







## **Contents**

Executive Summary

6/7

Introduction

8/9

Background

10/11

Position Statement

12/13

Gathering Principles

14/15

Day One: Gather

16/19

Day Two: Reflect

20/33

Day Three: Act

34/43

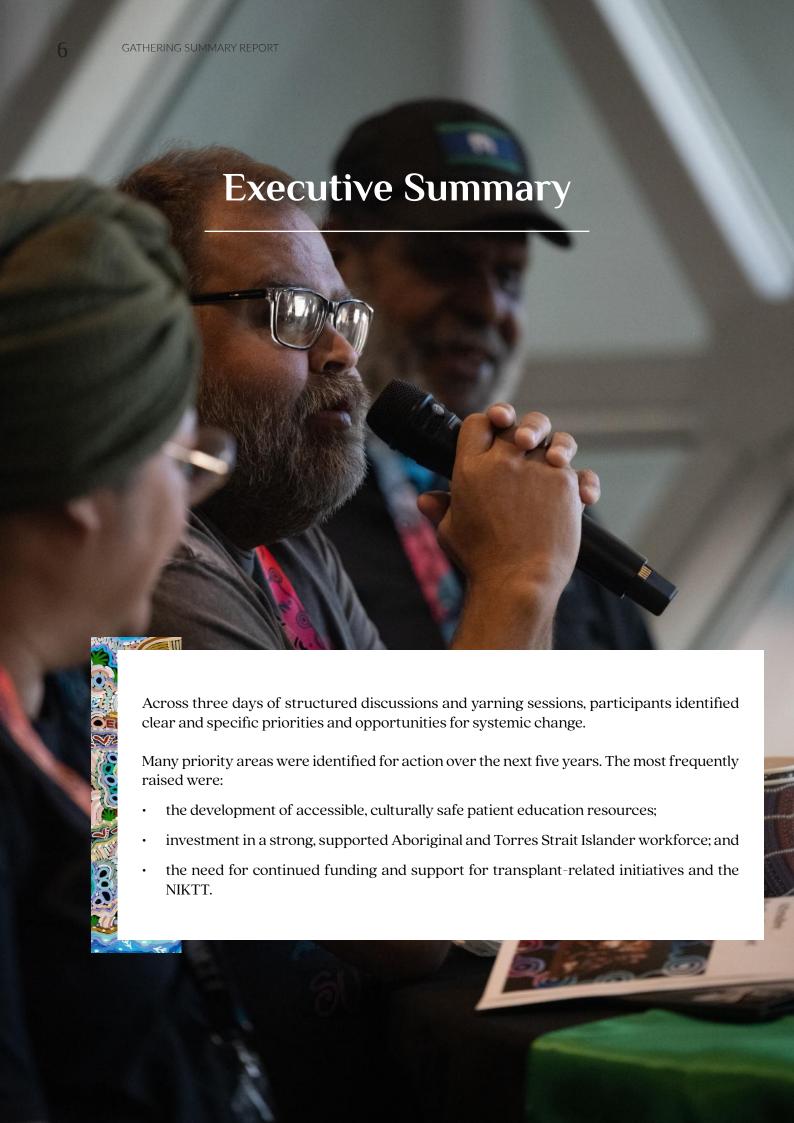
Outcomes: Priorities

46/47

Outcomes: Actions

48/49

Aboriginal and Torres Strait Islander readers are advised that this summary report contains images of people who have passed away.



Overall, solutions and priorities raised throughout the Gathering can be grouped into seven overarching themes:

- 1. Aboriginal and Torres Strait Islander workforce and leadership: Grow and support the Indigenous kidney health workforce, including peer roles, clinical staff, and regional leadership positions. Strengthen and fund Indigenous Reference Groups nationally;
- **2.** Cultural safety and better communication: Implement place-based, ongoing cultural safety training and hold services accountable for safe and respectful care;
- **3. Education and resources:** Develop culturally appropriate, visual, in-language education materials for patients and carers, with shared national templates adaptable by region;
- **4. Access to care:** Address transport and infrastructure barriers in rural and remote areas, provide metro assistance. Support mobile dialysis, outreach assessment teams, and continuity of care post-transplant;
- **5. Psychosocial, carer, and family support:** Fund respite, counselling, and support for carers and families, recognising their central role in patient well-being, provide well-being support for patients;
- 6. Funding, structures, and reform:
  Secure sustainable and flexible funding for community-led models, transparent Indigenous governance, and national coordination. Redefine KPIs and build transparent data systems; and
- 7. Prevention, early intervention, and longterm care: Invest in screening, prevention, and wrap-around care, from early CKD through post-transplant.

Participants proposed a wide range of concrete actions, including developing a standardised set of transplant information, creating transplant education videos, establishing a national network for Aboriginal health workers, embedding Indigenous roles in leadership teams, and increasing the amount of lived experience Aboriginal and/or Torres Strait Islander people in the kidney transplant workforce, including kidney champions (patients) and Aboriginal Health Practitioners.

Feedback from attendees was overwhelmingly positive. Participants appreciated the Gathering's inclusive format and emphasis on Aboriginal and Torres Strait Islander leadership, storytelling, and solution-building. The need to maintain momentum, secure sustainable funding, and continue meeting regularly as a national community of practice was a recurring theme.

The NIKTT Position Statement was reviewed and confirmed as fit-for-purpose, setting out clear next steps including: establishing a national body to represent Aboriginal and Torres Strait Islander peoples living with kidney disease; monitoring and reporting transplant equity outcomes annually; expanding the First Nations kidney health workforce; and ensuring transparent, accountable funding for Community-informed services and models of care.

These outcomes and recommendations will be shared with Community, clinical stakeholders, and governments, and submitted to the Federal Department of Health, Disability, and Aging. They will directly inform the implementation of Priority 2 and 4 of the *National Strategy for Organ Donation, Retrieval and Transplantation*, with a strong focus on Aboriginal and Torres Strait Islander self-determination, systems change, and sustained action.

## Introduction

In February 2025, the National Indigenous Kidney Transplantation Taskforce (NIKTT) held the NIKTT Transplantation Equity Gathering on Kaurna Yarta. It brought together more than 120 people from across Australia, including Aboriginal and Torres Strait Islander patients, carers, and health workers, alongside non-Indigenous clinicians, advocates, and policymakers.

The Gathering was a national opportunity to gather, reflect, and act together. The primary focus of the Gathering was to champion Aboriginal and Torres Strait Islander self-determination in kidney transplantation equity by sharing knowledges to guide future care and practice, aligning Community priorities with policy and best-practice clinical care.

This report provides a summary of the Gathering's program and outcomes. A more detailed report and all Gathering photos can be found on the NIKTT website: www.niktt.com.au.









## Background

The National Indigenous Kidney Transplantation Taskforce was established in 2019 to improve access to, and outcomes of, transplantation kidney for Aboriginal and Torres Strait Islander people. While First Nations peoples in Australia experience end-stage kidney disease at significantly higher than non-Indigenous Australians, systemic inequities continue to result in lower rates of waitlisting and therefore transplantation. The need to develop a Taskforce and build network of coordinated patients and clinicians came from the 2018 Transplantation Society of Australia and New Zealand (TSANZ) performance report that outlined clear recommendations to improve kidney transplantation access and outcomes for Aboriginal and Torres Strait Islander people. A conference held in Alice Springs in 2019, the National Indigenous Dialysis and Transplantation Conferece, was the first national meeting of this group.

In December 2022, the NIKTT hosted the inaugurall Gathering, held at Tandanya National Aboriginal Cultural Institute in Adelaide. This 2022 Gathering brought together Aboriginal and Torres Strait Islander patients, carers, and clinicians alongside non-Indigenous Taskforce members, clinicians, and policymakers to share experiences, identify priorities, co-design national recommendations. The event culminated in the endorsement of a shared Position Statement for transplantation equity for Aboriginal and Torres Strait Islander peoples. This Position Statement outlined a collective vision and a series of concrete recommendations, including the establishment of a national peak body,thegrowthofanIndigenous renal health workforce, the expansion of culturally safe transplant-related models of care, and the implementation transparent monitoring reporting mechanisms. and The full statement is available here: Transplantation Equity Position Statement 2022.

A key outcome from the first Gathering was the need for sustained momentum and collaborative action. In early the recommendations from the work of the Taskforce. as well as the Position Statement and key priorities raised in the Gathering, were submitted to all state and federal Ministers for Health and/or Indigenous Affairs and formally presented to the Assistant Minister for Indigenous Australians and the Assistant Minister for Health in March 2023.







Although structural change long-term and government investment remain ongoing challenges, the federal government provided bridging funding through the Indigenous Australians' Health Programme to sustain NIKTT's work for an additional year throughout 2024. This funding aimed to improve access to kidney transplantation for Aboriginal and Torres Strait Islander peoples through:

- Supporting the development and growth of Indigenous Reference Groups (IRGs) at transplant units;
- Developing a national data dashboard to track progress in closing the disparity gap in transplantation access;
- Contributing to the design of a proposed national peak body to lead equity work; and
- Convening a second national Gathering of patients, carers, clinicians, and advocates.

This 2025 Gathering was made possible through that bridging funding. It was not intended to replicate the 2022 event, but to build on it — deepening relationships, tracking progress, and moving from shared ideas into collaborative action.



National Indigenous Dialysis and Transplanation Conference 2019





Second NIKTT Gathering 2025



## **Position Statement**

Updated during the 2025 NIKTT Gathering on Kaurna Yarta, Adelaide, 18-20 February 2025.

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, as listed online, endorses the following recommendations to improve care before and after kidney transplantation:

- Establishment of a 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 Torres Strait Islander kidnev health workforce, including nurses, doctors, allied health professionals, patient navigators, transplantation coordinators, Aboriginal liaison officers, and Aboriginal health practitioners;
- The implementation and expansion of wraparound 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 selfdetermination 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 means 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 (overtand convert), as a key foundation of successful partnerships.

Delegates understand that kidney health, including care during kidney replacement therapy, is just one part of overall kidney care and 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;
- 2. 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;
- 3. Monitoring, recording, and reporting on improvements in workforce, program delivery, and transplant waitlisting and achieved transplantation;
- 4. 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;
- 5. Promoting transparency and accountability of funding, data, and information about kidney health services so that we can know how decisions are made, by whom, and what has been achieved;
- 6. Continuing to host Gathering meetings that raise awareness and facilitate capabilities of national networks.

A full list of the delegates who officially endorsed the Statement is available on the NIKTT website.



# **Gathering Principles**

The Gathering was designed as a culturally safe, inclusive, and participatory event grounded in Aboriginal and Torres Strait Islander leadership. Participation was coordinated through two pathways: targeted invitations and a formal Expression of Interest (EOI) process. All attendees were asked to confirm their understanding of the Gathering's guiding principles before registering, ensuring shared expectations around respectful engagement, collaboration, and care.

Invitations were extended to Aboriginal and Torres Strait Islander patients, carers, and community members, with careful attention to geographic, cultural, and experiential diversity, as well as key organisational stakeholders. Participation for patients and carers was supported through fully covered travel, accommodation, and meals to remove financial barriers.

The EOI process was open to clinicians, advocates, and policymakers. It included reflection questions to encourage genuine engagement in a Blak-led space. All applicants received a briefing pack outlining the Gathering's intent, agenda, and participation guidelines.

Cultural safety was central. The event's guiding principles, developed by Community and refined across both Gatherings, emphasised listening with respect, contributing with care, and making space for all voices. Participants could choose how and when to engage, including taking time away from sessions if needed.

A wide range of supports and intentional design elements were incorporated to enable meaningful and culturally safe participation.

- **Emotional and cultural support:** A Distress Protocol and on-site NIKTT staff provided support throughout the event.
- Welcome materials: Attendees received a pack with a Gathering booklet, program information, notebook, and a "Collective Booklet" introducing all participants by name, region, and perspective. This was shared in advance to support connection and trust.
- **Engagement tools:** Post-it notes, communal easels, and Mentimeter were used to gather real-time reflections and feedback.
- **Space design:** The venue layout prioritised small, circular tables that aimed to evoke the idea of campfires, to encourage yarning and disrupt hierarchy.
- Cultural setting: SAHMRI was selected not only for accessibility, but for its commitment to Aboriginal health equity and cultural safety.

A Mob-only opening day created a protected space for Aboriginal and Torres Strait Islander participants to connect, share stories, and set the tone for the days ahead.

Throughout the Gathering, a live artwork by Uncle Cedric Varcoe responded to the themes, stories, and spirit of the event. The evolving piece served as a collective visual expression and is featured throughout this report.

To ensure dialysis was not a barrier to participation, NIKTT worked with renal services across states to coordinate safe, flexible dialysis care for participants. This included the relocation of the SA Rural Support Service's mobile dialysis truck to Kanggawodli, where patients could dialyse close to the venue in a culturally safe setting.





# Day One: Gather

Day One of the NIKTT Gathering 2025 was dedicated to Aboriginal and Torres Strait Islander participants, including kidney patients, carers, family members, health workers, and community advocates. It provided a closed space for Mob to connect, share experiences, and begin shaping priorities for the future.

The day opened with a Welcome to Country by Ashum Owen, a Kaurna, Ngarrindjeri, and Narungga woman and leader of Ngangki Warra — a female-led cultural group that amplifies women's voices through culture, dance, and language. The Welcome was followed by an introduction to the purpose of the Gathering and a round of introductions among attendees. The morning and early afternoon centred on shared storytelling, with participants invited to reflect on their own journeys, sharing perspectives on what does, and does not, work for people in their regions for kidney transplant care.

In the afternoon, discussions continued with a session introducing the ANZDATA Aboriginal and Torres Strait Islander Health Working Group, and the final session brought together themes from across the day, with each region nominating a Kidney Champion to speak on their behalf in the cross-sector sessions planned for Day Two.

All sessions on Day One were Mob-only, with the space intentionally held for open, grounded discussion among Community. As such, no recordings were made from this day and quotes, themes, or key discussion points were not collated.









# Day Two: Reflect

Day Two of the Gathering brought together Aboriginal and Torres Strait Islander kidney patients and carers alongside First Nations and non-Indigenous health professionals and system leaders for a full day of collective learning and truth-telling. The program was designed to share regional stories of success and change to identify local, regional, and national priorities. Day Two was framed as a space for cross-sector exchange, where Community voices would lead the conversation and clinicians, policymakers, and service partners would contribute as active allies.

## Welcome to Country

Day Two began with a heartfelt and powerful Welcome to Kaurna Yarta by Jakirah Telfer, who comes from the dry forest clan, Mullawirra Meyunna, of the Kaurna people of the Adelaide plains region. Speaking first in language, Jakirah acknowledged the ancient spirits that remain present on Kaurna land and the living culture that continues to breathe through the people today. She welcomed delegates to Tarntanyangga, the dreaming place of the red kangaroo, and extended her greeting to Aboriginal and Torres Strait Islander attendees from all directions — honouring their lands, waters, skies, and laws.

Jakirah acknowledged the old spirit in new ways, by sharing a dance which spoke of the balance of women, family, and the sun. The song had been silent for over a hundred years, but Jakirah and her sister have brought it back to the people and back to Country. She expressed deep gratitude for the opportunity to share this sacred part of her culture in a space that felt safe and affirming. She closed by acknowledging the impact of colonisation on First Nations peoples and the importance of creating and protecting space for young people to lead.

"If they aren't giving us the space, they're taking it from us... So, I leave you with a language word — nakutha — meaning until our paths meet again, which is that circle, which is where our people come from, the first people of the first sunrise."



#### Overview of the NIKTT

The opening session of Day Two was led by NIKTT Co-Chairs Professors Stephen McDonald and Jaquelyne Hughes and focused on outlining the purpose, progress, and future direction of the Taskforce. The session began by inviting participants to reflect on the identities and perspectives they brought to the Gathering, using a word cloud to visualise the range of roles in the room. Stephen noted that the Gathering was designed to be different from typical medical meetings, and that discomfort — for both clinicians and Community — was a necessary part of making change.

Stephen provided the rationale behind the creation of the NIKTT, which was established in response to national data showing that Aboriginal and Torres Strait Islander people experience kidney failure at disproportionately high rates but are significantly less likely to receive a transplant. Analysis from ANZDATA confirmed that the main barrier was access to the transplant waitlist, rather than transplant success once listed. These findings could not be explained by medical factors alone and highlighted the need to address systemic and institutional contributors to inequitable access.

The NIKTT was established in 2019 under the Transplantation Society of Australia and New Zealand, with Commonwealth Government funding, to begin addressing these issues. Its core activities included pilot projects to improve access, support for Indigenous Reference Groups, improved data reporting through ANZDATA, and a commissioned report into cultural bias in kidney care. These activities informed the NIKTT's Final Report in 2023, and contributed to national policy discussions, including the development of the National Strategy for Organ Donation, Retrieval, and Transplantation, released in 2024.

The session also introduced current NIKTT initiatives, including the development of a national data dashboard to support transparency and local



quality improvement. The presenters noted that while the national strategy identifies improving access to transplantation for Aboriginal and Torres Strait Islander people as a top priority, there is not yet an associated implementation plan. They emphasised the opportunity for Gathering participants to help define what implementation should look like, based on existing work, evidence, and community experience.

They concluded by highlighting the opportunity — and responsibility — for the Gathering participants to collectively shape what happens next.

"There's not much point having a plan unless you're going to do something about it. [And] that's the opportunity. The document says "we're not sure what to do. The work of the NIKTT will inform implementation." What that means is the power is in the room. People in Canberra know they need to do something. They don't quite know what and how to do it. And that's called an opportunity." — Stephen McDonald

"And that's also called working together." — Jaqui Hughes



## Sharing Stories from South Australia

This session focused on kidney care initiatives in South Australia, highlighting culturally led models of practice and regional priorities identified by local Kidney Champions.

## Central and Northern Adelaide Renal Transplant Services (CNARTS)

Presenters: Kelli Karrikarringka Owen, Kate Tyrell, Sam Bateman, Richard Goldsmith, Arna Westhead, Donna Vigor

The CNARTS team presented their approach to embedding cultural leadership and Aboriginal governance in kidney care. Led by Aboriginal and non-Aboriginal staff working together, the team described their model at the Royal Adelaide Hospital (RAH), which combines clinical expertise, cultural authority, and place-based learning. The work is guided by the Indigenous Reference Group Purdita Purruna Wangkanthi ("Talking Kidney Health"), formed with NIKTT support and now funded directly by the hospital. The IRG identified eight priority areas for improving cultural safety; the team has begun actioning the first three, including a culturally safe model of care, ongoing engagement with Kaurna Elders, and the introduction of traditional healing practices such as organ cleansing ceremonies.

A key aspect of the model is the formal integration of cultural leadership into the clinical system. Kelli Karrikarringka Owen, a transplant recipient and Aboriginal leader, holds a designated cultural advisory role within the unit. Alongside her, a multidisciplinary "Kidney Dream Team" supports co-design and long-term change. The service has also grown its Aboriginal workforce from one to six staff, introducing new roles such as a Patient Navigator Coordinator, an Aboriginal Health Practitioner, and COMPASS Patient Navigators with lived experience. These roles aim to provide community-informed responsive, support throughout the kidney care journey.

To build broader cultural safety, the team developed "Walking in Two Worlds," a training course for hospital staff that focuses on place-based learning and challenges default assumptions about Aboriginal patient experiences. The course uses Kaurna Yarta to explore how health, culture, and Country intersect, and encourages staff to identify and address systemic barriers to care. While not intended for direct replication, the team encouraged other hospitals to develop their own culturally relevant programs in partnership with local Elders and Communities.



The presentation also identified future priorities, including succession planning for team roles, expanding workforce pathways, developing educational materials in Language, and progressing the remaining IRG priorities.

### **SA Kidney Champions**

South Australian kidney champions Arna Westhead and Richard Goldsmith identified three key priorities for improving kidney care:

### 1. Increase the First Nations kidney health workforce

There is a strong need to grow and support an Aboriginal and Torres Strait Islander workforce in dialysis, transplant, and care coordination roles. This includes creating career pathways and upskilling clinicians to take on specialised roles.

"We know that mob want care from mob, so increasing our First Nations workforce was a big priority." – Arna Westhead

#### 2. Expand cultural safety training for non-Indigenous clinicians

Cultural safety training should be delivered nationally and grounded in Aboriginal and Torres Strait Islander models of communication, such as clinical yarning. Increasing the First Nations workforce must not replace non-Indigenous responsibilities to deliver culturally safe care.

#### 3. Fund more dialysis chairs and expand access

Dialysis access remains limited in regional areas like Whyalla, Port Augusta, and the APY Lands. There is a need to increase the number of chairs in existing sites and establish new services in areas of unmet need. Funding should come from a combination of government, private, and philanthropic sources.



## Sharing Stories from Western Australia

### Kimberley Renal Services (KRS)

Presenters: Emma Griffiths and Nick Corsair

KRS, a community-controlled service based in Broome, shared their work in increasing transplant suitability assessments and embedding these into local models of care. They presented a continuous quality improvement initiative designed to ensure all dialysis patients received systematic transplant suitability assessments. The team developed a tool that enabled local GPs and staff to classify patients as ready, delayed, or currently unsuitable for transplant, with regular review by visiting nephrologists.

Of 66 patients assessed, the majority were found to have no permanent contraindications. Many had temporary barriers such as smoking or weight that could be addressed with support. Within 12 months, eight patients were added to the transplant waitlist.

The team also conducted interviews with patients and staff, identifying key themes:

#### 1. People wanted more information

Participants wanted to know more about the transplant process. They wanted more time with the transplant coordinator and then more follow up from the transplant team. They wanted lists of what needed to be done and where to get support

#### 2. Always waiting or forgotten

Some patients felt like they were waiting a while to hear back or proceed to do further testing. While some patient progressed others did not and left patients with a feeling or either being left out or having no idea of what was happening.

#### 3. Knowing what, but not how to make changes

A large challenge for those aware of what was stopping them getting on the waitlist, like weight loss, and giving up smoking weren't sure where to get support. More promotion and education on making change were identified as helpful.

KRS highlighted ongoing work to embed transplant processes into routine care, including hiring more staff, developing peer education models, and integrating transplant assessments into their electronic medical record. They noted the value of transplant recipients accompanying outreach trips, and flagged future priorities including post-transplant care models and capacity-building in local health services.





#### **WA Kidney Champions**

Keith McKinley and Maxine Gore shared lived experiences and identified priorities to improve kidney care in remote and regional communities:

#### 1. Increase dialysis access and capacity

Many patients in northern WA must travel long distances to access a small number of dialysis chairs, often facing delays and long waiting times. There was a call for more dialysis chairs, expanded services closer to home, and improved infrastructure to reduce travel burden and wait times.

#### 2. Secure safe and stable housing for dialysis patients

Overcrowding, homelessness, and unsafe living conditions remain significant barriers for people receiving dialysis. Some patients are living in makeshift shelters or outdoors while managing chronic illness.

#### 3, Improve transport services

Gaps in transport support make it difficult for patients to attend regular dialysis appointments. While some areas have taxis or dialysis trucks, others have no reliable options, leading to missed sessions and increased health risks.

#### "Kidney Transplant" - My Journey video

Dr Doris Chan, a kidney specialist from Western Australia, reflected on a collaborative pilot project undertaken as part of the NIKTT work, involving teams from Royal Perth Hospital and Kimberley Renal Services. The project focused on creating accessible and culturally appropriate health education materials for both patients and health professionals, particularly in remote regions where face-to-face education isn't always possible, so that educational materials could be passed on and re-educated to others in the region.

Recognising the need for consistent and shareable resources, the team developed a culturally tailored cartoon animation with the support of their health service and in collaboration with an Aboriginal artist, Peter Ryan, known for previous work on post-amputation care, and narrated by Darryl Jackson. The project involved close input from Aboriginal Liaison Officers, the Kimberley team, and Kelli Owen to ensure the language, tone, and imagery were culturally safe and meaningful. The animation is designed to support transplant education and promote understanding across diverse communities.

Dr Chan noted that the team is now seeking funding for a follow-up project focused on post-transplant care, aiming to continue building engaging and culturally grounded resources that can be used widely across WA. Watch the "Kidney Transplant" — My Journey video developed by the Government of Western Australia's North Metropolitan Health Service here:





#### Stories from the Northern Territory

### **Alice Springs Renal Unit**

Presenter: Kerry Dole

Kerry Dole, Renal Transplant Coordinator, presented on the development of the THRIVE model in Alice Springs — a patient-centred approach to dialysis with the ultimate goal of increasing transplant access for First Nations patients in Central Australia. THRIVE reframes dialysis as a space for growth, learning, and empowerment, rather than passive treatment. It is grounded in a strengths-based framework and co-designed with patients and clinicians.

Kerry also shared findings from a retrospective transplant outcomes study in Central Australia, led by Dr Sajan Thomas, which showed improvements in Aboriginal and Torres Strait Islander patient and graft survival post-2015, particularly in the first five years after transplant.

#### The THRIVE model includes:

- Training: Skills-building around kidney health and self-management
- Honouring: Valuing patients' strengths and experiences in shaping their care
- Resourcing: Supporting patients to become advocates and educators
- Inviting independence: Encouraging participation in self-care and decision-making
- **V**ehicle to transplantation: Supporting transplant readiness and follow-up
- Empowerment: Enabling patients to lead their care and influence others

The model is currently being piloted with a small group of self-nominated patients, with long-term plans for expansion. To make this model sustainable, Kerry identified the need for:

- Ongoing nephrologist time dedicated to the project,
- Partnerships with Aboriginal Community Controlled Health Organisations (e.g., Congress, Purple House),
- Aboriginal Health Practitioner and Patient Navigator roles embedded within government services, and
- Research partnerships to support evaluation and scale-up.



## **NT Kidney Champions**

Rowena Albert, a transplant recipient, and Onika Paolucci, an Aboriginal Health Practitioner for Renal Home Therapies, spoke on behalf of the Northern Territory delegation, sharing the priorities identified by Community members during the Day One yarns:

### 1. Timely waitlisting for transplantation

Patients should be waitlisted within six months of starting dialysis, with regular updates on progress.

### 2. Dialysis on Country

Care should be delivered by Aboriginal Health Practitioners and family members where possible, to maintain connection to Country and reduce the disruption of relocating.

## 3. Family and community support

Community and family members should be actively involved in supporting the mental and physical wellbeing of dialysis and transplant patients.

#### 4. Cultural health leadership and coordination

Transplant readiness teams should include Aboriginal Liaison Officers, interpreters, and Aboriginal Health Practitioners to ensure culturally appropriate face-to-face engagement.



## Stories from Queensland

## North Queensland Kidney Transplant Service (NQKTS)

Presenter: Michelle Harfield

Dr Michelle Harfield introduced the establishment of Queensland's second kidney transplant service, based at Townsville University Hospital, due to begin performing transplants by June 2025. Designed to serve North and Far North Queensland, the service is being built from the ground up with cultural safety, regional equity, and sustainability at its core. Michelle described the deliberate effort to embed values of equity and cultural respect across governance, care delivery, staffing, and evaluation — guided by recommendations from NIKTT's performance and cultural bias reports.

#### The model includes:

- Recurrent funding for an Indigenous Reference Group (IRG) co-designed with community members and chaired by Indigenous health leaders, recognised as subject matter experts;
- Dedicated Aboriginal and Torres Strait Islander health workforce embedded within the transplant service (not seconded to other areas), with a goal of establishing a strong, regionally-based transplant capability;

- Cultural information tools used at referral to capture individual needs related to housing, health literacy, spirituality, and support systems;
- Outreach clinics and a proposed one-stop "investigation day" model to reduce patient travel burden; and
- Evaluation structures, including key performance indicators related to patient displacement from Country, completion of cultural tools, and feedback from patients, workforce, and Community.

Michelle noted that strong political momentum in Queensland enabled the successful case for recurrent funding, and stressed that future sustainability depends on embedding values into structure and policy. She closed by acknowledging the importance of building upon existing work from the Princess Alexandra Hospital and NIKTT's outreach clinics, with the goal of creating a transplant service that reflects what patients say they want.



#### **QLD Kidney Champions**

Kidney recipient Julius Tabua and renal nurse Breanna Solomon shared priorities for Far North Queensland, particularly for Torres Strait Islander and remote communities. Their reflections focused on workforce development, patient education, and system infrastructure:

#### 1. First Nations workforce

There is a need for more Aboriginal and Torres Strait Islander health workers and clinicians, especially GPs, to support transplant workup, communicate effectively with patients, and help keep care closer to home.



#### 2. Education and advocacy

Both healthcare providers and patients require better education on kidney disease, prevention, and care pathways. More emphasis is needed in primary care to support early detection, health literacy, and family involvement.

#### 3. General workforce and infrastructure

Additional staffing is needed across both transplant and renal services, especially in remote and regional areas. Infrastructure improvements are needed to ensure coverage across the entire care continuum.

#### Stories from National Work

#### **Better Renal Services**

Presenter: Melanie Beacroft and Jason Agostino

Melanie Beacroft and Dr Jason Agostino presented on the Better Renal Services initiative — a national effort to improve dialysis access for Aboriginal and Torres Strait Islander people in remote and very remote areas. The program, funded by the Australian Government, is guided by the National Agreement on Closing the Gap and aims to deliver culturally responsive, community-led care.

Key features of the initiative:

- \$73.2 million was committed to build 30 four-chair dialysis units with workforce accommodation as needed, based on local need and community readiness;
- A Steering Committee, co-chaired by Mel and Jason,includesrepresentativesfrom Aboriginal and Torres Strait Islander organisations, kidney experts, and governments to guide site selection and planning; and
- To date, nine units have been funded, including completed infrastructure in Coober Pedy and a developing project on Badu Island.

Jason Agostino emphasised that infrastructure alone is insufficient:

"It's one thing to build a couple of buildings, it's another thing to have the appropriate staff there and to fund it appropriately so that it's sustainable."

He called out the unsustainable reliance on charity and short-term funding, stressing the need to embed local Aboriginal and Torres Strait

Islander health workforces into these services for long-term success.

Jason also described NACCHO's work to develop a national strategy addressing the "triple threat" of kidney disease, diabetes, and cardiovascular disease. This strategy will:

- Be informed by consultations with 146 Aboriginal Community Controlled Health Organisations (ACCHOs);
- Span the full continuum of care from prevention to palliative care; and
- Include targeted health workforce upskilling, including kidney care modules developed with Aboriginal RTOs and the Kimberley renal team.

A related workforce initiative is the Aboriginal and Torres Strait Islander Health Traineeships program, which has seen nearly 400 enrolments to date, offering a platform for future specialisation in areas like kidney care.

#### **Audience Discussion Highlights:**

- No single national kidney plan exists with a clear implementation pathway. Funding was directed toward dialysis infrastructure based on an election commitment, not a strategic assessment.
- Priority Reform Areas from the National Agreement on Closing the Gap were discussed as key levers for systemic change:
  - Shared decision-making with Aboriginal and Torres Strait Islander people,
  - Investment in the community-controlled sector,
  - Transformation of government organisations to eliminate racism,
  - Shared access to local data to enable community-led decision-making.

Jason noted that all levels of government, including states and territories responsible for transplant services, have signed onto these reforms — and are currently falling short in implementing them.

#### **NSW** and **VIC** Kidney Champions

Patient advocates Monica Kerwin (NSW) and Eugenia Flynn (VIC) shared lived experiences and regional priorities, highlighting ongoing barriers to culturally safe kidney care, particularly for carers and people navigating the system alone. Key priorities included:

#### 1. Carer Support and Respite

Carers need structured, culturally safe respite services. Many provide intensive care with little support or recognition, and trust is critical to handing over care.

"Having someone who knows families in a Community, who is trusted, who then can walk alongside them and provide that respite and provide that support would be really helpful" — Eugenia Flynn

#### 2. Culturally Appropriate Education

There is limited accessible education about kidney disease in regional areas. Information needs to be delivered early, in plain language, and through culturally relevant formats.

Eugenia and Monica both emphasised the need for Aboriginal kidney care specialists who can walk alongside patients and carers through the system.

#### 3. Prevention, Screening, and Outreach

Participants supported bringing mobile or outreach models (like breast screening vans) to kidney disease screening. New technologies enable earlier detection in schools and clinics.

### 4. System Gaps and Data Disconnection

Monica noted how cross-border arrangements and fragmented care systems disrupt service access



and data tracking. After moving to Adelaide from western NSW, her family experienced significantly better care — raising concerns about service equity across jurisdictions.

"They're not gaps anymore... Our people are seriously falling into sinkholes." — Monica Kerwin





# Day Three: Act

The final day of the Gathering brought together the full group of participants to focus on priority-setting, system change, and future directions. The day began with a powerful and unexpected performance: a live enactment of a transplant phone call by Richard Jenkins, a transplant recipient from Western Australia, and Dr Andrew Mallet, a nephrologist from Queensland. This set the tone for a session led by Dr Kate Wyburn, President of TSANZ, who introduced Australia's revised Kidney Only Allocation Algorithm (KOALA) and explained key changes designed to improve fairness, transparency, and clinical outcomes.

Throughout the day, discussions explored the systemic and practical implications of the National Strategy for Organ Donation, Retrieval, and Transplantation, presented by Rushika Wirasinha from the Department of Health and Aged Care. Attendees raised questions around equity, funding, and implementation, with a particular focus on ensuring Aboriginal and Torres Strait Islander leadership and lived experience are embedded across all stages of reform.

A summary of key priorities identified across the Gathering was then presented, followed by a participatory session on Positive Provocative Proposals, where attendees were invited to articulate problems they've experienced, propose solutions, and identify the supports required to make change happen. The NIKTT Position Statement was reviewed and confirmed, with participants suggesting changes to the wording and focus of the recommendations.





Richard and Andrew performed a transplant phone call, which has subsequently been turned into an animation to share as a resource with patients and carers to better understand what might happen once they are on the list. Watch the animation here:





# TSANZ Revised Allocation Algorithm: Kidney Only Allocation Algorithm

Presenter: Kate Wyburn

Dr Kate Wyburn, clinical transplant nephrologist and president of the Transplantation Society of Australia and New Zealand (TSANZ), presented an overview of the revised Kidney Only Allocation Algorithm (KOALA). She opened by acknowledging the significance of the role-played transplant phone call in grounding technical information in real patient experiences.

Kate explained that the kidney allocation system is a computer-based algorithm that determines which patient on the waitlist will receive an available donor kidney. While the previous system was applied equally, it produced unintended inequities. The revised algorithm aims to improve fairness, transparency, and clinical outcomes through six core changes:

- Better support for sensitised patients Uses a graded scale to ensure those with high antibody levels (due to previous transplants, transfusions, or pregnancy) are not disadvantaged
- 2. Improved prognosis matching Seeks to match donor kidneys to recipients based on predicted longevity, maximising overall life years gained
- 3. Support for younger patients Prioritises children and young adults through extended paediatric priority and better HLA matching to reduce long-term sensitisation
- 4. Adjustment for matchability by ethnicity Considers the difficulty of finding matches for patients with rarer immune profiles, rather than relying on fixed six-antigen matches
- Retention of time-based equity Time on the waitlist remains a central factor once clinical factors are addressed
- 6. Shift from tiered to continuous scoring Replaces rigid thresholds (e.g., PRA >95%) with a continuous score, allowing for more tailored and equitable decision-making.

Kate highlighted that allocation is only one part of the transplant journey, and that getting onto the waitlist remains the greatest barrier. She emphasised the importance of early education, staying well, and ensuring patients understand what to expect — including the possibility of travel for a transplant that may not go ahead.



Kate's presentation generated a range of questions from attendees, reflecting both the technical complexity of the algorithm and the real-world concerns of patients and providers navigating transplantation.

#### Q: How often is travel cancelled for transplants?

A: Kate confirmed that this is a real occurrence, with transplants sometimes cancelled last minute due to donor condition or surgical findings. She noted this can be distressing but also signals that a patient is being considered.

#### Q: How long is the average wait for a kidney?

A: Varies by blood type, state, and sensitisation. In NSW, average wait time has dropped from five to four years; for some patients it may be shorter.

## Q: What is the impact of prior transplants on matching?

A: Previous transplants can sensitise the immune

system, making matching harder. The revised algorithm prioritises sensitised and younger patients to address this.

#### Q: How do you know if someone is sensitised?

A: Determined via blood test sent to tissue typing labs. A PRA score reflects the percentage of potential donors a patient would react to. This data is visible in OrganMatch and available through nephrologists.

#### Call for standardised patient education

Dr Shilpa Jesudason proposed a national effort to develop a clear, accessible information sheet for all transplant candidates. She stressed the need for consistent communication across services, including helping patients understand whether they are on the waitlist and what it means.



#### National Transplant Strategy

Presenter: Rushika Wirasinha

Rushika Wirasinha, Director of the Organ and Tissue Policy and Programs Team at the Australian Government Department of Health and Aged Care, presented an overview of the *National Strategy for Organ Donation, Retrieval and Transplantation*, released in November 2024. She opened by sharing her personal journey from Sri Lanka to Canberra, and her path from medical research into health policy, framing her work as a way of translating practical ideas into systemic change.

The strategy was endorsed by all state, territory, and federal health ministers and sets out four national priorities and ten goals aimed at improving the organ donation and transplantation system. While the strategy does not include dedicated funding at this stage, its multijurisdictional endorsement provides a mandate for coordinated implementation and future investment.

Rushika focused particularly on Priority 2, which seeks to improve equitable access to transplantation for Aboriginal and Torres Strait Islander peoples and people in regional and remote areas. She acknowledged the NIKTT's leadership



in shaping this priority and stated that her team has worked closely with the Taskforce to develop an initial proposal to support its implementation — one that will continue to be refined in response to Gathering outcomes and broader consultation. She also referenced Priority 1 (system coordination and living donation) as relevant, while reaffirming that Priority 2 remains the primary avenue for embedding equity and Aboriginal and Torres Strait Islander governance.

Looking ahead, the Joint Organ and Tissue Steering Committee (JOTSC) will be responsible for developing an implementation plan. This plan will outline a mix of immediate and longer-term actions, some dependent on future budget decisions. Rushika acknowledged that while there are constraints ahead of the next federal election, (held in May 2025) there are still opportunities to build momentum and prepare funding proposals for upcoming budget cycles.

Following the presentation, Kelli Owen raised concerns about the lack of immediate funding and the absence of a clear implementation pathway:

"Our people are still dying on these machines. Our people are very sick and we are pushing through as hard as we can — and we hear that you are hearing us, but what do we now need to do if there is no way forward and no resourcing and no implementation plan?"

Rushika acknowledged the frustration, reiterating that funding decisions are made by government and that this year presents an opportunity to build awareness and momentum toward future implementation. She encouraged participants to continue raising the profile of this work in their communities and through conversations with local representatives.

Kelli concluded by urging attendees to act:



#### Positive Provocative Proposals

Facilitator: Jaqui Hughes

This session invited participants to shift from identifying problems to offering solution-focused proposals grounded in lived experience and real-world insight.

Framed around the idea that governments and systems can be shaped by the people they serve, the session encouraged attendees to act as solution builders — people who listen, collaborate, and bring ideas forward for change.

#### Each participant was asked to:

- · Reflect on a problem they have seen or experienced in kidney transplantation,
- Propose a solution they might lead or support,
- Identify who should be involved, what resources are needed, and how success could be measured,
   and
- · Collaborate with others to refine their ideas into positive, provocative proposals.

#### Case Study: "We Need Better Transplant Education"

Danielle Stephenson (RAH Transplant Nurse Unit Manager)

#### Problem:

 Patients lack clear transplant education from the perspective of lived experience

#### **Solution:**

- · National education toolkit
- Patient stories + videos

#### Supports needed:

- Funding
- Lived experience co-designers, digital media experts

Timeframe: Under 12 months

Widely supported by clinicians and audience participants

"We would like to work with NIKTT on these resources that can be adapted by each transplant units, they can be nationwide, but adaptable to each unit. And we'd like to include videos of patient stories because patient stories are very powerful educational resources"

#### What's the problem? Grouped by perspective

#### **Patients**

- Don't know if they're on the waitlist
- Delays in work-up
- No early education
- Lack of wraparound supports

#### Carers and families

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- Travel/ accommodation burden
- No mental health or respite care
- Excluded from care planning

#### Clinicians

- Isolation in roles (esp. AHPs)
- No access to full teams
- Lack of shared tools, working in silos

#### System advocates

- Promising ideas stuck
- No national plan
- No funding for successful local initiatives

#### What are the solutions? Grouped by theme

#### Access to care and service navigation

- Outreach models as ongoing, best-practice standard of care
- Optimised management of co-morbidities such as diabetes

#### Workforce development

- National AHP network/community of practice
- Funded Indigenous kidney champion roles
- Targeted kidney education for AHPs

#### Patient and Community voice

- Community-led lobbying
- Peer storytelling in services

#### **Education and prevetion**

- Earlier education, whole-of-journey education
- · Templates and materials created and pooled

#### System reform and strategy

- · National implementation plan that is action-orientated, nationally coordinated
- Sustainable funding for Community-led initiatives

#### System reform and strategy

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### What supports are needed? Grouped by support area

#### Leadership

NIKTT leadership and endorsement for network creation, national consistency, and policy advocacy

#### **Funding**

Government funding (Commonwealth and State) for workforce, outreach models, patient travel, and education initiatives

#### Collaboration

Collaboration with KHA, TSANZ, OTA, and government agencies to scale, align, and fund solutions

# Outo





## **Priorities**

#### Attendee priorities, grouped by theme

## Aboriginal and Torres Strait Islander workforce and leadership

Participants repeatedly emphasised the need to grow and support an Aboriginal and Torres Strait Islander workforce across clinical, community, and peer roles. This included calls for peer navigators, rural workforce development, and more Indigenous leadership in decision-making and governance structures. Indigenous Reference Groups were also seen as vital, with requests for consistent national coordination and long-term investment.

#### Cultural safety and better communication

A central concern was the lack of cultural safety within the health system. Participants called for place-based cultural safety training, better understanding of cultural practices and protocols, and tools like the Clinical Yarning Model to be embedded in practice. Many shared personal experiences of disrespectful language and communication, with strong calls for systemic accountability. The need for health services to understand and speak respectfully to Aboriginal and Torres Strait Islander people was a recurring theme.

#### **Education and resources**

There was widespread support for culturally appropriate education resources that explain the transplant journey and broader kidney care pathway in clear, accessible formats. Resources should be in-language, visual, and suitable for all ages. A centralised national hub was proposed to ensure access to up-to-date, reliable information for patients, carers, and clinicians.

#### Access to care

Participants spoke of the difficulties accessing early transplant workup, dental care, and specialist

appointments. They proposed expanded mobile dialysis access (e.g. trucks), more dialysis chairs in community, and increased outreach models for transplant assessment.

#### Psychosocial, carer, and family support

Caring for the carer was raised by many participants. Attendees stressed the importance of respite services, counselling, and including carers as part of the care team. Mental health and emotional wellbeing were raised frequently, including during dialysis and post-transplant.

#### Funding, structures, and reform

Many discussions pointed to the need for sustainable funding to support programs, workforce initiatives, and wraparound care models. Participants suggested flexible funding structures, philanthropic partnerships, and reforming current funding mechanisms. Several attendees also raised the importance of redefining how system performance is measured, including KPIs and dashboards that reflect equity in access and outcomes. National coordination and planning were described as essential to avoid duplication and improve impact.

## Prevention, early intervention, and long-term care

Participants strongly advocated for a whole-of-life approach to kidney care, from early prevention to long-term support post-transplant. Community-led screening programs, diabetes management, and school-based education were suggested strategies. Attendees also stressed the importance of chronic disease management tools, wraparound care, and improved transitions between paediatric and adult kidney services. Housing insecurity and post-transplant continuity of care were noted as significant barriers to maintaining health.

## **Actions**

#### Identified actions to be taken, grouped by theme

#### **Resources and Patient Education**

- Develop a minimum set of information that every patient being worked up or on the waitlist should receive, in language that is clear and understandable
- Create transplant education resources adaptable by each transplant unit, with patient videos as core components
- Work with NIKTT to develop and share culturally grounded and engaging pre- and post-transplant care resources
- Use traffic light systems to explain kidney function and test results in a patient-friendly way
- Produce A—Z dialysis induction booklets that cover the full journey, including aftercare and warnings
- Translate resources into local languages and ensure accessibility for both patients and families
- Implement early education about transplant before dialysis starts—and include culturally appropriate content for children and young people

#### **Workforce Development**

- Establish a national network or community of practice for Aboriginal Health Practitioners in kidney care
- Fund and embed roles for Aboriginal transplant educators, peer navigators, and cultural liaison officers in dialysis and transplant services
- Elevate the Indigenous health worker role to a senior leadership position, ensuring it is valued and visible

- Recruit more Aboriginal and Torres Strait Islander health workers across services, including in paediatric kidney care
- Partner with workforce agencies to train, mentor, and support regional staff working across the kidney care pathway

#### **Cultural Safety**

- Make cultural safety training mandatory in all services (e.g. annual in-person "Walking in Two Worlds" courses)
- Implement and standardise the Clinical Yarning model nationally across nephrology and transplant services
- Include First Nations clinicians in planning and delivery of clinical education and service models
- Address institutional racism and ensure safe, culturally welcoming environments for patients and staff

#### **Access and Navigation**

- Establish mobile dialysis trucks and increase dialysis chairs in rural and remote communities
- Fund and deliver home dialysis training and support to enable return to Country
- Provide transport assistance and accommodation support for patients travelling for treatment
- Support earlier transplant workup at CKD stage 4, including screening in schools and communities using outreach vans
- Ensure post-transplant support is available in regional areas

#### **Systems and Strategy**

- Create a national transplant scorecard to monitor and report outcomes by site and population group
- Use NIKTT to coordinate national pooling of resources, sharing adaptable tools and templates across jurisdictions
- Develop and implement a national action plan for transplant equity with defined drivers and accountability
- Collaborate with TSANZ, OTA, ANZSN, and governments to align funding, strategy, and implementation efforts
- Host regular national Gatherings to build capability, monitor progress, and share learning

#### **Advocacy and Governance**

- Establish a national body to represent Aboriginal and Torres Strait Islander people with kidney disease and transplantation
- Raise awareness of this work in an ongoing and visible way to keep transplantation equity on the agenda
- Strengthen and expand patient reference groups and Indigenous Reference Groups to inform service delivery
- Ensure funding transparency, so communities know how decisions are made and what is achieved.



# **Next Steps**

The 2025 Gathering set out clear priorities for improving kidney transplantation access and outcomes for Aboriginal and Torres Strait Islander people. These include establishing a formal First Nations-led governance body, investing in defined workforce roles such as transplant educators and navigators, and producing consistent, culturally relevant patient education materials. Participants also emphasised the importance of transparent data and reporting mechanisms to track progress, and the need for accountability across services and jurisdictions.

The outcomes of the Gathering will be submitted to the Federal Department of Health, Disability and Ageing to inform implementation of Priority 2 of the *National Strategy for Organ Donation*, *Retrieval and Transplantation*. A full report and the endorsed Position Statement are available online.

We encourage readers to:

- · Access the full report and share it with colleagues and networks
- · Get in touch with the NIKTT Secretariat to discuss opportunities for collaboration
- Advocate for the resourcing and implementation of the NIKTT recommendations through the National Strategy and locally.

The next phase of work will depend on continued national coordination, government commitment, and meaningful partnerships with Aboriginal and Torres Strait Islander communities. We look forward to continuing to progress this work with you.



## With thanks

We extend our heartfelt thanks to the patients, carers, and all attendees who travelled to Kaurna Yarta to take part in the 2025 Gathering. Your voices, experiences, and leadership were at the centre of this event. We also acknowledge the tireless efforts of the support teams and NIKTT staff who worked behind the scenes to make the Gathering possible.

We gratefully acknowledge the Australian Government Department of Health, Diability and Ageing for funding the National Indigenous Kidney Transplantation Taskforce.

We thank the Transplantation Society of Australia and New Zealand (TSANZ) for their ongoing partnership and commitment to improving transplantation equity.

We also thank our Gathering sponsors - A stellas and Vantive - for their generous support of this event.



