2025 NIKTT Gathering

Full Report

Artwork story

Created by Cedric Varcoe during the 2025 NIKTT Gathering

This artwork was painted live during the 2025 Gathering by Ngarrindjeri and Narungga artist Cedric Varcoe. Over three days, Cedric listened to the stories, experiences, and priorities shared by participants, capturing their voices, journeys, and hopes through the artwork.

At the heart of the painting is a central gathering circle, representing the event itself — a coming together of Aboriginal and Torres Strait Islander people from across the country. Radiating from this circle are message sticks, symbolising the knowledge, stories, and shared commitments being taken back to communities in all directions: north, east, south, and west.

> *"As they're coming together, they're coming to share and strengthen our communities and our people who are needing treatment and needing better access to treatment and education around treatment."*

On each side of the Gathering circle are a coolamon and a shield, each with a kidney at its core, and each honouring the roles of women and men. The coolamon reflects the nurturing, guiding role of women in caring for family and community, and in supporting awareness and education around kidney health. The shield speaks to the strength of men:

> *"The shield is significant for our men because it's what shields us in battle, in conflict. But not only that, also as we journey – it's healing us from the objects that are preventing us from journeying smoothly. As it protects our* miwi*, our spirit, it protects our community and our families."*

In the upper section, the painting shows the Welcome to Country held on Kaurna land, recognising the hosts of the Gathering and the spiritual connection to Country, waters, and sky. The sun and sky at the top of the painting represent the sun as the giver of life and the clouds as the burdens or challenges that can weigh on our spirit. Together, they show the shifting nature of our journeys: how the weather, like our wellbeing, can be light or heavy, but must be walked through together.

In the lower half of the painting, there are three warriors: two women holding message sticks and one man with a shield. They are patients, but also workers and advocates:

> *“They are advocating for our communities and our people who are dealing with [kidney disease] as patients or family members. They are advocating for better access to treatment… As they walk with the shield and the message sticks, they [bring that knowledge] back to our communities so they get that information correctly, to better understand. English can be sometimes our people’s fourth, fifth, sixth language – so it’s better when [these messages are] coming from our people to support our people in the language that we know.”*

Finally, on either side of the central circle are community gathering circles, representing the ongoing work happening within communities long before and after the event. These are places where local voices, culture, and knowledge are brought together to create safer, stronger, and more culturally respectful systems of care.

> *“The gathering circles represent the communities coming together, meeting in their own communities to support and embed better understanding and respect around cultural safety, cultural support, and looking after our people in a culturally appropriate way.”*

The painting tells the story of Community gathering to share knowledge, find strength in culture, and carry connections back to Country, where the journey toward better access to care continues through advocacy and support.

Acknowledgment of Country

The National Indigenous Kidney Transplantation Taskforce Secretariat acknowledges the Country, Custodians, and Community of the lands, seas, and skies on which we live and work.

The 2025 NIKTT Gathering was held on the traditional Country of the Kaurna people of the Adelaide Plains. We acknowledge and thank the Custodians who welcomed us to Country, and acknowledge our privilege in being able to gather, share, learn, and plan together on the Country of the Kaurna people.

Sovereignty was never ceded; this always was, and always will be, Aboriginal land.

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Executive Summary

The 2025 NIKTT Gathering brought together Aboriginal and Torres Strait Islander patients, carers, and health professionals alongside non-Indigenous clinicians, policymakers, and advocates to reflect on progress and define the next phase of work to improve equity in kidney transplantation. Across three days of structured discussions, yarning sessions, and collaborative problem-solving, participants identified clear and specific priorities and opportunities for systemic change.

Many priority areas were identified for action over the next five years. The most frequently raised were:

- The need to develop accessible, culturally safe patient education resources;
- The need to invest in a supported Aboriginal and Torres Strait Islander workforce; and
- The need for continued funding and support for transplant-related initiatives including the NIKTT.

Participants highlighted gaps in service access such as limited dialysis chairs, lack of support for early transplant workup, and fragmented post-transplant care. The need for better transport, support for carers, and better wrap-around support services were also consistently raised.

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 lived experience roles, clinical staff, and regional leadership positions. Strengthen and fund Indigenous Reference Groups nationally.
2. **Cultural safety and better communication:** Implement place-based 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. Support mobile dialysis, outreach assessment teams, and continuity of care post-transplant.
5. **Psychosocial, carer, and family support:** Increase opportunities for respite, counselling, and other support for carers and families, recognising their central role in patient wellbeing.
6. **Funding, structures, and reform:** Secure sustainable and flexible funding for community-led models and national coordination. Redefine KPIs and build transparent data systems.
7. **Prevention, early intervention, and long-term care:** Invest in screening, prevention, and wrap-around care, from early kidney disease through post-transplant.

Participants proposed a wide range of concrete actions, including developing a standardised set of informational materials given to patients, 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.

The NIKTT Position Statement was reviewed, 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.

Feedback from attendees about the Gathering 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.

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 of the *National Strategy for Organ Donation, Retrieval and Transplantation*, with a strong focus on Aboriginal and Torres Strait Islander self-determination and sustained action.

Introduction

In February 2025, the National Indigenous Kidney Transplantation Taskforce (NIKTT) held the second 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. Designed as a culturally safe and collaborative space, it focused on strengthening connections, sharing experiences, and setting priorities for the future of kidney transplantation equity.

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 an overview of the Gathering’s design, program, and outcomes. It aims to reflect the contributions of participants and support ongoing work to improve access to kidney transplantation for Aboriginal and Torres Strait Islander people.

Background

The National Indigenous Kidney Transplantation Taskforce was established in 2019 to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people. While First Nations peoples in Australia experience end-stage kidney disease at significantly higher rates than non-Indigenous Australians, systemic inequities continue to result in lower rates of waitlisting and therefore transplantation. [1] The need to develop a Taskforce and build a network of coordinated patients and clinicians came from the 2018 Transplantation Society of Australia and New Zealand (TSANZ) performance report [2] that outlined clear recommendations to improve kidney transplantation access and outcomes for Aboriginal and Torres Strait Islander people. The report listed 35 recommendations to improves access, mapped against state, territory, and Commonwealth Government responsibilities as well as actions to be taken up by a national taskforce.

Established in 2019, the National Indigenous Kidney Transplantation Taskforce was created in direct response to Recommendation 1 of the TSANZ report. The first meeting of this taskforce was held in Alice Springs, titled the National Indigenous Dialysis and Transplant Conference (NIDTC). The Taskforce was established with 35 members, comprising a diverse group of Aboriginal and Torres Strait Islander people, non-Indigenous allies, patients, clinicians, and organisational stakeholders. The Taskforce was charged with progressing three key recommendations from the TSANZ report: enhancing data collection around transplant waitlisting, investigating cultural bias in kidney care settings, and piloting models of care to improve access to the transplant waitlist.

Over a three-year period, the NIKTT implemented a broad program of work. This included the establishment of Indigenous Reference Groups at transplant units across the country, the commissioning of a national report on cultural bias in kidney care, and the piloting of eight distinct projects designed to test new approaches to improving equity in access to transplantation. In addition, data collection systems at renal units were expanded to better understand the barriers preventing Aboriginal and Torres Strait Islander people from being waitlisted. The initial phase of funding and activities concluded after these achievements, laying the foundation for continued national efforts in this area.

To share this work, the NIKTT held the first NIKTT Transplantation Equity Gathering in December 2022. The Gathering's aim was to bring together the people on the Taskforce alongside patients and Community members who had been involved in NIKTT activities. 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, and 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, the growth of an Indigenous renal health workforce, the expansion of culturally safe transplant-related models of care, and the implementation of transparent monitoring and reporting mechanisms. The full statement is available here: Transplantation Equity Position Statement 2022.

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[1] https://www.anzdata.org.au/wp-content/uploads/2024/12/10_first_nations_australians_2023_ar_2024_chapter_F_20241223.pdf

[2] https://www.anzdata.org.au/wp-content/uploads/2019/07/TSANZ-Performance-Report-Improving-Indigenous-Transplant-Outcomes-Final-edited-1.pdf

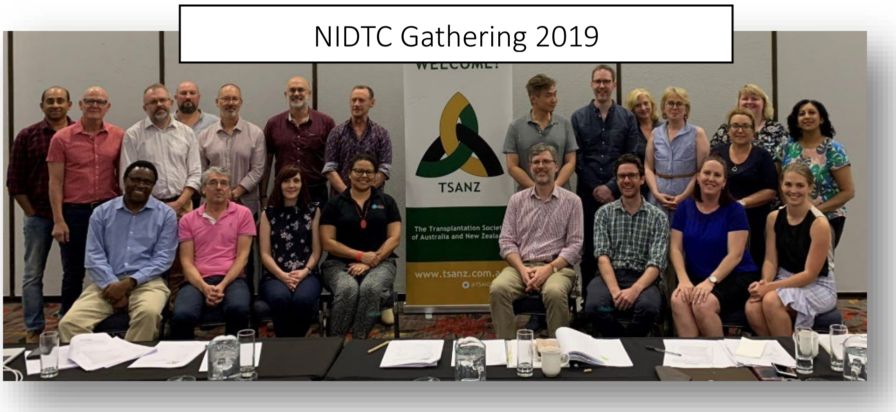
A key outcome from the 2022 Gathering was the need for sustained momentum and collaborative action. In early 2023, the recommendations from the work of the Taskforce, as well as the Position Statement and key priorities raised in the Gathering, were submitted to all state and federal Ministers for Health 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 and long-term 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.

NIDTC Gathering 2019



NIKTT Gathering 2022

NIKTT Gathering 2025

Approach to Participation

The Gathering was designed to be culturally safe, inclusive, and participatory. We took an intentional approach to participation, beginning with a carefully curated invitation list that prioritised geographic diversity, a range of perspectives and experiences, and the inclusion of new voices who had not attended the first Gathering. All potential attendees were asked to review and commit to the event's guiding principles before confirming their desire to attend. This was a deliberate step to ensure the Gathering brought together people who were willing to engage fully and contribute to collective action. Attendance at the Gathering was therefore coordinated through two processes: targeted invitations and a formal Expression of Interest (EOI) process.

Invitations.

Invitations were provided to Aboriginal and Torres Strait Islander patients and their carers, as well as key operational stakeholders. The NIKTT's National Community Engagement Coordinator contacted renal units across all states and territories to encourage them to share details of the Gathering with relevant dialysis and transplant patients. These potential patients were sent a registration form, and staff of the NIKTT Secretariat helped Community members to complete these forms as required. Care was taken to include representation from across jurisdictions and regions, as well as diversity in gender and age.

Community members were invited to attend the Gathering based on a range of factors, including previous engagement with NIKTT activities, their ongoing involvement in local kidney health efforts, and their willingness to contribute lived experience and insights to regional and national conversations about transplantation equity. These participants—patients on dialysis, transplant recipients, and their carers—brought invaluable expertise grounded in personal and Community experience.

To support Community participation, NIKTT covered all travel-related costs, including airfares, accommodation, and meals for the duration of the Gathering. This support was essential to ensuring equitable participation, as the Gathering depended on the presence, knowledge, and generous storytelling of Community members. We believed it was both appropriate and necessary that those asked to share their experiences and contribute to solutions should not face any financial burden in doing so.

EOI Process.

The EOI process was open to previous NIKTT members, clinicians, researchers, and policymakers working in transplantation and renal care. As we explicitly designed the 2025 NIKTT Gathering to be a space dedicated to championing Aboriginal and Torres Strait Islander leadership, knowledge, and self-determination, the EOI process aimed to uphold the integrity of this Blak-led space by encouraging potential attendees to reflect on their engagement prior to registration. We asked people to complete four short questions to demonstrate their commitment to engaging respectfully, contributing meaningfully, and participating as active learners (Box 1).

Potential attendees were supplied with an information booklet outlining the guiding principles of the Gathering (see below), the proposed agenda, the previous Position Statement, and the key goals and objectives for the Gathering. EOI responses were reviewed by NIKTT Secretariat staff and potential attendees informed that their EOI responses may be included in a booklet shared with attendees.

Box 1. Expression of Interest Form: 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.

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

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?

2. **Improving Care in Practice**

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. 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).

Guiding Principles for Participation

Cultural safety was embedded in every aspect of the Gathering. Participation was understood to be more than just presence — it meant listening actively and with care, and contributing where possible. Non-Indigenous allies were encouraged to prioritise listening, while all attendees were invited to share stories, ideas, reflections, and expertise in ways that aligned with the Gathering's values of respect, equity, and collaboration.

Guidelines for respectful engagement were shared with all attendees, including protocols such as "one speaker at a time," "no blame, no shame," and encouragement to use plain language. Participants were also reminded that they could choose how and when to engage — including the option not to speak, or to take time away from sessions when needed.

Whether people registered through an invitation link or through the EOI process, all potential attendees were asked to confirm that they had read and understood the principles and expectations of the Gathering (Box 2). These guiding principles and expectations were drafted by the NIKTT's National Community Engagement Coordinator, Kelli Owen, for the first NIKTT Gathering. They were reviewed and confirmed by the NIKTT Secretariat for the second Gathering.

Box 2. Gathering Expectations

Overall expectations

The NIKTT Gathering is a space for shared learning and understanding. Unlike academic conferences, there will be no formal presentations or plenaries. Instead, it will be a safe environment to hear from Community, exchange ideas, and privilege all voices in a decolonised space. This Gathering is both a celebration of achievements and a chance to plan future efforts. It is an opportunity for the kidney transplant community to share progress, report back to colleagues and stakeholders, and seek guidance from patient experts to implement meaningful changes.

This is an opportunity to hear from First Nations people and carers of this work and explore solutions together. It is also an opportunity to explore new ways of working together and co-designing action plans for equitable implementation and cultural understanding.

Gathering Values

- Community control and community participation is fundamental to all work going forward
- Self-determination and sovereignty are honoured at all times
- Culturally safe and competent practice, engagement, and knowledge exchange are essential
- Relationship building and advocacy are vital

Specific expectations

Every voice is listened to with respect

Many of us attending the Gathering will come from very different geographical, social, academic, physical, and community backgrounds. We are coming together with the shared goal of improving access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander peoples in Australia. Please be respectful and welcoming to all guests, with an open mind to learn more about each other.

What this means in practice: 1) one speaker at a time; 2) no blame, no shame; 3) we can agree to disagree respectfully; 4) leave your ego at the door before entry.

Focusing on the future and ways to improve

Although it may be tempting to explore or give voice to grievances, this is not the space to do so whilst together. We hope to focus on the positive experiences of working together for the betterment of Aboriginal and Torres Strait Islander kidney health care, and the opportunities in the future to improve access and outcomes. This means while it is important to acknowledge barriers, we are coming together to explore and find solutions, together. If there are particular issues that you have experienced, or if there are trauma triggers that you experience during the Gathering, please speak to Kelli Owen or the emcee – they are there to help guide and support all attendees.

A shared space means a shared way of working

We hope that attendees will respect both the schedule of activities and remain flexible where necessary. This means both respecting others' time and planning by attending activities on time, and also respecting the need for flexibility and fluidity when others are sharing experiences or speaking their kidney journey story. Use plain language that is understood by the majority of participants. If you are using medical language, 'please explain…'

Keeping an open mind

With the diverse attendance and experience represented throughout the Gathering, it is important to actively work towards exploring all aspects of kidney care and solutions. This means being aware of any preconceived notions of what may or may not work, thinking through alternative ways of practice or service delivery, being aware of differences in expectations for health care and wellbeing, and acknowledging and exploring different ways of knowing, being, and doing.

Cultural safety at all times

By attending the Gathering, every attendee is expected to maintain cultural safety at all times, with no exceptions. This means being mindful of language and making a determined effort to understand and adjust ways of working to respect and privilege our patients and the values the Gathering holds. Mindful language includes being cognisant of how others wish to be referred to and the limited use of clinical jargon or other languages when interpreters are not available.

Support, resources, and special elements provided

Creating a culturally safe and welcoming space for Aboriginal and Torres Strait Islander participants was a foundational priority in planning and delivering the 2025 NIKTT Gathering. From early preparation through to event delivery, we focused on enabling an environment where Mob could show up fully, share openly, and lead the conversation. To support active and meaningful participation, a range of supports, tools, and resources were made available throughout the event.

Cultural and emotional support

A Distress Protocol was developed, with clear points of contact and information about local services available to attendees, and the NIKTT Secretariat staff were onsite across all three days to assist with logistics, wellbeing, and general support.

Resources to support connection and engagement

All participants received a welcome pack including a printed Gathering booklet, event lanyard, notebook and pen, session details, consent forms, and the Collective Booklet — a resource designed to foster connection by listing each attendee's name, region, and perspective.

In recognition of the importance of relationality and knowing who is in the room, the *Collective Booklet* was shared with attendees ahead of the event. This resource included short bios, photos, and reflections from participants — sharing who they are, where they're from, and their role or perspective on kidney care. The booklet helped familiarise everyone with the diverse voices present and provided a starting point for connection and mutual respect. It was particularly valuable for Mob travelling from remote and regional areas, who could see themselves reflected in the broader story of the Gathering.

Post-it notes and pens were placed on all tables, inviting attendees to write down reflections and add them to communal easels located throughout the venue. Mentimeter, an online engagement tool, was used to collect real-time reflections and feedback during sessions, accessible via phone, tablet, or laptop.

Designing a culturally responsive space

The physical environment of the Gathering was carefully considered. Tables were arranged in small circular clusters — to be like sitting around mini fire-pits, with gum leaves and string lights bringing "the outside in" — to encourage yarning-style discussions and disrupt typical conference hierarchies. Each table group blended different voices and perspectives, with support available to ensure everyone could speak and be heard.

The Gathering was held in the auditorium of the South Australian Health and Medical Research Institute (SAHMRI), which also houses the NIKTT Secretariat. While SAHMRI offered practical advantages as a central, accessible venue, its selection was also based on cultural considerations. The space was chosen for its commitment to cultural safety and its alignment with the values underpinning the Gathering. SAHMRI has an active Reconciliation Action Plan, a dedicated Aboriginal Health Equity research theme, and an internal Indigenous Collective that informs organisational practices.

Live artwork

Throughout the three days, a live artwork by Ngarrindjeri and Narungga artist Uncle Cedric Varcoe unfolded in response to the stories, energy, and themes shared in the room. This evolving piece became a powerful visual representation of the collective journey and is featured throughout this report.

Mob-only day: Blak Space

The Gathering opened with a Mob-only day — a closed session for Aboriginal and Torres Strait Islander participants, including patients, carers, health workers, and community leaders. This dedicated space allowed people to connect, share stories, and raise concerns in an environment free from external expectations. It created a strong and grounding start to the Gathering, setting the tone for the days that followed.

Catering and procurement

Wherever possible, Aboriginal and Torres Strait Islander-owned businesses were engaged as vendors and suppliers for the Gathering. A full list of these vendors is available online.

Dialysis Coordination and Support

Significant cross-jurisdictional planning and collaboration was required to ensure that dialysis patients — particularly those travelling from remote, regional, or interstate areas — could participate fully in the Gathering while continuing to receive safe and appropriate care. This work involved coordination across multiple services and teams, and we gratefully acknowledge the efforts of everyone involved.

The Central Northern Adelaide Renal and Transplantation Service (CNARTS) worked closely with interstate renal teams, the Rural Support Service (RSS) team operating the mobile dialysis truck, and staff at Kanggawodli to ensure that dialysis schedules could be adapted to support patient attendance. Chairs were made available across several locations, with staff graciously adjusting business as usual to accommodate our interstate visitors.

The RSS mobile dialysis truck usually travels to remote South Australian communities such as the APY Lands, Coober Pedy, and Yalata. For the Gathering, it was temporarily located in Adelaide at Kanggawodli to provide dialysis close to the venue in a culturally safe setting. With three chairs on board and the ability to live-stream the Gathering webinar to those dialysing, the truck enabled continuity of care for dialysis expert patients, allowing them to remain connected to the event and community throughout their stay.

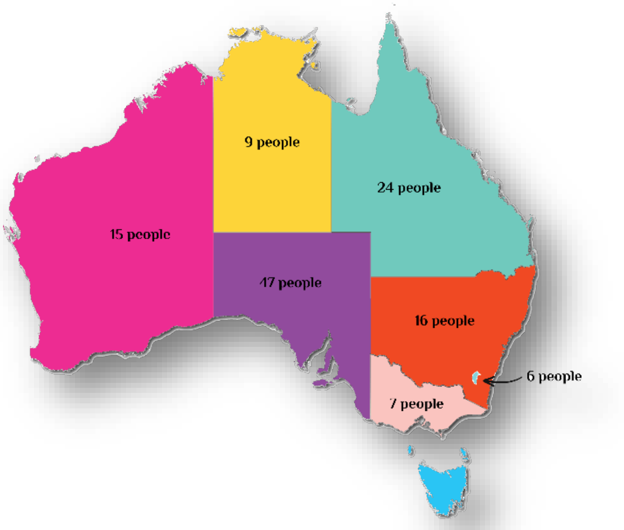
This coordinated effort ensured that dialysis was not a barrier to participation and reflects the shared commitment across services to make the Gathering accessible to all.

Attendees

A total of 126 people attended the 2025 NIKTT Gathering, travelling from across most states and territories to meet on Kaurna Yarta. The Gathering brought together a broad mix of participants, with a deliberate focus on ensuring strong representation from Aboriginal and Torres Strait Islander communities, especially those with lived experience of kidney disease.

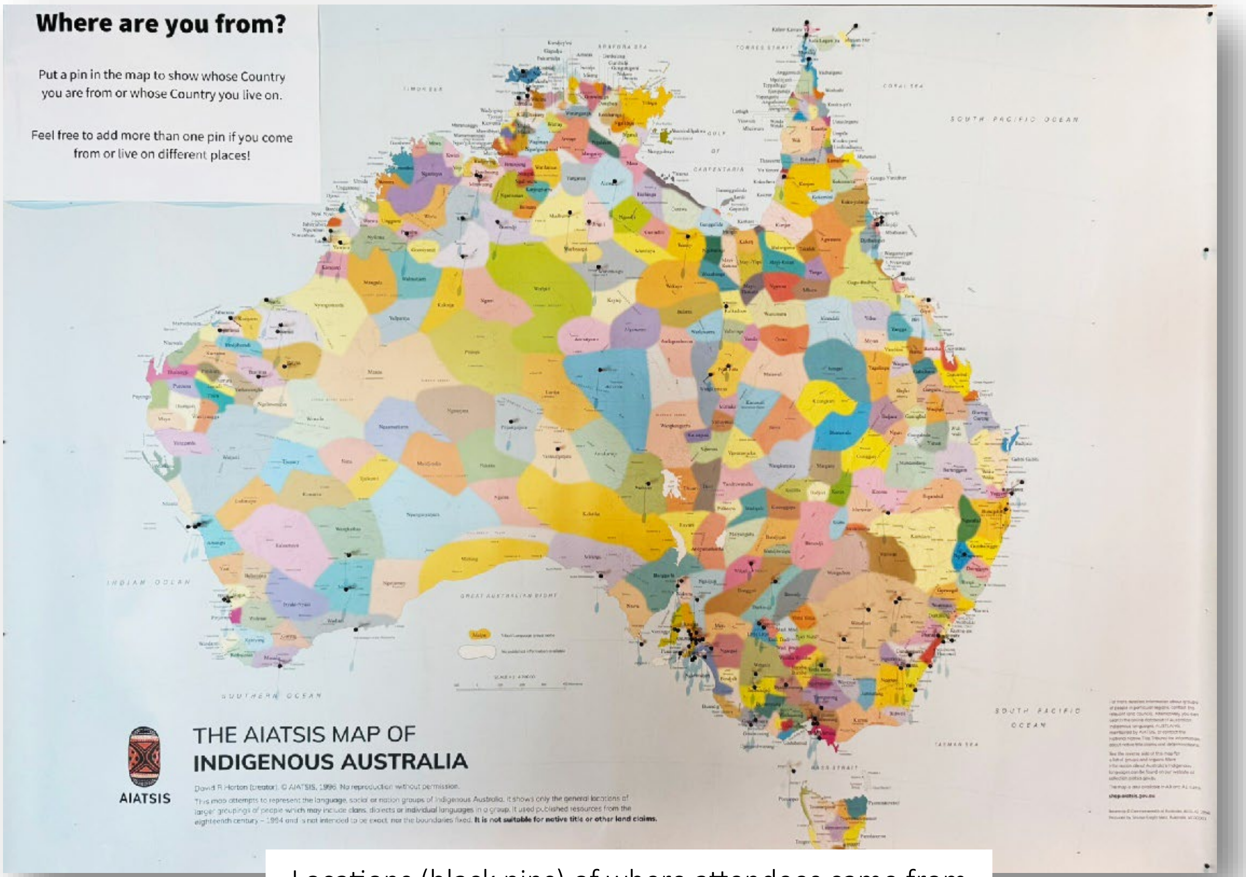
Among attendees, 67 identified as Mob, and 59 as allies. Participants included kidney patients and transplant recipients, carers and family members, Aboriginal and Torres Strait Islander Health Workers and Liaison Officers, community advocates, clinicians (including nephrologists, nurses, transplant coordinators), researchers, government policy staff, and representatives from peak bodies and support organisations.

The diversity of experiences, perspectives, and knowledge shared across the three days reflected the national scope of the work and the importance of cross-sector collaboration to improve kidney transplant equity.



	ACT	NSW	NT	QLD	SA	VIC	WA	Total
Mob		**11**	**9**	**17**	**17**	**4**	**9**	**67**
Advocate		1			5			6
Carer		5	2	5		1	4	17
Clinician			2	6	2	1		11
Consumer		5	4	6	7	2	5	29
Gov't stakeholder					1			1
Secretariat			1		2			3
Ally	**6**	**5**	**1**	**7**	**31**	**3**	**6**	**59**
Advocate					3	1		4
Clinician	1	4	1	7	22	2	6	43
Gov't stakeholder	5				1			6
Secretariat		1			3			4
Sponsor					2			2
Total	**6**	**16**	**10**	**24**	**48**	**7**	**15**	**126**

For more information on who came to the Gathering, view the Collective Booklet here:



Locations (black pins) of where attendees came from

Mob and Allies at the beginning of Day Two

Program overview

In response to the high demand voiced from the 2022 Gathering for greater opportunities to hear stories from patients and providers on successes and challenges in kidney transplant care, the 2025 Gathering ran for three days, from the 18th-20th of February.

The Gathering agenda was crafted to create opportunities for sharing, learning, and connection. While a core structure was in place, flexibility was built into the program to allow space for the organic flow of conversation and to respond to the needs and interests of attendees. To support inclusivity and cultural respect throughout the event, each session in the agenda was marked with specific indicators:

- Mob Only: These sessions were reserved exclusively for Aboriginal and Torres Strait Islander (and other First Nations) attendees. The “Mob Only” label signified a culturally safe space for Blak participants to share, connect, and speak freely. These sessions created opportunities for deep and community-specific dialogue without external perspectives.
- Ally Friendly: Sessions marked “Ally Friendly” were open to all attendees, including non-Indigenous allies, supporters, and professionals committed to improving kidney health equity. Allies were invited to participate with openness and respect, listening and contributing in a way that upheld the values of the Gathering.

A number of social events also took place throughout the Gathering to encourage informal connection and celebration of Aboriginal and Torres Strait Islander culture, traditions, and local services. These events were free for all attendees.

Day 1: Gather. Aim: To create a dedicated space for Aboriginal and Torres Strait Islander patients, carers, families, health workforce, and leaders to share experiences, celebrate successes, and identify challenges and opportunities in kidney transplantation equity

Day 2: Reflect. Aim: To bring the kidney community together from all jurisdictions to share knowledge, highlight achievements, and discuss practical strategies to improve access to transplantation and kidney care

Day 3: Act. Aim: To review identified gaps and opportunities, and reach a consensus on priorities for advancing kidney transplantation equity.

Day 1: 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.

Attendees at the beginning of Day One; Mob only photo

Day 2: Reflect

Program Overview

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.

2.1 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.

"This is my country and this country is my bloodline. The songs of the land echo on the waters of my coast and carry on the winds the voices of the old people. What I just said in language is acknowledging the ancient that still lays sleeping here, but also the culture that still lives and breathes through us."

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."*

2.2 Revisiting the Position Statement

The day then began by setting the scene – asking people to read aloud the Position Statement from the first Gathering, to ground people in what has come before, ask them to reflect on where we are now, and think about where we are going next.

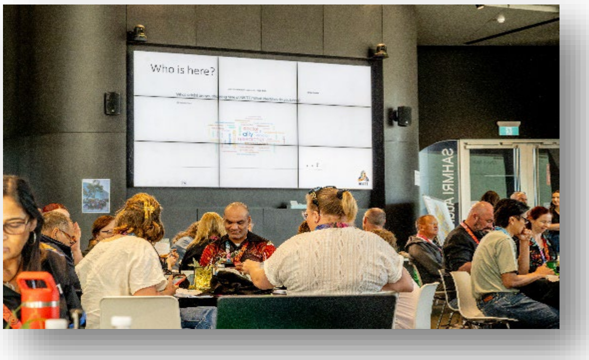
> *At the inaugural NIKTT gathering in 2022, many delegates contributed to and endorsed the position statement focused on improving transplantation equity for Aboriginal and Torres Strait Islander people. As we come together again at 2025 gathering, we will reflect on, update, and renew this statement. Throughout the gathering, there will be opportunities for you to share your insights, feedback, and lived experiences to help shape the revised statement. Your contributions, whether through discussion, written reflections or shared ideas will be woven into the updated position statement, capturing the collective voices and priorities of this gathering. On the final day, we will come together to review the updated statement, ensuring it reflects the aspirations and commitments of those involved.*

The 2022 Position Statement was read aloud by selected attendees.

2.3 Introduction to the NIKTT: Where have we come from? Where are we going?

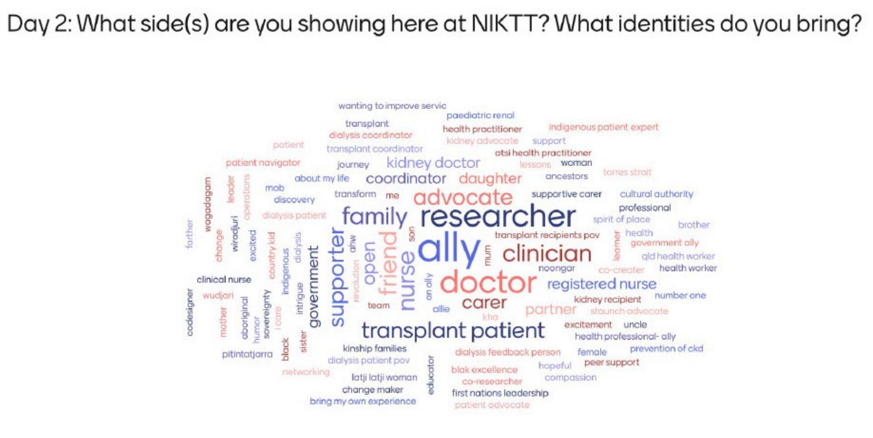
Presenters: Stephen McDonald and Jaquelyne Hughes, Co-Chairs of the NIKTT

This session provided a foundational overview of the NIKTT, tracing its evolution, outlining its core activities, and highlighting its ongoing role in advocating for systems change.



It began by asking people to identify who they were – what 'sides' were they showing and what identities did they bring to the Gathering. This was done in order to understand who was in the room and what types of backgrounds and identities people brought to the room (image below).

Stephen then welcomed participants by acknowledging the diverse experiences and expertise in the room, noting that the Gathering was intentionally designed to feel


Day 2: What side(s) are you showing here at NIKTT? What identities do you bring?

different from traditional medical meetings. He emphasised that discomfort — for both clinicians and Community — was part of the necessary process of transformation.

Background and Rationale for NIKTT

Stephen recounted the historical and structural basis for NIKTT's formation. Disproportionately high rates of kidney disease among Aboriginal and Torres Strait Islander peoples, combined with significantly lower rates of kidney transplantation, underscored the urgent need for action. Data from ANZDATA revealed that Aboriginal and Torres Strait Islander people had far fewer kidney transplants than non-Indigenous people, and critically, this is because Aboriginal and Torres Strait Islander people were far less likely to be placed on the transplant waitlist in the first place.

> *"We looked at where on that [journey to a kidney transplant] the blocks were, and, overwhelmingly, the blocks were at the stage of people not getting onto the waiting list. Once Aboriginal and Torres Strait Islander people got onto the waiting list, the chances of getting a kidney transplant were about equal [to non-Indigenous people]." — Stephen McDonald*

Analyses show that medical factors alone do not account for this disparity, indicating the presence of systemic and institutional issues influencing referral and waitlisting practices.

Professors Hughes and McDonald emphasised that Australia's kidney care system already possesses the clinical tools and infrastructure needed to support people with kidney failure, highlighting that the challenge lies not in medical capability, but in ensuring equitable access to that system.

> *"The system knows how to support people who have kidney disease, to support people to live with different forms of kidney failure treatment, whether that's peritoneal dialysis, haemodialysis or transplantation. The system says that we are required to be efficient, to be well, to be transplanted because this is what donating life is... So, we have all of the major markers [for an efficient system] and we just need to put the detail into this." — Jaqui Hughes*

Stephen noted that many previous pieces of work have contributed to this discussion now, including work in Darwin called Indigenous Patient Voices,[3] work in Victoria around quality indicators,[4] and work in South Australia through ANZDATA on the survival benefit of kidney transplantation for Aboriginal and Torres Strait Islander people.[5] Those pieces of work have shown us that Aboriginal and Torres Strait Islander people have

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[3] Hughes et al. Gathering Perspectives – Finding Solutions for Chronic and End Stage Kidney Disease. Nephrology, 2018. https://onlinelibrary.wiley.com/doi/10.1111/nep.13233

[4] Ling et al. Impact of Victorian Quality Indicator (QI) on Kidney Transplant Wait-Lists for Indigenous and Nonindigenous Australians. American Society of Nephrology, Poster presentation, 2024. https://journals.lww.com/jasn/fulltext/2024/10001/impact_of_victorian_quality_indicator__qi__on.3710.aspx

[5] Bateman et al. The survival benefit of deceased donor kidney transplantation for Aboriginal and Torres Strait Islander people, 2006–20: a retrospective national cohort study. Medical Journal of Australia, 2024. https://onlinelibrary.wiley.com/doi/full/10.5694/mja2.52361

the same desire and potential to benefit from transplant care as any other Australian, yet systemic barriers continue to prevent equitable access to this life-changing intervention.

As Stephen explained, NIKTT was established not just to describe these inequities, but to actively demonstrate how to overcome them. Through pilot projects, enhanced data collection, and Indigenous-led governance, NIKTT provided both proof-of-concept and pathways forward:

> *"One of the key things that NIKTT was set up to do was to start a process of fixing it — of showing how to fix it, and what the fixes looked like." – Stephen McDonald*

Establishment and Structure of NIKTT

Stephen gave an outline of how the NIKTT was established in 2019 under the auspices of the Transplant Society of Australia and New Zealand (TSANZ) and funded by the Commonwealth Government. Initially, the Taskforce was charged with four primary workstreams:

- **Pilot Projects**: Local, small-scale projects in WA, NT, QLD, and SA to test new models to improve access to waitlisting and transplantation,
- **Indigenous Reference Groups (IRGs)**: Local groups embedded at clinical sites to centre First Nations voices in service design and delivery,
- **Data and Reporting**: Collaboration with ANZDATA to enable more detailed analysis of why people were not being waitlisted, and
- **Cultural Bias and Institutional Racism**: A commissioned report to examine cultural bias in kidney care systems.

The insights and outcomes from these activities informed NIKTT's Final Report, submitted to the Federal Government in 2023.

Progress and Achievements

Several tangible impacts were noted during the introductory session. For example, remote outreach by Perth transplant teams, as funded through the NIKTT pilot project scheme, directly led to increased waitlisting in remote WA communities. An IRG established at the Royal Adelaide Hospital led to the introduction of smoking ceremonies for transplanted organs, and Patient Navigator programs in SA and the NT were very well received by Community and clinical teams, and led to further funding through the Medical Research Futures Fund for ongoing investigation.

These results of NIKTT-funded pilot projects, as well as the enhanced data collection, the cultural bias report, and the establishment of IRGs were published as a special supplement in the *Medical Journal of Australia*. NIKTT and other key stakeholders were invited throughout 2023 and 2024 to meet with the Federal Department of Health to provide insight into the creation of a National Strategy around organ transplantation, which was published in late 2024 as the National Strategy for Organ Donation, Retrieval, and

Transplantation. The NIKTT provided a series of recommendations to the Commonwealth Government, as pictured below, and were provided an additional 12 months of funding to cover Secretariat work for 2024. This funding provided for the continuation of the NIKTT as a core group of Secretariat members, and supported the establishment of a data dashboard, the continued support of IRGs, the development of a plan for a sustained national body of consumers, and the hosting of this second Gathering.

Recommendations presented to Assistant Ministers

1

Immediate improvements to access and services

- Outreach Assessment Clinics
- Indigenous Reference Groups
- Increased Aboriginal and Torres Strait Islander renal health workforce

2

Ongoing Secretariat to monitor and progress transplantation equity

- Ongoing monitoring – "dashboard"
    - Activity, outcomes
    - Development cultural safety assessment
- IRG - maintaining focus and development
- Developing proposal for a national body
- Consultation / development around non-kidney transplants

3

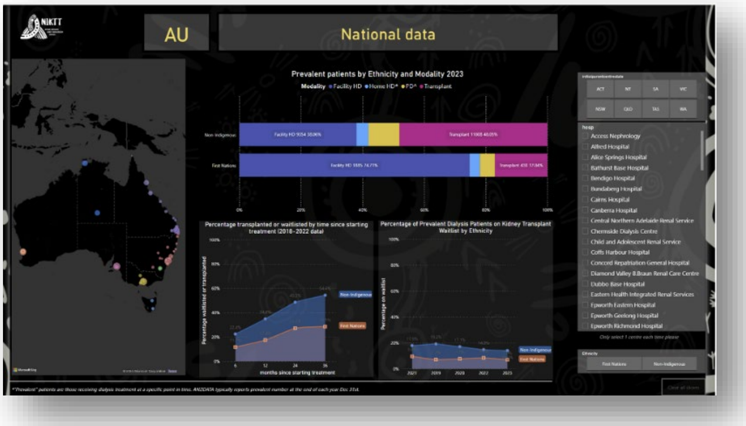
Investigate additional measures to address drivers of inequity

- Additional barriers to access
- Additional barriers across whole pathway

NIKTT

Current Focus and Forward View

The session introduced deliverables from the current phase of NIKTT, including the development of a national data dashboard. This interactive platform will allow clinicians, services, and jurisdictions to visualise transplantation metrics disaggregated by Indigenous status and filtered by location. The tool aims to support local accountability and quality improvement.



"One of the critical things about anything in health is actually having transparency and having a degree of accountability, so we know how we're doing and how we are not doing… What the Dashboard does is it allows you to look not just at the national level data, but [also] how things are going in your hospital or in your state… It's helpful to know how the whole country is doing, but I can't change the whole country. But perhaps I can change where I work, and so having that information is really, really important." – Stephen McDonald

"There is so much opportunity with a dashboard that we can look to frequently to see what are our efforts put into the activity needed to show that we are producing the data that meets key performance indicators that are working for people with high need. How do you know that you can celebrate that you are doing well in your service if you don't have data to show where you've come

> *from, what we're invested in now, what you're going to do in a health system that should be working well. We should be able to work really hard with intensive effort for things that we need to change. We should make it sustainable so that we don't have to work that hard anymore because that system works and then we can re-pivot and work into something else because we need to have efficiency for our people. We must never always have a hard story. We work hard, we do well, we tackle the next thing. We work hard and we do well. We must insist on bringing relief." – Jaqui Hughes*

Jaqui and Stephen noted that while the government's National Strategy acknowledges the importance of equity and prioritising access to transplantation for Aboriginal and Torres Strait Islander people, informed by the work of the NIKTT, it currently lacks an implementation plan.

> *"There is a clear national strategy, and in that, the Federal Government has said that Priority Area number two is actually fixing this problem [of inequitable access to transplantation for Aboriginal and Torres Strait Islander people]. It is not priority 23, it is right up there at the top. There is an explicit commitment to do that. And that sounds wonderful until you ask "what are you doing about it? How are you going to do it?" The answer is: they haven't made a plan. There is no implementation plan for this document." – Stephen McDonald*

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*

2.4 Sharing Stories from Across the Country: South Australia

Participants then heard a series of regional updates from Aboriginal and Torres Strait Islander kidney champions and clinical allies working across the country. Each presentation shared successes, challenges, and innovations from local services, IRGs, and community-led programs.

2.4.1 Central and Northern Adelaide Renal Transplant Services

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

The South Australian First Nations Kidney Team from the Royal Adelaide Hospital (RAH) presented on how they deliver culturally embedded, patient-informed, and system-responsive kidney care. Led by Aboriginal and non-Aboriginal staff working in partnership, the team described the unique structure and guiding principles behind their work at the RAH. Their approach integrates Aboriginal governance and leadership, workforce innovation, lived experience, clinical expertise, and place-based education to improve transplantation equity.

Indigenous Governance and the Role of *Purdita Purruna Wangkanthi*

A key foundation of the work at RAH is the Indigenous Reference Group *Purdita Purruna Wangkanthi* – “Talking Kidney Health”, established with funding from the NIKTT to guide culturally safe, community-led improvements in care. The group was formed during COVID-19 and meets regularly online, with members from across South Australia and the Northern Territory. Their initial report identified eight key priorities to improve safety and cultural responsiveness at the hospital. The first three priorities—developing a culturally safe model of care, maintaining ongoing consultation with Kaurna Elders, and embedding traditional healing practices such as smoking ceremonies—are now being actioned. Notably, the hospital held its first organ cleansing ceremony in 2022, recognising the spiritual and cultural importance of connecting donor organs to recipients' bodies.

“The IRG wasn't possible without the work of NIKTT and RAH talking and collaborating of how do we do this right ways. The right way was listening to the way that we work, and we were allowed the space to do that… Professor Toby Coates gave us a five-year commitment to work together to start addressing [the IRG’s prioritised] themes. We can't do all of them at once, [so] we started on the first three this case. We wanted a safe model of care, but we wanted ongoing consultation with our Kaurna Elders as well as being able to produce an organ cleansing ceremony – traditional healing our way within the Western medical way. We can't have one or the other. We could have them both together for our healing… Everything comes back to our Indigenous Reference Group and we are accountable to our group and our Elders in the way in which we work.” – Ms Kelli Karrikarringka Owen

Cultural Leadership Embedded in the Clinical System

The success of the work at the RAH has been driven by embedding cultural authority within the hospital. Kelli Karrikarringka Owen – a Kaurna, Narungga, and Ngarrindjeri sovereign woman who is the NIKTT National Community Engagement Coordinator, a transplant recipient, and Aboriginal leader – was appointed to a paid, formal cultural advisory role within the renal unit. Her leadership ensures Aboriginal governance is not an afterthought but a foundational component of service design and delivery. The team that works alongside her – known as the "Kidney Dream Team" (*Purdita Muna Pirku*) – works across disciplines and is grounded in a shared commitment to co-design, deep listening, and long-term systems change.

The RAH renal unit has expanded its Aboriginal workforce from one to six staff, creating space for roles not previously seen in the sector. These include:

- A Patient Navigator Coordinator who acts as a bridge between clinicians and patients, shaping the role responsively based on community needs,
- An Aboriginal Health Practitioner working across dialysis, transplant, and CKD teams to understand where cultural and clinical knowledge can be best applied, and
- COMPASS Patient Navigators with lived experience of kidney disease, who guide and support patients through their journey, improve health literacy, and build trust in the system.

Each role is developed with patients at the centre, aiming to transform health service delivery by acknowledging that Aboriginal patients want services provided *by* Aboriginal people.

Walking in Two Worlds: Education and Place-Based Learning

To support cultural safety system-wide, the team developed the "Walking in Two Worlds" training course for hospital staff. The course challenges default assumptions and teaches staff to see the invisible barriers Aboriginal patients face. It includes place-based learning on Kaurna Yarta, using local stories, sites, and history to build understanding of how Country, culture, and health are inseparable.

> *"Walking in two worlds is about shining a light on what it's like for Aboriginal people accessing our service. That's always at the forefront – it's not about changing the patients that come in, it's about changing the staff delivering those services and changing our mindsets [so] that we can understand and actually start to see some of those invisible barriers that people face every day when they come upon the service." – Kate Tyrell*

This model is not intended to be replicated wholesale elsewhere – instead, other hospitals are encouraged to work with their own Elders and Communities to develop locally grounded cultural education.

Enablers and Organisational Commitment

The team credited the long-term commitment of RAH leadership – particularly renal unit executives, consultants, and managers – as a key enabler of success. These leaders supported governance structures, prioritised Aboriginal workforce development, and embedded funding into core operations (e.g. the Indigenous Reference Group is now funded by the hospital independently of NIKTT). They also acknowledged the courage of Aboriginal patients who, despite personal health challenges, continue to contribute to shaping the system for the better.

> *"At the grassroots, we have patients who are choosing, even though they're living with chronic disease and have gone through traumatic journeys, they have the guts and the courageousness and the care about their people to choose to step back into the system and to help us guide the journey." – Kelli Karrikarringka Owen*

Succession, Sustainability, and Systems Change

The SA team identified several next steps:

- Succession planning for *Purdita Muna Pirku* and future workforce growth,
- Continuing to embed and expand Aboriginal workforce roles across the renal journey,
- Developing culturally appropriate educational resources, across the kidney health journey, in Language for patients and families, and
- Progressing the remaining themes identified by the IRG and embedding more members into *Purdita Purruna Wangkanthi*.

2.4.2 South Australian Kidney Champions

Presenters: Arna Westhead and Richard Goldsmith

Three priorities – everyone who is here from SA came together to figure out three priorities as clinicians and consumers to see.

1. Increasing First Nations workforce

There is a strong need to build and support a First Nations workforce in dialysis, transplant care, and coordination roles. This priority includes upskilling Aboriginal and Torres Strait Islander clinicians to take on specialised roles across the kidney care pathway.

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

2. Increased cultural safety training for non-First nations clinicians

This training must be implemented nationally, with an emphasis on models that are grounded in Aboriginal and Torres Strait Islander ways of communicating — such as the clinical yarning model. Increasing the First

Nations workforce must not come at the expense of non-Indigenous responsibility to provide culturally safe care.

3. Funding for more chairs

Many regional and remote communities in SA, such as Whyalla, Port Augusta, and the APY Lands, continue to face shortages of dialysis chairs. There is a need to increase the number of chairs in existing sites and to establish new services in areas with unmet need. Funding strategies should include government, private, and philanthropic sources to meet demand and support equitable access.

2.5 Sharing Stories from Across the Country: Western Australia

2.5.1 Kimberley Renal Services: Achieving equitable access to transplant suitability assessment for Aboriginal patients in the Kimberley

Presenters: Emma Griffiths and Nick Corsair

Kimberley Renal Services (KRS) is a remote Aboriginal community-controlled renal service based out of Yawuru Country in Broome. Dr Emma Griffiths and Nick Corsair shared how their team supports over 160 dialysis patients and 40–50 pre-dialysis patients across a vast area, coordinating complex care across multiple services, without the support of an on-site nephrologist and about 2,000 kilometres away from tertiary kidney and transplant services. Their approach reflects the strength of community control, creative models of care, and a commitment to ensuring Aboriginal patients in the Kimberley are not excluded from life-saving kidney transplants.

Addressing Systemic Gaps in Access

The team began by acknowledging that at the beginning of their project, there has been a stagnation in transplant service delivery: it had been four years since a Kimberley patient had received a kidney transplant and there was active dialogue about how transplantation was “not in [the] best interests” of Aboriginal patients, contributing to further exclusion and delay. Despite regular dialysis and long engagement with health services, many patients had never been assessed for transplant suitability — the first required step in accessing the transplant pathway.

In response, KRS launched a designed and implemented a continuous quality improvement (CQI) project to systematically conduct transplant suitability assessments for all of their patients. They developed a simple, one-page tool that could be completed by local GPs and the transplant coordinator, and reviewed by visiting nephrologists every three months. Each patient was classified as “green” (good to go), “orange/yellow” (temporary barriers), or “red” (not suitable at this time).

The team assessed 66 patients, of which 21 had no identified contraindications, 42 had temporary contraindications, and just 4 had permanent contraindications.

> *“What we found is that most of our patients didn't have permanent contraindications that we could identify at the start. In other words, the idea that most of our patients were not suitable for transplantation wasn't backed up by our initial assessments. A number of our patients had what we would call temporary contraindications, which is another way of saying short-term barriers to progressing, but they were largely aspects such as smoking treatment adherence and body mass index… things that we needed to actively partner with patients to help them progress through as opposed to medical contraindications that meant that they were likely to be unsuitable for transplantation in the longer term.” – Emma Griffiths*

Within 12 months, eight of the 21 "green" patients had been successfully waitlisted and 1 of the "yellow" temporarily contraindicated patients had been listed.

What Patients and Staff Said

KRS staff conducted interviews with patients and staff about their experiences with renal transplant suitability assessment and work up. Patients consistently said they wanted more information, clearer guidance on what was needed, and regular contact with staff to avoid feeling forgotten. Many shared confusion about why others had progressed to transplant while they remained on dialysis without explanation. Staff echoed these concerns, noting that care systems were often inaccessible and poorly communicated — especially for patients navigating treatment off-Country or across multiple services.

Three main themes were identified:

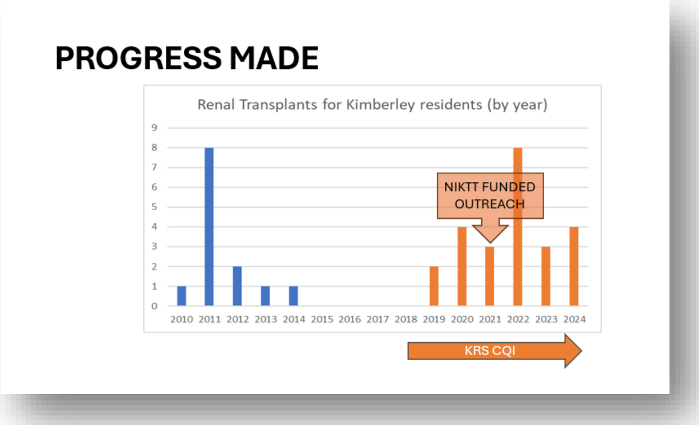
1. *People wanted more information*
    a. Participants wanted to know more about the transplant process. They wanted more time with the transplant coordinator and then more follow up from the transplant team. They wanted lists of what needed to be done and where to get support.
2. *Always waiting or forgotten*
    a. 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. 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.

Aboriginal care coordinators and patient care assistants highlighted the need for culturally safe, plain-language information delivered consistently and often. They stressed that Aboriginal workforce involvement was essential at every point along the journey, from early conversations about transplant to post-operative care.

> *"Our CQI approach achieved an increase in the number of patients assessed. The systematic approach also identified where other improvements could be made both individually and as a service. Most of the contraindications I ever said were able to be modified. So, there was very little that we actually found that meant that patients could not be worked up for a transplant and patients wanted more information and support."—Nick Corsair*

Sustaining Change and Embedding Systems

Since the beginning of their CQI project, the Kimberley Renal Services team has seen an increase in the number of kidney transplants in the region. Supported by three NIKTT-funded outreach visits, the team has completed more assessments and workups, now supporting 24 active transplant patients in the region.



PROGRESS MADE

To continue this trend, the KRS team is continuing to develop models of care that work for the region. This includes better regional coverage with an additional transplant coordinator for the East Kimberley and more staff, including Aboriginal care coordinators, focused on transplant pathways and delivering education. The team believes peer education is a critical component of good care models, with transplant recipients now accompanying staff on outreach trips to share their experiences with others.

> *"When I deliver education throughout the Kimberley, I always have a patient with me, and a patient from that particular region. And that's what resonates really... I can stand there for a couple of hours and give information, but what really, really hits home is patients that have actually received a transplant, who've been on that dialysis machine, next to the people we're talking to." – Nick Corsair*

Plans are underway to formalise and acknowledge this as part of the workforce in a more definitive way.

KRS is also scoping and developing a transplant module within its electronic medical record system to embed routine and systematic transplant suitability assessments. This will hopefully allow for the generation of reports on patient progress and follow-up needs. These tools, like the data dashboard, will support better care coordination and allow teams to track how they're doing over time.

Looking ahead, KRS is looking to co-design pre- and post-transplant model of cares. This includes helping patients learn skills in anticipation of a transplant, as well as building local service capacity to support patients after transplant.

> *"We really want to get some bright ideas about what supports people pre- and post-transplant to develop that model of care. Being in a region without a nephrologist, we are also looking at capacity*

> *building our [Aboriginal Community Controlled Organisations] and our primary care services so when that transplant patient walks in, everyone's ready to provide appropriate care to the transplant patient. These are our ideas that are on the table and we're hoping that everyone comes up to us with other suggestions today and tomorrow so that we can keep building a great regional and remote kidney transplant model for our patients." – Emma Griffiths*

2.5.2 Western Australian Kidney Champions

Presenters: Kieth McKinley and Maxine Gore

The voices of patients and their families from Western Australia highlighted persistent challenges with dialysis access, transport, accommodation, and support in remote and regional communities.

Keith McKinley, a transplant recipient from WA, spoke of the inequities experienced by people on dialysis in the north. He described how many patients must travel long distances to access a small number of dialysis chairs — sometimes only four to six available — and often face long waits or delays due to limited scheduling. He shared concerns raised by other patients about being required to clean dialysis chairs themselves after long treatments, something not expected in metropolitan centres. There was a strong call for increased dialysis capacity — more chairs, more services closer to home, and improved infrastructure to reduce patient burden and waiting times.

Maxine Gore, who spoke as a support person for her niece Jody, added that safe and stable housing remains a significant barrier for many dialysis patients. Overcrowded housing and homelessness were raised as urgent concerns, with some people living in makeshift conditions or outdoors while trying to manage chronic illness. She also highlighted major gaps in transport services, noting that while some areas have consistent support through taxis and dialysis trucks, many others do not — with unreliable transport causing missed dialysis sessions and putting patients at risk.

Comment from the audience

Sam Bateman, kidney doctor in SA: "Just about smoking, there was a big bunch of mob there that were temporary contraindications for smoking, whereas we don't see smoking as a contraindication necessarily for transplant. We try and encourage smoking cessation but maybe we need to have a think about what smoking looks like and whether that really does need to be a contraindication for transplantation."

Nick Corsair: "Initially it was very much cessation for three months, otherwise we would not start workup. We've now adopted a plan where if somebody engages with smoking cessation services or shows that they are actually giving up smoking, we'll start the workup... And that's been fairly successful. We've had quite a few patients that have given up by the time they've been waitlisted."

Stephen McDonald: "I don't do the transplant assessments in WA but I certainly have done for South Australia and Northern Territory. Just to emphasise that there's an important distinction between smoking itself [and the problems smoking causes]... Smoking is bad. Smoking causes lung disease and many people who are smokers have lots of repeated lung infections and it's the repeated infections that can cause a danger at the time of transplantation. So there's this fine distinction. One cigarette every year, it's not going to matter but there are people that are smokers who have repeated lung infections and stopping smoking will actually lead to improvement in that and that is a really important thing to emphasise. So sometimes the smoking stopping may not make sense other times it is a really, really important message to give and then also follow that message up obviously with how to actually help people stop smoking. So just didn't want to let that moment go by without remarking that smoking actually is bad for you and causes a lot of problems and some of those problems stop people getting onto the transplant list, not the smoking itself, it's the problems that smoking causes.

Gary Torrens, Clinical Nurse Consultant from QLD: "It's about what people are smoking as well. I think that's the big thing. [So in SA], smoking isn't seen as say a contraindication but with smoking [marijuana] is that seen the same way?"

Stephen McDonald: "It's not an absolute contraindication, but we do very, very, very strongly want people to actually try giving up. But if you've genuinely tried and you've absolutely failed and your lungs are still okay, then we will list you. What you smoke doesn't affect that judgement except in the sense that what you smoke does have all those [other] health effects."

2.5.3 Reflections on Health Education Resources

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:

2.6 Sharing Stories from Across the Country: Northern Territory

2.6.1 Alice Springs Renal Unit

Presenter: Kerry Dole

Kerry Dole, Renal Transplant Coordinator from Alice Springs, shared insights from Central Australia on improving care experiences and transplant access for First Nations patients living with kidney disease, especially young people. She spoke of how their aim in Alice Springs was to work out how they can partner with patients to make dialysis a more fun environment with the ultimate goal in getting more patients to transplantation.

THRIVE: Reimagining Dialysis

Kerry introduced the THRIVE cohort model, co-developed with nephrologist Dr Megan Brown, which aims to help patients thrive on dialysis with the ultimate goal of getting to transplant. The model reframes dialysis as a site of learning and empowerment — not just treatment — and promotes a holistic, strengths-based approach to care.

The THRIVE acronym stands for:

- **T**raining: Providing clients with the skills they need to maximise agency and improve outcomes, with training provided around all things kidney-health related through to transplantation;
- **H**onouring: Using a strengths-based approach to allow clients to be their best but also to be able to have their voices heard within the dialysis environment, to make the dialysis experience the best it can be for them;
- **R**esourcing: Providing clients with the support to be their best selves and to step into advocacy and community education as kidney warriors;
- **I**nviting independence: Allowing for graded independence in treatment from simple steps such as checking blood sugar levels independently to doing self-care dialysis;
- **V**ehicle to Transplantation: Partnering closely with the pre-transplant nurses and providing close follow up with a nephrologist to aid in completing workup and staying optimised on the waiting list as well as providing essential skills to thrive post-transplant; and
- **E**mpowerment: Recognising the role clients have in optimising their own health but also in being advocates in their own communities. THRIVE aims to equip clients and support them in these roles.

> *"The guiding principles around this are that many people in Central Australia are living with kidney disease, who have the highest incident rates of [chronic kidney disease], the highest numbers of patients on dialysis, and the lowest rates of getting to transplant. We know from today and from*

these meetings, our patients have incredible resilience and strength and we need to tap into that and use that to be the vehicles to get the patients on the journey of care that they want." – Kerry Dole

Kerry emphasised that for many Aboriginal patients in Central Australia, dialysis has become a regular part of life — but it doesn't have to be a passive, disconnected, or feared experience. Instead, the team envisions dialysis units as sites of education, fun, and empowerment. THRIVE creates space for patients to choose how they engage: whether resting under a blanket or actively learning about medications, eligibility, and navigating the health system. It hopes to see clients become "equipped and supported to be effective advocates and community champions."

Kerry spoke of what is needed to make this model work, including the need for dedicated work time from a nephrologist, collaborations with Aboriginal Community Controlled Organisations like Central Australian Aboriginal Congress and Purple House, getting patients with lived experience (Patient Navigators) embedded in the government service, employing an Aboriginal Health Practitioner, and embed the design in research.

The project is currently beginning with a small cohort of four self-nominated patients, with plans to grow.

Transplant Outcomes: Evidence from Central Australia

Kerry also presented findings from a retrospective study led by Dr Sajan Thomas to assess the graft and patient survival in a Central Australian renal transplant cohort. The data showed that:

- Graft survival and patient survival have both improved over time, particularly since 2015 and particularly in the first five years;
- Among Indigenous patients, graft and patient survival improving from 66% pre-2015 to 84% post-2015; and
- While gaps remain between Indigenous and non-Indigenous outcomes over the long term, the early post-transplant period has seen notable improvements, with the gap between Indigenous and non-Indigenous patient and graft survival closing in the first 5 years post-transplant.

Kerry closed by acknowledging that while funding and workforce remain challenges, these cannot be excuses for inaction.

2.6.2 Northern Territory Kidney Champions

Presenters: Rowena Albert and Onika Paolucci

Rowena Albert, a transplant recipient speaking on behalf of the Northern Territory delegation, shared the priorities identified by Community members during the Day One yarns. The reflections highlighted the importance of timely access to transplantation, culturally grounded care, and sustained connection to Country and family throughout the treatment journey.

Key priorities included:

1. Patients being waitlisted for transplant within six months of starting dialysis, with regular updates on how this is being achieved,
2. Receiving dialysis care on Country, delivered by Aboriginal Health Practitioners and supported family members, to keep mob connected to Country,
3. Community and family caring for the mental and physical health of patients, and
4. Cultural health leaders to be part of the transplant readiness team, so face-to-face Community visits from doctors and nurses are done in partnership with Aboriginal Liaison Officers, interpreters, and Aboriginal Health Practitioners, as well as strong transplant coordinators.

2.7 Sharing Stories from Across the Country: Queensland

2.7.1 North Queensland Kidney Transplant Service: Building cultural safety and capability into the North Queensland Kidney Transplant Service

Presenter: Michelle Harfield

Dr Michelle Harfield, a nephrologist based in Townsville, introduced the soon-to-launch North Queensland Kidney Transplant Service (NQKTS). Speaking with personal insights, Michelle spoke about the development of the second transplant unit in Queensland.

Establishing an Expanded Transplant Service

While kidney transplantation in Queensland has historically been centralised at the Princess Alexandra Hospital in Brisbane, growing demand and geographical challenges prompted the Queensland Government to fund a second transplant site. Beginning in 2018, Queensland Health established an advisory group to determine if, when, and where a second transplant service should be created in Queensland. All Hospital and Health Services (HHS) were invited to submit an expression of interest, with Townsville University Hospital announced as the second site in 2021, and the North Queensland transplant business case was approved in 2023. Although based in Townsville, the service is designed to serve the entire North Queensland and Far North Queensland region.

The service has received substantial funding and is set to begin performing transplants by June 2025. Early recruitment has already seen the appointment of transplant surgeons, nephrologists, Indigenous health workers, and a social worker, with further workforce development underway.

Kidney Transplant Service Charter

A defining feature of NQKTS is its commitment to embedding cultural safety and world-class kidney transplant services. The service represents its values in its stakeholder-reviewed charter, which outlines how they aim to achieve:

- A service that meets the needs of Aboriginal and Torres Strait Islander People, so they feel safe and respected throughout their transplant journey;
- North Queensland patients will spend less time away from home during their transplant work up and surgery; and
- A network of clinicians within five HHSs who share the same drive to improve transplant access and outcomes for their patients.

In order to achieve these aims, the team asked themselves: “how do you embed cultural safety and capability, and how do you implement that?” Drawing directly from the NIKTT Performance Report as a blueprint for how to address cultural equity and cultural safety, the service embedded recommended practices into their model of care and governance structure.

The domains published within the NIKTT Cultural Bias Report[6] guided the principles of what the service is trying to achieve:

1. **Inclusion of Aboriginal and Torres Strait Islander people**
   A statewide Indigenous Reference Group for kidney transplantation has been established in partnership with the Queensland Kidney Transplant Service, with representation from across Queensland. Chaired by senior Indigenous health workers, the group includes people with lived experience of kidney transplantation from across Queensland — framed by Michelle not as "consumers," but as "subject matter experts." This group is funded on a recurrent basis within the transplant service itself and plays a core role in identifying barriers and informing care models.

2. **Aboriginal and Torres Strait Islander workforce**

   NQKTS has secured funding for a number of Indigenous Health Workers to guide the transplant journey for patients. It is therefore building a dedicated Indigenous health workforce that is embedded specifically within the kidney transplant service, and therefore not able to be seconded to other areas. This approach aims to create a network of supported, regionally based practitioners who are experts in transplant pathways.

3. **Service delivery, approach, and models of care**

   The service is developing a cultural information gathering tool to be used at the point of initial referral, collecting information about patients' literacy, housing needs, spirituality, and other things that are important to them to inform bespoke, patient-centred care plans.

> *"A cultural history for our patients is actually just as important as a medical history." – Michelle Harfield*

While the team hopes to introduce, and has funding for, peer navigators, the passing of a planned patient representative has delayed this component. However, outreach remains a critical focus. The service is exploring ways to bring pre-transplant assessment clinics and investigation services closer to home — including to the Torres Strait, Mount Isa, Doomadgee, and Mornington Island — reducing the number of trips required and time

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[6] Hughes et al. Cultural bias in kidney care and transplantation: review and recommendations to improve kidney care for Aboriginal and Torres Strait Islander people. Medical Journal of Australia, 2023. https://onlinelibrary.wiley.com/doi/full/10.5694/mja2.52110

patients spend displaced from family and Country. Michelle stressed that even routine testing — like echocardiograms and bone scans — can result in multiple, burdensome trips for dialysis patients. A potential solution under consideration is a single-day, all-in-one investigation service model based on successful examples from Aotearoa New Zealand.

4. **Structure and policies**

   To ensure lasting change, NQKTS has key performance indicators and feedback-informed outcome measurements to monitor change, including: how many trips people are taking away from home and the time spent displaced from Country; whether cultural investigation tools are completed; and feedback from patients, the IRG, workforce, and Community elders. The service has further embedded cultural safety practices into its core operations and reporting structures by ensuring recurrent funding for the Indigenous Reference Group and dedicated Indigenous health roles.

Enabling Sustainability

NQKTS doesn't want their ideals to become flash-in-the-pan ideas, so they are embedding their values in the Charter, and making sure those values are embedded throughout the models of care they deliver. They are going to track key performance indicators to ensure delivery is evidence-based, and they are going to ensure that policies reflect recurrent funding models of the Indigenous Reference Groups and the Indigenous health workforce. This service will be evaluated through both KPIs and stakeholder feedback, ensuring workforce, Community, patients, the IRG, NIKTT, and statewide health equity strategies inform service delivery and evaluation.

Michelle closed by summarising that this service is based on what has come before, through the NIKTT reports and the work done by the Princess Alexandra team in Brisbane. The service is building on the previous models of care, including the NIKTT-funded outreach assessment clinics, to create a sustainable model of care that works for patients, based on what patients say they want.

Questions from the audience

"How did you secure recurrent funding models?"

Michelle Harfield: "We asked for everything that we wanted, and the political environment was such that the Queensland government wanted to demonstrate that they were actually going to make a dent in this issue. They don't know how to make a dent in this issue, but they were happy to fund a group of people that dreamed big enough to do it. And we asked for everything… we were lucky in that sense because the recurrent funding is what's really needed to ensure that you have a sustainable service that's hopefully going to help. But political pressure is the only way that we got it."

In terms of paediatric services

Michelle Harfield: “I've been talking to Rowena [Lalji”, she's a paediatric nephrologist, and I'm hopeful that NIKTT and the Queensland government can actually get behind the paediatric kidney transplantation side of things because they have nothing. They don't have Aboriginal and Torres Strait Islander health workers and there's some really sick children that she cares for and she's doing a wonderful job, but they need to have as much recognition as we are getting.”

In terms of workforce

Michelle Harfield: “We are looking at taking the role of an Indigenous health worker forward to actually value what it's supposed to be like. That role has been a nebulous thing for such a long time and I think it's been undervalued as a role within the actual the service. I think that we are hopeful that by actually matching that, making it a senior role with a voice on our senior leadership team, that we have a sustainable way of making sure that somebody like Brett [Mooney] or somebody like Kelli [Owen] or these big names that have that advocacy gene actually continue going.”

2.7.2 Queensland Kidney Champions

Presenters: Julius Tabua and Breanna Solomon

Julius Tabua, a kidney transplant recipient of nearly four years from Thursday Island in the Torres Straits, and Breanna Solomon, a Renal Nurse currently working in Far North Queensland, spoke about the priorities for their area, including:

1. First Nations Workforce:

Need more Indigenous health workers to help patients better understand and feel more comfortable, as well as more First Nations clinicians in Far North Queensland, such as GPs, to help patients get on the list and stay closer to home.

2. Education and advocacy:

Education given to health workers and patients so that everyone understands good renal care, including prevention of CKD in the primary healthcare space and getting family and friends in for health checks.

3. General Workforce and Infrastructure

Increased workforce for renal- and transplant-specific roles across units and in primary care, in order to cover all aspects of transplantation.

2.8 Sharing Stories from Across the Country: National Work

2.8.1 Better Renal Services

Presenters: Melanie Beacroft and Jason Agostino

Mel Beacroft and Dr Jason Agostino co-presented on the Better Renal Services initiative, a national program funded by the Australian Government to expand dialysis access in remote and very remote Aboriginal and Torres Strait Islander communities.

Mel Beacroft, from the First Nations Health Division of the Department of Health and Aged Care, emphasised that her team prides themselves on doing work differently to other public sector divisions. They use the priority reforms of the National Agreement on Closing the Gap to centre and guide their work, ensuring they are working in partnership with Aboriginal people and organisations.

Under Anthony Albanese's first-term government, $73.2 million in funding was announced for the Better Renal Services for First Nations Peoples initiative. This funding set out to build 30 four-chair dialysis units in communities of the largest need in remote or very remote locations, alongside workforce accommodation as required. Rather than the government alone deciding where to build, the Better Renal Services Steering Committee was established to guide decisions collaboratively. This committee is co-chaired by Mel and Jason, and includes Aboriginal and Torres Strait Islander representatives, community-controlled health services, kidney experts, and state health departments. Together, they assess local need, community readiness, and clinical feasibility.

To date, nine dialysis units have been funded, including the first opened in Coober Pedy in June 2023, and an ambitious project underway on Badu Island in the Torres Strait. Mel underscored the intent of the program: to bring people home to Country, close to family and community, to live well while receiving care.

Dr Jason Agostino, Senior Medical Advisor at NACCHO – the National Aboriginal Community Controlled Health Organisation – is a non-Indigenous General Practitioner and epidemiologist based in Yarrabah. He highlighted the importance he has seen for people having dialysis care delivered close to home and on Country – in Yarrabah, the shift from daily travel to Cairns for dialysis to having a local, state-run seven-chair dialysis unit on-site was really significant.

Jason stressed that his role, and interest, in being part of the Better Renal Services committee is to make sure what they do lasts:

"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." – Jason Agostino

Jason stressed that the current reliance on charity and extant government funding for dialysis on Country – as seen in services like Purple House and Kimberley Renal Services – is unsustainable.

"Purple House is just really lucky that they're very good at raising a lot of money because what they're getting from the government doesn't cut it. We shouldn't have dialysis units dependent on charity, which is where we're at." – Jason Agostino

A truly equitable system that works must include long-term funding and support, including a sustainable workforce. Noting that dialysis infrastructure alone is not enough, nor is the current model of a nurse-led, four-chair unit because it's difficult to maintain the staffing, Jason emphasised the need to build a local Aboriginal and Torres Strait Islander health workforce.

Jason highlighted that there are opportunities available within the Better Renal Services initiative, including the fact that infrastructure and units are being built, and that it's an important first step for the government to be investing in kidney disease.

Jason also spoke to NACCHO's development of a new national strategy targeting the interconnected burden – or "triple threat" – of kidney disease, diabetes, and cardiovascular disease. As can be seen in many Communities, these conditions cause a great deal of suffering and have common reasons for coming into being as well as how we can prevent and manage them. To develop the Strategy, NACCHO sent a survey to their member organisations – 146 Aboriginal Community Controlled Health Organisations across Australia – and asked them what's worked in these areas and why. The Strategy will span the full continuum of care, from prevention to palliative care, and will be informed by community consultations and an expert group of Aboriginal and Torres Strait Islander health leaders and other sector leads.

Linked to this vision is the 500 Aboriginal and Torres Strait Islander Health Traineeships program announced alongside Better Renal Services. This represents a significant expansion of the current national health workforce, and there have already been close to 400 enrolments. With this program comes the opportunity to further upskill this workforce in specific areas. NACCHO is working with Aboriginal Community Controlled registered training organisations (RTOs) to develop specialist training modules, including areas like diabetes and kidney care. Jason flagged upcoming work with the Kimberley renal team to shape kidney care–specific training for health workers and practitioners, with the goal of strengthening locally driven care well beyond dialysis delivery.

Questions from the audience:

Q: Is there an overarching plan in existence, from the Federal Government, about the whole spectrum of kidney disease?

Mel Beacroft: "Great question. Short answer is no, there isn't. There's a whole lot of plans and strategies that exist in Commonwealth government. We do have a kidney plan, but I think it doesn't necessarily have in terms of, you talked a little bit this morning about implementation of ideas and things, so I don't think that we've really explored everything in that particular plan. Where I work in First Nations health division because partnership and the community control sector is so important, we're sort of biding a bit of time if you like to let NACHHO do their work so that we can partner with them on what that might look like for the community control sector... At the moment we're focusing on dialysis, that's what we've got money for. But ideally we'd like to expand and do a whole lot of more things.

So, you're doing dialysis because that's what you've got money for. So who decided that's what you've got money for and what was the metric that they used to decide?

Mel Beacroft: "It's an Australian Government commitment. It was committed to in the election campaign and budget, so we're enacting that promise, if you like."

Jaqui Hughes: "So what Mel just said is go speak to your local member, because it's your local member that generates ideas which come to cabinet, which get prioritised in terms of major policy."

Q: How does the Closing the Gap framework — particularly its national targets — provide an opportunity to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people?

Jason Agostino: What I've been taught by my Aboriginal leadership at NACCHO is that my focus needs to be, and probably what I need to communicate all the time, is around the priority of reform that are within the National Agreement on Closing the Gap. So when the Prime Minister, the premier, or chief minister, of each state and territory signed up for these agreements, they signed up to four priority reforms... that they signed up to and therefore everyone that works underneath them in the government has signed up to.

(1) The first is around genuine shared decision making with Aboriginal and Torres Strait Islander people. So I guess the fact that this committee that around choosing where dialysis goes is co-chaired with NACCHO, even though I'm a non-Indigenous dude, is a reflection of that trying to achieve that commitment around shared decision making and that should happen at all levels of government;

(2) The second is to invest in the Community Controlled sector. A lot of funding still goes through mainstream, non-Indigenous organisations. And the belief is that the more that we put funding into Community Controlled Organisations, the more they're accountable to the community and the better spending of that funding. That actually means taking funding away… from non-Indigenous organisations that are working in Aboriginal and Torres Strait Islander spaces and putting it into the Community Controlled Sector;
(3) The third is about transforming government organisations. So, basically trying to eliminate or basically eliminating racism from government organisations. That's obviously on them, but it's about us putting pressure on them; and
(4) The fourth is around shared access to data so that communities can make decisions for themselves, informed by the data about their communities.

In thinking about this group [at the NIKTT Gathering], a lot of people here work at state governments, and a lot of the work around kidney transplants lays on state governments. They've signed up to this – they signed up to these priority reforms. The productivity commission has made it very clear that everyone is doing rubbish about implementing these priority reforms. That they're all doing it too slow, that the progress of change is too slow. The theory is that's why we're not making the progress that we want on the targets because we're not doing these things that the Coalition of Peak says it is really important for making progress for Aboriginal and Torres Strait Islander people.

2.8.1 New South Wales and Victorian Kidney Champions

Presenters: Monica Kerwin and Eugenia Flynn

Patient voices from New South Wales and Victoria highlighted overlapping priorities, challenges, and opportunities for improving kidney care and support — particularly for carers, for those navigating the health system alone, and for communities still without local dialysis services. Monica, a Barkindji woman from western NSW, and Eugenia, a Larrakia and Tiwi woman living in Melbourne, shared their lived experience and the collective reflections of participants from their regions.

Carer Support and Respite

Both speakers emphasised the urgent need for carer support, including structured respite. Carers, often on call 24/7, are relied upon to manage complex conditions, navigate appointments, and coordinate medications. Yet, they receive little direct support themselves. Participants called for the health system — not just NDIS or home care programs — to recognise carers as essential contributors to patient care, and to create roles or programs that offer trusted, culturally safe respite, delivered by trained Aboriginal health professionals who understand community context and needs.

> *"When you are caring for someone with that level of complexity, how do you hand that over?... You have to trust the other person who's taking care of your loved one... 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*

Culturally Appropriate Education

Monica spoke about the lack of accessible education around kidney disease — particularly in regional NSW. She described how her family's understanding of dialysis and transplant only came once they had to face it directly, and how they had to cross state lines into South Australia to find culturally safe, supportive care. She called for education to begin earlier — in schools, playgroups, and community spaces — using plain, culturally relevant language. She stressed the importance of breaking down medical jargon into understandable "slang lingo" to support real understanding in Community. Eugenia echoed this need, reflecting that when people are first diagnosed with kidney disease they are bombarded with hard-to-understand information. There needs to be culturally specific resources provided without jargon, delivered by mob in a way that's appropriate for Blak fullas.

Eugenia reinforced the need for Aboriginal health workers trained specifically in kidney care, who can walk alongside patients and carers as trusted guides. Both women called for more Aboriginal workforce embedded within hospitals, clinics, and community services — not just generalist roles, but specialists who understand the journey of kidney disease, and who can provide ongoing, relational support.

Prevention, Screening, and Outreach

There was strong consensus on the importance of screening and early intervention, noting the success of outreach models for other diseases (e.g. breast screening vans), with calls for similar services focused on kidney disease. Eugenia noted that new technologies now allow for easier screening, which could be brought into schools and clinics to help detect early signs and inform prevention.

Systems Gaps and Data Disconnection

Monica highlighted how cross-border service arrangements — such as being treated through Broken Hill but living in NSW — can disrupt data collection, continuity of care, and access to resources. She shared that their family received better support after relocating to Adelaide, despite being NSW residents. This raised concerns about how regional services are funded and coordinated, and whether Community members are being counted or supported appropriately if they fall outside typical service boundaries.

Monica closed by saying that the term "gaps" no longer captures the severity of what's happening:

> *"They're not gaps anymore in this day and age. You shouldn't be calling them gaps. Our people are seriously falling into sinkholes." – Monica Kerwin*

2.9 What are the priorities for the next 5 years?

Facilitators: Stephen McDonald and Jaquelyne Hughes

The final session of Day Two invited participants to begin articulating the national priorities for kidney transplantation equity over the next five years. The group was invited to shift gears — from listening and reflection into active priority-setting. This session was designed to be the first of several opportunities to identify, discuss, and ultimately refine the priorities that should shape the future of kidney transplantation equity work. Attendees were asked to begin thinking about their personal priorities and to write down three on paper or the whiteboard as a starting point for tomorrow's small-group work.

> *"This is the start of the discussions to say: what should the next round of NIKTT — or the next round of national efforts — actually look like?" – Stephen McDonald*

Jacqui opened the conversation by sharing her initial list of priority themes, emphasising that this was only a starting point and that collective input would shape the direction going forward. Her identified priorities included:

- **Wellbeing**: As expressed by Monica Kerwin from NSW and others, focusing on the wellbeing of people with kidney disease and transplant, their families, and those who care for them, are very important, so we need to develop work on this;
- **Data-informed confidence**: "Seeing ourselves succeed in treatment for people who have kidney failure." Ensuring that Aboriginal and Torres Strait Islander people can see evidence of progress through dashboards and monitoring, so that we have data to inform and give us confidence that we are doing good work;
- **Workforce leadership**: Strengthening and sustaining Aboriginal and Torres Strait Islander leadership within the health workforce. Our business is definitely to close gaps;
- **Bespoke resources for high-area needs**: Advocating for bespoke investment in areas of high need to ensure equitable service delivery. "We can't improve things if we don't have the resources or a plan to do so." This includes resourcing actions on cultural safety, as "we don't just automatically have cultural safety because we say so – that's a special bespoke resource"; and
- **Health optimisation**: Prioritising pathways so people are transplant waitlist suitable – this means health optimisation available for everyone who has stage 4 CKD to be optimised and ready for transplant workup within six months of starting dialysis.

Stephen encouraged people to think about how to enact these priorities – "What does it actually look like? What are the actual things?" He then invited other speakers to contribute their perspectives, starting with Ross Francis from Queensland.

Local Experience: Princess Alexandra Hospital (QLD)

Stephen McDonald: *"Ross, could you tell us a little bit about two things that you and the people around you are doing to make things better and then one thing that you would like to do?"*

Dr Ross Francis, a nephrologist and transplant physician at the Princess Alexandra Hospital in Brisbane shared his reflections on work underway in Queensland. He started by saying that much of what his team would like to do had been mentioned throughout the Gathering, including delivering care close to home and creating educational materials in Language and in a way that people can understand and interact with. He highlighted the significance of the North Queensland transplant service being designed from the ground up with Community input, with many of the key priorities built into the design from the beginning. He spoke about how funding is clearly a barrier in many other parts of the country, and hopefully how the new transplant service can be used as a model to lobby for more funding in other areas.

In terms of what he suggests people could do, he said his focus is to start looking at the barriers to care – and summarised his priorities into three main areas:

> *"From our local experience, [something that's slowing people down is] probably access to tests and investigations. How can we get strategies to help people to do that, whether it's bringing people to bigger centres to access tests in a one-stop shop or whether it's doing outreach and taking people with us.*
>
> *There are other issues of smoking cessation, we've talked about that and how can we help with that? Should we still be doing that? That's a complex issue in itself.*
>
> *Weight loss is another issue. Some patients are told that they have to lose weight to access the list. Losing weight's all straightforward. How can we help people to do that? Can we help them to access newer medications? Can we help them to access weight loss surgery if that's appropriate for that patient? And we've been lucky in Queensland that we've been able to lobby for specific access to bariatric surgery for transplant patients who would otherwise be ineligible and that's providing another avenue for patients who otherwise would probably sit on dialysis for many years." – Ross Francis*

Brett Mooney, an Aboriginal & Torres Strait Islander Kidney Health Worker at the Princess Alexandra Hospital, then spoke about the foundational importance of cultural safety — not just for patients, but for Aboriginal and Torres Strait Islander staff. Reflecting on his early experiences working across the state, Brett described how the initial NIKTT-funded engagement activities in Townsville and Mount Isa set a new tone:

> *"We took the staff out of their comfortable clinician offices and we put 'em right in the middle of the community. I mean, cultural safety needs to be the first consideration for everything because when you're a health worker, your cultural safety is at jeopardy." – Brett Mooney*

This approach laid the groundwork for relationships and trust, later informing strategic planning for the transplant unit in Townsville. He emphasised that protecting the wellbeing of Aboriginal and Torres Strait Islander staff must come first — "because if you break someone who's trying to help their people, you may never come back from that." He also described work done with a 14-year-old transplant recipient in Tweed, where he and Gary coordinated wraparound supports by engaging external services when local clinics were overburdened. Brett advocated for cultural safety, funding, and more engagement programs as the highest priorities.

Weight-Based Exclusions and Inconsistency

Kim Francis, a transplant patient from South Australia, shared her frustration with being told to lose weight for transplant despite being only 71kg at the time:

> *"I [was] told that I needed to lose weight to get a transplant. At that time, I only weighed 71 kilos. I'm five foot seven, how much weight am I supposed to have on me?" – Kim Francis*

Stephen, recognising there were no transplant surgeons in the room, acknowledged the inconsistency, noting that weight thresholds are not clearly defined and vary between surgeons. He emphasised that weight should not be treated as a permanent barrier and that the health system needs to support access to weight loss options and appropriate assessment.

Role of the Organ and Tissue Authority

Stephen encouraged highlighting a slightly different perspective, particularly the role of national organisations in driving change. He pointed to the Australian Organ and Tissue Authority (OTA) as an example — noting that while the OTA does not deliver direct care, do fund and create programs that drive change:

> *"The number of deceased donors in Australia is very substantially greater than it was 15 years ago, and that's due to a change in programs, funding, and structures." – Stephen McDonald*

He then invited OTA CEO Lucinda Barry to speak, asking: *"We know this is a priority area — improving equitable access to kidney care — what is the AOTA going to do about it? What are you planning to do about it?"*

Lucinda Barry AM, CEO of OTA/DonateLife, shared reflections on the agency's role in national coordination and system reform. She described OTA as a federal agency established to increase organ and tissue donations, enabling more Australians to receive transplants — a mission that has seen measurable success over the past decade through collaborative partnerships with state and territory governments, communities, and the clinical sector.

Lucinda acknowledged that despite overall increases in transplant rates, equity remains a major challenge, particularly for Aboriginal and Torres Strait Islander peoples. She credited the NIKTT for advancing understanding and partnerships, including through Indigenous Reference Groups and patient navigator models. She also noted the importance of cultural governance, acknowledging Kelli Owen's role on the OTA Board as critical for ensuring accountability and co-design.

Lucinda spoke about the National Strategy for Organ Donation, Retrieval, and Transplantation, noting that the OTA is a facilitator for co-creating and co-designing:

> *"[The National Strategy has] highlighted about equity of access for First Nations people, and we have worked closely with the [NIKTT] to really look at what could be done on the learnings that they've had for the last four years." – Lucinda Barry*

She highlighted emerging work on a living donation strategy that is being put forward, which would address some of the discussions around pre- and post-transplant support, and how some Aboriginal and Torres Strait Islander people have raised concerns about living donation.

> *"Sitting in Northern Territory at Purple House chatting to a couple of the guys who had their transplants... [Someone] said, 'I got a transplant from a brother back in the eighties, but then when it failed in the nineties, I wasn't allowed to get a living transplant again.' And he was upset about that. He said, 'how come people are telling me that my family can't donate to me and yet white men get their donated kidney from their family?' There needs to be a bigger conversation about it and we need to listen and we need to work out that if that's the way it goes. Because we do know that if you give a kidney as an Aboriginal and Torres Strait Islander that you've got greater risk that your kidney that's left may fail. But how do we support you if that does happen? Because it may not, but if it does." – Lucinda Barry*

Finally, Lucinda committed to strengthening OTA's own internal cultural safety journey, sharing that the agency is in the process of developing its first Reconciliation Action Plan and has engaged the DonateLife network in cultural safety initiatives nationally. "We've still got lots to learn," she said, "We're willing to listen — but we're also your advocates."

Mental Health and Carer Burden

Two key areas were raised by other participants:

- The lack of mental health services in regional and remote areas, especially for patients working towards transplantation; and
- The impact on children of parents with kidney disease, including limited access to support services. A single mother shared an emotional account of her son's experiences growing up while she was on dialysis. Another participant echoed her concerns and highlighted positive examples of carer support in South Australia.

Governance and Indigenous Leadership

Stephen invited Kelli to reflect on what Indigenous governance could look like moving forward. Kelli suggested that while South Australia has models in place via the state Voice to Parliament, other regions will need bespoke, community-led structures. She stressed the need for conversations to be grounded in local knowledge, with traditional owners playing a key role in developing governance frameworks that can feed into state and national systems.

Closing Reflections

Jacqui closed the session by encouraging attendees to take a moment to write down three priorities while the conversation was fresh in their minds. She reminded the group that the next day would involve more in-depth, solution-focused group work, with Stephen emphasising the need to find solutions and determine the actual steps to do to get change happening.

Jaqui ended with a powerful reminder that Aboriginal and Torres Strait Islander people have always had systems of planning, action, and care:

> *"I just wanted to acknowledge 65,000 years of survival had an action plan. We had a project management plan, we had people doing tasks, we reviewed what we were doing. We were living in an environment that allowed us to thrive. This is not new business, this is just usual business... This is family business and it's not normal family business to be living in an environment of genocide where we have to have Australian human rights exercises around our rights to be in the places of our own country. So thank you everyone for coming here with that attitude of getting on with our business. We have national priorities to close the gap. We have government law to drive our agenda for advancement and we can all find a way of driving an advancement for people to live well with kidney failure through accessing transplantation, if that's a good pathway forward. Thank you for your priorities." – Jaqui Hughes*

2.10 Gala Dinner

The day concluded with a relaxed Gala Dinner — an opportunity for continued conversation, connection, and celebration. For many, it was the first time reconnecting in person since 2022. The evening showcased incredible talent found within the Gathering attendees, with NIKTT member Rochelle Pitt providing the main entertainment for the evening, while attendees Leanne Taylor, Matilda D'Antoine, Robert Champion, and Eddie Peters also got up on stage to share their musical talents.

A photo booth and props helped capture the evening, with guests printing copies for themselves and enjoying a good laugh amongst friends.

Day 3: Act

Program Overview

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. Framed by Jaquelyne Hughes as a way to centre lived experience and "invite people into the space," the performance illustrated the emotional weight and significance of receiving a transplant offer. 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. These proposals ranged from patient education materials and national workforce support networks, to culturally safe communication protocols and coordinated governance structures.

The NIKTT Position Statement was reviewed and confirmed, with participants suggesting changes to the wording and focus of the recommendations.

The day concluded with space to review held-over discussions and unanswered questions, finally culminating in a group photo.

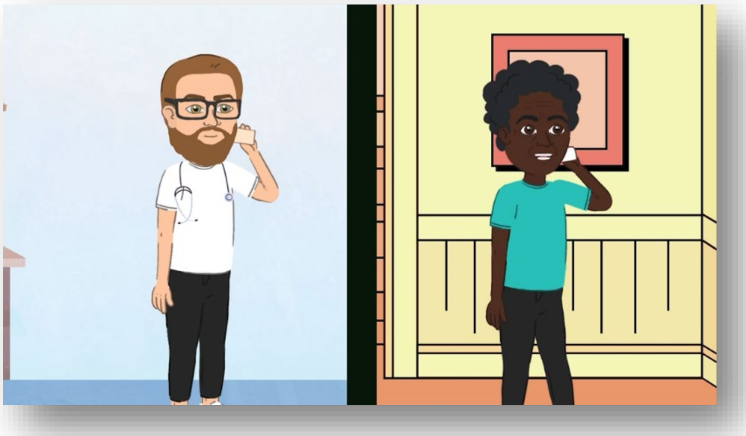
3.1 A Transplant Phone Call

Day Three started with an impromptu performance by Richard Jenkins, a transplant recipient from Western Australia, and Dr Andrew Mallet, a nephrologist from Queensland. In order to introduce the first session of the day about the updated TSANZ Kidney Allocation Algorithm, Jaqui Hughes invited everyone to the space by listening to a reproduction of a phone call someone might receive were they to be allocated a kidney.

"We're going to reproduce, maybe not accurately, but just for the spectacle of engaging into this space." – Jaqui Hughes

Richard and Andrew then 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:



3.2 TSANZ Revised Allocation Algorithm: Kidney Only Allocation Algorithm

Presenter: Kate Wyburn

Dr Kate Wyburn, a Sydney-based clinical transplant nephrologist and president of the Transplantation Society of Australia and New Zealand, presented an overview of Australia's revised Kidney Only Allocation Algorithm (KOALA). She opened by acknowledging the privilege of sharing space with Community and emphasised the importance of making the "dry" topic of allocation meaningful through understanding its real-life impact on patients, as evidenced by the re-enacted phone call with Richard and Andrew.

Kate described the allocation system as a computer-based algorithm that determines who receives a donor kidney once on the waiting list. While the current system applies equally to all patients, it has limitations and unintended inequities. The revision aims to improve fairness, transparency, and clinical outcomes through six key changes:

1. **Address needs of sensitised patients in a more nuanced way**
   Patients with high sensitisation (due to prior transplants, transfusions, or pregnancies) have more difficulty finding compatible kidneys. The revised system uses a graded scale to ensure these rare matches are not missed.
2. **Improve prognosis matching**
   Donor kidneys will be better matched to recipients based on expected longevity — e.g., giving kidneys that are going to live a long time to people who are going to live a long time — to maximise total life years gained from each transplant.
3. **Improve outcomes for young patients**
   The algorithm prioritises minimising time on dialysis for children and young adults, extending paediatric priority benefits beyond age 18 and tapering them out to age 35. It also prioritises better HLA (human leukocyte antigen) matches for young people to reduce long-term sensitisation.
4. **Address inequities by ethnicity – "Matchability"**
   The new system accounts for the fact that people from some ethnic backgrounds have rarer immune profiles and are harder to match. Instead of focusing solely on perfect six-antigen matches, the system considers how likely a person is to find a match at all and adjusts so that any disadvantage for those with uncommon HLAs is minimised.
5. **Retaining queueing equity**
   Time on the waitlist remains a key factor in the allocation process. Once clinical priorities are accounted for, people who have been waiting longer will still be prioritised.

6. **Move away from a tiered system to a continuous score**
   The previous tiered system created rigid cut-offs (e.g., priority at PRA (panel reactive antibody) >95%, paediatric bonus ending at 18). The revised model replaces these with a continuous point system that more fairly accounts for individual circumstances.

Kate concluded by highlighting that while allocation is only one small part of the transplant journey, it's vital that it is as fair and transparent as possible. She invited continued feedback during the consultation phase and reinforced the importance of early education and wellness for patients. Kate noted that the transplant phone call enactment highlighted how important it is to know the details of what's going to happen before two o'clock in the morning, encouraging people to attend education sessions. She also spoke about the importance of staying well once on the list, so that people are able to receive an offer, noting that the greatest barrier remains getting onto the waitlist in the first place.

Questions from the audience

Travel for transplants that don't proceed

A participant referenced the role-play session where a patient expressed frustration about travelling a long way for a transplant that doesn't go ahead. They asked: "could [you] explain some of the truth in how that happens and could that be a reality?"

Kate explained that unfortunately this is a real possibility. Even after a potential match is identified, many factors—such as the donor's condition at time of donation, surgical findings, or newly identified issues—can prevent the transplant from proceeding.

> "At times we almost say that there's a 30 to 50% chance that sometimes things won't go ahead depending on the donor characteristics. It's really hard to do anything other than let people know because otherwise there's a longer delay. But I think it's really important and… in some ways, if there's a bright side, you are getting offers – you are coming up on the allocation, you do understand the process… but it can be really tough." – Kate Wyburn

How long is the average wait for a kidney?

Kate responded that this varies greatly by individual factors such as blood type, sensitisation, and location.

> "It does depend on blood group, it does depend a bit on state because most of our allocation is done within a state – but if it's a great match or a great thing, we'll fly kidneys around the country. It also does depend on how sensitised you are. So, a lot of those things. But depending on where you are, the average in New South Wales was up as high as five years, it's probably down [now to] around four. But it does depend on a lot of different things. But that's a long time. Some places it's less and for some blood groups it's less, it's down to two years… but that's a hard one to answer." – Kate Wyburn

Impact of previous transplant on matching

A mother asked whether her son, who had a previous transplant and is now rejecting, asked whether it would be harder to match, because he's already got a donor kidney?

Kate confirmed this can be the case. If the first transplant sensitised the immune system, it may be harder to find a compatible donor the second time. She reassured that the algorithm prioritises sensitised patients and younger recipients to reduce disadvantage in such cases:

> "What we really want to do though [with the KOALA project], is that if someone is sensitised and is tricky to match that they'll get priorities. Being young you get priorities… but it really depends on what the actual immune system is doing – what it's seen – and they're the things that we are trying to prioritise so that any disadvantage in that sort of situation is minimised." – Kate Wyburn

How do you know if someone is sensitised?

Stephen asked: "How do you know whether somebody is sensitised? Is that a scan or is it an exercise? How do you actually find that information out?" Kate explained this is determined by a blood test sent to tissue typing labs, which assesses antibodies and how sensitised people are. The result is a PRA (panel reactive antibody) score, available on OrganMatch. Patients can access this information through their nephrologist.

Call for standardised, patient-friendly information

Dr Shilpa Jesudason – a nephrologist and Head of Unit at the Central Northern Adelaide Renal and Transplantation Service – noted that even clinicians find the system complex, saying how even with a PhD in transplant immunology, she still finds it hard to understand sometimes. She called for for developing a clear, standardised information sheet for all patients being worked up for transplant or on the waitlist:

> "I think we're really ready to distil a lot of this very complicated information down into really clear messaging with pictures, with figures. I think every patient who's on the wait list should have a piece of paper that basically gives them this information in some sort of standardised way – that we as a transplant community have all come together and said 'this is the information that every patient should have as a bare minimum.' I'm not just talking about really complicated things like the level of antibodies. I'm talking also about things like 'are you actually on the wait list?' Because I see a lot of patients who think that they are waitlisted and they're not.
>
> **So, I think we could determine as one of the outcomes from today that we come up with a minimum set of information that every patient who is being worked up or is on the wait list should have in a language that is clear and understandable to them.**" – Shilpa Jesudason

3.3 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 Retrieval and Transplantation*, released in November 2024.

She began by reflecting on her personal journey—from migrating from Sri Lanka to growing up in Canberra, to working as a medical researcher with a focus on immunology before transitioning into health policy. Her current role combines her passion for finding practical solutions with the opportunity to drive systemic change.

Rushika explained that the National Strategy was endorsed by all state, territory, and federal health ministers, highlighting its broad commitment and authority. The strategy outlines four priorities and ten goals aimed at improving coordination and outcomes across organ donation, retrieval, and transplantation. Although the strategy itself does not come with dedicated funding, its endorsement by all health ministers lays the groundwork for future resourcing and implementation.

A key focus of her talk was Priority 2, which addresses equitable access to transplantation for Aboriginal and Torres Strait Islander peoples and for people in regional and remote areas. She acknowledged the critical work of the National Indigenous Kidney Transplantation Taskforce (NIKTT) in shaping this priority and emphasised the importance of Community-led and co-designed implementation. Rushika noted that her team has worked closely with NIKTT to shape an initial proposal, that will be further refined based on Gathering discussions, to support Priority 2 implementation.

She also highlighted Priority 1 as important to think about in this context, which focuses on improving coordination across the national system, including a new goal on supporting living donation. This priority intersects with NIKTT’s work, but Priority 2 remains the main avenue for embedding Aboriginal and Torres Strait Islander leadership and equity-focused initiatives.

Looking ahead, Rushika explained that the Organ and Tissue Steering Committee (JOTSC) will lead the development of an implementation plan for the strategy. This plan will outline specific activities, some of which can begin immediately, while others will depend on new funding. The implementation plan itself will go back to health ministers for final endorsement.

Rushika acknowledged that while Commonwealth budget opportunities are limited in the short term—particularly ahead of an upcoming election—there are ongoing efforts to package funding proposals and explore future budget opportunities to support the strategy’s full implementation.

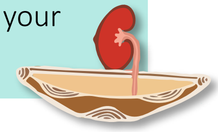
Questions from the audience

> **Kelli Owen:** “So we've got a lot of our mob that have travelled across lots of different nations here and I think there's a lot of understanding of processes and systems that are not understood. You talked about four years for this strategy to be pulled together, but there's no money... So, what do we do when we are electing people in these positions that are in our government to help fund where we are? Because 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? If there is no plan to drive forward our next steps, what do we do? What would you recommend us to do?"

Rushika: "So I think it's tricky timing from a Commonwealth perspective at the moment because of the upcoming election. The strategy was released in November last year, but I think this year is the time of opportunity to build the momentum to map the activities in the implementation plan. And as I mentioned, there's that second sort of budget process later in the year, but I do have to stress that it is a decision of government… I think raising awareness about all this really important work in an ongoing way is the way to get the message across."

Kelli: "So that would be something like our people going home and talking to their local representatives, going in and having these conversations that we've been having here. You'll need to go home back to your representatives and tell them what you experienced here, what you heard, what you think that we should be doing to get those conversations started in your local areas. These are the people that you elected in your areas, in your states and your territories and they're your voices in Canberra… Our voices have got to be heard somewhere."



To follow on from this, the NIKTT team wrote up a template letter than people could adapt for their own electorates, as available below.

Subject: Urgent Support for the Implementation and Funding for the National Strategy for Organ Donation, Retrieval and Transplantation

Dear [Elected Representative],

We, the undersigned Community members and advocates for Aboriginal and Torres Strait Islander health, write to you with urgency regarding the *National Strategy for Organ Donation, Retrieval and Transplantation* and the critical need for its full implementation and funding for Priority 2.

For too long, Aboriginal and Torres Strait Islander people have faced barriers to accessing kidney transplantation, despite the well-documented inequities in end-stage kidney disease. Transplantation is a lifesaving treatment, yet our people continue to be left behind due to systemic barriers, inconsistent policies, and a lack of culturally safe pathways. The National Strategy represents an opportunity for meaningful change, but it cannot succeed without genuine engagement with Community voices and the resources to support real action. Jurisdictional change must make this happen.

We are calling on you, as our elected representative, to:

1. Ensure the full implementation and ongoing funding for the local and regional levels of the strategy to improve kidney transplantation access and outcomes for Aboriginal and Torres Strait Islander people

2. Actively engage with Aboriginal and Torres Strait Islander communities, including Elders, patients, carers, and advocates, to shape policies that reflect our lived experiences and needs

3. Hold decision-makers accountable for embedding Community-led solutions, including workforce development, culturally safe care, and transparent reporting on transplant access

This is not just about health policy—it is about equity, justice, and the right to live. Too many of our people are dying on dialysis while waiting for fair access to transplantation. We need urgent action, not further delays.

We ask for your leadership in advocating for this within Parliament and ensuring that our voices are heard, respected, and acted upon. We welcome the opportunity to meet with you to discuss this matter further and look forward to your response.

Yours sincerely,

[Delegates of the 2025 NIKTT Gathering]

Please find the strategy here: https://www.health.gov.au/resources/publications/national-strategy-for-organ-donation-retrieval-and-transplantation

3.4 What are the priorities and solutions for the next 5 years?

Facilitators: Stephen McDonald and Jaqui Hughes

This session began by showing the Gathering attendees a summary of what had been collated throughout so far, from sticky notes left on easels as well as key priorities and goals written down in other sessions.

The summarised priorities were shown as below, with attendees encouraged to reflect on the priorities and think about their own – whether they had changed throughout the Gathering sessions, if anything was missing from the list below, and what some solutions to fixing priorities might be.

- **Accountability by health systems** (cultural safety, anti-racism, cultural leadership and governance, clinical yarning model, waitlist gaps vs post-transplant outcome, contra-indicators)
- **Indigenous Workforce** (patient navigators, Identified clinicians)
- **Non-Indigenous workforce** (relationality, clinical yarning, culture and law responsiveness)
- **Early education** (diet, work up resources, navigators, journey, water restrictions, weight, resources in language, patient stories, state specific, preventive measures, screening)
- **Kinship** (seeing the patient as part of their kinship system, who is caring for the carers, caring for the children with sick parents, Community members)
- **Returning to Country and staying on Country** (providing care on Country, sorry business, dying on Country)
- **Holistic approach** (mental health, dental, post-transplant care, paediatric, pharmacist, diabetes, etc)
- **Essential non-medical infrastructure** (transport to and from dialysis, travel back to Country, accommodation for both staff and patients)
- **Prioritising Community relevant outcomes and reflecting these in KPIs** (reinvent and rethink KPIs)
- **Increased accessibility** (more chairs, dialysis trucks, more transplant, live transplantations)

Participants were encouraged to write down, with others on their tables, the top five priorities they believed were important for the NIKTT and this group to take forward to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander peoples in Australia.

These answers were collated and are summarised in the Priorities and Actions section below. A full list of each priorities note can be found in the Supplementary Materials.

3.5 Positive Provocative Proposals (PPPs)

Facilitator: Jaqui Hughes

The session opened with a reflection on the role of the public in shaping public health systems. Participants were reminded that governments exist to serve the people, and that calling for change can be done not only through critique, but also through constructive, positive proposals. This session was framed as an opportunity to bring forward solution-focused ideas to inform system reform in kidney transplantation.

Participants were invited to share a problem they had seen or experienced, propose a solution, and list the key supports needed to bring that solution to life. Specifically:

- Participants were asked to take a few minutes to reflect on a problem they've experienced or identified;
- Then, they were asked to write down a solution and consider if it's something they would like NIKTT to take forward;
- They were reminded that they could identify as solution builders—people who listen, learn from others, and contribute collectively; and
- Ultimately, bring forward positive, provocative proposals grounded in lived experience, with the potential to be shaped into funded, actionable reforms.

Attendees were guided by the following framework:

1. In Kidney Transplantation, from my position as [....], my solution, that I will lead for [priority] is..
    a. Problem:
    b. 1st step – who should be working together for the solution with you
    c. 2nd step – what resource is needed
    d. 3rd step – how would you know it is fixed (data/ measurement)
    e. 4th step – check in with a second solution person, to get it right

The following is a summary of these collected problems and proposals. The full table of proposals can be found in the Supplementary Materials.

Problems, grouped by stakeholders who voiced these concerns

Carers / Family Members

- High costs and burden of relocation, accommodation, and transport
- Lack of tailored support, including mental health, counselling, and peer support
- Limited involvement in decision-making and planning

Patients

- Poor access to clear information: am I on the list? What does transplant involve?
- Delays in transplant work-up and access to surgeons
- Inability to work due to illness; limited financial and systemic support
- Lack of early-stage education around kidney health and transplant

Health Workers

- Isolation in roles and limited professional support or networking, especially for AHPs
- Lack of access to other specialist team members (such as transplant surgeons)
- Jurisdictions working in silos
- Patients not having access to education/resources to help them understand their condition
- High burden of CKD and other conditions in First Nations communities

Advocates, Researchers, Policy Makers

- Limited funding and resourcing for promising solutions
- No national plan to scale or coordinate community-led innovations
- Lack of traction despite strong existing local initiatives

Key Solutions Proposed, grouped by theme

Service Access and System Navigation

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

Workforce Development

- National AHP/W network or community of practice, to workforce with training, mentoring, peer connection, and resources
- Kidney and transplantation education for AHPs
- Creation of a newly funded role for Indigenous kidney health advocates/champions/leaders across all jurisdictions

Patient and Community Voice

- Encouraging community to talk about their priorities with decision-makers, policy makers, and funders

Education and Prevention

- Earlier education about transplant, starting before dialysis, with holistic and culturally safe information

System Reform and Strategy

- Lean on NIKTT to create resources for lobbying decision-makers for change
- NIKTT to coordinate national pooling of resources to create templates, helpful resources across states
- Creation of a national implementation plan that is action-oriented, with clear drivers and accountabilities
- Propose ‘inspiring’ solutions to policy makers, like “End Dialysis by 2050”, to advocate for top priorities
- Sustainable funding for initiatives like NIKTT and other access-enabling wrap-around services
- Priority for First Nations people in allocation algorithm

Supports Required

- NIKTT leadership and endorsement: For network creation, national consistency, and policy advocacy
- Collaboration with KHA, TSANZ, OTA, and government agencies: To scale, align, and fund solutions
- Government funding (Commonwealth and State): For workforce, outreach models, patient travel, and education initiatives

A few groups of people shared their proposals:

1. Clinicians from the Royal Adelaide Hospital working in renal transplant, as represented by Danielle Stephenson

I am a…

> *"Transplant Nurse Unit Manager at the Royal Adelaide Hospital, and my table is all clinicians working in renal transplant."*

I have heard about or experienced this problem…

> *"We've had a lot of experience talking to patients, but we haven't got the lived experience. And the one thing that we've identified that we've heard from our patients is the lack of educational resources. And we've all very passionate about this, hence my hand going up quite quickly to talk about it."*

My solution…

> *"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."*

Key supports of my solution…

> *"What we would need to achieve this, number one is funding for resources, obviously. We need skilled people to help, so we need people with lived experience. We need people who can work in photography, cinematography, people who can draw – anything that can help with resources for our*

> *patients. What we thought about would be a dashboard so that patients could see which modules they've done for education and they could do it at their own pace: They could do it all at once [or] they could do it one by one, [and] they could do it over and over again."*

Jaqui Hughes then asked: *"Are there others here who think that that would be something that they'd like to support that problem solution on?"* To which most people in the audience raised their hands and agreed that if the problem-solution was registered with the NIKTT, they would be happy for the NIKTT to contact them again to discuss the process of taking that further forward.

Jaqui asked the RAH team what they thought the timeframe on a problem-solution like this would be.

> *Danielle Stephenson: "Honestly I think it's achievable. It's a short-term goal that we can achieve. I don't think it needs to take more than a year really. And there's lots of people who are invested in this."*

2. Patient voices, as raised by Kim Francis and summarised here for brevity

I am a…

> Aboriginal woman and transplant recipient who has experienced repeated disrespect in the way clinicians—particularly younger nurses—speak to me and other Aboriginal women. I am speaking from both personal experience and shared conversations with other women in Community.

I have heard about or experienced this problem…

> Many of us—particularly older Aboriginal women—are frequently spoken to by clinicians using patronising, infantilising language, such as "love," "sweetheart," "good girl," and "darling."
>
> This language is not only offensive but continues a colonising, maternalistic dynamic in clinical care. It disregards our autonomy, our dignity, and our identity. These patterns persist across hospitals and are rarely addressed at a systemic level. I know I'm not alone—others from different language groups and

regions have shared similar experiences of being disrespected through tone, terminology, and assumptions.

My solution…

We need a national approach to culturally safe language education in transplant and renal care settings that includes:

- Localised guidance on respectful, community-informed language use, developed by and with local Aboriginal and Torres Strait Islander communities in each state/territory
- Mandatory cultural awareness training for all transplant and renal staff, including a focus on communication, respect, and addressing unconscious bias
- Cultural care plans that are actually implemented and updated in practice—not just documented—and that include preferences for how patients want to be addressed

Key supports of my solution…

Funding to expand and tailor cultural awareness training across all transplant and dialysis units nationally and support from NIKTT to drive national consistency while empowering state-based communities to define what respectful communication looks like for them.

3.6 Question and held-over discussion time

The below is a summary of the held-over questions and discussions from throughout the three days of the Gathering. These questions were either raised in other sessions and parked due to time constraints, or were written on post-it notes for attention later.

1. Q: Can a kidney doctor tell me why I have renal failure or kidney failure?

Dr Sharon Ford, the President of the Australia and New Zealand Society of Nephrology, responded that most of the time, yes – kidney doctors should be able to explain why. She noted that sometimes it may be unknown or performing the tests to determine the cause, such as a biopsy, might be too dangerous, but patients have a right to ask and be told if the cause is known.

> *"Most of the time we should be able to give you information about why your kidneys have failed. I think that's really a right to know that and it's basic information that we probably should offer and if we don't, you should absolutely ask us. It's our job." – Sharon Ford*

A participant added that despite having had renal failure for eight years, they still didn't know why they have kidney failure. Stephen clarified that not knowing and not being told are two different things, noting that communication is key, and patients should feel empowered to ask if they don't know.

> *"I just wanted to just make a point for uncle, his question about he didn't understand why he had renal failure. I just wanted to make a point there. That's why it's really important that we invested on the Indigenous health practitioner, health workers on the ground where they can step in and advocate for you. Up in Queensland, we sit in with our patients, where we know where they don't understand English is a third or second language and we sit there and consult with the doctor and the patient with their consent to break it down for them, bring it down to grassroots level language so that you do understand why you've got renal failure. That's why it's really important – We need those health workers [and] for NIKTT to [advocate] in each state health services for health workers." – Athena Tamwoy*

2. Q: Does diabetes medication contribute to kidney failure?

Dr Ford said that, in general, diabetes medications help reduce kidney damage. She noted that it's very rarely medications that have a toxic effect on the kidneys, especially in diabetes. Dr Paul Snelling also added that screening in early diagnosis is very important because some newer medications for diabetes not only don't hurt your kidneys, but in fact can slow loss of kidney function, sometimes by up to 50, 60, or 70 percent of what could be done before. He noted that if people have risk factors, they need to get screened so we can prevent or delay kidney failure by 10-20 years, possibly, with the right medication. Paul added that family members of people with kidney disease should also be screened.

Kelli emphasised the importance of early preventative methods, saying:

> *"Dr. Snelling diagnosed me at 19 in Darwin and I did not listen to him because I didn't feel sick. I wasn't sick and I didn't trust doctors. So these medications have come such a long way that could have slowed the prevention or me being on that machine in my forties if I had to taken and listened to Dr. Snelling." – Kelli Owen*

Another participant asked if these were diabetes medications that have improved – Paul confirmed and named SGLT2 inhibitors and Ozempic that reduce progression of kidney disease. He noted that this is an exciting time: "This is the time where if we can pick people up early, we can put things off by decades."

3. Q: How do we improve communication across state health services?

Nikky Isbel, president-elect of the TSANZ, suggested one way of dealing with this issue would be to have a dedicated person within each jurisdiction to coordinate this work:

> *"It is the really difficult relationship between having federal and states-based services. We thought it would be a good idea for each state to have a person who was in charge for that state of coordinating our response to the NIKTT agenda, so that there was someone who was appointed by and was working within the state health service for the improvement of all of the things we've been talking about, and being in charge of actually implementing that at state-based levels – talking to the transplant units, talking to the communities, talking to the Aboriginal Health services. It [would be] their responsibility and their role to do that and then to talk to their colleagues in other states as a network below NIKTT of a state-based implementation person whose job it was to roll some of this stuff out… this would be someone who'd be at the intersection: [they'd] be very, very clinical, but have the skills to advocate at a state government level and to feed into federal colleagues." – Nikky Isbel*

Stephen noted that this would be a wonderful suggestion about how to actually implement change through accountability and responsibility.

In terms of patient records, Stephen went on to acknowledge that communication between states is limited, with "dotted lines on the map [meaning] systems don't talk to each other and results don't come back and forth." Jason raised that My Health Record can help, though acknowledged it is limited. He noted that it is a starting point though, and that it is one thing people can control with their doctors locally – he advocated for people to request their information be put into My Health Record for easier communication between clinical teams across jurisdictions.

4. Q: What are we doing for our young people?

Dr Rowena Lalji shared that Queensland Children's Hospital does a large proportion of dialysis and transplants for Indigenous children nationally but lacks an Indigenous kidney health worker. They are advocating for this role but have not secured funding:

> *"[Queensland Children's Hospital] ha[s] done more than 40% of transplants for Indigenous kids around Australia over the last five or six years – so, our numbers are actually the largest in Australia, but it's actually a real deficit within our state because once the North Queensland kidney transplant unit is up and running, they will have Indigenous health workers in their transplant unit. The PA now has two and the children's hospital has none. Actually Gary and Brett have been coming across under the hat of the Queensland Kidney Transplant Network – and also out of the goodness of their hearts – because they can see that there's a gap. But we've really been struggling to attract funding for a dedicated role. That's a really big huge gap because we have an opportunity to actually increase kidney health awareness, not just for a child, but for a family and for a community." – Rowena Lalji*

Stephen suggested the answer to the question then was "not enough," noting though that there were good suggestions being put forth.

Kelli added that peer support and virtual connection between young transplant recipients is growing, including gaming sessions and family conversations, advocating for continued connection between paediatric patients.

5. Q: What should renal staff be aware of to make dialysis and kidney transplantation culturally safe?

Kelli noted the need to respect cultural protocols, such as gender rules, and ensure patients can safely voice these needs, is really important. She reiterated that it should be on the health workers to understand the cultural protocols and cultural differences in order to account for these needs.

Another participant shared how their mother-in-law was made uncomfortable by male nurses attending to her hygiene needs — and asked why patients must educate staff themselves.

6. Q: What support is there for carers (e.g. EAP-type programs)?

Chris Forbes from Kidney Health Australia said they believe support should be extended to carers, families, and living donors:

> *"That it's a really great question because we need to support not just carers, but we believe that patients, their families, and carers and even living donors need support along that journey of their kidney health. A donor has to give up work for weeks and weeks at times, and only gets minimum wage, so we're going to start to advocate for companies to be paying them their full wage for what is a generous gift of life."*

They are developing a new program called Kidney Health for Life and are open to co-designing support models, including digital and in-person options.

7. Q: How do we ensure accurate information is shared, particularly when misinformation spreads (e.g. TikTok)? How do you go about making sure that there's the right story that gets out there to people?

Lucinda Barry clarified that the Australian Organ Donor Register is secure and managed by the federal government through Services Australia. She mentioned that there is extensive security around the Register and that it's only accessible to the DonateLife teams in each state or territory.

> *"It is very secure. It's held by government, it's got people's personal information in there so that we treat it like that.. [People on TikTok] definitely do not have any kind of access to that. That's your information. And we only use that information when we need to use it. The register is actually set up so that people can go in and indicate that they want to be an organ or tissue donor at the end of their life. It's really important in that process to allow people to put their views forward and put it down on the register. And then that register is only checked if you are basically in intensive care on a ventilator and not going to survive and donation is potentially an opportunity." – Lucinda Barry*

8. Q (additional, from the floor): Is it true that our family can't donate to us?

Ross Francis responded that every living donor is individually assessed. About 50% are found unsuitable or decide not to proceed. Being Aboriginal or Torres Strait Islander is not a disqualifier. It depends on health, kidney function, and individual risks.

> *"So living donation, we assessed a lot of living donors and it's a really complicated process. We don't want to make two people unhealthy by taking a kidney away from someone. We don't want the donor to end up on dialysis. That wouldn't be appropriate. So if you look at all of the donors that come forward to have screening, about 50% of them, the conclusion is either they decide they don't want to donate having heard exactly what the process involves or we recommend that they don't donate because we think it would be a risk to their health. So it's actually a really complicated question to answer because it's very personal. And for someone who's come forward as a donor, we will look at their health and their family history and we'll look at their kidney tests, whether they've got good kidney function, where they've got signs of early kidney disease like blood or protein in their urine. And we'll make assessment based on all of that information and we'll counsel them really carefully about what we think the risks might be for them and then we should be a shared decision with that patient. So I think in this day and age, it shouldn't be a blanket yes or no. It should be a much more nuanced conclusion based on the actual person what we're dealing with, the patient who might be donating." – Ross Francis*

Stephen noted that in 2023, of the 1,088 kidney transplants done in Australia, just 70 were for Aboriginal and/or Torres Strait Islander people and just two of those were living donor kidney transplants. For non-Indigenous people, there 255 living kidney donations. Stephen thus stated that this indicates the systems don't seem to be working equitably, asking Nikky from TSANZ, "are there ways [to make this work more equitably] and what should we be doing to change that?"

Nikky Isbel said the idea that Indigenous people can't be living donors is a myth and needs to be challenged:

> *"Living donation is a huge myth... So it's about being assessed and nobody, as Ross has said, wants for people to be harmed by the process of becoming a living donor. But there's also harm to the family of not being a living donor as well with people going on to dialysis. So, I think it's all about having an assessment, having that conversation with the local units, and knowing that because you're Indigenous doesn't mean you cannot be a living donor. You need to be assessed as a living donor and a decision and a discussion being made about what are your risks and what are the health concerns if there are any, and what are the issues for you as an individual. I think the myth should be busted that people who are Indigenous can't be living donors, but they need to be assessed." – Nikky Isbel*

Sam Bateman, a nephrologist from South Australia, noted that things are done differently across jurisdictions though and this must be addressed:

> *"We need to acknowledge as a health system that things are done differently depending on which transplant assessment unit is assessing you. Things that may fly in one region don't fly in a different region. Maybe what we need to talk about and gain some sort of consensus on [is] if you are being assessed to be a living donor and you were a First Nations person, then that is not seen to be a contraindication because I think that it's potentially a bit naive – based on the rates of living donors coming from First Nations people – that that doesn't play a factor in at this point in time. So maybe to get some clarity across the country about what is deemed acceptable." – Sam Bateman*

Nikky confirmed that this issue is on the agenda for the national Living Donor Working Group.

Position Statement

Participants were invited to revisit the Position Statement first developed and endorsed at the 2022 Gathering. This review was designed to assess whether the Statement remained fit-for-purpose — whether its priorities still reflected the current needs and realities of Aboriginal and Torres Strait Islander peoples navigating kidney transplantation, and whether any elements had since been addressed or required revision.

The group reaffirmed the core recommendations outlined in the original Statement. These included the establishment of a national peak body (or organisation/network) to coordinate efforts and connect regional and unit-level work; the continued development, support, and succession planning for an Aboriginal and Torres Strait Islander kidney health workforce across clinical and non-clinical roles; and the expansion of wraparound support services for patients, particularly those travelling for transplant workup. No participants indicated that any of these priorities had been resolved or were no longer relevant, and the group agreed they remained essential to guiding the next phase of NIKTT's work.

A key theme that emerged during the review was the need to improve the clarity and accessibility of the Statement itself. Participants expressed concern that the language was too complex and could exclude the very people it was intended to serve. Several people called for the Statement to be rewritten in simpler, clearer terms — ensuring it could be understood by patients, carers, family members, and non-clinicians.

Several important content gaps were also identified. One participant highlighted the absence of any reference to primary health care and Aboriginal Medical Services — which are often the most trusted and accessible points of care for Community members. They called for the inclusion of dedicated renal staff within these services, such as renal nurse educators or health workers, to support culturally safe, place-based yarning and education both before and after transplant.

Participants also reinforced the importance of support for carers and families, particularly when navigating complex care systems for children, Elders, and young adults. Though this had been included in the original statement, it was strongly reaffirmed as a continuing priority. Other themes raised included the importance of transparency and accountability in how decisions are made and how services are funded across all levels of government and health systems.

The Position Statement was thus updated as below to reflect these discussions.

Transplantation Equity for Aboriginal and Torres Strait Islander Peoples with Kidney Disease

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

Delegates, as listed below, 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 below, 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 convert), 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 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, as listed below, therefore endorses the following actions for the next phase of the work to improve transplantation equity:

1. 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** (e.g. through an annual score-card) 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 t**ransparency and accountability of funding** of 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.

Priorities and Actions

The priorities, solutions, and actions needed that were raised during the NIKTT Gathering have been listed below and then grouped into seven key themes for clarity.

Priorities for the next five years, as listed by attendees from most to least commonly mentioned

1. Resources

Development of accessible, culturally appropriate, and language-specific education about kidney care—from early stages to post-transplant—including patient stories, visual aids, induction booklets, and clear communication tools.

2. Workforce

Expansion and support of a strong Aboriginal and Torres Strait Islander health workforce across all roles, with dedicated training, lived experience, peer navigators, and culturally safe positions embedded in services.

3. Cultural safety

Implementation of in-person, place-based, ongoing cultural safety training and standards for all healthcare staff. Holding clinicians to account for racist practices and calling out racism.

4. NIKTT advocacy

Continued national advocacy to address systemic inequities, influence policy and funding, and expand models of culturally safe care led by First Nations communities.

5. Standards in clinical practice

Establishment of culturally informed clinical standards, care plans, performance indicators, and accountability processes to ensure equitable treatment and clinician responsibility.

6. Increase dialysis chairs

Provision of more dialysis chairs, mobile units, and home therapies to improve access and allow people to receive care on or closer to Country.

7. Workup improvements

Enhancement of transplant workup processes through increased outreach assessment clinics, early preparation and screening, better access to primary care (e.g. dental), and tailored supports to help patients become eligible for transplant.

8. Whole of kidney journey

Coordination of care across the full kidney journey—from prevention and early detection to transplant and post-transplant—especially for children, families, and those with chronic conditions.

9. Support for carers

Strengthening support systems for carers through respite services, counselling, and practical supports that acknowledge the broader role of family and Community in care.

10. Data dashboard

Development and use of transparent data dashboards to monitor equity, track progress, and hold systems accountable through meaningful indicators and reporting.

11. Funding support

Securing dedicated and sustainable funding for culturally safe services, transplant journeys, NIKTT operations, and holistic models of care.

12. Health in general

Improving access to healthy food, weight management, diabetes support, and broader health promotion to optimise transplant readiness and patient wellbeing.

13. Transport

Ensuring reliable, accessible, and affordable transport to and from dialysis and other health services, especially in regional and remote areas.

14. Wrap-around services

Delivery of holistic and integrated supports—before, during, and after transplant—including multidisciplinary care, financial support, and long-term follow-up.

15. IRGs

Establishment and strengthening of IRGs nationwide to embed First Nations leadership and advice in kidney care strategies and decision-making.

16. Wellbeing

Embedding psychosocial and emotional wellbeing into transplant care, recognising patients as whole people with family, cultural, and mental health needs.

17. Post-transplant care

Building post-transplant care pathways, including transitions from paediatric to adult services, and ensuring ongoing culturally appropriate support. Providing regionally based post-transplant support to ensure continuity of care outside major urban centres.

18. Housing

Addressing housing insecurity and overcrowding to enable stable, safe living conditions for people needing regular dialysis or transplant care.

19. Allocation algorithm

Reforming the kidney allocation algorithm to prioritise access for First Nations patients, including pre-emptive transplants where appropriate.

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 for the next five years

Participants at the Gathering identified the following specific actions—raised directly in discussion or echoed across multiple contributions—as practical steps toward improving transplantation equity.

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 workers 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

Feedback

Feedback was sought during and after the Gathering, with attendees sent an online form to complete post-event. This included the following questions:

Priorities

- What were the main takeaways for you from the Gathering?
- What do you think the top three (or five!) priorities areas are going forward for transplantation equity?
- Did this change for you because of the Gathering?
- Do you have anything you want to share since reflecting post-Gathering?
- If you had a magic wand, what would be one outcome or action discussed at the Gathering that you want to see achieved first?

Experience

- What did you like most about the Gathering?
- What did you like least about the Gathering?
- Was there anything that you thought was missing from the Gathering?
- Did the information provided to you before the Gathering adequately prepare you for the Gathering?
- Which parts of the program did you like the most?
- Which part of the program did you like the least?
- Could we have done anything differently in terms of the program or structure of the Gathering?

Organisation

- Do you think the Gathering was well organised?
- How did you find the length of the event?
- How satisfied were you with the meeting venue (SAHMRI)?
- What could have made the venue experience better?
- How satisfied were you with the Gathering Facilitator?
- What could we improve on in terms of Gathering organisation in the future?
- Do you have any comments or suggestions for us to improve future Gatherings?

Participants provided overwhelmingly positive feedback on the Gathering, reflecting appreciation for the opportunity to come together in a space designed to prioritise Aboriginal and Torres Strait Islander voices and leadership.

Attendees described the Gathering as inclusive, “impactful,” and “uplifting,” with a strong sense of unity and shared purpose. The structure of the program — including the dedicated Blak space on Day One, open round-table discussions, and a focus on lived experience — was noted as a key strength. Several participants shared that the Gathering created a sense of belonging and validation that is often missing from broader health system conversations.

> *“Thoroughly enjoyed it and was very moved by the people that told all of us about their renal journey.”*

> *"Noted so much generosity and good spirit of people there. Good to see people working together."*

There were, however, consistent calls to keep the momentum going. In particular, attendees emphasised the need for sustainable and flexible funding, to ensure the initiatives discussed — including implementation of the National Strategy, NIKTT's continued work, creation of resources, and workforce development — can be actioned and implemented, as well as the need to create culturally appropriate transplant education resources relevant to each jurisdiction.

> *"Its easier to feel part of a group when you are there. It is harder to maintain collective momentum when we are apart. We need to create structures that support collective action."*
>
> *"The biggest takeaway for me was that together we can all make a difference in this area, and, that the diversity of approaches and different things being tried around the country are in fact our strength."*
>
> *"I really enjoyed the breaking out and working on solution-enabling. It makes the Gathering a place of shared ownership, shared championing and shared responsibility. The EOI process was terrific to enable to solution-enabling, because it helped NIKTT Gathering members to know we were working together for equity and outcomes."*

In terms of what was missing from the Gathering, participants noted that Tasmania was not represented, that there were clinical roles missing – such as transplant surgeons and clinical leaders of transplantation units – and that there should have been more representation from Government stakeholders, including Ministers.

Conclusion and Next Steps

The 2025 NIKTT Gathering was held to reflect on progress to date and to chart priorities for the next phase of work toward transplantation equity. Over three days, participants identified key barriers, shared practical experiences, and developed proposals for change. The result is a clear set of priorities and recommendations that reflect both immediate needs and long-term structural goals.

Many calls to action focused on three areas:

- the development of practical, culturally relevant educational resources, shared and stored centrally,
- investment in the Aboriginal and Torres Strait Islander kidney health workforce, and
- sustained funding for Community-led, nationally coordinated initiatives and action.

Participants stressed the need for clear, accessible patient education—resources in language, visual communication tools, and state-specific materials that explain each stage of the transplant journey, including waitlisting, testing, and what to expect after transplant.

Workforce was raised repeatedly—not just the need for more Aboriginal and Torres Strait Islander staff, but also funded roles with clearly defined responsibilities, such as transplant educators, peer navigators, and cultural support workers embedded in renal units. Participants described the isolation many First Nations staff face and called for a national network or community of practice to offer connection, training, and mentoring.

Cultural safety was described as a foundational issue. Health workers and patients shared ongoing experiences of racism, poor communication, and clinical spaces that remain culturally unsafe. Many participants recommended making cultural safety training an in-person, context-specific training opportunity across all services and finding a way to make non-Indigenous clinicians accountable for anti-racist practice.

Beyond these core areas, other priorities included:

- increasing the number of dialysis chairs and mobile dialysis services in remote areas,
- supporting patients through the transplant workup process from early CKD stages,
- providing respite and support services for carers, and
- building a transparent data platform and accountability tools to track progress.

The Gathering also included structured sessions to identify specific problems and propose targeted solutions. Patients raised concerns about delays in workup, lack of transparency, and inadequate information or resources across all stages of the journey. Carers called for counselling, respite, and practical help during long relocations. Health workers raised systemic issues—fragmented services, lack of access to specialist support, and underfunding of successful local initiatives.

Proposed solutions included:

- embedding outreach models as standard practice,
- establishing an implementation plan for the National Strategy with clear deliverables and shared accountability,
- using NIKTT to pool resources nationally and develop shared tools across jurisdictions,

- creating a national workforce leadership roles, and
- encouraging policy-makers to back transformative, long-term goals with sustained funding.

These themes were carried through into the 2025 Position Statement. The Statement calls for a series of next steps, including:

1. 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 (e.g. through an annual score-card) 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 of 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

The outcomes of the 2025 Gathering provide a detailed roadmap for the work ahead. While the vision of transplantation equity remains clear, delegates were consistent in their message: achieving this vision requires sustained leadership by Aboriginal and Torres Strait Islander peoples, adequate and targeted resourcing, and a shift in how services are structured, staffed, and made accountable to the communities they serve.

The outcomes of the Gathering will be shared with Community, clinical partners, professional bodies, and government stakeholders. The priorities and recommendations will be submitted to the Federal Department of Health, Disability, and Aging, and will inform the implementation of Priority 2 of the *National Strategy for Organ Donation, Retrieval and Transplantation*.

Supplementary Materials

Priorities

Written in the perspective of:	*Priority*	*Theme*
Clinicians/Patient Experts (SA)	Increase out reach services and more chairs, for instance Doctors going to Purple House. As well as a transition room for people that don't want to rush off. Prioritise increasing chairs at Kanggawodli (8-10 chairs), and Cooper Pedy & Yatala getting chairs, Providing more feed for patients that arent just inpatients	Outreach services
Clinicians/Patient Experts (SA)	Talk with local government and charities to support providing and funding appropriate care	Funding support
Clinicians/Patient Experts (SA)	Literature that explains kidney care in language. Culturally safe communication, yarning and training taylon conversations and have a yarn- treat patients like people and focus on the person	Resources
Clinicians/Patient Experts (SA)	More First Nations health workers, nurses, doctors and nephrologists. Overall creating spaces for Mob in hospitals	Workforce
Clinicians/Patient Experts (SA)	Culturally safe spaces for Mob in the hospital	Cultural safety
Patient Experts (WA)	Housing, 10 in one house, some have alcohol problems, no room for everyone	Housing
Patient Experts (WA)	Transport: To and from dialysis. The transport is often non-accessible, closes at 5pm, Taxis don't always show up, Geraldton transport issues, Broome taxis not accepting cab charge	Transport
(NSW)	Support systems for carers. Respite/who do we go to? From Community roles respite when theres not family? Counselling respite? Training/health system	Support for carers
(NSW)	Introduction into dialysis child package culturally with Aboriginal educators- Community connector persons and Aboriginal health worker support for health workers- someone to feedback results.	Aboriginal workforce
(NSW)	Traffic light system A4 piece, Kidney screening in Community rural NSW/VIC screening.	Resources
(NSW)	Transparency around information AMS around education and how they are supporting Community	Resources
Clinicians (WA)	Respect to patients: Practitioners being late, but patients arent allowed to be late. Treating Aboriginal patients all the same "painting us with one brush". Not accomodating when patients missing days, not letting them come another day	Standards in clinical practice
Clinicians (WA)	Dialysis priorities: More/spare chairs. Staff need to understand law + culture. Allowing dialysis patients to dialyse whereever they are travelling, more accissible. More dialysis staff and more sessions for dialysis. Dialysis truck needed in midwest. Not enough chairs for everyone in Geraldton. Port Headland and Broome need chairs/truck, foring people to relocate	Increase dialysis chairs

Clinicians (WA)	Accomodation: Headland needs more accomodation, people who are homeless are needing to come to dialysis. Housing, 10 in one house, some having alcohol problems. Bigger caters	Housing
Clinicians (WA)	Patients are not gaining info on what services are avalible. Rewards for patients attending dialysis?	Resources
Clinicians (WA)	Aboriginal health worker role	Workforce
Clinician	"I am a Kidney Doctor. I don't have the staff or the resources to make sure my patients fully understand what transplant is and means to them. I need Aboriginal colleagues who have the time allocated and appropriate resources to yarn about transplant journeys. NIKTT can help with resources and advocating state government to staffing".	Workforce
Clinician	"I am a Kidney Doctor I cant get my First Nations patients living donor/pre-emptive transplants due to the impacts of colonisation. I want an allocation algorithm that prioritises First Nations people and allows them to receive pre-emtive deceased donor transplants. NIKTT can advocate for changes to the allocation algorithm".	Allocation algorithm
N/A	Welbeing: Recipients are people, who are loved by family	Wellbeing
N/A	NIKTT Data Dashboard: Seeing ourselves succeed in kidney failure	Data dashboard
N/A	Workforce: Aboriginal and Torres Strait Islander people are leadup	Workforce
N/A	Funding programs about cultral saftey, with special resources for high need areas	Funding support
N/A	Health optimised to be TX waitlisted suitable starting at CKD stage 4	Workup improvements
N/A	Rethink what is considered as KPI's. Rethink and reinvent	Data dashboard
N/A	Address inequities not only nationally but also between State and Territories	NIKTT advocacy
N/A	Education for all stages including support services	Resources
N/A	Transplant Education: Patient stories (videos), Resources in language, Resources that are easy to read, State specific, Information in dialysis units, Who to contact if more info wanted	Resources
N/A	Transplant workup: Primary healthcare- breast screen, dental, FOBT, weight loss and support. (There is no dental in regional areas!)	Workup improvements
N/A	First Nations workforce: Cultural saftey for workforce, Partnering with health workers, Two way learning/teaching cultural support along with education	Workforce
N/A	Post transplant care: Who does this? 3 monthly 15 mins with kidney specialist, GN6OIN6 not just for first 12 weeks, Forums linking people with dietician, pharmacist, transplant coordinators, cultural support ongoing	Workup improvements
(VIC)	Supporting Victoria to create a Patient Reference Group of local leaders and Elders (We seem to be behind in this)	IRGs
(VIC)	National cultural saftey education for healthcare workers	Cultural safety
(VIC)	Improved education on CKD/Dialysis/Transplant delivered by patient advocates that is easily accessible to all	Resources

(VIC)	Propper funding of transplant journies including the psychosocial and welbeing components of health that should be part of the service of transplant care	Funding support
N/A	Dental assessment at or before starting dialysis	Workup improvements
N/A	Educational resources for transplant and workup	Resources
N/A	Dedicated transplant supporters in all dialysis units to help with the transplant workup	Workforce
N/A	More First Nations staff representation in rural areas	Workforce
N/A	Education at young ages about kidney problems	Resources
N/A	Culturally appropriate education for staff	Cultural safety
N/A	More dialysis chairs in Communities (Remote)	Increase dialysis chairs
N/A	NIKTT to develop resources- CKD prevention, pre and post transplant and how to cope if TX is failing- building resilliance	Resources
N/A	Lack funding allocated to NIKTT and other recurrent funding + philanthropic $$$	Funding support
N/A	IRG's up and running everywhere	IRGs
N/A	Shared culturally appropriate education resources	Resources
N/A	Aboriginal workforce- funded peer navigators for renal services	Workforce
N/A	Support for patients and their carers	Support for carers
N/A	More transplants	NIKTT advocacy
N/A	Patient and family support from those with lived expereince (First Nations)	Workforce
N/A	Community/PHN education around CKD, transplant pre and post, screening and genetic testing	Resources
N/A	Workforce: Aboriginal transplant coordinator	Workforce
N/A	Education for Non-First Nation people. Throughout hospitals to create cultural saftey	Cultural safety
N/A	Transplant workup resources. Including people in remote areas, transport and access	Resources
N/A	Aboriginal workforce	Workforce
N/A	Help to lobby our own health services	NIKTT advocacy
N/A	Psychosocial health, councellers, psychologists in workplaces, Allied health in the workplace/OT/Physical	Wellbeing
N/A	Regional support for patients locally after transplant	Post-transplant support
N/A	Support for patients- transport to and from dialysis at home and in metro	Transport
N/A	Culturally safe training implemented to all staff and structures in healthcare to support Aboriginal workforce	Cultural safety
N/A	Whole of kidney journey rather than just transplant	Whole of kidney journey
N/A	Making clinical care easier to understand with easy to understand resources and navigators	Resources
N/A	Early workup- Prior to Community HD	Workup improvements
N/A	Weight: Meds/bariatric surgery access/access to healthy food	Health in general
N/A	Return to country: Home therapies, capacity in current units, ISD Home/Headling/New units	Increase dialysis chairs
N/A	Place-based planning and implementation	NIKTT advocacy

N/A	Intergration of First Nations imput/advice to Clinical Dept. Strategy and ops	NIKTT advocacy
N/A	Cross-sector partnership to deliver wrap-around holistic early, pre and post kidney/TX care	Whole of kidney journey
N/A	Primary care support (Pre and post transplant)	Support for carers
N/A	KPI's for our service so we can track our performance- can we use the same as others?	Data dashboard
N/A	Aboriginal transplant educators	Workforce
N/A	Expand the NIKTT Model to dialysis + CKD care, set this up over the next 5 years	Whole of kidney journey
N/A	Workforce embedded within services	Workforce
N/A	Supporting First Nations leaders eg. Clone Kelli, Jaqui and others	Workforce
Pediatric perspective	Service delivery being able to deliver services on Country/closer to home eg. All children on haemodialysis have to relocate to capital cities without any support for other siblings and care givers	Increase dialysis chairs
Pediatric perspective	Culturally appropriate education for both child and families in language, difficulties accessing interpreters to assist with this	Resources
Pediatric perspective	Peadiatric services both pre/post eg. Health workers for kids managing things like diabetes, or nephrotic syndrome. To increase the longevity of transplant by implementing services such as transition to adult services	Whole of kidney journey
N/A	Accountability for structural/systematic impacts (ie. Waitlist gaps vs post-transplant outcome similiarities)- Who is accountable?	Data dashboard
N/A	Understanding of patients as a part of their support system + network are kids, carers, Community members)	Support for carers
N/A	Non-concensus on basic contraindications, this means it can be weaponised by clinicians- Is there accountability/Reporting process?	Data dashboard
N/A	Cultrually safe clinical spaces within workplaces for staff & patients	Cultural safety
N/A	Dialysis units in remote Communities or more dialysis trucks	Increase dialysis chairs
N/A	Support for carers, family and children	Support for carers
Clinician (SA)	"I am a First Nations nurse working within the transplant unit at the RAH. I have noticed how clinicians around me (inclusive of Drs, nurses, allied health), do not know how to interact with MOB in a cultrually safe way. Yarn with me is a journal article that describes using the Clinical Yarning Model with patients. I would liike to see in service education in ALL health services using the Clinical Yarning Model. I want it to be a standard of care that clinicians use this model"	Standards in clinical practice
N/A	Focus on implementing manditory cultural saftey training for clinicians eg. Walking in two worlds course delivered in person every year (Like hand hygine complete every year refresher)	Standards in clinical practice
N/A	Clinican Yarning Model taught to all clinicians andc recognised as the standard of culturally safe communication. IMPLEMENT	Standards in clinical practice
N/A	Language group specific resources around CKD, PD, vascular access, HD, medications, transplant work up, transplant, post transplant care	Resources

Advocate	I will address the problem of inequity to access to transplant and promise the best kidney failure treatments to ATSI people	--
Advocate	By advocating for the society to support ATSI people to lead the kidney care community in finding solutions and to then play our role brining together, encourage, and facilitate all of our members using their expertise to work together to achieve those solutions	NIKTT advocacy
N/A	Provide training for Indigenous Health Practitioners (renal unit), whether by on going training or certification	Workforce
N/A	Recruit extra Indigenous Health Practitioners (renal unit), by providing educational sessions to school students by Indigenous Health Practitioners OR organisation (Health Services) offering traineeship	Workforce
N/A	Collaborate with other people in NIKTT network leading similar work (NT)	NIKTT advocacy
N/A	More funding for Healthwork	Funding support
N/A	Training programs	Workforce
N/A	Community transport	Transport
N/A	Support systems for carers- Respited	Support for carers
N/A	More jobs need to be created for Community	Workforce
N/A	Support systems for carers, trust and understanding need to prioritised for respite as many are expereincing fear of the unknown. How can we support people better, Community support, family support, cleaning/house duties, police, hospital, GP's, and specialists	Support for carers
N/A	Jobs need to be created in the health system, Community lead and trained. ACHO's to be trained in all areas	Workforce
N/A	There is a lack of induction to dialysis, instead of it just being a schedule of times. More information needs to be explained. We need to develop a good package ofd induction. Booklets with everything from AZ. Including aftercare, warnings, positives. User friendly designs for all information	Resources
N/A	Paitents require better, more accessible communication about time on the waiting list, instructions about monthly results using the traffic light system. Results also being delivered on time.	Resources
N/A	There is a lack of home visits in rural areas, causing people to feel isolated. Could screening van or unit go into schools and Communities (ie. Like the Pink Bus for Brest Cancer) or providing an easy screenming tool to be used at all times	Workup improvements
Patient Experts	Fiancial hardship: Emergnecy releif programs for people with chronic disease, Specified housing/hostels, Subsidies for food, transport, hospital parking, ect. Up front payments rather than reimbursements	Transport
Patient Experts	Access to appropriate foods (cost of healthy food is expensive). Access to help for losing weight- to help with being healthy for transplantation. Hotels specifically for renal patients with the right foods ect.	Health in general
N/A	Diabetes management to prevent diabetic nephropathy. Education around food/drink, Optimisation of anti-hyperglycemic medication (GLP1's) with 3 monthly Hba1c	Health in general

	testing (active physicians), Continous glucose monitoring accessible for Type 2 diabetes	
N/A	Screening for genetic causes of CKD (Family database?)	Whole of kidney journey
N/A	Template of cultral care plans completed by nephrologists and/or Transplant Coordinators in conjunction with First nations clinicians. Uploaded onto Sunrise	Standards in clinical practice
Patient Experts (WA)	Offer more knowledge about keeping ourselves healthy (diets) making petients clean up after themselves (PSA jobs), more care in dialysis unit, caring for patients.	Health in general
Patient Experts (WA)	Making patients who need to dialyse longer wait longer than those who have shorter dialysis	--
Patient Experts (WA)	No knowledge whatsoever about what is happening on kidney journey- Not giving information to have a second chance at life	Resources
N/A	More dialysis chairs and access to dialysis buses to help people return home to Country	Increase dialysis chairs
N/A	Prevention- Screening early, education (especially of children andyoung people)	Whole of kidney journey
N/A	Help those on dialysis get ready for transplant- lose weight, get fit and healthy	Workup improvements
N/A	Rename racism and hateschemes from the system and be more culturally appropriate and nuanced. Espcially in larger cities	Cultural safety

Positive Provocative Proposals

I am a...	*I have heard about or experienced this problem...*	*My Solution...*	*Key supports of my solution...*
AHP	All areas are in isolation recreating same role without guidance without support	A workforce network to do sharing of resource, training, mentoring, cultural safety and responsivness. Make aware of our skill set and knowledge and growing work force- NOT nurse lead, AHP,	NIKTT/NAATSIHWP/Other peak bodies/RTO's/Urgent
AHW and renal nurse	Working in isolation, lack of an Aborginal workforce group or community of practice for renal patient support, education and care through all stages of renal disease	Start a renal AHP/W community of practice for education and sharing of resources. Just don't want to see Community continuing to have to re-invent stuff when they are a lot of great resources out there we could share and also learn and prolem share together in the renal space	NIKTT/CATSINAM Happy to facilitate/help set up the renal community of practice within NIKTT. If supported, or thougt would be of benefit to workers
Carer/family member	Relocation and accommodation	My governance and state funding	Health agencies/ Government funding/ NIKTT Initatives
Carer/family member	Lack of money More support particularly for carers/family Transport Counselling Holistic approach to patient Early intervention	Invite Ministers to Gatherings	Let them meet grass roots people and the "REAL" problems that exist
Carer/family member AND Patient Expert/Transplant AND Clinician/ Government	Lack of peer support Need for normal language health information that is accessible for all ages through different mediums (Written and Verbal)		Mob/ Rural groups/ Health groups/ KHA

Carer/Patient Expert AND Clinician/researcher AND Ally	Communication about kidney transplant when starting on dialysis	Education around transplant process early on. Before starting dialysis	Peer mentors or health worker lead education- Yarning Circles Written material that is language/culturally appropriate Tv Ads/Radio about kindney disease
GP/ transplant coordinator	Poor access to TX surgeon- delays in work up	Secure outreach as ongoing/standard model of care	NIKTT- letter of support RHW- funding and travel support KRS letter of rationale/explaining need/benefit
Health professional (Kerry Dole)	1) Implementing (getting acceptance) the work/voices of the NIKTT into the executive local health + everyday practice + local government 2) Each state working in silos	1) Ask NIKTT to help by compiling a power point that health professionals can use to talk to their Directors + Executive + local government 2) Ask NIKTT to help distribute to each state the problem being faced and how can work as a team to solve the problem (each state can offer expertise, resources ect. Eg. Nationals educators template, all states pool resources and develop national template	1) NIKTT Co-chairs + Program manager Director of nursing Local Patient Navigators + peoples with a voice 2) NIKTT Co-chairs + Program manager Fellow TX Coordinators
Kidney Advocate and Ally working to improve kidney health at a national level	There are many passionate people working on great solutions but these are often fragmented and not part of a bigger picture plan. There is limited sharing and awareness of patient stories, expereince and initiatives	A national implimentation plan that not only focusses on what needs to be done but who can help drive action and outcomes	Can organisations like KHA, TSANZ, and other support, scale, create awareness. I think if we can bring all groups and voices together, we can create traction and make a change. I see ipportunities for KHA to help with expanding the reach of great things that have been developed by small teams and individuals to work with the NIKTT to make sure that things that have been

			developed that right way can gain National traction. Whats done in First Nations health should be how things are done in health- it should be the normal not the exeption.
Kidney Doctor	People not understanding about their kidney disease	Get kidney transplant training into the AHP circulation so we can get specialised kidney and transplant AHP's to help people understand and take control of their journeys	
Kidney Doctor (The group has AHPs, patients, KHA)	Lack of support for AHP's, sense of isolation and needing to start from scratch. Disconnect with other elements of the clinical team	An AHP network minimum NIKTT (or Aboriginal workforce network)	NIKTT Governance/leadership Champion AHP's to drive this A spirit of sharing and openness Clearly defined roles and understanding of the role of an AHP (as opposed to a nurse/social worker ect), each unit to do this Prioritising AHP knowledge on certain issues KHA educational modules for AHP's- accredited by NAATSIHWP now- need to be leveraged
Kidney Doctor and Renal Clinician lead for WA (Doris)	Heard and seen inequity in accessing kidney transplant for First Nations due to multiple complex issues	Lobby for fundraising, establishment of Renal Indigenous Work Force	NIKTT's solution of voice
Leader of Kidney Health Organisation	We, the kidney community (patients, clinicians, families, carers), are but one ofmany communities that need government (Federal + States), support to improve kidney health of those living with this disease and the 2.0m Australians that are undiagnosed. We 'compete' with other health organisations and other non-health funding requests	I know that providing an inspiration that is readily 'remembered' by Policy makers,Politician significants provide breakthrough to then have more detailed discussions.	

		"End Dialysis by 2050"- a prositive proactive proposal. I believe we need to add aninspiration. Advocating on top at the key priorities to open doors and drive engagement	
Patient Expert/@ home dialysis (Daniel Kingsley)	No information about transplant status- am I on the list? I am a long way from help and my new kidney and transplant test	Before we start or when we start disalysis have more information about it- if I am on the waitlist and what I need to do. The specialists visit Community for testing and for my care after transplant, getting testing done while training even in one day testing. NIKTT to make standard We need government support, then my family can support and also get checkups	We need Government support in funding, training, medication, and access via roads and planes Drs, AHP's nurses and better testing
Patient Expert/Pre dialysis (Jane)	Problem of accessing service to help with transplant work up for Community	Problem with lack of/not enough knowledge early kidney disease in Community espcially young people	Meeting with local Elders (with information from NIKTT to take back to Elders With Elders, meet with local member
Patient Expert/Transplant	Forud relocation Accomodation Transport	Funding	Approaching local members in Government sponsorship. Charities (liasing with) and mining in WA support
Patient Expert/Transplant	Kidney Failure, being unable to work	Everyone who can get access to a transplant and to get off dialysis	Within 6 months a chat about transplant and on the waiting list OR Waitlisted before dialysis AND options for living donations
Patient Expert/Transplant (Rowena Albert)	Stage 2 AHP's nurse and other allied health prevent early stage of kidney diease	Stepping outside and reach outside to people + education	Continue with delivering services outside with education

Public servant/policy maker	Trying to make change without funding Travelling from remote settings to city to access transplant	Talking with Community around their opportunity for private/non-Gov funding to support NIKTT	The Gathering will further discussions in network Eg. BHP dialysis chairs+clinic
Queensland Team	Our "unofficial/unfunded", State Coordinator is leaving us. We need to replace him	To create a new, funded, role as a State Indigenous Kidney Health Advocate/ Champion/Leader. The role is advocacy, coordination, networking, to monitor gap identification education	NIKTT to endorse this model Funding (State baned)
Staunch advocate/ Clinician	Diabetes being the leading cause of CKD for MOB	Active, intense, and optimised management of diabetes. Coupled with education within schools around diabetes	Resources created in conjunction with department of education to be rolled out in schools- Prevention Continuous glucose monitoring avalible for Mob (Type 2) Optimisation of medications for Mob (GLP1) Consultation within government around access to food in Community (caps on prices)
Staunch advocate/ Registered nurse CALHN	First nations people experience CKD at higher rates than their non-First Nations counterparts but receive kindney transplants at lower rates	In the spirit of EQUITY not just equality	First Nations should be considered a priority in the allocation alogrithm Lower rates of living donors so could First Nations people get pre-emptive deceased donor transplants?

Sticky Notes

Vehicle used	*Type of message*	*Message*
Sticky Note	Access to treatment	Access for options to kidney TX, work up Access to test for communities
Sticky Note	Access to treatment	In Kimbely, need dialysis units close for desert people
Sticky Note	Access to treatment	Outreach delivery ongoing at clinics and assessments with resourcing assets to complete assesments, requiering less travel and with family involved
Sticky Note	Access to treatment	Better access to specialist medical professionals for rural and remote Communities
Sticky Note	Access to treatment	Government should work with Aboriginal and Torres Strait Islander people to get home from the cities. Not one at a time/whole Communities
Sticky Note	Advocacy	Talking with local government members Raise awareness of kids xxx in Community
Sticky Note	Advocacy	At a National level: KPI length on DX then onto TX assessment (work up) UNDRIP Human Rights
Sticky Note	Advocacy	Lobby government re-funding for CKD agencies
Sticky Note	Advocacy	Better advocacy about transplant within each State and Territory, prioritising a ATSI driven workforce
Sticky Note	Advocacy / communication	Advocacy for my health, you have to speak up and work together. Eg. A cultural health worker in a transplant readiness team to connect
Sticky Note	Comments	Self Determination amoung this group is DEADLY
Sticky Note	Comments	"They get sick of me talking up", what happens to people in good-ways and not good-ways when we talk up
Sticky Note	Comments	"You have to be your biggest motivator, get yourself off and do it again"
Sticky Note	Comments	"Always go for your treatment, to stop the fluid building up, and breathe better. Go to the Doctor/Clinic check your kidney and be safe. I'm not on dialysis, I'm still doing healthy"
Sticky Note	Communication	AMS + Renal relationship building
Sticky Note	Communication	Communication across state health services. How do we improve this? For people living in VIC who are from SA
Sticky Note	Communication	Provide health promotion in language other than English
Sticky Note	Communication	Need more internet access in our First Nations Community in the outback (WIFI)
Sticky Note	Communication / Education	Could NIKTT comission a set of videos similar to WA example to cover core concepts like work up, transplant, and allocation
Sticky Note	Communication / Education	Kidney allocation annimated video to explain the new allocation algorithum- as culturally safe as possible.
Sticky Note	Cultral saftey	Learn language, people want people to care about them
Sticky Note	Cultrual saftey	Drs and Nurses need to be educated on our family and kinship systems to be come more flexible
Sticky Note	Cultural safety	Cultural safety through audit, monitoring, place basded, training T.O's/ Elders

Sticky Note	Cultural safety	Cultural inclusion in treatment
Sticky Note	Cultural safety	Informed care addressing racism in mainstream services
Sticky Note	Cultural safety	Supported without suspicion
Sticky Note	Cultural safety	Discussing appropriate/acceptable language when speaking to indigenous patients
Sticky Note	Cultural safety	The nurses there need to learn to respect and have cultural awareness for Elders and all Indigenous people. They need to communicate with us. Talk up for me and my people, our people
Sticky Note	Cultural safety	Working on culturally safe communication, implementing the clinical yarning model
Sticky Note	Cultural saftey	Health staff using "Stable" as a term to talk about unstable kidney function
Sticky Note	Cultural saftey	Health practitioners call out racism, take accountability, and raising it. Not leaving it up to Patients
Sticky Note	Cultural saftey	Giving power back to the patient when healthcare staff taking accounability with language
Sticky Note	Cultural saftey/ Models of care & Support	There needs to be a better/safer complaints process- either a clinic based Indigenous complaint process or an Indigenous Complaint Unit
Sticky Note	Cultural saftey/ Models of care & Support	Clinicians must call it out, there must be a better complaints process, it is not on patients
Sticky Note	Education	Culturally "better" language/resources/training- having a resource library in regional areas
Sticky Note	Education	Prioritise education preventative measures
Sticky Note	Education	Resources for Mob eductaion
Sticky Note	Education	Improved culturally safe education information
Sticky Note	Education	Recognising the work to know about mental strength when there are hard things faced in health journies
Sticky Note	Education	Ask questions like: What did you want to know early in CKD?/ What did you want to know when you started?
Sticky Note	Education / Communication	Educaction and Information pre DX and Post TX about prevention and preservation our way to share in languages
Sticky Note	Eductaion	Lack of eductaion about kids Meeting with Elders in Community
Sticky Note	Eductaion	Offer important information to patients and carers. Please don't expect us to know what to ask for (ie. Matching, rejection).
Sticky Note	Eductaion	Workforce Development Day, after Community Day?
Sticky Note	Eductaion	Booklet for kids, using pictures, and bold words that a child would understand
Sticky Note	Gathering Takeaways	No more kidney secrets
Sticky Note	Gathering Takeaways	Resource- Mob Together
Sticky Note	Gathering Takeaways	Tiktok videos myth busting
Sticky Note	Gathering Takeaways	Is it time to rename the NIKTT? National Indigenous Kidney Taskforce (so it covers all Kidney issues?)
Sticky Note	Gathering Takeaways	Health system must be accountable, not patients

Sticky Note	Gathering Takeaways	One word, "Identity", so many sides of the true story have been heard here
Sticky Note	Gathering Takeaways	Cultural Leadership and Governance
Sticky Note	Gathering Takeaways	Prioritise: Mental health, Program funding, Children
Sticky Note	Gathering Takeaways	Advocacy for transplant, welbeing for mental health, bring CKD patients back to Country
Sticky Note	Gathering Takeaways	More chairs, more funding, more education, more health workers
Sticky Note	Gathering Takeaways	Prioritise co-designing patient resources Living donation? Patient Navigation
Sticky Note	Gathering Takeaways	Meeting needs a (More?) Aboriginal people with kidney disease in big cities
Sticky Note	Gathering Takeaways	Cultural saftey, health optimisation pre TX testing and for waitlisting, and Patient Navigator/ Coordinator roles
Sticky Note	Gathering Takeaways	Partnering with reaserchers on funding applications for work supporting NIKTT's mission, as well as increase activity and diversity action
Sticky Note	Gathering Takeaways	Culture is a protective factor
Sticky Note	Gathering Takeaways	Prevention and early detection
Sticky Note	Greivences	There is not enough support for carers of patients who may have a longer or extended journey in hospital with dialysis
Sticky Note	Greivences	Carers require more support: making their life feel much better and make their dream come true
Sticky Note	Greivences	Support for carers
Sticky Note	Greivences	We don't know what to do, and if we take you to a local hospital, there are no specialists there that can help you
Sticky Note	Greivences	I miss the ability to travel
Sticky Note	Greivences	Why are resources always given in cartoon format for First Nations? It gives the tone that we are children
Sticky Note	Models of care/support	Support for kids with sick parents eg. Camps/fun days
Sticky Note	Models of care/support	The best model of care is not one model, what does this look like? The model needs to change with patients needs
Sticky Note	Models of care/support	First Nations mental health workers for renal. How can we support this?
Sticky Note	Models of care/support	Primary health service nurses and educators could ring up + have a yarn with patients for preventive checkups and post checkup
Sticky Note	Models of care/support	Building resources for local contexts eg. Unit-specific booklet
Sticky Note	Models of care/support	Indigenous kidney health worker in each TX unit as standard of care

Sticky Note	Models of care/support	"The problem isnt us", complaints require too much effort
Sticky Note	Models of care/support	Accountability and positionality of staff (Policy)
Sticky Note	Models of care/support	Jurisdictional collaboration, cross border, for primary care and tranplant care
Sticky Note	Models of care/support	More renal units and dialysis machines in Communities Government needs too explore kidney problem in Health
Sticky Note	Models of care/support	Sustainable/succession workforce. Allied/ACHHO/ALO/AHP multi diciplinary approch involving nurses, doctors, PNC, PN and executives
Sticky Note	Models of care/support	Housing Transport Social worker specific Renal Psych SENB whole body
Sticky Note	Models of care/support	improvement prioriries: Workforce, Welbeing (Education?), Data/evidence, Carers/supports, Care plans/models of care specifically about assessment and investigation
Sticky Note	Models of care/support	Addressing multimorbidity and situations related to kidney care with the whole persons needs
Sticky Note	Models of care/support	Co-design programs- with planned evaluation of these programs
Sticky Note	Models of care/support	kelli says Onika + Jaqui model of care rolled out nationally
Sticky Note	Models of care/support	Would like to see more Aboriginal identified positions to support the local journeys
Sticky Note	Models of care/support	More Aboriginal healthcare workers
Sticky Note	Models of care/support	More focus on First Nationas healthcare workers and well as increase dislaysis at home
Sticky Note	Models of care/support	Provide social and emotional wellbeing support for patients and carers
Sticky Note	Models of care/support	Support groups for carers. Something like an EAP? Could KHA help?
Sticky Note	Models of care/support	More ingigenous kidney doctors, care from our carers, indigenous kidney nurses
Sticky Note	Models of care/support	Provide support for home dialysis clients espcially if client or carer does not have health background
Sticky Note	Models of care/support	1) Getting people ready for transplant (Work up, losing weight) 2) Consistent (Not a different doctor each time in the clinic) with culturally specific services in hospital system, ACCOS does this well. 3) Make resources to allow those away from home for work or opportunity to return home to Country while on dislaysis for a holiday or funeral. (Remote Communities reject interstate visitors even though T.Os)
Sticky Note	Models of care/support	Provide an Indigenous Nurse Navigator (Specifically for rural) and social worker attached to the Renal Units
Sticky Note	Models of care/support	Primary Healthcare need a renal/transplant coordinator to follow up patients on the transplant list if and when called
Sticky Note	Models of care/support	Screening days at ATSI events

Sticky Note	Models of care/support	Priorities: Relevant resources (Culturally appropriate), Living donation focus, Changing behaviours of clinicians
Sticky Note	Question	Can a copy of the presentations be emailed to participants?
Sticky Note	Question	What is the process of getting a transplant?
Sticky Note	Question	How do you get people in to do their health checks?
Sticky Note	Question	How do we create a black pathway for Mob to care for Mob
Sticky Note	Question	How can service support carers/family better? What would help you?
Sticky Note	Question	How do I become a Patient Advocate for change / a Patient Navigator
Sticky Note	Question	Why is weight a priority?
Sticky Note	Question	What is the process of starting prevention for kidney health? What are we doing for our young people?
Sticky Note	Question	How do we get continuous glucose monitoring for Mob with Type 2 Diabetes ?
Sticky Note	Question	Are SA nephrologists refering to TX suitability assessment soon after someone starts? How long? How is the conversation approched?
Sticky Note	Question	Can a Kidney Dr tell me why I have Renal Failure?
Sticky Note	Question	How many (%) transplanted kidneys are live doners?
Sticky Note	Question	I've been wondering if this is a conspiracy theory on Tiktok or if this is true and affects Mob. Someone asked "Why do Jehovah Witness Elders oversee the Australian Organ Donor Registry?"
Sticky Note	Question	Who's on JOTSC now? How do patients have their voice included in the plans
Sticky Note	Question	How many Patient Navigators are in Australia and how do we get more into the job? Love this holistic approach the Patient Navigators offerer
Sticky Note	Question	Why are there no kidney surgens a part of NIKTT?
Sticky Note	Question	Why is 'treatment adherence' a risk factor to receiving a transplant?- there is a root cause to that issue that cannot be labled 'non complience', obviously situational, but cannot be too quick to generalise
Sticky Note	Question	What is avalible to support my personal welbeing?
Sticky Note	Question	How can we get funding for ceraers taking leave without pay while looking after people?
Sticky Note	Question	Why isnt CKD on the NDIS qualifying list? How do we advocate to be on it? Espcially on patients and carers need. Support if they have no family to support them, carer streams ect.
Sticky Note	Question	How can we get more patient navigators
Sticky Note	Question	Why is CKD not accepted on NDIS?
Sticky Note	Question	What makes a good relationship with patient and Dr? Why does this impact transplant work up?
Sticky Note	Question	Do you meet the person that donated the kidney?
Sticky Note	Question	Who cares for the carers? Including financial help?
Priorities Notes	Suggestion	The kidney transplant call role play was valuable. I learned a lot about the questions and responses. I have a health promotion idea to have a card by your phone or on your mobile about good questions to ask or whats important to bring up when you do get the phone call- Also make a videoof this in language

Magic Wand Sheets

Written from the perspective of:	★	★	🪄
Clinician	Lack of culturally appropriate Aboriginal health workers to educate Community with CKD on what the journey will look like	Not enough satelite dialysis units for Community who live remotely and have to travel long distances to dialysis	More kidney buses in Australia to support clients with CKD (holidays, remote communities ect.). To increase quality of life. More trained AHP kidney journy educators
Consumer	Transplantation- made to feel comfortable by RAH/Hampstead nurses eg. Easy to connect with	Change	I had to rely on public transport to get around
Clinician			Strategic positioning of Aboriginal and Torres Strait islander health workers
Clinician			Funding ATSI workforce
Consumer	Transplantation (Waiting 8 years). Had lots of education about transplant, lost weight, every 2nd night received at home dialysis	Change	Duty of care is important
Consumer	Relatively healthy, yet assumed that I was diabetic.	Flinders Medical centre doesn't understand why I have renal failure	Education around patient right to support
Consumer	Please don't speak to me using patronising language		Talk up, not down
N/A	Being part of the kidney journey towards improving kidney warriors journey	Having learning and expereinces with kidney journey	Getting people on machines and supporting Community
Carer/Family member	family support, espcially my mum, she is my hero	Cultural equity at the transplant centre at P.A hospital	Better outcomes and cultural safety around usage of medical language. Prevention within the Communities, Cape and Torres
N/A	I want to see recommendations that are evidence based, actually get impemented	I want NIKTT to be recognised by our peak body and funded appropriately by Government and Philanthropists	I want more money put into kidney disease prevention within the primary health care space
Consumer	Dialysis patients journeys/stories helping to guide and shape prevention measures to prevent kidney failure	Understanding prognostics, what it means and bhow to navigate this journey. Being your own advocate/ champion	Working up to get on the transplant list was challenging on PD + Haemo however, once I was active it didn't take long. Very greatful and thankful
Consumer	We wish for a bigger dialysis centre in Kununurra and also in		

	Wyndham, Halls Creek, and Fitzroy Crossing		
Consumer	Support person for new patients, such a scary process	Support for kids with parents/carers with CKD, or on dialysis	More Indigenous support workers across the board
Consumer	Being long term patients, since birth, we have a great relationship with our renal team	The support from our nephrologist is awesome. He's concerned about our care as much as we are	More renal doctors and facilities in rural communities, too many families have to relocate to access medical care
Carer/Family member	My daughter struggled for 7 years and through her journey she showed me strength and courage as she had to go through it at first on her own. Staff were amzaing all the way but the distance between us created lack of support. I had to take time off work without pay to travel to Brisbane to help with duties as well as looking after Kass. There was household chores and my lubbly grandson Lucas. I never recieved carers payments at all so never had any other financial support.	How do we get payments if we don't register as a carer, plus time off work?	Prevention, recognition, education, research, and respect for all. More staff (ATSI) and avalibility of funds for support
Clinician	ATSI workforce principal clinicians	All along transplant workup timeline	Inclusion of expert patients in welfare/ 2/3 outreach clinics guided per year
N/A	Care and support after transplant		NIKTT approaches all political parties and gets support so we don't need to worry with change of parties in elections
N/A	Developing and supporting Indigenous health workforce in all aspects of kidney care	Distinguish a structure of nephropathy for renal treatment	
N/A	Lack of education resources	NIKTT- work on resources that can be adapted by each Transplant Unit. Videos of patient stories	Funding for resources, skilled people to help, lived experience resources, moduels of learning with video and text. Data dashboard
N/A			Floaters: more chairs and Aboriginal workers
N/A			Care after transplant if the first kidney was rejected
N/A			For all Mob that are on dialysis to receive a transplant
N/A	Close access to dialysis near my hometown	Previous transplant learning from that experience and knowing how to manage it	To get on the waitlist

N/A	Funding allocation and grow Indigenous workforce		
N/A			For everyone to get a transplant as soon as possible
N/A	Early kidney disease education for young people	Access services for TX workup	Meeting with local Elders, getting info for NIKTT, meeting with local members
Consumer	Problem: Ross wants a transplant ASAP, like many Mob. The first step is to ask everyone you engage with for dialysis/ GPs. No clear answers/impression that I shouldn't be asking," Am I on track for...?"	Second step. For NIKTT to advocate for change so patients like myself can access all my patient information	Third step, own solution. Bought a house in Charters Towers, where his business will be, and better access to the transplant he is hoping for
Consumer	8 years home dialysis on my own, I made the mistake once of putting the needle in	Everytime I walk in to the renal unit, they patronise me for 1 mistake in 8 years. Why would I chose to miss dialysis?	Clinical staff need to listen and not patronise, now I have a reputation for being non compliant
N/A	Roadblock in Cairns, had a falty machine for 4 years. Viewed as a liar/non compliant. No one believed him		
Consumer	In kidney transplantation, from my position on a patient, my solution, that I will lead for in	That our patients are listened too, our concerns are respected, and that communication is clear and well we feel that our carers actually care about us, not just for us	We also need better explantion about why we need to take certain medication, and what they help, and why they need to be taken. And if bad side effects, they are checked. "no shame" communication if things go wrong,
N/A	Ongoing support of NIKTT to continue to be a catalyst for change	Local solutions, National issues	Money/resource (new, not repurposed), to support delivery of well-intended policy
N/A	Local resource development and preventative education	Lobby- collective group- locally	Money to attach to policy, develop resources, education, living donors