

# Navigating care through connection: How patient navigators strengthen the care experiences of Aboriginal and Torres Strait Islander peoples living with kidney failure



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## Abstract

**Purpose** Evidence suggests that patient navigators (PNs) can improve patient engagement, emotional wellbeing and clinical outcomes. This study explored how PNs influence the care experiences of Aboriginal and Torres Strait Islander peoples living with kidney failure, from the perspectives of patients and health service staff.

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<sup>1</sup>Passed away during the course of this work. In accordance with cultural protocols the name used here reflects Mr Ross's mourning name.





**Methods** Qualitative data were collected through kidney journey mapping and yarning interviews across four kidney health services employing PNs in the Northern Territory and South Australia. Data were thematically analysed to understand patient care experiences with and without PN support.

**Main findings** Patients reported challenges around inadequate communication, difficulty accessing appropriate services and support, poor cultural safety, and the emotional toll of treatment. Support included family and patient networks, positive relationships with health staff, and holistic models of care. PNs played a supportive role by sharing their kidney journey experiences, providing cultural connection, peer support and bridging systemic gaps.

**Principle conclusions** PNs strengthened patient care experiences by addressing service gaps, improving cultural support and sharing from lived experience. Embedding PNs into standard kidney care is a critical step toward achieving culturally safe, equitable and responsive health systems.

**Keywords:** Patient navigator; Aboriginal and Torres Strait Islander peoples; Indigenous peoples; Kidney failure; Lived experience; Care experiences

## Highlights

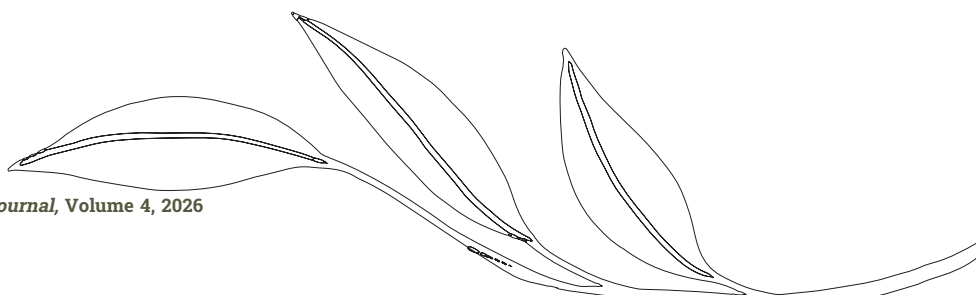
- Aboriginal and Torres Strait Islander peoples living with kidney failure face several barriers to waitlisting and transplantation.
- Patient navigators can improve patient experiences and engagement with care by enhancing cultural safety and providing peer support to bridge gaps in kidney health services.
- Patient navigator lived experience is deeply valued by patients and health professionals, and can influence multiple aspects of care.
- Embedding patient navigators in kidney health services is key for equitable, culturally responsive care.

## Introduction

Since time immemorial, Aboriginal and Torres Strait Islander peoples have lived in strong, sovereign societies, grounded in deeply rooted systems of knowledge, relational authority and cultural responsibility – caring for one another and Country through interconnected practices of kinship, decision-making structures and wellbeing (Dudgeon et al. 2010). Colonisation has violently disrupted these systems, imposing structures of control that continue to oppress Aboriginal and Torres Strait Islander cultures and communities, while restricting access to the

resources necessary for health, healing and cultural continuity (Griffith et al. 2016; Hughes et al. 2023a; Paradies 2016).

These effects are reflected in the incidence rates of kidney failure requiring replacement therapy experienced by Aboriginal and Torres Strait Islander peoples, which are three times higher than those for non-Indigenous peoples (Bateman et al. 2024b; Hughes et al. 2023a; Hughes et al. 2023b). Despite the higher rate of kidney failure, Aboriginal and Torres Strait Islander peoples face significantly lower rates of



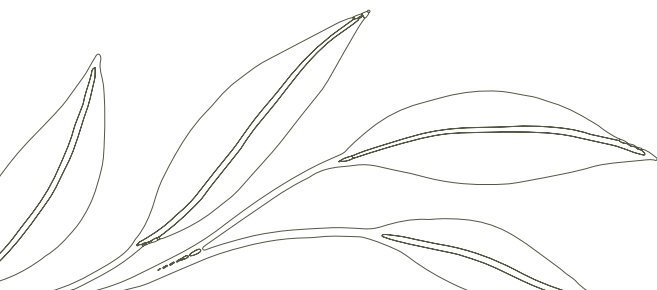


kidney transplant waitlisting (Hughes et al. 2023a). This is largely due to systemic barriers during the pre-transplant work-up and assessment process, such as geographical isolation, inadequate cultural safety, racism, and the lack of culturally appropriate, patient-friendly resources and education (Chaturvedi et al. 2024). However, once waitlisted, access to transplantation becomes more equitable for Aboriginal and Torres Strait Islander peoples (Bateman et al. 2024a).

There is growing recognition of the need for culturally safe, person-centred models of care in response to these systemic failures (Cundale et al. 2023; Hughes et al. 2023b; Kelly et al. 2020; Poitras et al. 2022; Tunnicliffe et al. 2023). One emerging approach is the implementation of patient navigators (PNs) – trusted individuals who offer personalised support to people facing complex health challenges. PNs work in diverse roles, including clinical, non-clinical and community-based positions. They may also bring unique perspectives as an Indigenous person or as a person with lived experience of a specific health condition. In Australia, PN programs have been implemented in cancer, mental health and chronic disease care (Bernardes et al. 2018; Thackrah et al. 2022), with evidence suggesting that PNs with lived experience can improve engagement, emotional wellbeing and clinical outcomes (Golestaneh et al. 2022; Kha-Moua and Paulus 2021; Longley et al. 2023; Pascoe et al. 2025; Sullivan et al. 2018). Indigenous PNs can also play a crucial role in bridging cultural divides, fostering trust, and facilitating two-way communication between patients and healthcare services (Bernardes et al. 2018; Pascoe et al. 2025; Pascoe et al. 2022; Rankin et al. 2022; Thackrah et al. 2022; Whop et al. 2012). In the context of this project, PNs were non-clinical, Aboriginal and Torres Strait Islander individuals with lived experience of kidney disease and transplantation.

Despite a growing body of literature on PNs, there is limited evidence on how these models specifically function within kidney and transplantation services for Aboriginal and Torres Strait Islander peoples in Australia. Preliminary findings from programs such as Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation's (Purple House) 'Patient Preceptors' (Pascoe et al. 2025; Pascoe et al. 2022) and the National Indigenous Kidney Transplantation Taskforce (NIKTT) 'On Track to Transplant' pilot program at Port Augusta Regional Hospital (Cundale et al. 2023; Flinders and Upper North Local Health Network Incorporated 2021) demonstrate the value and acceptability of Aboriginal and Torres Strait Islander PNs in kidney care. These programs have enhanced patient engagement and support through non-clinical interactions and culturally relevant activities (Cundale et al. 2023; Pascoe et al. 2025; Pascoe et al. 2022). However, there is still limited understanding of how PN roles are implemented across different contexts. Further research grounded in the experiences of Aboriginal and Torres Strait Islander patients and communities is needed to bolster these findings and inform future evaluations of how these roles operate in practice.

The Connecting Our Mob: Patient navigators As Sustainable Supports (COMPASS) project was established to implement and coordinate PN programs across four kidney health services on Larrakia, Arrernte, Kurna and Barngarla Country. Specifically, this study took place across Top End Renal Service, Purple House in both Darwin and Alice Springs, Central Adelaide Local Health Network (CALHN) at Royal Adelaide Hospital, and Flinders Upper North Local Health Network (FUNLHN) at Port Augusta Hospital. Purple House is an Aboriginal community-controlled health service that delivers culturally safe dialysis and support to Aboriginal and





Torres Strait Islander peoples from remote communities across South Australia, Western Australia and the Northern Territory. CALHN and FUNLHN are state-run health agencies providing primary, secondary and tertiary healthcare throughout the region. The Royal Adelaide Hospital serves as the sole transplant centre for both the Northern Territory and South Australia, requiring all patients from these areas to travel to Adelaide for kidney transplantation. While PN programs are already established at the Darwin Purple House site and Port Augusta Hospital, new PN positions were created in Adelaide and the Alice Springs Purple House site through the COMPASS program.

The overarching aim of this study was to explore the experiences of Aboriginal and Torres Strait Islander peoples navigating kidney care and to examine how PNs influence those experiences. The direction of this study was shaped by the voices of the PNs themselves who identified gaps in coordination, connection and support across healthcare services where they were employed. Furthermore, this study directly responded to priority areas identified and supported by community, as outlined in the CARI Guidelines' Recommendations for Culturally Safe Kidney Care for First Nations Australians and the updated NIKTT Position Statement, launched at the 2025 NIKTT Gathering ([National Indigenous Kidney Transplantation Taskforce 2025](#); [Tunnicliffe et al. 2023](#)).

## Methods

### Positionality statement

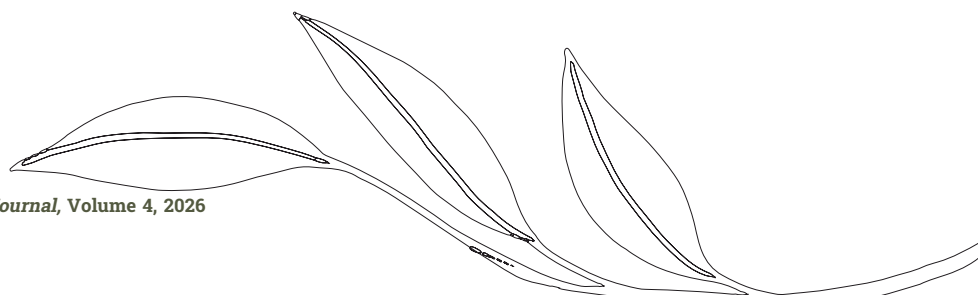
This study was grounded in the ongoing collaborations between Aboriginal PNs and both Indigenous (KKO, KOD, MD, MC, JR, CA, DC, NW, PH, RL, IB, KTV) and non-Indigenous (KC, IH, SB, SM, JK, SM, SJ, KT, HH, MM, KH, SWM, GG) researchers and clinicians. Kurna,

Narungga and Ngarrindjeri woman KKO, a kidney transplant recipient, led this work as senior chief investigator (CI), providing cultural governance and strategic direction by ensuring that the research remained grounded in community priorities, cultural knowledge systems, and the lived realities of Aboriginal and Torres Strait Islander peoples navigating kidney disease and the health system. PNs and CIs (JR, CA, DC, NW, PH, RL) brought critical expertise shaped by their lived experience, kinship obligations and community engagement. The research team itself reflected diversity across gender, geographical location, community and cultural backgrounds. This enriched the research by bringing place-based perspectives to the research process. The non-Indigenous co-authors (IH, KC, SB, SM, JK, SM, SJ, KT, HH, MM, KH, SWM, GG) acknowledge their position within colonial systems and remain committed to reconciliation, reflexivity and accountability.

### Study design and methodology

This qualitative study was led by Aboriginal peoples with lived experience of kidney disease and transplantation. It utilised a decolonising research approach that privileged Aboriginal and Torres Strait Islander peoples' knowledges through *ganma* (knowledge sharing) and *dadirri* (deep listening) ([Dudgeon et al. 2020](#); [Sharmil et al. 2021](#)). These guiding principles of respectful listening and self-reflective knowledge sharing influenced the design, collection and analysis of this research, positioning Aboriginal and Torres Strait Islander peoples' voices, preferences and experiences at the centre of the research and interpretation of the findings.

Community engagement activities were undertaken with the Purdita Purruna Wangkanthi ('Talking Kidney Health') Indigenous Reference Group and through the





relational networks of the Aboriginal CIs. While this input did not alter the study design, it confirmed the cultural appropriateness of the approach and helped maintain trust through regular feedback and transparent communication. Engagement followed cultural protocols and responsibilities for doing business on Country to ensure that local knowledge and relationships were respected throughout.

Qualitative data were collected using two methods: kidney journey mapping (KJM) and yarning. KJM was adapted from health journey mapping methods (Kelly et al. 2021), which have been used to map health and treatment journeys of patients throughout the life course of their experience and their interaction with health services. To improve cultural responsiveness, KJM was informed by the principles of *dadirri* to create a safe, reflective space for community members to share their stories at their own pace. Yarning is a process of storytelling that privileges Indigenous ontologies by centring relationality, collaboration and sharing knowledge from a place of lived experience (Kennedy et al. 2022). In research, it has been used as a culturally safe method of data collection that breaks through power imbalances by placing all participants as both learners and knowers (Byrne et al. 2021; Geia et al. 2013; Kennedy et al. 2022; Poirier et al. 2022).

KJM and yarning interviews followed a semi-structured format and were conducted in English by a team of Aboriginal (KKO, IB, MD) and non-Indigenous (IH) researchers.

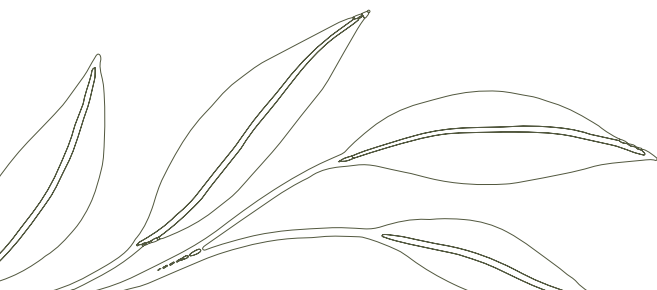
### Recruitment and data collection

KJM participants were Aboriginal and Torres Strait Islander adults (aged more than 18 years) who had commenced or were about to commence treatment for kidney failure at one of the four pilot sites. Yarning

participants were health service staff currently working with or overseeing PNs at these sites or were PNs themselves.

Purposive sampling was guided by site coordinators and/or PNs with existing participant relationships and insight. This ensured that the data collection approach remained sensitive to their circumstances at the time. As part of the consent process, PN participants were reassured that their involvement would not impact their employment or relationships with the research team. Additionally, all participants were advised that they retained ownership of their personal information and that their knowledge and cultural heritage would be respected and acknowledged in all research outputs. In recognition of participant time and expertise, including the treatment burden experienced by dialysis patients, a \$100 gift voucher was provided upon completion of KJM interviews. A distress protocol was also developed to assist researchers in mitigating the risk of distress and re-traumatisation to the participant.

Data collection occurred between May 2023 and December 2024 in three distinct rounds: (1) first round KJM with patients, which explored their experiences of kidney care, including their interactions with health services, perceptions of support or lack thereof, and instances where they felt safe or unsafe; (2) second round KJM with patients, which examined the role of PNs and their influence on patients' care and wellbeing; and (3) yarning, which provided additional insights into the role and contributions of PNs, capturing perspectives from health service staff, which included PNs, clinical staff (doctors, nurses, psychologists, Aboriginal health practitioners), and operational staff (managers, health executives, Aboriginal liaison officers, project officers and human resources staff).





Data were collected in quiet spaces across all four COMPASS sites, along with Top End Renal Service, to protect the privacy and confidentiality of participants. Participants received a copy of their transcript and an interview summary, with the opportunity to confirm accuracy and provide additional insights or corrections. All electronic and hardcopy data were securely stored and accessed only by authorised staff.

## Data analysis

Inductive thematic analysis was undertaken using NVivo 14 (Lumivero, Denver, CO, USA). Initial codes and descriptive summaries were independently generated by a team of Aboriginal (MD, KTV) and non-Indigenous researchers (IH), then refined through iterative discussions with members of the chief investigator team, who provided support to interpret and triangulate findings. Any conflicts arising during the triangulation were resolved through consensus among the team, to ensure culturally relevant and rigorous interpretation of the data.

In alignment with principles of decolonising and community-based research, preliminary findings and themes were shared with participants and community stakeholders through research and community sharing days, summary reports and oral presentations. This feedback process validated the findings and ensured that interpretations were reflective of participants' lived experiences and perspectives.

## Ethics

This research forms a component of the COMPASS project, which has ethics approval from the Central Adelaide Local Health Network Human Research Ethics Committee (#18228), South Australian Aboriginal Health Research Ethics Committee (#04-22-1023), and Human Research Ethics Committee of Northern Territory Health and Menzies School of Health Research (#2022-4475).

## Results

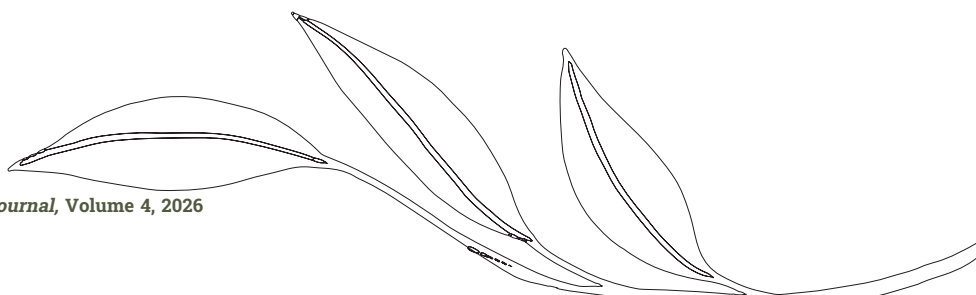
From 74 interviews, 76 participants were interviewed (KJM = 37, yarning = 39). All KJM participants were patients, had received a formal kidney failure diagnosis, and were either just about to commence or had commenced dialysis treatment (female = 23, male = 14). Out of the 37 KJM participants, 29 (78%) had relocated since their initial diagnosis of kidney failure. Specifically, four (11%) moved from remote to metropolitan areas, nine (24%) from remote to other remote areas, 12 (32%) from remote to rural areas, and four (11%) from rural to metropolitan areas. The remaining eight (22%) participants had not relocated since receiving their initial diagnosis. All yarning participants were health service staff (female = 28, male = 11). Of these participants, eight (21%) were PNs, 16 (41%) were clinical staff and 15 (38%) were operational staff. Thirteen (33%) of the yarning participants identified as an Aboriginal or Torres Strait Islander person.

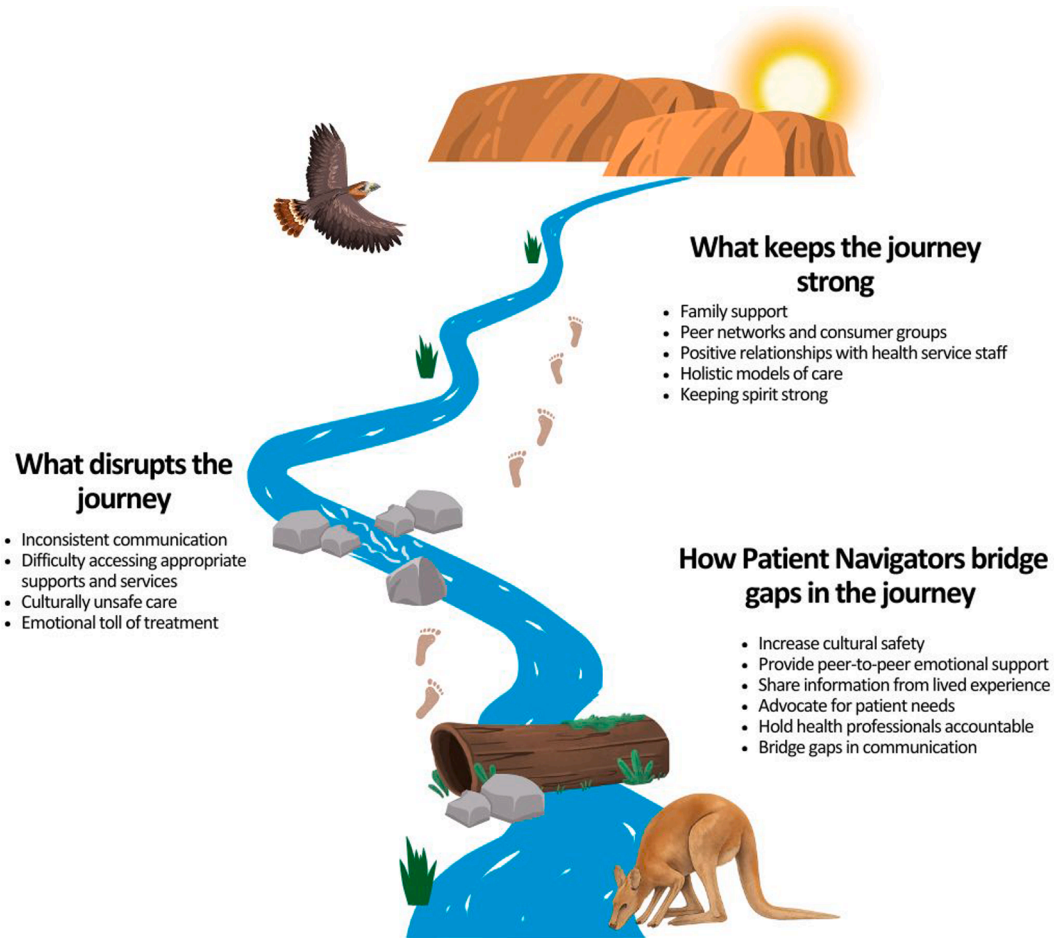
Three main themes were found from the interviews: (1) What disrupts the journey; (2) What keeps the journey strong; and (3) How patient navigators bridge gaps in the journey (Figure).

### 1. What disrupts the journey

Patients discussed several structural and individual-level challenges throughout their kidney journeys. A major barrier was inconsistent or absent communication from health staff, which left patients confused and underinformed about treatment plans, options and procedures:

*You wonder why us patients were confused, they are all telling us different stories, you know what I mean? How can we be on one road when three different angles are coming at us? (Participant 2, KJM)*





**Figure:** Themes and subthemes from the thematic analysis of patient and health service experiences before and after the implementation of PNs.

*I think they should be telling us this stuff [referring to treatment option]. Because, you know, we, we in the dark sitting on the chair. (Participant 18, KJM)*

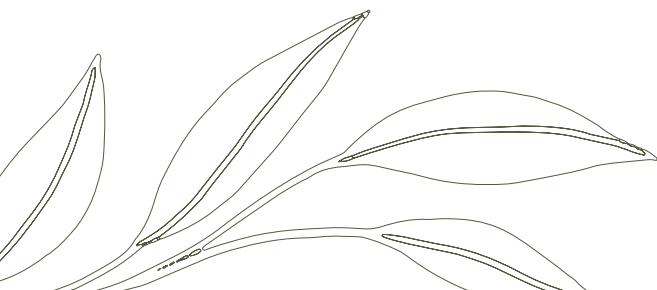
Patients highlighted several challenges around accessing social support, such as travel reimbursements and aged care packages. Several described the challenges they faced during the administrative processes:

*I filled that in. Yeah. And I still haven't got money [...] But that's not the first time [...] I spent \$600 on*

*accommodation and fuel and I never seen [reimbursement]. (Participant 17)*

*And just one day [aged care] rang up and said, no, we can't help you anymore [...] I think it was you know, I had to go down and get a Centrelink number. Oh, no. I had to do an asset testing, but this should have happened before I got the package? (Participant 19)*

Patients also raised issues around the availability, affordability and suitability of accommodation, housing and transport for themselves and their families:





*It's too hard for find accommodation here too. All the hostels all booked out. There's no way to stay for us.*

(Participant 2)

Patients recalled several instances where they felt culturally unsafe within health systems. These experiences were compounded by cultural stereotyping and minimal representation from Aboriginal and Torres Strait Islander staff:

*I had a nurse saying to me one day in [health service] earlier this year, 'Hey you mob are all the same right? You all speak the same right?' I said, excuse me, said we are all Aboriginal, doesn't mean we all speak the same, we all different, you know. (Participant 2, KJM)*

*I said to that lady last week, 'do you have any ALOs [Aboriginal Liaison Officers]?' She said, 'I only one'. Well, to me that's not good enough. 90% of the patients in [health service] are Indigenous. (Participant 2, KJM)*

Finally, several patients spoke of the emotional toll of relocating to undergo treatment, resulting in disconnection from community and Country. Patients also expressed sadness over having to be on dialysis, and no longer being able to work as a result:

*We are always homesick because, we a long way. We want to go back and do dialysis back in home. Close to family. (Participant 3, KJM)*

*I miss working [...] I started doing night shift and I said nah I'll just stick to dialysis. (Participant 16, KJM)*

## 2. What keeps the journey strong

Despite facing several challenges throughout their kidney journey, patients were able to derive strength and motivation from external support networks, as well as nurturing their own spirit. Patients identified that family played a central role in helping interpret medical information, sharing insights from their own

lived experience with kidney disease, offering caregiving and encouraging patients to persist with treatment:

*When I get information, I take it back to my sister so she can read it. And then explain to me in our way what they are talking about. (Participant 17, KJM)*

*Yeah, she's our granddaughter. She helps us with cleaning, cooking, she get medicine for us too.*

(Participant 1, KJM)

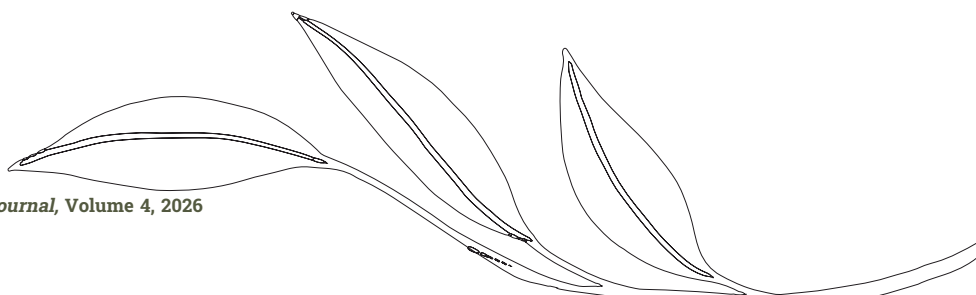
Patients found strength in connecting with other patients and families navigating kidney care, particularly through peer networks and consumer groups. This connection offered reassurance and a sense of solidarity:

*I like it, working with [consumer group]. I really like it yeah, it's good. Like get to meet new people and have a yarn. Talk about the supports we are getting from the doctors and that. (Participant 13, KJM)*

Positive relationships with health service staff further supported patients, especially when professionals were friendly and took the time to talk and explain information:

*They always say good morning to me. Later in the afternoon, in the morning they uh, say good morning and have a yarn and they come in, have a yarn, you know. (Participant 12, KJM)*

Holistic, integrated models of care such as Aboriginal community-controlled health organisations (ACCHOs) and aged care services were also valued. These organisations considered patients' social circumstances and needs, such as reminding patients about appointments, assisting with necessities such as food, clothing and medicine:





*She [from ACCHO] come around and talk to us, helping us, and they're telling us I got the appointment coming up, you know, sorting our medicines too, you know. Yeah, it's really good for us [...] Every Friday they give us big box of food to save it for Saturday and Sunday. The tucker. They're really supporting us all along.*  
(Participant 1, KJM)

Patients stressed the importance of keeping their spirit strong through practicing culture. This involved being on Country to carry out activities such as hunting and cooking. Patients also kept their spirit strong by surrounding themselves with family, faith and maintaining independence in daily life:

*For like my spirit strong. Like when I start and got this transplant, I used to go out bush with the ladies and with [ACCHO].* (Participant 7, KJM)

*I was praying, praying for myself. Then I got a little bit better. And I believe this cross, because every Sunday church, every Sunday to the church here.* (Participant 6, KJM)

*I work, I wash my clothes. Even when I go to work in the morning at school. I have rest and I do things... cooking. That's what I do.* (Participant 5, KJM)

### 3. How patient navigators bridge gaps in the journey

The support that PNs provided was diverse, deeply relational and grounded in their lived experience of kidney disease and transplantation. PNs were able to build trust through their shared language, culture and experiences to provide reassurance, guidance on treatment decisions and advocacy in clinical settings. Their presence made patients feel supported and less alone in navigating their kidney journey.

Patients recalled how supportive relationships were formed through shared cultural connections and language:

*They come and ask me at the hospital. What's your name? Where you from? And I introduced myself to them. And they told me their skin name, and I said, uh, I gave them my skin name. And, and I told them, well where I'm from and [PN] told me, oh, we neighbour, I'm from [community]. [...] from there we, we started talking and they gave me all these papers and then information about them.* (Participant 21, KJM)

For one patient, the reassurance of having support from an Indigenous PN who had faced similar challenges helped build trust and provide peace of mind:

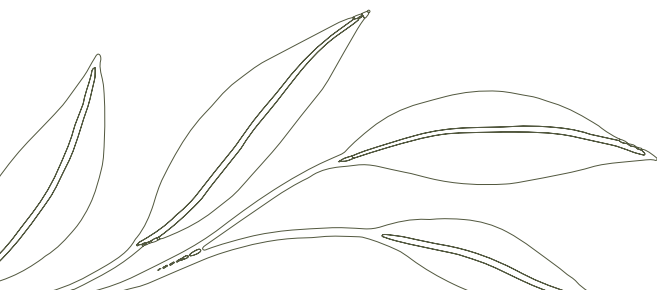
*I'm glad there was Indigenous people to say yes this is what happened. You know, so a lot of people tend to listen to other Aboriginal people, and it's just eased in my mind.* (Participant 34, KJM)

Patients frequently expressed how they felt PNs were reliable and dependable, and always available beyond clinical settings. These interactions made patients feel valued as individuals:

*Weekend. Weekdays. One o'clock in the morning. She's always been there for me [...] That like, it makes me feel like I'm a person. This fellow checking up on me, you know, I haven't been in hospital in over a month, you know? And he's calling me every two weeks.*  
(Participant 38, KJM)

Patients described how hearing personal stories about the PN's kidney journey provided reassurance and support. Participant 34 shared how it helped ease their fear and anxiety around the journey, while participant 23 expressed how it provided them with encouragement and motivation to persist with treatment:

*You know when I first went through this I was scared. I really was. But talking to [PN] has given me the*





*confidence in myself. [PN] done this so I can do this.*  
(Participant 34, KJM)

*He was telling me all the way, you have to fight, keep on telling them you've got new kidneys.* (Participant 23, KJM)

Drawing on their own experiences, PNs provided information on treatment options, preparing for transplant, and life after transplant. This firsthand knowledge provided patients with comfort in knowing what to expect:

*But yeah, it's good experience talking to (PNs). Listening to what they went through. Listening to what they could eat and can't eat after the surgery.*  
(Participant 32, KJM)

In one instance, information and support from a PN helped a patient make the life-saving decision to commence dialysis, something that they had previously opposed:

*[They] did [PN] helped make decision to go on dialysis. 'Cause like I said I wasn't gonna do it. I wasn't gonna do it. I was thinking, well I might as well just die, I don't care. But ever since I went on to dialysis, it was like after I felt a whole lot better. I tell people I don't know why I was scared for [...].* (Participant 34, KJM)

By guiding patients through clinical conversations and asking key questions, PNs enhanced informed decision-making and acted as advocates. Both patients and health professionals highlighted this as a key benefit of PNs:

*So, they can ask the questions that the patient might not necessarily know what to ask.* (Participant 19, yarning)

*Having a voice when I felt like I was voiceless. Especially in the health department, when you're*

*wanting to know certain things that you don't know that you've got no way of asking. That patient navigator has that, you know, authority to go to the doctor, listen what's going on?* (Participant 38, KJM)

Health professional and executive participants also highlighted the role of PNs in holding them accountable to ensure they are delivering culturally safe, responsive care:

*She's been really comfortable in encouraging non-Aboriginal staff to be culturally safe.* (Participant 17, yarning)

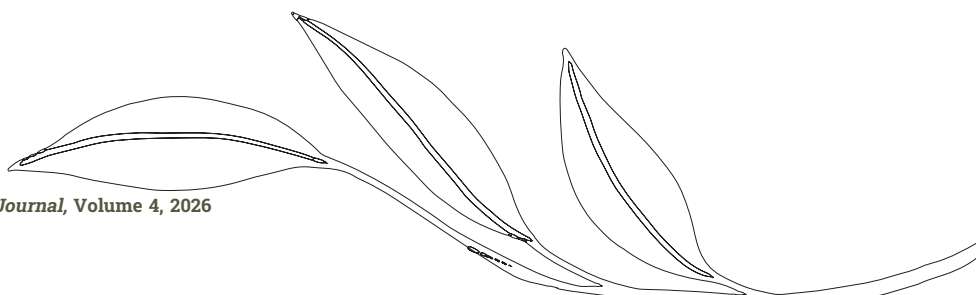
*[PN] was so good because he put me on the spot, and he was like what's happening with these medicine lists. You know, they're too big, we can't carry them around, we need smaller ones. I was like, I've got to do something about that. So, he's been helping keep me accountable to getting a few things, you know, that are better for patients.* (Participant 24, yarning)

Several health professional participants acknowledged that PNs improved patient comprehension, often stepping in to interpret medical information and ensure informed consent:

*I'll say [PN], do you think they understand [...] and they may speak in a different language amongst themselves and then that's when [PN] sort of go, 'he doesn't understand'. Can you please interpret what I've said type thing. So that's really helped.* (Participant 19, yarning)

*She went there and explained everything to this patient, the procedure, because I think it's been more than three times that she already missed the appointment.* (Participant 15, yarning)

Relational connections were central. Patients felt a sense of comfort and reassurance when they had





familial ties in their PN, while others described the bond as kin-like:

*She was talking to me, I was happy. When she talk to me because that's my cousin's daughter. My sister's daughter. (Participant 27, KJM)*

*'Cause I had my daughter in hospital with me a couple of nights. Because I had no one else to take her. So they, [PN] provided, like so much care. She treated (inaudible) like she was her own niece, you know? So like, that's auntie. That's auntie. (Participant 38, KJM)*

*They support me 100%. Yes, they're (PNs) like brothers, big brothers to me. (Participant 24, KJM)*

Inspired by the support they received, several patients expressed interest in becoming PNs themselves. Seeing it as an opportunity to share their experience and support others through the journey:

*After I got my, after I get a new kidney. Yeah. I probably, I probably would. Go, get back in, get into the workforce as a navigator. (Participant 35, KJM)*

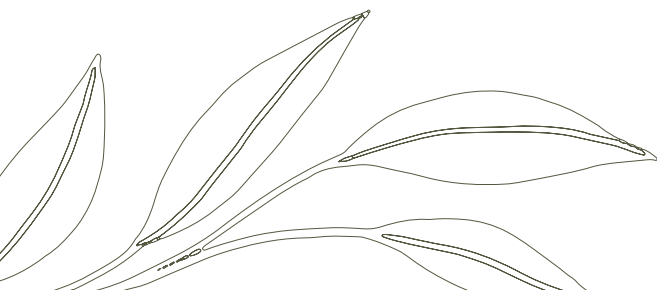
*That'd be good to pass the knowledge to other people. Tell them what the journey's gonna be like [...]. (Participant 31, KJM)*

## Discussion

This study explored Aboriginal and Torres Strait Islander peoples' experiences of kidney care and how PNs influence these experiences, considering perspectives from both patients and health staff. While the challenges identified are not new, having been raised by Aboriginal and Torres Strait Islander communities for decades ([Bateman et al. 2023](#)), the findings reinforce the continued need for culturally safe care and highlight the specific contributions of PNs within a system that often fails to meet the needs of Aboriginal and Torres Strait Islander peoples.

This research highlighted the vital role of PNs in promoting cultural safety at both individual and system levels, including identifying when the system is culturally unsafe and contributing to accountability and opportunities for meaningful change. Through shared cultural connection and lived experience, PNs established trusting, meaningful relationships with patients. As a result, patients felt safer and more comfortable seeking support from PNs and were receptive to the peer-to-peer emotional support and knowledge they provided. Beyond direct patient support, health service staff highlighted the crucial advocacy role that PNs play, particularly in ensuring accountability within healthcare systems. As cultural brokers, PNs who share their lived kidney experience are vital to bridging gaps in patient-provider communication and care by providing interpretation support and sharing cultural knowledge.

This study illustrated the significance of family kinship networks in patient care, demonstrating how PNs directly support family members. It also identified an opportunity for PNs to step into professional roles usually fulfilled by family, particularly for patients who relocate for treatment. Interestingly, several participants in this study expressed interest in becoming PNs post-transplant, seeing it as an opportunity to support new patients navigating kidney care while also easing their own transition and healing process. This presents a meaningful and sustainable employment pathway that strengthens Aboriginal and Torres Strait Islander workforce development, an area recognised in this study and also a longstanding priority for both community and government ([Australian Government 2022](#); [National Indigenous Kidney Transplantation Taskforce 2025](#); [Northern Territory Government 2022](#); [SA Health 2023](#)).





The overall care that PNs provide Aboriginal and Torres Strait Islander patients and their families demonstrates their contribution to patient journeys. This aligns with previous research, primarily from a North American cancer care context, further emphasising the value of these roles (Bernardes et al. 2018; Groot et al. 2024; Pascoe et al. 2025; Rankin et al. 2022; Thackrah et al. 2022; Whop et al. 2012). However, a defining aspect of this study is its focus on PN lived experience, both as an Aboriginal and Torres Strait Islander person and as someone with kidney disease, and how this is core to the work of the PNs. It acknowledges lived experience as a legitimate and powerful form of knowledge, valued by both patients and health professionals, capable of influencing multiple aspects of care. By questioning colonial paradigms that prioritise clinical expertise and reinforce the idea that knowledge is commonly derived from formal education, PNs advocate for holistic, culturally responsive healthcare approaches that improve experiences and health outcomes for Aboriginal and Torres Strait Islander peoples.

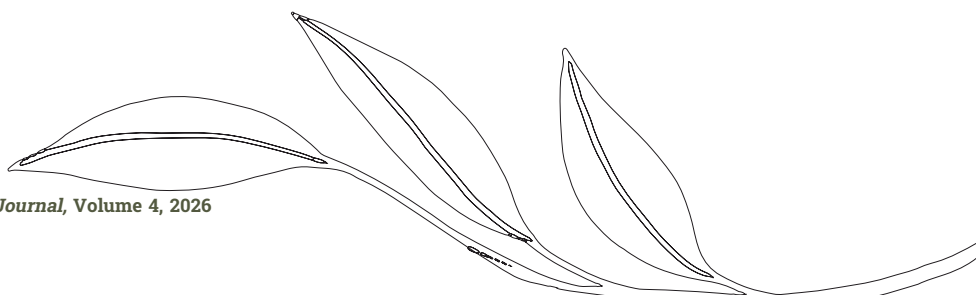
While PNs have demonstrated promise in addressing challenges that patients face within the healthcare system, particularly through improving care coordination, communication and cultural safety, their role is limited by structural and system-level barriers beyond their scope. These include inadequate access to accommodation, housing and transport, as well as administrative constraints around obtaining financial assistance. Therefore, PNs cannot be looked at as an all-encompassing solution to addressing broader systemic issues. To better support patients, reforms are needed to tackle the social determinants of health (e.g. accommodation, housing, transport, financial assistance). These issues are integral to a patient's ability to access and benefit from treatment and must

be prioritised as part of delivering comprehensive care. Health service staff and institutions have a role in identifying these needs and advocating for strategies that deliver more holistic, patient-centred care. While PNs can provide cultural safety, health service staff and institutions must remain conscious of the colonial load and take responsibility for addressing the ongoing effects of colonisation and systemic inequity.

Whilst PNs have shown a pathway to improve the care and experiences of Aboriginal and Torres Strait Islander patients with kidney failure, understanding of these roles stems from temporary programs and pilot research. These roles demand long-term, sustained initiatives that prioritise self-determination and embed culturally safe care into health systems (Devitt et al. 2017; Kelly et al. 2022; Mick-Ramsamy et al. 2019; Tunncliffe et al. 2023). Importantly, embedding PNs must go hand-in-hand with incorporating Aboriginal and Torres Strait Islander voices, knowledge and sovereignty in the development and leadership of these models. To truly change outcomes, these programs must be led by Aboriginal and Torres Strait Islander peoples and accountable to the communities they serve.

Future research is needed to assess the long-term outcomes of PN programs, examine cost-effectiveness to inform health policy and funding, and evaluate broader applicability across different settings. Scaling these programs will require sustained investment, culturally fit-for-purpose training, and a commitment to Aboriginal and Torres Strait Islander workforce development.

Whilst the findings from this study offer valuable insights, it is important to acknowledge certain limitations that may have influenced the data. Efforts were made to conduct interviews in quiet locations at





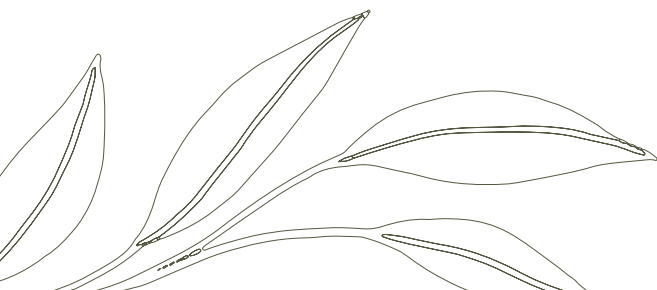
pilot sites, but participants' familiarity with the setting or staff presence may have influenced responses. Additionally, the sampling approach tended to favour individuals who were more engaged with healthcare and proficient in English, potentially excluding important perspectives and challenges. To ensure broader representation in future studies, early involvement of translators or interpreters is recommended. Gender dynamics, such as the presence of female interviewers and dual roles of some investigators as both researchers and service users, may have influenced participants' responses and the interpretation of findings.

## Conclusion

This study highlights the complex experiences of Aboriginal and Torres Strait Islander peoples navigating kidney care and the critical role of PNs. Their contribution transcends practical assistance; it is deeply rooted in cultural connection, advocacy and mentorship. Beyond helping patients navigate the health system, PNs embody self-determination, offering relational support grounded in shared lived experience. Embedding PNs into standard kidney care practice is a critical step toward achieving culturally safe, equitable and responsive health systems. However, to be truly effective, these roles must be developed and led in partnership with Aboriginal and Torres Strait Islander communities to ensure that the models are accountable to the people they serve. Further research is needed to identify system enablers and blockers, with a focus on the necessary support for PNs. These insights will contribute to the development of evidence-based strategies and recommendations aimed at strengthening existing PN service provision and support the integration of PN programs into the healthcare system.

## Author contributions

M. D'Antoine and I. Haklar were involved in multiple aspects of the study, including securing ethics approvals, co-developing the kidney journey mapping (KJM) tool, collecting data, reviewing and deidentifying transcripts, coding data, interpreting findings, sharing results back to community, and drafting the manuscript. M. Cachagee contributed to coding and analysis of data, interpretation of findings, community engagement, and writing of the manuscript. K. Cundale contributed to the original grant proposal, helped shape the study design and methodology, supported interpretation of findings, and provided senior researcher input into the manuscript. S. Bateman, S. McDonald and S. Jesudason offered clinical and research expertise, contributed to the design and methodology, and reviewed and provided input into the manuscript. J. Kelly was involved in co-designing the KJM tool. As a co-designer of the original health journey mapping tools, she provided input into the modified tool used in this study and contributed to the manuscript. K. O'Donnell supported the study design and methodology, contributed to the interpretation of results, and provided feedback on the manuscript. I. Brown was involved in co-designing the KJM tool, collecting data and contributing to the manuscript. K. Temple contributed to transcript coding, interpretation of findings and manuscript. J. Ross, D. Croker, N. Wilkshire, P. Henwood, C. Algy and R. Lester were the original patient navigators from Purple House and Port Augusta Hospital, whose lived experiences, insights and advocacy laid the foundation for this work. Their identification of critical gaps in care and their deep understanding of community needs are the very reasons why this project came into being. They played central roles in community engagement and consultation, co-developed the KJM tool, informed the study design and methodology,





supported recruitment, interpreted findings and led the dissemination of results within their communities. Each also provided oversight and input into the manuscript. K. Tyrell, H. Hall, M. Misener and K. Herman supported recruitment efforts and employment of navigators at each of the project sites. They were involved in interpreting results and contributing to the manuscript. S. W. Majoni contributed to study design, ethics approvals, recruitment and manuscript. G. Gorham provided guidance on study design, contributed to interpretation of results and reviewed the manuscript. K. Owen was the driving force behind this project. As the lead on this work, she provided vision, leadership and oversight across all aspects of the study. This included conceptual design and methodology through to community engagement, recruitment, data collection and interpretation of results. Her lived experience as an Aboriginal woman and kidney transplant recipient shaped the direction and purpose of the research. She also played a central role in overseeing the writing and finalisation of the manuscript. This work would not have been possible without her commitment, insight and guidance.

## Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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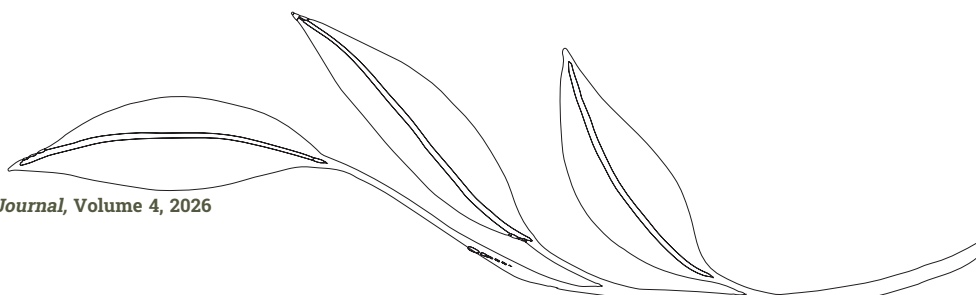
We respectfully acknowledge the Traditional Custodians of the lands on which this project was conducted: the Arrernte people of Mparntwe (Alice Springs), the Larrakia people of Garramilla (Darwin), the Barngarla people of Goordnada (Port Augusta) and the Kurna people of Tarndanyungga (Adelaide). We honour their enduring connection to Country and pay our deepest respects to their Elders past, present and emerging.

This work stands on the shoulders of those who have paved the way. We especially acknowledge the Panuku mob from Purple House in the Northern Territory, whose decades of compassionate and dedicated support to patients and families have been an inspiration and guiding force. We also gratefully recognise the NIKTT, whose vision and funding enabled pilot PN projects across Australia, including the vital 'On Track to Transplant Project' in Port Augusta that laid the foundation for this work.

We pay our deepest respects to all kidney warriors, both those who continue to walk with us and those who have returned to the Dreaming. Your strength, journeys and teachings remain a profound source of guidance and motivation.

We would also like to acknowledge Aunty Christine Franks, Senior Academic at the University of Adelaide, for her thoughtful review of the final draft of this paper to ensure it was culturally respectful.

Finally, we acknowledge with heartfelt sorrow the passing of one of our chief investigators, Jampitjinpa Ross, during the course of this project. Mr Ross's leadership, wisdom and unwavering dedication



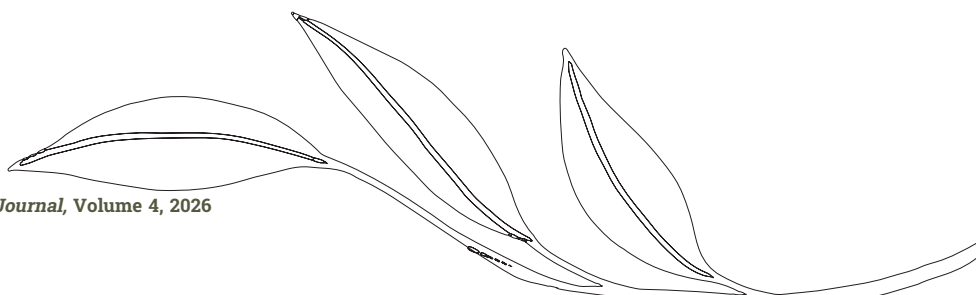
continue to inspire us and form a lasting legacy within this work.

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