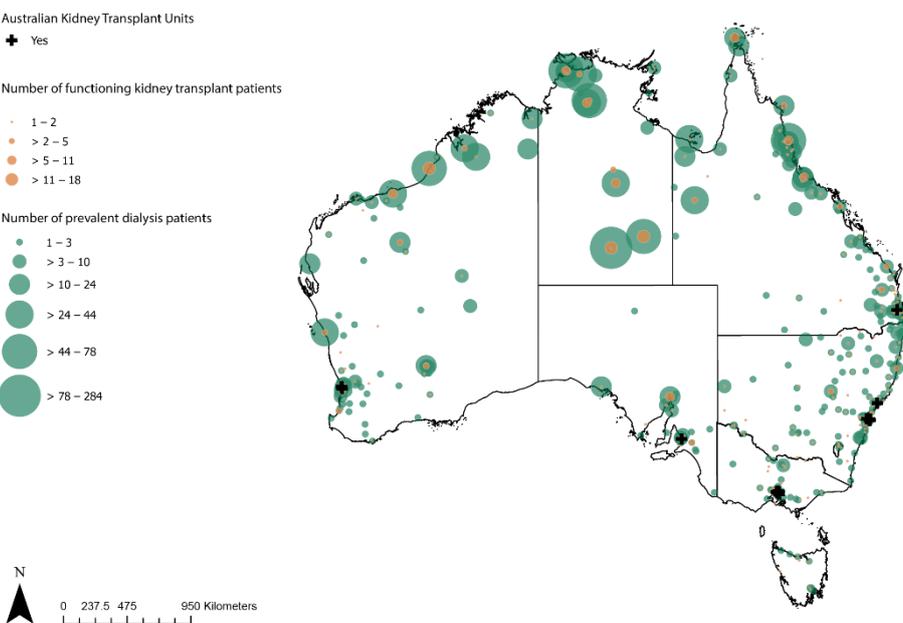
2.2.1 Performance and Benefits of Activity 2 Deliverables

Task: Identify units for new Indigenous Reference Groups. To determine the highest-priority locations for new Indigenous Reference Groups (IRGs), NIKTT’s National Community Engagement Coordinator, Kelli Owen, conducted a comprehensive assessment of where Aboriginal and Torres Strait Islander patients are most affected by kidney disease.

Using data from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA Registry), we analysed the geographic distribution of dialysis and transplant patients across Australia. As shown in Figure 1, which maps patient numbers based on their home location postcode, the

Northern Territory, Queensland, Western Australia, and New South Wales/Australian Capital Territory had the highest concentrations of Aboriginal and Torres Strait Islander people on dialysis.

However, as the map illustrates, most Australian kidney transplant units are concentrated in the southern regions, often far from the communities with the highest patient need. This geographical mismatch highlights the barriers to accessing



transplant care, reinforcing the need for IRGs to represent locations where patients are most impacted.

FIGURE 1. PREVALENT ABORIGINAL AND TORRES STRAIT ISLANDER DIALYSIS AND KIDNEY TRANSPLANT PATIENTS, END OF 2023

With existing IRGs already established in Adelaide, Central Australia, Brisbane, and Geraldton, the focus for new IRG development was on areas where Aboriginal and Torres Strait Islander patients receive care but where NIKTT had not yet initiated discussions about IRGs. This strategic approach ensured that new IRGs were established in locations where they could have the greatest impact on improving equity, access, and culturally safe care for Aboriginal and Torres Strait Islander patients navigating the kidney transplant pathway.

Task: Establish new IRGs. Engagement with nephrologists and Heads of Unit at transplant hospitals was undertaken to discuss how units could establish IRGs, what support the NIKTT could provide, and who would champion the IRGs from within each hospital. Units were engaged throughout Western Australia, Tasmania, New South Wales, Victoria, and Queensland, ensuring broad national outreach. Ongoing discussions were maintained with Sir Charles Gairdner Hospital, Royal Prince Alfred Hospital, Westmead Hospital, John Hunter Hospital, and Royal Melbourne Hospital. In Tasmania, consultations were conducted with Tasmanian Aboriginal Corporation and Kardli Aboriginal Corporation to explore opportunities for IRG establishment.

The Royal Melbourne Hospital sought internal funding to support IRG development, while John Hunter Hospital submitted an application to meet local ethics and research group requirements. During the course of this grant funding, these applications were not completed by each relevant unit.

For other units, such as Sir Charles Gairdner Hospital, the Royal Prince Alfred Hospital, Westmead Hospital, the Royal Melbourne Hospital, and Jon Hunter Hospital, support for IRG establishment and development was provided through the sharing of workforce strategies, consumer inclusion frameworks, and Quality Standards documents.

Task: Provide support to existing IRGs. At Princess Alexandra Hospital, the existing IRG was disbanded, and a combined Brisbane-Townsville IRG was re-established using state funding. Meanwhile, Royal Adelaide Hospital received funding for an engagement trip to the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, further strengthening Indigenous community connections.

Regular monthly meetings were maintained with transplant hospitals to support IRG development. Job descriptions and supporting documents for workforce roles, including Aboriginal Health Practitioners, Patient Navigators, and Community Engagement Coordinators, were shared to assist hospitals in preparing business cases for IRG funding. Aboriginal Health Directors and Heads of Units were connected to facilitate discussions on operational requirements.

Task: Document IRG activity. IRG activity was tracked and compiled by the National Community Engagement Coordinator and the Community Project Officer, including detailed lists of IRG contacts, meetings taken, and Communities engaged.

2.2.2 Outcomes and Learnings of Activity 2

Throughout the reporting period, the NIKTT Secretariat worked closely with transplant units across multiple states and territories to establish and support Indigenous Reference Groups. Despite strong engagement and interest, the ability to successfully establish and sustain IRGs remained significantly constrained by systemic funding and workforce barriers.

IRG Establishment Process and Roadblocks. The process of developing an IRG requires a structured and multi-step approach, including:

- Regular monthly meetings with hospital leadership and transplant units
- Facilitating connections between Aboriginal Health Directors and Heads of Units (HOUs) to ensure strategic alignment
- Identifying and securing the support of a local Aboriginal and/or Torres Strait Islander person willing to lead and champion the IRG within the unit.

Key Barriers to IRG Implementation. Across multiple transplant units, we found two primary roadblocks repeatedly emerged:

1. **Lack of long-term hospital support.** While there was broad agreement on the value of IRGs, many hospitals struggled to commit to the long-term funding and structural support required to sustain them. Without a clear operational funding stream, IRGs risked being short-term or tokenistic rather than embedded within hospital systems as permanent governance structures.
2. **Need for dedicated First Nations leadership.** A core principle of the IRG model is that it must be Indigenous-led to ensure that Aboriginal and Torres Strait Islander voices drive decision-making, policy development, and care models. However, most hospitals lacked a funded position for a First Nations person to lead or chair the IRG, making it impossible to establish a sustainable group. Without dedicated funding for positions such as Patient Navigators, Aboriginal Health Practitioners, or Community Engagement Coordinators, there was no operational workforce to run the IRG. Even where hospitals supported the concept of IRGs, they were unable to progress without First Nations leadership embedded in the system.

Development of the IRG Checklist. Recognising the ongoing challenges in establishing and sustaining Indigenous Reference Groups (IRGs), the NIKTT Secretariat developed an IRG Checklist (see [Appendix B](#)) to guide transplant units through the process. This resource provides a clear, step-by-step framework to ensure that each IRG is properly structured, resourced, and embedded within hospital governance before becoming operational.

The checklist outlines key milestones necessary for IRG development, including:

- Initial consultations with transplant unit leadership to align the IRG with existing strategies, policies, and action plans.
- Identifying potential funding streams to support ongoing IRG operations.
- Securing formal commitments from the transplant unit and broader hospital leadership.
- Engaging local Aboriginal Community-Controlled Health Organisations (AMS/ACCHOs) to ensure cultural and community alignment.
- Identifying key Indigenous clinical leaders, advocates, and patients to form the IRG’s core membership.
- Planning and logistics for the first IRG meeting, including venue, transport, catering, and cultural protocols.
- Developing a Terms of Reference, formalising governance structures, membership, meeting schedules, and priority-setting processes.

The IRG Checklist was developed in direct response to the barriers encountered throughout the year, where hospitals expressed interest in forming IRGs but struggled with funding limitations, workforce constraints, and procedural uncertainties. By providing a structured, practical tool, the checklist aims to reduce barriers, streamline the establishment process, and support transplant units in embedding IRGs as sustainable governance structures.

Lessons Learned and Next Steps. While significant groundwork was laid in engaging transplant units, providing workforce guidance, and linking stakeholders, the overarching takeaway from the past year is clear: IRGs cannot be successfully implemented or sustained without formal hospital

commitment to long-term operational funding and Indigenous leadership. Moving forward, the establishment of IRGs will require a structured advocacy approach to:

- Secure dedicated funding streams for IRGs within hospital budgets.
- Ensure that First Nations positions are embedded within transplant units.
- Continue engaging hospital leadership and government stakeholders to formalise IRGs as permanent structures rather than *ad hoc* initiatives.

While progress was made in setting the foundation for IRG growth, the lack of systemic investment remains a fundamental barrier. Sustained funding, strong hospital commitment, and dedicated First Nations workforce roles will be essential for IRGs to be fully implemented and have a lasting impact. To this end, the NIKTT strongly recommends that implementation of the *National Strategy for Organ Donation, Retrieval, and Transplantation* funds and supports the ongoing recommendations that IRGs are embedded within transplantation units nationally.

2.2.3 Proposed Future Structure and Governance

As part of NIKTT's work towards embedding a sustainable governance model for transplantation equity, efforts were directed towards developing a structured framework that integrates regional IRGs and Regional Community Coordinators (RCCs) into both regional and national strategic plans for transplantation equity work. This proposed structure envisions a regionalised model of Indigenous governance that connects local IRGs with state and national oversight bodies, ensuring coordinated and community-led decision-making.

The NIKTT worked throughout this grant period with representatives from both the Department of Health and Aged Care and the Australian Organ and Tissue Authority to determine the best way to structure such a model that allowed for Community-led governance through IRGs. This structure was proposed through the NIKTT's budget submission proposal, a summary of which is attached in [Appendix C](#).

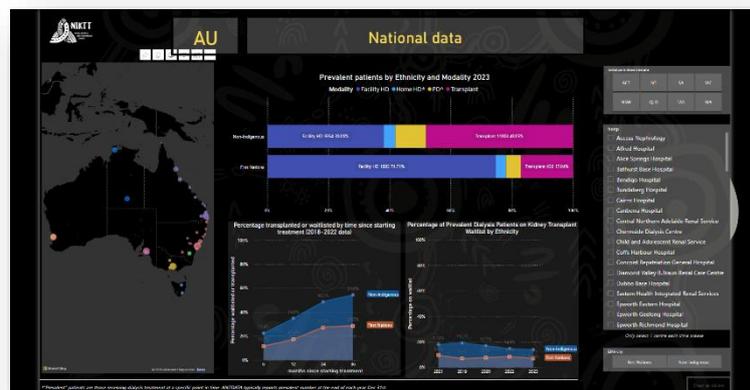
The model developed seeks to first establish IRGs at key transplant units that care for the majority of Aboriginal and Torres Strait Islander kidney patients (before eventually expanding to all kidney transplant units), with the Groups supported by Regional Community Coordinators (RCCs). These RCCs would act as key facilitators, working alongside IRGs, to ensure direct engagement between transplant units, Aboriginal and Torres Strait Islander communities, the broader NIKTT structure and government partnerships, and policy bodies. RCCs would provide operational and cultural leadership, ensuring that transplantation equity efforts remain aligned with both local health service needs and Indigenous governance priorities.

Through continued discussions with Commonwealth stakeholders, the intent is to formalise IRGs within transplant units as permanent advisory bodies, with RCCs serving as a mechanism for community-led oversight, engagement, and support for both patients and healthcare providers. This structure would allow for better coordination across jurisdictions, ensuring that Indigenous voices remain central to transplantation policy, service delivery, and long-term equity planning.

2.3 Activity 3: Equity Data Dashboard

Activity 3 Objective

To develop a comprehensive data dashboard to monitor equity in kidney transplantation, enabling both Community and Clinical stakeholders to assess equity at various levels.



2.3.1 Overview of the Equity Data Dashboard

The Equity Data Dashboard is an interactive tool designed to track and visualise key equity metrics in kidney transplantation across Australia. It provides stakeholders—including clinicians, policymakers, and Community representatives—with an up-to-date, comparative analysis of transplantation access and outcomes for Aboriginal and Torres Strait Islander people and non-Indigenous Australians. The dashboard integrates data from the Australia and New Zealand Dialysis and Transplantation (ANZDATA) Registry, allowing users to assess disparities at the national, state, and hospital levels.

Dashboard Pages and Functionalities. The following is a brief overview of each page, or view, of the current dashboard. Screenshots have been included, with South Australia and the Central and Northern Adelaide Renal and Transplantation Services (CNARTS) unit chosen as examples of filtering.

Page 1: National Data Overview. This page provides a broad overview of kidney replacement therapy and transplantation data across Australia. A bar graph displays the number of prevalent dialysis patients by ethnicity and treatment modality, while two line graphs illustrate trends in the percentage of patients who were transplanted or waitlisted by time since starting treatment (2018-2022) and the percentage of prevalent dialysis patients on the transplant waitlist by ethnicity (2018-2023). A filter allows for refinement by state and hospital (parent unit). On the left, an interactive map provides a geographical representation of each hospital unit, color-coded by jurisdiction and proportionally sized to reflect the number of patients seen at each site. As selections are refined, the map dynamically adjusts to focus on the selected jurisdiction or hospital.

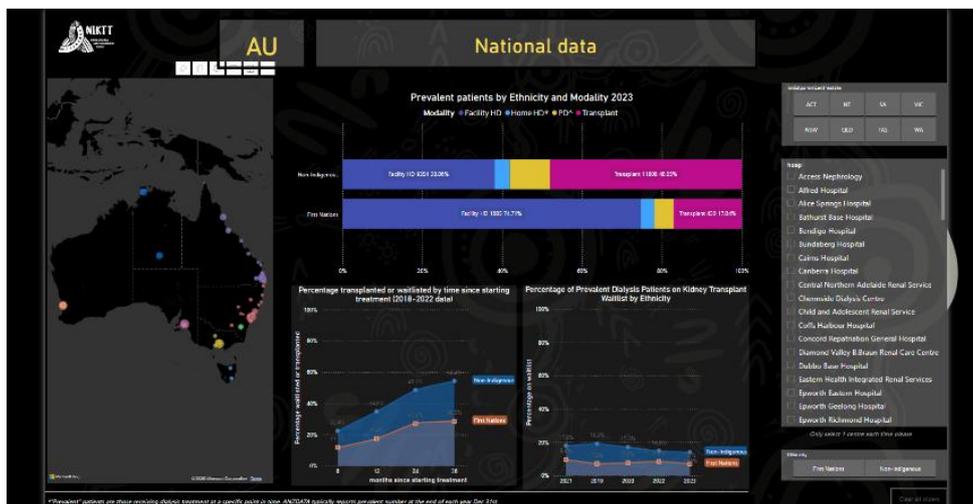


IMAGE 1. SCREENSHOT OF PAGE 1: NATIONAL DATA



IMAGE 2. SCREENSHOT OF PAGE 1: SOUTH AUSTRALIAN DATA

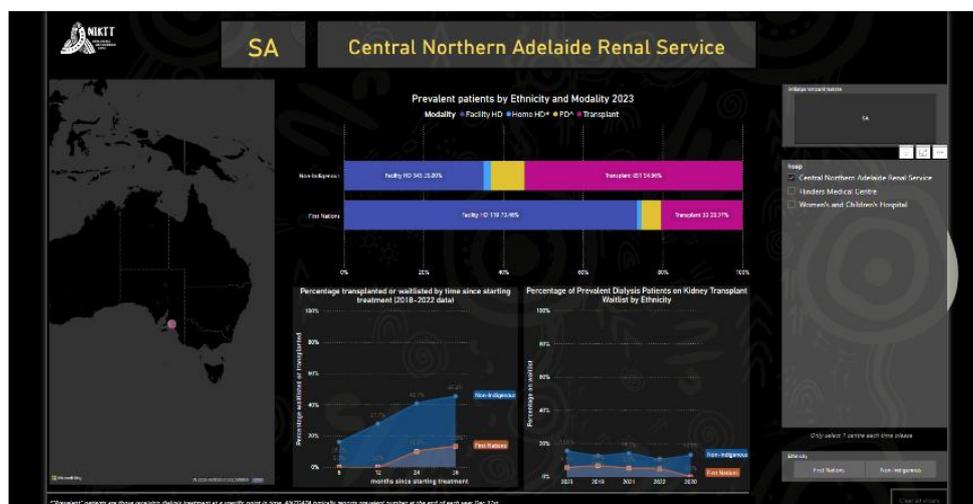


IMAGE 3. SCREENSHOT OF PAGE 1: SA UNIT-SPECIFIC DATA

Page 2: Equity in Transplant Care – Hospital, Transplant, and Waitlist Insights (2018-2023).

This page enables direct comparison of transplantation and waitlisting outcomes between First Nations and non-Indigenous patients across different hospital units. The data are displayed in two side-by-side columns, one for First Nations and one for non-Indigenous patients. Metrics include the number of incident patients by year, the percentage of patients transplanted or waitlisted by time since starting treatment, and the percentage of waitlisted patients categorised by the duration of time since they were listed. Multiple hospitals can be selected for comparison.

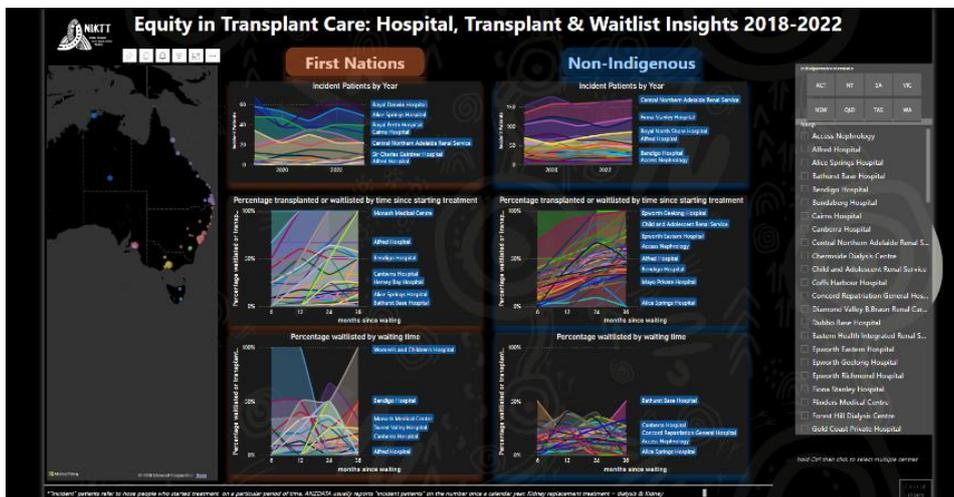


IMAGE 4. SCREENSHOT OF PAGE 2: NATIONAL DATA

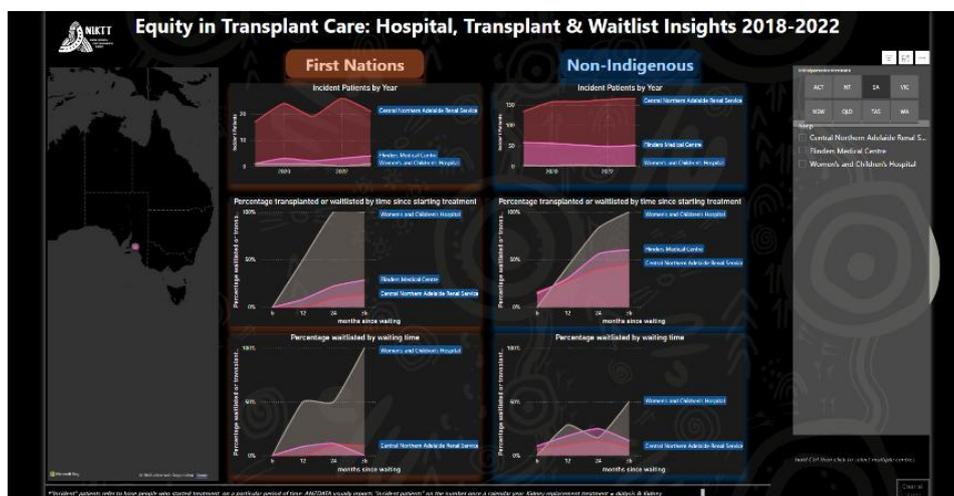


IMAGE 5. SCREENSHOT OF PAGE 2: SA DATA

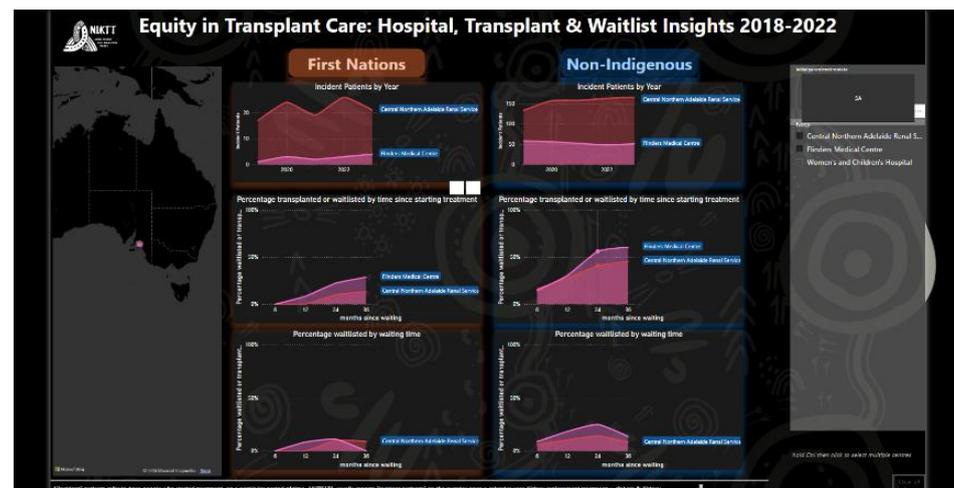


IMAGE 6. SCREENSHOT OF PAGE 2: SA UNIT COMPARISON

Page 3: Transplant Waitlist Equity – First Nations vs. Non-Indigenous (2019-2023). This page provides a comparative analysis of waitlisting trends over time. At the top, three percentage statistics are shown: the percentage of active transplant waitlisted patients under 45 years old, over 65 years old, and the overall percentage of patients on the active transplant waitlist. Below, line graphs track these percentages from 2019-2023, with separate lines for overall waitlist percentages, those under 45, and those over 65. Filters allow data to be viewed at the jurisdictional or hospital level.

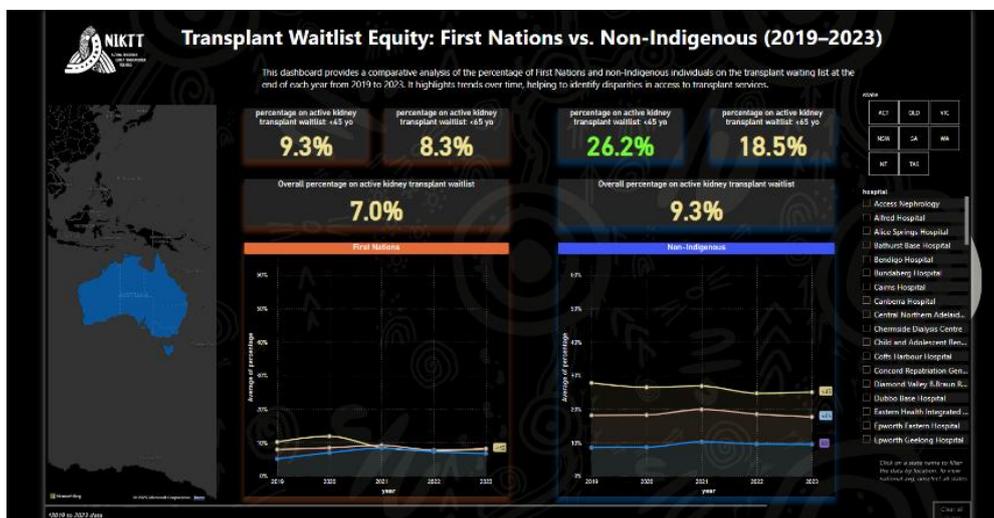


IMAGE 7. SCREENSHOT OF PAGE 3: NATIONAL DATA

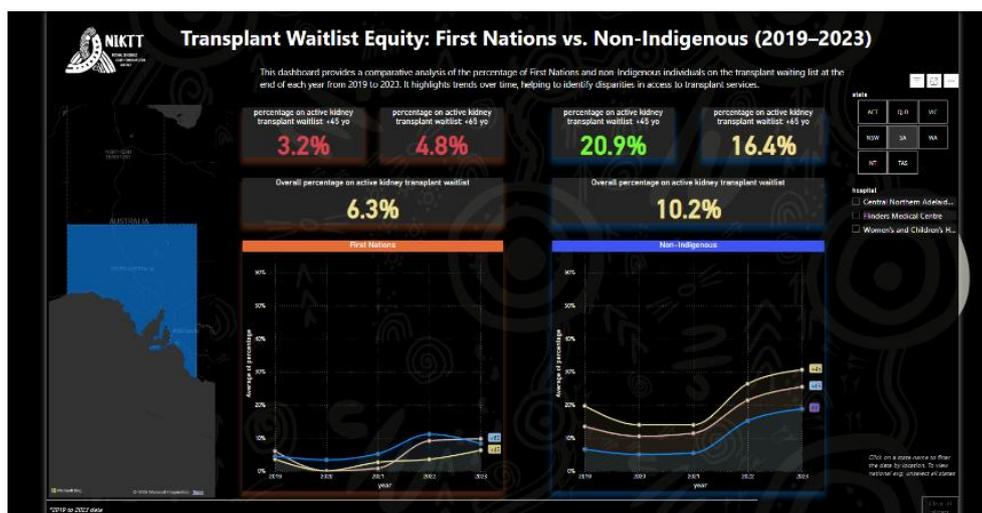


IMAGE 8. SCREENSHOT OF PAGE 3: SA DATA

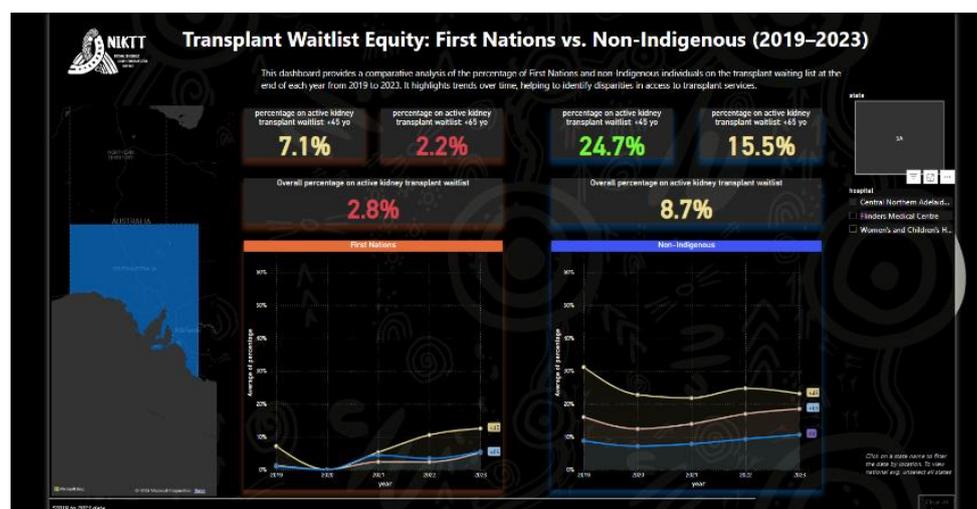


IMAGE 9. SCREENSHOT OF PAGE 3: SA UNIT-SPECIFIC DATA

Page 4: Percentage of Prevalent Dialysis Patients on the Waitlist (2019-2023). This page provides a breakdown of the percentage of dialysis patients who were on the transplant waitlist at the end of each year, categorised by ethnicity and state. Two tables display the data—one for First Nations patients and one for non-Indigenous patients—organised with states and territories as rows and years (2019-2023) as columns. To provide a visual representation of performance, the percentages are colour-coded: green for the highest percentages, yellow for mid-range performance, and red for the lowest percentages. Filters allow for further refinement by state and year.

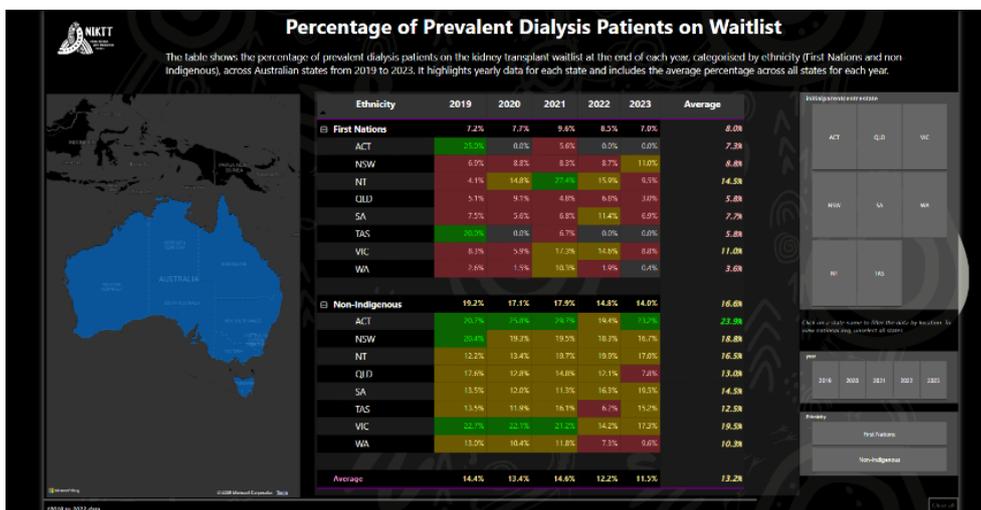


IMAGE 10. SCREENSHOT OF PAGE 4: NATIONAL DATA

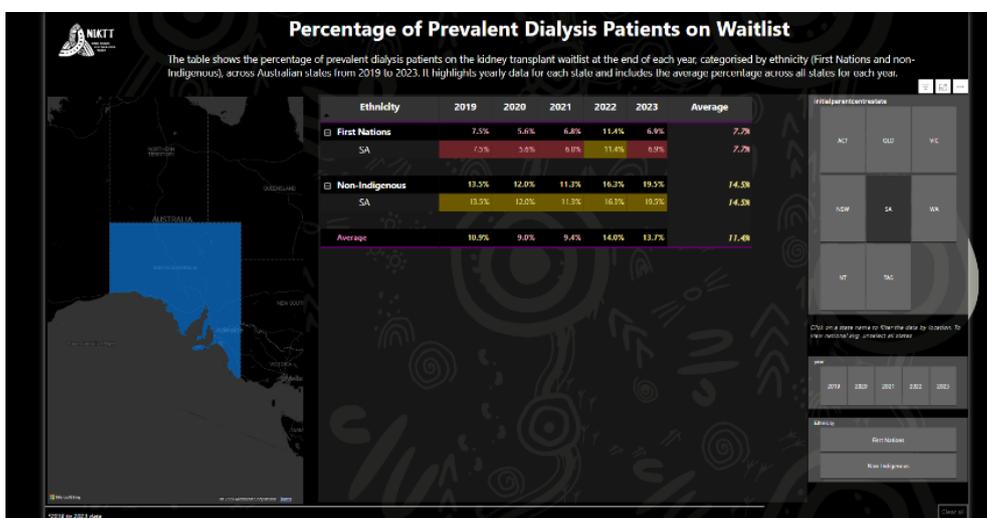


IMAGE 11. SCREENSHOT OF PAGE 4: SA DATA

Page 5: Percentage Waitlisted or Transplanted by Months Since Starting Treatment (2019-2023). This page focuses on time-based transplantation equity trends. Two tables categorise patients by ethnicity, tracking the percentage of individuals who were waitlisted or transplanted at 6, 12, 24, and 36 months post-KRT initiation. The top table presents data for First Nations patients, while the bottom table provides the same metrics for non-Indigenous patients. Colour-coding highlights jurisdictions with the highest, mid-range, and lowest percentages over the five-year period, offering a clear comparison of transplantation and waitlisting performance across Australia.

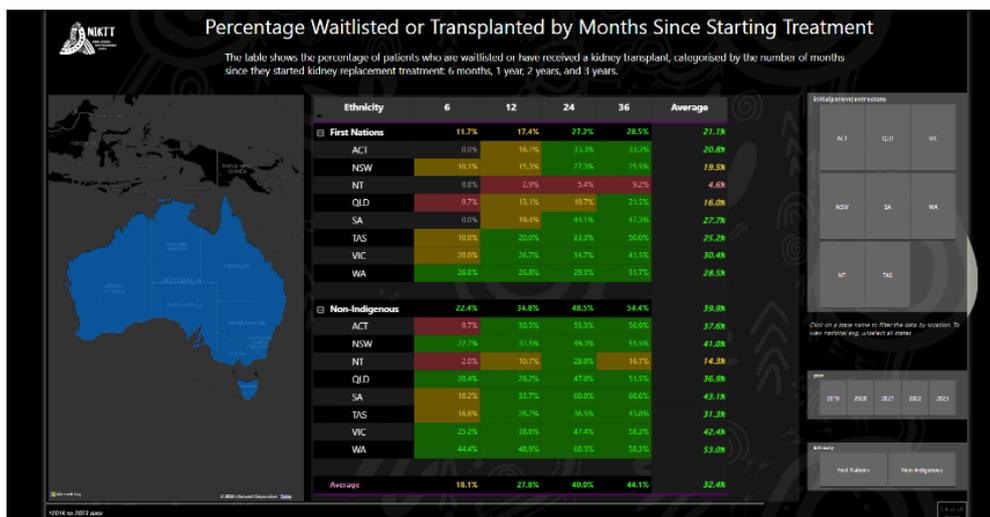


IMAGE 12. SCREENSHOT OF PAGE 5: NATIONAL DATA

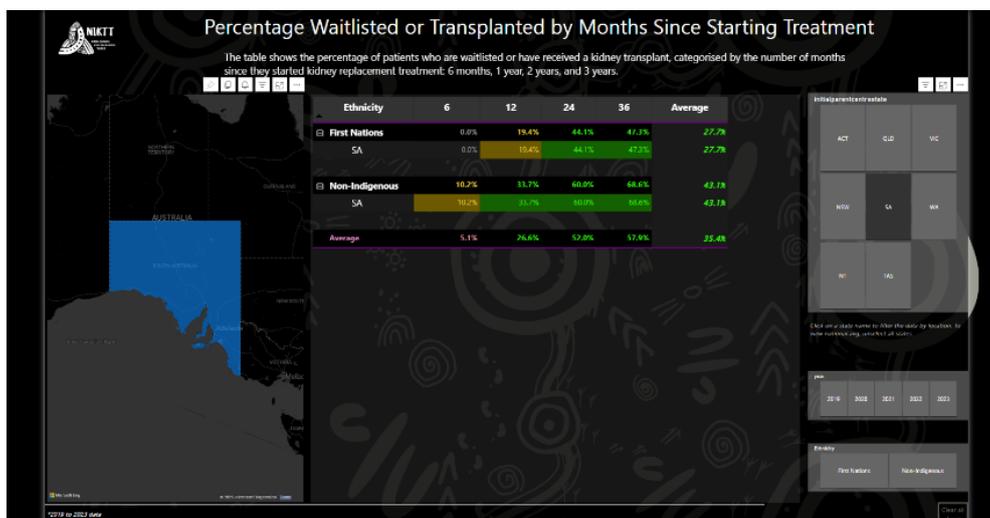


IMAGE 13. SCREENSHOT OF PAGE 5: SA DATA

2.3.2 Performance and Benefits of Activity 3 Deliverables

Task: Determine equity metrics through literature review, consultation, and key stakeholder engagement. The dashboard incorporates validated equity indicators, endorsed by ANZDATA and the Australian and New Zealand Society of Nephrology (ANZSN), ensuring alignment with clinical and research best practices. The inclusion of ANZSN’s Indicator 3: Transplantation Waitlisting allows stakeholders to monitor progress in timely access to transplantation.

Task: Develop and test the framework for the Data Dashboard. The dashboard was developed with interactive, user-friendly features designed to enhance data transparency and usability. Extensive internal testing within the NIKTT team ensured that the dashboard:

- Provides meaningful hospital and jurisdictional comparisons.
- Incorporates interactive maps and colour-coded performance metrics to support quick interpretation.
- Allows flexible filtering to enable both broad and detailed analysis of transplantation equity trends.

Task: Review the usability of the Data Dashboard. Preliminary usability testing was conducted internally, refining features such as geographic mapping, data filtering, and performance visualisation. These enhancements ensure that stakeholders can effectively use the tool to identify priority areas for intervention. External user testing will occur during the upcoming bridging year (2025-2026) with key stakeholders, including clinicians, Heads of Units, consumers, and government representatives.

Task: Launch the Dashboard. The dashboard was presented at the NIKTT Gathering in February 2025 to over 120 attendees, including patients, carers, clinicians, and government representatives. The demonstration showcased:

- The tool’s ability to compare transplantation outcomes across different units and jurisdictions.
- The interactive nature of the mapping and visualisation features.
- Its potential for informing clinical decision-making and policy development.

The dashboard will be further refined based on stakeholder feedback and formally presented at the TSANZ ASM conference. Ongoing consultation will continue over the next 12 months to optimise usability and ensure effective implementation.

2.3.3 Outcomes of Activity 3

The Data Dashboard represents a critical tool for advancing transplantation equity. It enables up-to-date, data-driven insights into disparities in access to kidney transplantation for Aboriginal and Torres Strait Islander patients.

Development of the dashboard successfully:

- Integrated key equity metrics, endorsed by ANZDATA and ANZSN, to track disparities in waitlisting and transplantation.
- Established an interactive platform prototype that allows users to analyse data by location, hospital, and demographic group.
- Was launched at the NIKTT Gathering 2025, with an initial demonstration to key stakeholders, fostering engagement and discussion.
- Created a foundation for future usability testing and stakeholder engagement to ensure the dashboard meets the needs of both Community and clinical users.

This dashboard serves as a foundational tool for monitoring transplantation equity, supporting data-driven advocacy, strategic decision-making, and targeted policy interventions to improve outcomes for Aboriginal and Torres Strait Islander patients.

2.4 Activity 4: Transplantation Equity Gathering



Activity 4 Objective

To host an annual Gathering that fosters collaboration between Community members, clinicians, and advocates, driving progress towards transplantation equity.

2.4.1 Overview of the Gathering

The NIKTT Gathering was held in February 2025, bringing together over 120 attendees, including patients, carers, clinicians, policymakers, researchers, and advocates from across Australia. The Gathering provided a crucial platform to discuss progress, challenges, and priorities in kidney transplantation equity, while reinforcing the importance of Community leadership and Indigenous governance. The event was structured over three days, each designed to prioritise Aboriginal and Torres Strait Islander peoples' voices, jointly identify challenges and solutions, and confirm a collective Position Statement.

Day 1, Gather: Blak Space (Mob-Only) Day. The Gathering was grounded in cultural authority and Indigenous governance, beginning with a mob-only, Blak space day that ensured Aboriginal and Torres Strait Islander patients, carers, and health leaders could speak freely, identify shared challenges, and develop collective solutions without external influence.

This day focused on:

- Providing a space for Mob to come together, get to know each other, and share stories in a more culturally safe environment.



- Discussing regional transplant and dialysis challenges, opportunities, and priorities.
- Identifying regional champions – key individuals who could advocate for improvements in their local contexts and share stories from their experiences.
- Sharing information about the future of NIKTT governance, exploring a shift toward a regionalised, Indigenous-led structure.



A participant reflected:

"This was the first time I've been in a room like this, where we could talk openly about what's happening in our hospitals and dialysis units. We need these spaces more often."

Key Themes & Priorities from Day 1:

- *Funding for Indigenous Reference Groups (IRGs):* Attendees emphasised the need for long-term funding to support existing and new IRGs, ensuring regional voices are included in policy and service decisions
- *Greater regional investment:* The importance of expanding support beyond urban hospitals to rural and remote dialysis units
- *Embedding Community leadership into governance structures:* Attendees reaffirmed that future policy decisions must be Indigenous-led, advocating for a regional governance model that strengthens local decision-making

One attendee noted:

"We are not an afterthought. We are there when co-designing is truly happening. We're not just a box to tick. We have the solutions because we live this life."

Day 2, Reflect: Equity in Practice & Systems Change. The second day of the Gathering opened to all attendees, including clinicians, policymakers, and researchers. Sessions focused on systemic barriers and practical solutions for improving transplantation outcomes.

This day focused on:

- Presentations from ongoing projects that were established based on NIKTT-funded pilot sponsorship, showcasing successful initiatives in Community-driven transplant support.
- A preview of new transplant unit infrastructure plans, which were designed to incorporate NIKTT recommendations to improve cultural safety and accessibility.
- Discussions on workforce and policy gaps, particularly in embedding cultural competency in hospital settings.

A Community member emphasised:

"Our mob aren't getting waitlisted fast enough, and when they do, there are so many roadblocks. We need doctors and hospitals to take this seriously and listen to what we're saying."

Key Themes & Priorities from Day 2:

- *Expanding the Aboriginal and Torres Strait Islander workforce in kidney care:* Patient navigators, coordinators, and Aboriginal health practitioners were identified as critical roles to improving transplant outcomes
- *Improving the transplant assessment and waitlisting process:* The barriers faced by patients in the work-up process were discussed, particularly delays, inconsistent communication, and a lack of culturally safe pathways.
- *Gaps in patient and community education and support:* Many attendees emphasised that better resources and peer support networks are needed.
- *Need for improved data, monitoring, and accountability:* Many emphasised that data transparency is key to tracking systemic failures and driving change.

A powerful moment came when a Community leader challenged the system:

"It's a violation of our rights that healthcare professionals aren't informing us of our choices on dialysis treatment."



Day 3: Policy, Proposals, & National Strategy. The final day focused on policy commitments, systemic change, and defining the next steps for embedding equity in kidney transplantation at a national level.

The day focused on:

- The updated kidney allocation algorithm presented by Professor Kate Wyburn from TSANZ, detailing how it aims to improve fairness, transparency, and equity in kidney allocation.
- The reaffirmation of NIKTT's Position Statement, solidifying priority areas for action moving forward.
- A highlight of the day was the interactive demonstration of the transplant phone call experience, where transplant patient Richard and nephrologist Andrew role-played a real-life scenario of receiving a kidney transplant offer. This provided deep insight into the emotions, uncertainties, and logistical challenges faced by patients. This demonstration will be turned into an animated video to share with Communities around the country.

One transplant recipient shared:

"That call changes your life in a second. We need more support to navigate what comes after—it's not as simple as just getting the kidney."

Key Themes & Priorities from Day 3:

- Increasing Aboriginal and Torres Strait Islander representation in the transplant workforce.
- Ensuring cultural competency training for clinicians and hospital staff.
- Developing stronger communication networks across health jurisdictions.
- Establishing a resource library or database for kidney- and transplant-related materials relevant for Aboriginal and Torres Strait Islander people.

A final takeaway came from a non-Indigenous clinician:

"As healthcare professionals in this room, we should all be making a commitment to call out racism and inequity when we see it happening in our units and services."

2.4.2 Performance and Benefits of Activity 4 Deliverables

Task: Create Conference Master Plan. The Gathering was developed to ensure a culturally safe, patient-centred, and solution-focused event. A comprehensive conference master plan was created to track key details, including attendees, agenda development, sponsorship, budget, travel arrangements, communications, and logistics.

Planning was informed by continuous consultation and lessons from the previous Gathering. The NIKTT Secretariat led the process with input from key partners to ensure the event structure aligned with the needs of Aboriginal and Torres Strait Islander patients and the broader kidney health sector. The decision to structure the event across three days was based on direct feedback from past attendees.

A key element of the master plan was ensuring accessibility and inclusivity for all attendees. The plan outlined logistical support, including travel and accommodation arrangements, honoraria for patient participants, and the integration of essential services such as on-site dialysis for those requiring treatment. The plan also incorporated a communication strategy to keep attendees informed, manage stakeholder engagement, and coordinate outreach to ensure broad participation.



The overarching theme, "Gather. Reflect. Act.", was selected to align with the Gathering's purpose of bringing people together, acknowledging challenges, and driving action. The master plan served as a working document, continuously updated to track stakeholder engagement, budget allocations, and event logistics, ensuring that planning remained coordinated and responsive to evolving needs.

Task: Organise Sessions & Confirm Attendees. The Gathering successfully engaged over 120 attendees (67 of whom were First Nations people, and 59 non-Indigenous people), ensuring representation from key sectors, including Community leaders, government representatives, clinicians, researchers, and policymakers. Sessions were designed to facilitate meaningful discussions around Community-led priorities and solutions, ensuring that the voices of Aboriginal and Torres Strait Islander patients and families were central to the event.

75 patients and carers were invited, with 46 attending. Patients and carers were selected to ensure a diversity of experiences and contexts, including individuals at different stages of the kidney care journey—pre-dialysis, dialysis, transplant recipients, and those receiving palliative care. Selections were made based on nominations from clinicians, health organisations, and community networks, prioritising individuals identified as kidney champions—people who actively advocate for better kidney care within their regions and communities. This approach ensured that discussions at the

Gathering were informed by lived experience and the perspectives of those most affected by kidney disease.

133 clinicians, advocates, government representatives, and other stakeholders were invited, with 80 attending. For clinicians, researchers, and other key advocates, attendance was managed through an Expression of Interest (EOI) process to ensure alignment with the Gathering's objectives. The EOI form (Appendix D) invited applicants to outline their role in kidney care, how they contribute to improving patient outcomes, and their understanding of and agreement to adhering to the principles and expectations for the Gathering. This process ensured that attendees were actively engaged in improving Aboriginal and Torres Strait Islander kidney health and that the event included a balanced mix of clinical and community perspectives. The EOI process also allowed for the identification of participants willing to contribute through presentations, discussion panels, or other forms of knowledge-sharing.



To facilitate attendance and ensure that logistical barriers did not prevent participation, full travel and accommodation support was provided for patients and their carers. This included:

- Airfares and transport for attendees from different regions, ensuring geographic diversity.
- Accommodation and meals, ensuring all invited Community members could fully participate without financial burden.
- An honorarium for patients and carers to recognise their time, contributions, and expertise.

Given that some attendees required dialysis during the event, arrangements were made for dialysis to be provided on-site through a mobile dialysis unit stationed at Kangkawodli, a dedicated Aboriginal health facility. This ensured that those requiring treatment could attend without disruption to their care. Coordination with local renal units allowed for seamless scheduling of dialysis sessions.

The structure of the sessions was designed to balance community-led discussions, clinician input, and policy engagement, ensuring that all perspectives were heard while centering the voices of Aboriginal and Torres Strait Islander patients and families.



The first day was designated as a Mob-only space, allowing Aboriginal and Torres Strait Islander patients, carers, and families to share experiences in a culturally safe environment without external pressures. Sessions focused on personal journeys with kidney disease, experiences with the health system, and reflections on barriers to care. Activities encouraged collective storytelling and peer support, creating a foundation for the discussions that would follow on subsequent days.

The second day brought together all attendees, including clinicians, kidney health organisations, and policymakers. Sessions were structured around regions of Australia, with key themes highlighted:

- Equity and access to transplantation – examining barriers and enablers to increasing waitlisting and transplantation rates for Aboriginal and Torres Strait Islander patients.
- Community-led solutions in kidney care – showcasing initiatives where Indigenous governance and Community solutions have improved outcomes.
- Clinician and health service responsibility – exploring ways to embed cultural safety, improve patient-provider communication, and address systemic issues within the renal care pathway.
- Policy and system-level change – discussions on how national, state, and territory health policies can better align with Community-identified needs.



These discussions were structured to be interactive and participatory, ensuring that patients and families had space to respond and guide the conversations.

The third day focused on identifying priorities and next steps, ensuring that discussions from the Gathering translated into actionable outcomes. Facilitated discussions aimed to consolidate key messages from previous sessions and identify gaps requiring further work.

A key principle in session planning was ensuring that Community voices were not just heard but actively shaped the dialogue. Moderators and facilitators were briefed to ensure that discussions remained culturally safe, respectful, and solution oriented. Opportunities for informal networking and yarning circles were also incorporated to strengthen relationships between attendees and allow for deeper discussions outside of formal sessions.

Task: Host the Gathering. The Gathering was structured to foster both formal discussions and informal connections, ensuring that attendees had multiple opportunities to engage with one another. Each attendee received a conference welcome pack, which included: an information package outlining the agenda, principles and expectations, key hosts, vendors, and sponsors; an attendee collective booklet featuring photos, names, and affiliations of participants to encourage networking and recognition; and a notepad, pen, and lanyard, ensuring attendees had resources to engage fully in sessions.

The event also included a conference dinner, which served as a key opportunity for attendees to connect in a more relaxed setting. The dinner featured a live performance by Rochelle Pitt (Soul Mumma), who was later joined by several attendees, including Uncle Eddie Peters and Uncle Richard Champion, creating a shared cultural experience through music.

One of the highlights of the Gathering was the incorporation of live art by Uncle Cedric Varcoe, a renowned Ngarrindjeri and Narangga artist, who painted throughout the event. His artwork visually captured the themes and discussions emerging over the three days, providing a meaningful representation of the Gathering’s purpose and outcomes.

An impromptu but impactful moment came from Dr. Andrew Mallet and transplant patient Richard Jenkins, who performed an unscripted but highly engaging reenactment of the moment a patient receives a transplant call. This sketch provided an informative yet deeply moving insight into the emotional experience of transplantation, resonating with both clinicians and patients.



Throughout the event, multiple opportunities for informal yarning circles and spontaneous storytelling allowed attendees to engage beyond structured sessions. These spaces facilitated deeper conversations, strengthened connections, and reinforced the importance of lived experience in shaping kidney care policy and practice.

Cultural elements were carefully integrated into the Gathering to create a setting that was welcoming, meaningful, and reflective of Aboriginal and Torres Strait Islander traditions. Upon arrival, attendees were gifted a Kaurna

shield pin, a symbolic welcome to Country that recognised the deep connection of the event to Kaurna land. The Gathering opened with two Welcome to Country ceremonies conducted by young Kaurna women, reinforcing the importance of respecting and acknowledging the Traditional Custodians of the land.

The event space was designed to reflect cultural themes of gathering and storytelling. Tables were decorated with gum leaves, soft lighting, and greenery arranged to mimic campfires, creating an environment that encouraged yarning and connection. Care was taken to ensure that vendors and suppliers reflected Indigenous businesses wherever possible. Tea bags, coffee, snacks, catering, printed materials, pens, tissues, and water were sourced from Aboriginal and Torres Strait Islander-owned companies, reinforcing the commitment to supporting First Nations enterprises.



These cultural components, along with the deeply personal contributions from artists, musicians, and storytellers, helped foster an atmosphere of respect, reflection, and collaboration throughout the Gathering. By embedding cultural protocols and traditions into the event, the Gathering was able to create a space that was not only informative but also deeply connected to Community, identity, and history.

Task: Complete Gathering Follow-Up. Following the Gathering, multiple initiatives were undertaken to ensure continued engagement and impact. A Position Statement ([Appendix E](#)) developed through the Gathering discussions is now being reviewed by attendees, providing them with the opportunity to read, reflect, provide feedback, and formally endorse the statement. This document will serve as a key advocacy tool to guide future policy and sector-wide improvements.

A post-event survey was distributed to attendees to gather feedback on the Gathering's structure, sessions, and overall impact. Insights from this survey will inform future iterations of the event and guide the development of ongoing initiatives.

A Community-facing report is being developed to summarize the key themes, discussions, and outcomes of the Gathering in an accessible format. Additionally, potential manuscripts and academic publications will be explored to document findings and share insights with a broader audience.

The Gathering's outcomes will also be presented at the upcoming Lowitja Conference, ensuring that the key messages and recommendations reach a national platform. This continued engagement and dissemination of learnings will help embed the Gathering's outcomes into broader health policy and practice.

2.4.3 Outcomes of Activity 4

The Gathering successfully strengthened networks, advanced policy discussions, and reinforced the need for Indigenous-led governance in transplantation. The event provided a platform for critical discussions, deepened stakeholder relationships, and ensured that Community voices remained central to the ongoing work of the NIKTT.

Key Outcomes:

- **A clear direction for NIKTT governance** – The Gathering reaffirmed the importance of regional and Community leadership, with strong endorsement for strengthening Indigenous governance structures within kidney transplantation.
- **Greater awareness of systemic barriers and practical solutions** – Discussions highlighted the ongoing challenges faced by Aboriginal and Torres Strait Islander patients in accessing transplantation and identified actionable solutions that align with Community priorities.
- **Momentum for policy advocacy and funding strategies** – The Gathering reinforced the need for increased investment in Indigenous-led kidney health initiatives, with a focus on equity and access to transplantation services.
- **Stronger sector-wide engagement** – Participation from government representatives, health services, and consumers and carers ensured that key decision-makers heard firsthand accounts from Community members, clinicians, and patient advocates.

- **Commitment to ongoing knowledge sharing** – Outcomes from the Gathering will be presented at the upcoming Lowitja Conference, ensuring that key messages reach a national audience and contribute to broader discussions on Indigenous health.
- **Development of resources and publications** – A Community-facing report is being developed to summarise key themes and discussions from the Gathering, alongside potential manuscripts and academic publications to document insights and findings for broader dissemination.
- **Endorsement of the Position Statement** – A draft Position Statement was introduced at the Gathering, with attendees reflecting on its content and purpose. Moving forward, attendees will have the opportunity to formally review and endorse the statement, ensuring it reflects the perspectives and priorities of those involved. This Position Statement will then be shared broadly with State, Territory, and Federal government representatives
- **Post-event evaluation and feedback** – A survey was distributed to all attendees to gather reflections on the Gathering’s impact, structure, and effectiveness. Insights from this evaluation will guide future iterations of the Gathering and inform next steps for the NIKTT.

The strong engagement and momentum generated through the Gathering will directly inform future strategies, policy discussions, and funding advocacy efforts, ensuring that Indigenous-led solutions remain at the forefront of kidney transplantation equity in Australia.



2.5 Activity 5: National Consumer Network Plan

Activity 5 Objective

To develop a proposal for a national body that represents the kidney health priorities of Aboriginal and Torres Strait Islander communities.



2.5.1 Overview of Activity

The objective of this activity was to develop a proposal for a national body that represents the kidney health priorities of Aboriginal and Torres Strait Islander communities. While the initial plan included direct Community consultations, the focus during this period shifted toward securing long-term structural and financial support for a sustainable governance model.

Rather than engaging Community prematurely—before clear commitments were secured—the NIKTT Secretariat concentrated on drafting a long-term strategy and implementation plan within a budget proposal to be submitted to the Commonwealth Government. This plan outlines the governance structure, financial requirements, and operational framework for an Indigenous-led consumer network, ensuring that future engagement with Community is meaningful and backed by concrete commitments. (Please see [Appendix C](#) for a summary of the budget submission.)

During this period, the Commonwealth Government, through the Jurisdictional Organ and Tissue Steering Committee (JOTSC), formally requested NIKTT's support in developing a plan for co-designing the implementation of Priority 2 of the *National Strategy for Organ Donation, Retrieval, and Transplantation*. Recognising NIKTT's expertise in Indigenous governance and consumer-led health structures, JOTSC invited NIKTT to submit a budget proposal outlining how an Indigenous-led national consumer network could be embedded within the broader implementation framework.

Key activities undertaken during this period included:

- Engaging with government stakeholders, the Organ and Tissue Authority (OTA), and the Commonwealth to align governance structures with national strategies.
- Participating in an OTA workshop in Canberra (July 2024) to contribute to the First Nations co-design of an implementation plan for the National Strategy for Organ Donation, Retrieval, and Transplantation.
- Presenting a proposed governance model to Fifine Cahill (JOTSC) to embed Aboriginal and Torres Strait Islander leadership and decision-making within Priority 2 of the strategy.

- Drafting and submitting a budget proposal at JOTSC's invitation, detailing the structural and financial requirements to establish an Indigenous-led national consumer network for kidney health.

This work laid the foundation for the formalisation of the potential National Consumer Network, ensuring that when Community engagement occurs, it is informed by structured governance, sustainable financial support, and clear pathways for implementation.

2.5.2 Performance and Benefits of Activity 5 Deliverables

Task: Engage Relevant Community Elders and Other Stakeholders to Plan Consultations.

Rather than conducting widespread consultations, the Secretariat engaged key Community members through targeted discussions to shape the governance structure and strategic direction of the consumer network. These engagements provided critical insights into:

- The role of a national Indigenous-led consumer network in driving kidney transplantation equity.
- How a regional governance structure could strengthen local and national decision-making.
- The necessity of securing long-term funding before expanding consultations.

By working in close collaboration with Aboriginal and Torres Strait Islander leaders, the Secretariat ensured that the proposed structure aligns with Community priorities and governance expectations.

Task: Conduct Community Consultations and Stakeholder Meetings. Due to the focus on longer-term planning and funding uncertainties, widespread Community consultations did not take place during this period. Instead, efforts were directed toward consultations with key government and policy stakeholders to solidify a governance and funding pathway, as well as Community consultations at the Gathering and through established IRGs.

The Secretariat traveled to Canberra in July 2024 for an OTA-hosted workshop, where it contributed to planning for how a First Nations co-design could contribute to implementation of the *National Strategy for Organ Donation, Retrieval, and Transplantation*. Representatives from OTA, TSANZ, and the Department of Health and Aged Care were present for this workshop, where plans were presented to Fifine Cahill, convenor of JOTSC, that outlined the proposed governance structure embedding Aboriginal and Torres Strait Islander leadership and decision-making within Priority 2 of the strategy.

At the time of reporting, we are awaiting feedback from the Department of Health and Aged Care on next steps for submitting the budget proposal that would fund this governance approach.

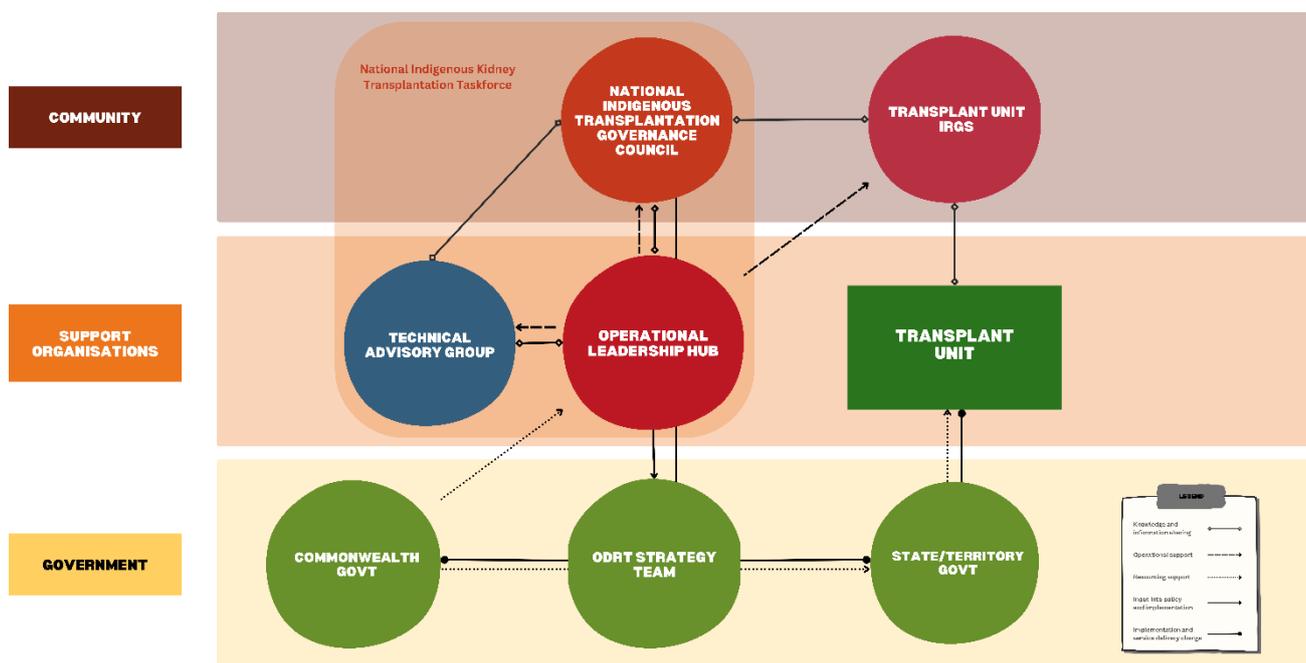
Task: Draft National Consumer Network Proposal. A drafted proposal for what consumer engagement, Indigenous governance, and a national network could look like was included in the budget submission proposal.

The drafted plan included:

- A regional governance model, ensuring that Aboriginal and Torres Strait Islander kidney patients have a structured voice at local, state, and national levels.
- A National Governance Council to oversee strategic direction, funding allocation, and policy alignment.

- A Technical Advisory Group (TAG) composed of Indigenous health professionals, nephrologists and transplant physicians, researchers, and policy experts to provide evidence-based guidance to the Council and NIKTT.
- Mechanisms for regional representation, allowing Community voices to influence decision-making at multiple levels.
- Sustainable funding pathways, ensuring that the consumer network can function as a permanent, Indigenous-led entity rather than a short-term project.

This structure went through numerous iterations amongst the NIKTT, in consultation with OTA and TSANZ, and with the Department of Health and Aged Care. Below is the latest version of a possible structure for ongoing transplantation equity work that is led, governed, and overseen by Aboriginal and Torres Strait Islander people.



Task: Finalise National Consumer Network Plan. The finalisation of the consumer network plan is contingent on government feedback and funding confirmation. While the original goal was to develop and implement the network within this period, the Secretariat made a strategic decision to focus on securing financial and structural backing first. The budget proposal submitted to the Commonwealth outlines clear funding pathways for long-term implementation and what the structure and governance of this national network would look like. Please see [Appendix C](#) for the summary of this budget submission.

Engagement with OTA, JOTSC, and the Commonwealth has ensured that the consumer network would be recognised within national kidney health and transplantation policies. Future work will involve refining governance structures, securing funding, and then expanding Community engagement once there is clear financial and policy commitment.

2.5.3 Outcomes of Activity 5

Significant progress was made in establishing the governance, policy, and funding framework necessary for a national consumer network to succeed.

Key outcomes include:

- A structured regional governance model that connects Community-led decision-making at the local, state, and national levels.
- Integration of the consumer network into the broader kidney health policy landscape, ensuring that it is formally recognised in government planning and budget submissions.
- Ongoing engagement with JOTSC, the OTA, and Commonwealth agencies, ensuring that the network is backed by government commitment before expanding to full-scale implementation.
- A sustainable funding proposal, embedded within the Commonwealth budget request, positioning the network for long-term viability rather than short-term consultation.

Moving forward, the Secretariat will focus on:

- Securing government approval and funding commitments to formalise the governance structure.
- Further refining the implementation strategy, including defining operational roles and responsibilities within the governance body.
- Re-engaging Community through structured consultations, ensuring that the consumer network is Community-driven and responsive to patient needs.

By prioritising structural sustainability over immediate rollout, the Secretariat has positioned the National Consumer Network for long-term success, ensuring that it will have the financial, policy, and governance foundation necessary to operate as a permanent and impactful body.

3. Challenges

3.1 Challenges Faced During the Grant Period

Throughout the grant period, the NIKTT Secretariat navigated several structural and systemic challenges that affected the pace, scope, and sustainability of its work.

Lack of sustainable funding for IRGs and broader initiatives. Despite strong interest and engagement in Indigenous Reference Groups, many transplant units could not formally establish or sustain these groups due to a lack of dedicated financial and workforce support. Without secure funding for First Nations leadership positions and operational costs, hospitals will continue to struggle to integrate cultural governance and Indigenous-led decision-making into clinical settings. Similarly, uncertainty around ongoing funding for the NIKTT itself created instability, limiting the ability to plan long-term initiatives or provide clear guidance to Community on the future of transplantation equity efforts.

Capacity constraints and competing priorities. The small size of the Secretariat team meant that substantial resources had to be directed toward developing a national budget submission alongside the Commonwealth Department of Health and Aged Care. While this work was critical for long-term sustainability, it reduced capacity to advance other planned activities, including broader Community engagement and expansion of IRG implementation efforts, and delayed the Gathering until the end of the grant activity period.

Policy and bureaucratic barriers. While there was high-level recognition of the need for Aboriginal and Torres Strait Islander governance in transplantation, translating this recognition into policy action was slow and fragmented. The absence of formal policy mandates requiring IRG implementation left hospitals to navigate these efforts without institutional backing, creating barriers to securing internal funding or workforce commitments.

Uncertainty about the future of NIKTT. Many Aboriginal and Torres Strait Islander patients, families, and health workers sought clarity on the long-term vision for transplantation equity. However, without confirmed funding beyond the grant period, the Secretariat was limited in its ability to provide definitive answers or secure concrete commitments from stakeholders. This lack of certainty impacted engagement.

3.2 Strategies and Actions Taken to Address Challenges

Despite these obstacles, the NIKTT Secretariat implemented several key strategies to mitigate the impact of these challenges and continue progressing its objectives.

Advocating for long-term funding. The development of a comprehensive budget submission in collaboration with the Commonwealth Department of Health and Aged Care provided a structured, evidence-based case for long-term investment in transplantation equity. This submission highlighted the need for permanent IRG funding, workforce positions, and governance structures to embed Indigenous leadership within transplant units.

Providing resources and guidance to hospitals. Recognising funding limitations, the Secretariat worked closely with transplant units to provide guidance, workforce documentation, and strategic advice on how to advocate for internal funding allocations. The IRG Checklist was developed to support

hospitals in navigating the process of IRG establishment, ensuring that units had clear, structured pathways for implementation.

Transparent communication and Community engagement. While uncertainty around funding persisted, the Secretariat maintained open and honest communication with Community, clinicians, and stakeholders. The NIKTT Gathering provided a platform to discuss future governance models, emphasising the shift toward a regionalised, Community-driven structure that could continue the work regardless of short-term funding cycles.

Positioning equity efforts for long-term impact. The launch of the Data Dashboard, strengthened partnerships with government agencies, and formalisation of the Position Statement at the Gathering all contributed to solidifying Indigenous governance and equity as permanent priorities in transplantation. These initiatives ensured that even in the absence of guaranteed future funding, equity remained a core focus in policy and clinical practice.

As of early March, 2025, the NIKTT was informed that it was successful in its application to the Grant Opportunity 7419: Indigenous Australians' Health Programme National Indigenous Kidney Transplantation Taskforce.

4. Learnings

Over the past 12 months, the National Indigenous Kidney Transplantation Taskforce (NIKTT) has made significant strides in embedding Indigenous governance, cultural safety, and equity-driven reform into the kidney transplantation landscape. Through the activities delivered under this grant, several key learning outcomes have emerged, informing both the ongoing challenges and the necessary next steps for sustaining long-term change.

Sustainable, embedded, and dedicated funding is essential for lasting change. One of the most critical lessons learned is that equity initiatives cannot be sustained without dedicated, long-term funding. This was particularly evident in the struggles of hospitals to establish or maintain Indigenous Reference Groups without guaranteed financial support. While there is strong will from clinicians and health services to embed cultural safety and Indigenous leadership, the lack of structural funding for Aboriginal and Torres Strait Islander workforce positions and IRG operational costs remains a major barrier. The need for secure, embedded funding within hospital budgets—rather than short-term project grants—has been reinforced as a core priority for future advocacy.

National strategies must be matched with regional and local implementation. The work of the IRGs and regional engagement efforts highlighted the importance of balancing national coordination with local solutions. While NIKTT has set strong national frameworks and guidance, individual transplant units and communities have vastly different needs and challenges. Regional governance models, Indigenous-led decision-making, and localised strategies are essential for ensuring that policy translates into real-world improvements in transplantation access and outcomes. This was reinforced through the Gathering discussions, where regional champions and community voices emphasised the need for place-based approaches. Future work must focus on strengthening regional coordination and ensuring that national policies are adaptable to different settings.

Data is a powerful tool, but must drive action. The Data Dashboard demonstrated the value of transparent, real-time data in identifying disparities and advocating for change. However, data alone does not drive change—actionable strategies must follow. The next steps must focus on embedding the dashboard into clinical governance and policy decision-making, ensuring that health services are held accountable for addressing inequities in waitlisting and transplantation rates. Additionally, further work is needed to expand Community access to the data, ensuring that Aboriginal and Torres Strait Islander patients and families can use these insights to advocate for themselves within the healthcare system.

Indigenous leadership and cultural safety must be embedded at all levels. A recurring theme across all grant activities was the central role of Indigenous leadership in driving meaningful change. The appointment of the Community Co-Chairs and National Community Engagement Coordinator has shown that when Aboriginal and Torres Strait Islander people are in leadership positions, programs and policies become more effective, culturally safe, and responsive to community needs. However, the work of the NIKTT has also highlighted that cultural safety cannot be an optional add-on—it must be systematically embedded within clinical governance, workforce structures, and patient care pathways. Future work must continue to advocate for mandatory cultural safety training, Indigenous-led service models, and formalised Indigenous governance in transplantation units.

Uncertainty in funding and policy undermines progress. One of the most significant challenges throughout the grant period was the uncertainty surrounding the future of the NIKTT and its initiatives. Without committed long-term funding, it was difficult to provide clear answers to Community members, plan for sustained engagement, or ensure that successful programs could

continue. This uncertainty creates instability, impacts trust, and limits the ability to build on momentum. Moving forward, a key priority must be securing long-term investment in transplantation equity initiatives to ensure that Aboriginal and Torres Strait Islander leadership in this space is not dependent on short-term grants and project-based funding cycles.

Collective voices and networks drive change. Despite these challenges, the Gathering demonstrated the strength of collective voices, shared experiences, and multi-stakeholder collaboration. The event reinforced that transplantation equity is not just a clinical issue—it is a movement driven by Aboriginal and Torres Strait Islander patients, families, clinicians, and advocates working together. The success of the Gathering, the reaffirmation of the Position Statement, and the strong engagement from policymakers and government representatives highlight that when Aboriginal and Torres Strait Islander people’s voices are centered and systems are held accountable, meaningful progress is possible.

5. Financial Report and Budget Proposal Overview

5.1 Financial Report

Please see the Income and Expenditure Report from 1 July 2024 to 30 January 2025, as per the Standard Grant Agreement 4-J1UOL4U, the Financial Acquittal Report has been submitted with the Final Report.

Income and Expenditure Report

1 July 2024 to 30 January 2025

	GST inc.	GST exc.
INCOME		
Funding Agreement	\$357,680	\$325,164
Funding Agreement	\$357,680	\$325,164
Gathering Sponsorship (2025)	\$5,500	\$5,000
TOTAL INCOME		\$655,328
EXPENSES		
SAHMRI	\$338,519	\$307,745
TSANZ Secretariat	\$19,161	\$17,419
SAHMRI	\$338,519	\$307,745
Auditor costs	\$1,529	\$1,390
TSANZ Secretariat	\$17,632	\$16,029
NIKTT Gathering (2025)	\$5,500	\$5,000
TOTAL EXPENSES		\$655,328
BALANCE		\$0

5.2 Budget Proposal Overview

The Budget Proposal outlined in [Appendix C](#) presents two funding scenarios for the continuation of the National Indigenous Kidney Transplantation Taskforce (NIKTT): Full Implementation and Reduced Implementation. Both scenarios aim to sustain NIKTT's progress toward equitable kidney transplantation access, strengthened Aboriginal and Torres Strait Islander governance, and systemic improvements in kidney care across Australia.

- The Full Implementation model enables maximum impact and ensures comprehensive service delivery and has a total budget of \$28,854,817 (exc. GST) over four years.

- The Reduced Implementation model maintains essential activities but requires trade-offs in engagement, staffing, and project reach and has a budget of \$17,688,261 (exc. GST) over four years.

Both scenarios reaffirm NIKTT's commitment to fostering equitable and culturally safe kidney care for Aboriginal and Torres Strait Islander Communities. The decision between these approaches depends on funding availability and prioritisation of key initiatives.

For a detailed financial breakdown and justifications, refer to Appendix C of this report.

Appendix A. Activity Work Plan

The following appendix contains an adapted table that outlines the deliverables, performance indicators, and timeframes of the original work plan for the Activity as well as corresponding "Progress" and "Status" columns which provide an update on completion of agreed activities and performance indicators.

Activity 1: National Indigenous Kidney Transplantation Taskforce Secretariat					
Task(s)	Deliverable(s)	Performance Indicator(s)	Timeframe	Progress	Status
Appointment of Project Manager	Project management maintained for 12 months, including detailed workplans, reporting, personnel management, implementation support, and activity oversight	<ul style="list-style-type: none"> • Activity workplans created • Grant staff hired and trained • Activity progress and success 	First month	<ul style="list-style-type: none"> - Activity workplans created and approved - Project Manager hired and onboarded 	Complete
Appointment of Community Engagement Coordinator	Communities actively and purposefully engaged and re-engaged across Australia; Cultural protocols around research, service delivery, consultation, and project implementation maintained at all times; Support and guidance provided for Indigenous Reference Groups; Supervision and leadership over Consumer Network Plan creation	<ul style="list-style-type: none"> • Grant staff hired and trained 	First month	<ul style="list-style-type: none"> - Community Engagement Coordinator hired and onboarded 	Complete

Appointment of Community and Clinical Chair	Cultural (and clinical) governance and guidance for Secretariat and grant activities; Expertise provided on grant activities, outcomes, and recommendations going forward	<ul style="list-style-type: none"> • Grant staff hired and trained 	First month	- Community and Clinical Chair appointed	Complete
Appointment of Clinical Chair	Clinical governance and guidance for Secretariat and grant activities; Expertise provided on grant activities, outcomes, and recommendations going forward	<ul style="list-style-type: none"> • Grant staff hired and trained 	First month	- Clinical Chair appointed	Complete

Activity 2					
Task(s)	Deliverable(s)	Performance Indicator(s)	Timeframe	Progress	Status
Identify units for new Indigenous Reference Groups	List of identified units and local 'champion(s)'	<ul style="list-style-type: none"> • Number of units assessed and contacted • Stakeholder agreement and commitment to new IRGs 	End of month 2	<ul style="list-style-type: none"> - All units assessed - Four new units contacted 	Complete
Establish new IRGs	Newly established IRGs	<ul style="list-style-type: none"> • Number of new IRGs established • Membership numbers • First meetings held 	End of month 8	<ul style="list-style-type: none"> - Introductory meetings held with 2 units - Champions identified - Challenges being recorded and worked on 	Complete

Provide support to existing IRGs	Existing IRGs supported to host continued meetings	<ul style="list-style-type: none"> • Number of meetings held • Number of members engaged • Activities undertaken 	Ongoing; end of month 10	- Support provided to 2 existing IRGs	Complete
Document IRG activity	Annual report on IRG activities	<ul style="list-style-type: none"> • Groups submitting overview/summary of activities • Report progress 	End of grant	Not started	Complete

Activity 3: Equity Data Dashboard

Task(s)	Deliverable(s)	Performance Indicator(s)	Timeframe	Progress	Status
Determine equity metrics through literature review, consultation, and key stakeholder engagement	Comprehensive list of equity metrics to be considered	<ul style="list-style-type: none"> • Robust list of metrics developed and key measures decided 	End of month 3	- Metrics decided and extracted from ANZDATA	Complete
Develop and test the framework for the Data Dashboard	Dashboard framework developed in partnership with ANZDATA	<ul style="list-style-type: none"> • Dashboard development progress • Feedback on prototype 	End of month 6	<ul style="list-style-type: none"> - Dashboard wireframe in progress - Feedback not yet collected 	Complete
Review the usability of the Data Dashboard	Usability assessment and feedback report	<ul style="list-style-type: none"> • Completion of report • User satisfaction with Dashboard features and function 	End of month 9	Not started	Complete
Launch the Dashboard	Officially launched Equity Data Dashboard	<ul style="list-style-type: none"> • Launch progress • Initial utilisation rates 	End of month 11	Not started	Complete

Activity 4: Transplantation Equity Gathering

Task(s)	Deliverable(s)	Performance Indicator(s)	Timeframe?	Progress	Status
Create conference master plan, including theme, agenda, location, and date	Master plan for lead up to conference, including details on the theme and agenda	<ul style="list-style-type: none"> Progress towards finalised plan Stakeholder feedback on theme and agenda 	End of month 1	<ul style="list-style-type: none"> Date and venue set Stakeholder agreement on theme and agenda 	Complete
Invite attendees, organise sessions, and confirm sponsorships, vendors, and conference requirements	List of invited stakeholders, speakers, and session topics; Sponsorships from relevant organisations sought; plans implemented on schedule	<ul style="list-style-type: none"> Completion of invitations Confirmed attendance, sponsorship, and vendors 	End of month 6	- Ongoing	Complete
Host the Gathering	Well-coordinated, culturally safe, equity-focused Gathering held	<ul style="list-style-type: none"> Hosting of Gathering to budget and plan Attendee feedback and satisfaction 	End of month 11	Not started	Complete
Complete Gathering follow-up	Gathering findings and feedback report	<ul style="list-style-type: none"> Feedback surveys completed Gathering report complete 	End of month 12	Not started	Complete

Activity 5: National Consumer Network Plan

Task(s)	Deliverable(s)	Performance Indicator(s)	Timeframe	Progress	Status
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Engage relevant Community Elders and other stakeholders in order to plan consultations	Series of endorsed consultations planned and stakeholders invited	<ul style="list-style-type: none"> • Number of Communities engaged • Number of stakeholders engaged 	End of month 2	<ul style="list-style-type: none"> - Three Communities engaged - Stakeholders engaged at academic conferences 	Complete
Conduct Community consultations and stakeholder meetings	Culturally sensitive Community consultations conducted across Australia; Stakeholder meetings held	<ul style="list-style-type: none"> • Number of consultations held • Number of Community members in attendance • Number of stakeholders consulted 	End of month 6	<ul style="list-style-type: none"> - No consultations with Community held yet 	Complete
Draft National Consumer Network proposal	Initial framework for network drafted	<ul style="list-style-type: none"> • Number of Communities re-engaged and provided with draft proposal • Number of stakeholders draft proposal shared with 	End of month 9	Not started	Complete
Finalise National Consumer Network plan	Finalised plan for Network that integrates feedback from Community and stakeholders	<ul style="list-style-type: none"> • Plan progress • Plan communicated 	End of month 12	Not started	Complete

Appendix B. IRG Checklist

New IRG Checklist	
MILESTONE	
1. Initial consultation with Director/HoU	
Indigenous Reference Group Overview	
Identify how IRG can align with current strategies, policy or action plans	
Identify potential funding stream	
2. Local support and commitment to establish IRG	
Letter of ongoing support and commitment from Transplanting Unit	
Community connections, involvement and support.	
Local AMS/ACCHO identified and invited to be a part of change	
3. Identify clinical leaders and staff within the hospital	
Identify clinical leaders and staff within the hospital (advocacy and support)	
Keep advocates and allies informed / Bring them along on the journey	
Identify Aboriginal and Torres Strait Islander person who can lead IRG and priorities from within the hospital	
4. IRG membership determined	
Identify patients	
Engagement and relationship building	
Cultural mapping (ensure adequate representation)	
5. Organise first IRG meeting	
Venue	
Transport	
Additional support requirements for members joining meeting online	
Catering	
Sitting fees	

6. First IRG meeting held	
Development of Terms of Reference (purpose, governance, membership, meeting schedule, level of administrative support, dispute resolution process, etc)	
Record minutes	
7. Priorities identified	
Unpack themes	
IRG Priorities Identified	
Priorities shared back to Transplantation Unit for consideration	

Appendix C. Budget Submission Proposal Summary

Executive Summary

This proposal presents an implementation plan from the National Indigenous Kidney Transplantation Taskforce (NIKTT) to support the policy priorities of the Commonwealth Department of Health and Aged Care. It outlines Phase 1 (2026-2030) of NIKTT's strategic approach to improving access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people.

Phase 1 focuses on establishing a sustainable, Aboriginal and Torres Strait Islander-led governance and advisory framework that directly supports the Department to close the gap in kidney transplantation equity. Central to this phase is the creation and enhancement of Indigenous Reference Groups (IRGs) and an Aboriginal and Torres Strait Islander Governance Council. These bodies will serve as the primary drivers of culturally safe, Community-centred strategies that can be implemented nationally. Throughout Phase 1, the NIKTT will further evolve as a focused and coordinating national entity, empowering consistent Community engagement through regional and targeted initiatives, fostering collaborative networks, and utilising data-driven approaches to strategically guide and implement vital improvements in kidney transplantation care.

NIKTT seeks funding for four years to continue its role as a dedicated driver of change, building on its prior achievements and laying the groundwork for future expansion.

Specifically, Phase 1 will:

- **Establish a robust Governance Council:** Ensuring that Aboriginal and Torres Strait Islander leadership, voices, and lived experiences drive national transplant policies and strategies
- **Develop and coordinate a Technical Advisory Group (TAG):** Bringing together clinical and technical expertise to support the Governance Council's work and ensure best practices in kidney care guide strategic change
- **Maintain and enhance a national data platform:** Tracking transplant rates, waitlisting rates, and cultural safety metrics, providing insights that hold governments and services accountable to strategic objectives
- **Advance best practice models of care through national collaborations and Community-driven pilot projects:** Facilitating partnerships between Community, transplant units, policymakers, and service delivery stakeholders to identify barriers to care, develop culturally safe interventions, and share learnings nationally

Future phases will build on the successes of Phase 1, enabling broader implementation of these initiatives and ensuring long-term improvements in kidney health equity. At its core, this proposal is built on the fundamental requirement that Aboriginal and Torres Strait Islander governance and Community leadership are privileged in the plans, strategies, and actions taken to achieve equity in kidney transplantation. This proposal thus represents a meaningful shift towards the long-term sustainability of Aboriginal and Torres Strait Islander peoples' leadership within the national transplantation landscape, aligning with the Priority Areas and Goals of the Strategy.

The establishment of the NIKTT's systems and governance structures will be an iterative process, ensuring that time is taken to engage consistently and meaningfully with Aboriginal and Torres Strait Islander Communities. This approach allows for the foundations of the NIKTT's governance and programs to be robust and culturally appropriate, but it also means that full establishment may take

longer. The priority is to set up these systems in a way that honours Community consultation and delivers long-term, sustainable outcomes.

NIKTT has consistently engaged with the Department of Health and Aged Care, particularly through the Jurisdictional Organ and Tissue Steering Committee (JOTSC), in providing feedback on the *National Strategy for Organ Donation, Retrieval, and Transplantation* (Strategy). At JOTSC's request, NIKTT has helped co-design the following proposal in order to aid implementation for Priority 2 of this Strategy. This proposal details the Commonwealth's role in this plan, and NIKTT's established relationships with Community, clinicians, and policy advisers ensure it aligns with the needs and priorities of all stakeholders.

Budget Proposal Overview

This proposal outlines two budget scenarios for the continuation of the National Indigenous Kidney Transplantation Taskforce: *full implementation* and *reduced implementation*. Both scenarios aim to support the strategic goals of NIKTT, including improving kidney transplantation equity, strengthening Aboriginal and Torres Strait Islander Community governance, and fostering systemic changes within kidney care across Australia.

Full implementation represents an ideal budget allocation to maximise impact across all NIKTT activities, ensuring robust governance, comprehensive engagement, and meaningful project delivery. This approach prioritises achieving all goals at a high capacity, with investments in personnel, Community-led projects, cultural safety monitoring, and infrastructure development.

Reduced implementation represents a streamlined budget designed to achieve core priorities while operating within fiscal constraints. This version reduces staffing, travel, and engagement budgets and narrows the scope of some initiatives without compromising the overarching goals of NIKTT. Key adjustments in this model include:

- **Personnel:** Reduced FTE for roles like Regional Community Coordinators (RCCs) and a reduction in FTE for some positions such as the Data Platform Specialist
- **Projects:** Decreased funding for individual projects
- **Engagement and Infrastructure:** Leveraging existing platforms and reducing travel and event frequencies

Rationale for reductions

The reduced implementation budget is tailored to maintain the momentum of NIKTT while accounting for a tight fiscal environment. However, reductions may impact the depth of Community engagement, the scale of project outcomes, and the ability to rapidly address emerging needs across all jurisdictions.

Comparison

- **Full Implementation** requires a total investment of \$28,854,817 (excl. GST) over four years, ensuring full delivery of NIKTT's strategic objectives at maximum capacity
- **Reduced Implementation** requires \$17,688,261 (excl. GST) over four years, representing a leaner approach to achieving NIKTT's goals while managing resources prudently

Both models reflect the commitment of NIKTT to fostering equitable kidney care for Aboriginal and Torres Strait Islander Communities. The decision between these scenarios depends on funding availability and prioritisation of program activities.

Appendix D. Gathering Expression of Interest Form

Expression of Interest: 2025 NIKTT Gathering

The 2025 NIKTT Gathering is a space dedicated to championing Aboriginal and Torres Strait Islander leadership, knowledge, and self-determination. To uphold the integrity of this Blak-led space, we invite expressions of interest (EOIs) from those committed to engaging respectfully, contributing meaningfully, and participating as active learners.

The purpose of the 2025 NIKTT Gathering is to ensure future care and practice in kidney transplantation align with Community priorities, supported by policy and clinical excellence. We ask you to complete this EOI to demonstrate your commitment to these values and principles.

Please complete the questions below as thoughtfully and honestly as possible. There are no word limits or minimum requirements for your responses – we encourage responses that reflect your genuine commitment to learning, sharing, and supporting the values of the Gathering.

For any questions, please reach out to Kelli Owen (National Community Engagement Coordinator: kelli@anzdata.org.au) or Katie Cundale (Program Manager: katie@anzdata.org.au).

For more information on the 2025 NIKTT Gathering, please see the information brochure here: [heyzine.com/flip-book/2025-NIKTT-Gathering](https://www.heyzine.com/flip-book/2025-NIKTT-Gathering)

Please note: selected EOIs may be included in a booklet shared with attendees.

* Required

Tell us about your ways of working

1. Your Involvement in Care *

Tell us about your work in the care or support of Aboriginal and/or Torres Strait Islander people, particularly in relation to kidney disease, failure, or transplantation. How do your experiences or expertise in health care align with improving access to kidney transplantation for Aboriginal and Torres Strait Islander people?

Reflecting on the health care provided by you or within your hospital, how can care for Aboriginal and Torres Strait Islander people be improved?

3. Understanding Expectations *

Please read the expectations section of the information package: [heyzine.com/flip-book/2025-NIKTT-Gathering#page/10](https://www.heyzine.com/flip-book/2025-NIKTT-Gathering#page/10)

Please confirm that you have read and understood the principles and expectations of the Gathering

4. Sharing Your Voice and Expertise *

The Gathering values diverse perspectives and shared successes. Would you like to contribute by sharing a success story, practice, or insight that could inform discussions and improvements in kidney transplantation? Let us know what this is and how you might like to present the work (e.g., presentation, poster, video, paper, or discussion topic).

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Expression of Interest: 2025 NIKTT Gathering

* Required

Your details

5. **Full name**

Enter your answer

6. **Email address**

Enter your answer

7. **Organisation and role**

Enter your answer

8. **Country you're travelling from (living on)**

Enter your answer

9. Please select the day(s) and events you will be attending *

- Gathering Day 1, Tuesday 18th February [Mob only]
- Gathering Day 2, Wednesday 19th February
- Gathering Day 3, Thursday 20th February
- Meet and Greet welcome, Tuesday 18th February, evening
- Dinner, Wednesday 19th February, evening

10. Please let us know if you have any dietary preferences, mobility needs, or other requirements to ensure your full participation in the Gathering *

Enter your answer

Back

Submit

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Appendix E. 2025 Position Statement

Position Statement

Transplantation Equity for Aboriginal and Torres Strait Islander Peoples with Kidney Disease
Delegates attending the 2025 NIKTT Gathering support the continued strategic efforts by Aboriginal and Torres Strait Islander peoples, in partnership with advocates, to advance Aboriginal and Torres Strait Islander peoples' rights to optimal health and wellbeing through equitable and accessible kidney transplantation.

The delegation endorses the following recommendations to improve care before and after kidney transplantation:

- Establishment of a **peak body that leads national efforts to improve care**, develops resources, advocates for change, shares knowledge, and monitors research and service delivery;
- Ongoing support and career development opportunities for the Aboriginal and Torres Strait Islander **kidney health workforce**, including nurses, doctors, allied health professionals, patient navigators, transplantation coordinators, Aboriginal liaison officers, and Aboriginal health practitioners;
- **The implementation and expansion of wrap-around support services**, including support groups and patient reference groups;
- Aboriginal and Torres Strait Islander people experience healthcare free of racism, through ongoing cultural awareness, training, safety, and accountability;
- Relevant education and sharing resources created that are designed by and delivered by Aboriginal and Torres Strait Islander people;
- Transparency of information in an understandable and accessible way, supporting family decision making for live kidney donation and transplantation;
- Young peoples' kidney health and wellbeing prioritised and improved through transplantation, in the next phase of strategic transplantation equity work;
- Identify and address the unmet needs of carers, adult patients, children and young adults, and elders navigating transplant access and care.
- The delegation endorses the rights of self-determination and leadership by Aboriginal and Torres Strait Islander peoples who are best positioned to understand the needs of their own communities.
- The delegates find it crucial that improving kidney failure outcomes through transplantation and partnering effectively with existing health services. Delegates also support the safety and rights of all workers, ensuring the right to work without oppression and racism (overt and covert), as a key foundation of successful partnerships.
- Delegates understand that kidney health, including care during kidney replacement therapy (like transplantation), is just one part of overall healthcare. It must be supported by a range of services that focus on health and wellbeing as a whole. To improve health outcomes, individual efforts require their **own funding and governance, led by Aboriginal and Torres Strait Islander leadership**. We acknowledge that without appropriate resources, others may struggle to partner in this work. The

NIKTT has learned, through equity and access projects, that improving transplantation equity requires **additional funding that isn't covered by current service procedures.**

The delegation therefore endorses the **following actions** for the next phase of the work to improve transplantation equity:

- Establishing a body to **represent Aboriginal and Torres Strait Islander peoples living with kidney disease and transplantation**, which will oversee and support networks, resources, reporting, monitoring, and accountability;
- Ongoing **development of programs to facilitate better access to transplantation** with a focus on improving the health of people with CKD so they can be waitlisted;
- **Monitoring, recording, and reporting** (e.g. through an annual score-card) on improvements in workforce, program delivery, and transplant waitlisting and achieved transplantation;
- Working with workforce partners to grow an experienced, culturally safe, and resourced Aboriginal and Torres Strait Islander regional workforce across all levels of prevention, transplant access and post-transplant care in Community-controlled health services;
- Promoting transparency and accountability of funding of kidney health services so that we can know how decisions are made, by whom, and what has been achieved;
- Continuing to host Gathering Meetings that raise awareness and facilitate capabilities of national networks