

Perspectives of a proposed patient navigator programme for people with chronic kidney disease in rural communities: Report from national workshops

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Abstract

Aims: People who live in rural areas have reduced access to appropriate and timely healthcare, leading to poorer health outcomes than their metropolitan-based counterparts. The aims of the workshops were to ascertain participants' perspectives on barriers to access to dialysis and transplantation, to identify and prioritize the roles of a rural patient navigator, to discuss the acceptability and feasibility of implementing this role and identify possible outcomes that could be used to measure the success of the programme in a clinical trial.

Methods: Rural patients ($n = 19$), their caregivers ($n = 5$) and health professionals ($n = 18$) from Australia participated in three workshops. We analysed the data using thematic analysis.

Results: We identified four themes related to access to dialysis and transplantation: overwhelmed by separate and disconnected health systems, unprepared for emotional toll and isolation, lack of practical support and inability to develop trust and rapport. Four themes related to the role of the patient navigator programme: valuing lived experience, offering cultural expertise, requiring a conduit, and flexibility of the job description. The key roles prioritized by participants were psychological support and networking, provision/consolidation of education, and provision of practical support.

Conclusion: Rural patients, caregivers and health professionals believed that programmes that include navigators with lived experience of dialysis and kidney transplantation and cultural expertise, especially for Aboriginal Australians, may have the potential to improve patient experiences in accessing healthcare.

KEYWORDS

chronic kidney disease, dialysis, patient navigator, rural, transplantation

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Summary at a Glance

Rural patient navigator programmes have potential to improve access to kidney replacement therapy for rural patients. Workshops were held to inform the co-design and implementation of a rural patient navigator programme for adults with CKD, with a particular focus on improving access to all modalities of dialysis and kidney transplantation. The programme will include the features prioritized by the participants (rural patients, caregivers and their health providers) including education, cultural safety and connection, communication, valuing of lived experience and being flexible to the differing needs of people from different communities.

1 | INTRODUCTION

People with chronic kidney disease (CKD) residing in rural areas who require dialysis or kidney transplantation, face many barriers to access healthcare, contributing to their increased risks of mortality, morbidity, and hospitalization.^{1–3} Barriers to healthcare access include limited availability of primary care and specialist services, limited transportation options, centralized transplantation centres, socioeconomic disadvantage and relocation for treatment.^{4,5} With increasing remoteness, there is a greater risk of people with CKD will require dialysis or transplantation, or conservative care, and experience delayed or missed diagnosis of CKD.^{6,7} This is coupled with decreasing availability and access to dialysis and transplantation services.^{8,9}

Patient navigator programmes have the potential to improve access and reduce disparities for rural people with CKD.^{4,10} A patient navigator (or peer navigator, patient preceptor) is a non-medical individual whose responsibility is to provide personalized guidance to patients and their families as they interact with and move through health care systems.^{10–14} Patient navigator programmes are increasingly being implemented in cancer, diabetes, mental health, and HIV care to improve processes of care and reduce disparities in access associated with low socio-economic status or cultural and linguistic diversity.^{10,12,15–18}

Several studies have examined the roles of a patient navigator in early CKD, in children with CKD, in specific cultural groups and in improving waitlisting for transplantation.^{12–14,19,20} Studies in the United States have shown patient navigators working with minority groups, such as Latinos,¹⁸ in both the dialysis and transplantation populations have the potential to improve outcomes for patients, but did not specify inclusion of rural patients.¹⁸ In cancer research, rural patient navigator programmes have been shown to address disparities in access to care and improve patient quality of life.¹¹ However, the transferability of these findings to rural CKD to improve access is unknown, as are the preferences and priorities of rural patients, caregivers and health professionals regarding rural patient navigators.

The aim of this paper was to inform the development of a clinical trial of patient navigators for rural people with CKD (PAVER-CKD) to improve access to dialysis and transplantation. The aims of

the workshops were to ascertain participants' perspectives on barriers to access to dialysis and transplantation, to identify and prioritize the roles of a rural patient navigator, to discuss the acceptability and feasibility of implementing this role and identify possible outcomes that could be used to measure the success of the programme in a clinical trial.

2 | METHODS

We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) framework.²¹

2.1 | Context

We conducted three workshops: a national online workshop for rural patients, caregivers and health professionals, and two in-person workshops held in a rural community (population 22 000 people, a satellite dialysis unit and 208 miles to transplanting centre) with patients and caregivers. Ethics approval was provided by The University of Sydney (2020/869). Participants provided informed consent prior to the videoconference workshop through email. For the in-person workshop, consent was gained at the start of the workshop. The Modified Monash Model classifies a location as metropolitan, regional centre, large, medium, or small rural town, remote, or very remote.²² Rural is referred to in this study as being inclusive of the Modified Monash Categories (MMC) 2–7, with MMC 1 being Metropolitan.

2.2 | Participant selection

Rural patients, caregivers and health professionals were invited to attend the workshops through standardized email invitations to the investigator's professional networks. The workshops were advertised through consumer networks, social media and the Australian and New Zealand Society of Nephrology (ANZSN). A snowballing technique was used whereby

participants nominated other participants who they believed could offer a different perspective about the role of a rural patient navigator.

Forty-two participants attended the workshops including 19 patients, 5 caregivers and 18 health professionals. Thirty-two attended the videoconference workshop, and 12 attended the in-person workshops. Twenty-three (55%) participants identified as female, and 10 (24%) participants identified as Aboriginal or Torres Strait Islander. The characteristics of all participants are shown in Table 1. Five of the participants had experience as a patient navigator/preceptor through work with the Purple House or the National Indigenous Kidney Transplantation Taskforce (NIKKT).^{13,23}

2.3 | Workshop programme and materials

The workshop programme and facilitators guide are included in Data S1. The in-person workshops each had 5–7 participants (facilitator NSR, co-facilitators AT, MH). For the videoconference workshop, participants were pre-assigned to one of five facilitated breakout discussion groups, each with six to seven participants. Each group had one trained facilitator (NSR, AT, AV, KM and SAC) and one co-facilitator (AMG, AVZ, CC, EA and MH). To guide discussions, each facilitator used a standard run sheet which was used in all workshops (Data S1). The questions were based on a literature review of rural patient and care partners' perspectives of access to dialysis and transplantation, a systematic review of patient navigator programme and discussion among the investigator team.^{4,16}

The workshops included four sections: discussion of participants' perspectives on access to dialysis and transplantation for rural patients; presentation and discussion of the acceptability and feasibility of a rural patient navigator programme; prioritization of roles of a rural patient navigator and finally, the participants were asked about outcome measures that would be appropriate for evaluating the success of a programme. Participants in each group were shown a list of 18 possible roles of a rural patient navigator e.g., psychosocial support, making appointments (the full list is available in Data S2), which were identified from a systematic review and a previous workshop investigating patient navigator programmes for patients with early CKD.^{16,19} Participants reviewed the roles, and additional roles were added if not on the list. They then ranked the top three roles that they believed were the most important. The rankings were weighted and recorded with the first choice weighted at three points, second choice two points and the third choice one point. A similar ranking technique has been used in other workshop studies.¹⁹ For the online workshop only, a final plenary session was held where a spokesperson of each breakout room provided a summary of the discussions of each group.

2.4 | Analysis

All breakout and workshop discussions were recorded and transcribed verbatim. Transcripts were imported into Hyper

TABLE 1 Participants characteristics

	n	%
Sex		
Women	23	55
Men	19	45
Age group (years)		
18–19	1	2
20–29	1	2
30–39	8	20
40–49	9	22
50–59	15	38
60–69	6	14
70+	1	2
Ethnicity		
Caucasian	31	74
Aboriginal/Torres Strait Islander	10	24
Asian (Thai)	1	2
Current treatment modality of patient participants (N = 19)		
Kidney transplant	10	53
Satellite haemodialysis	5	27
Home haemodialysis	2	5
Peritoneal dialysis	2	5
Role of participant		
Patient	19	45
Caregiver	5	12
Health professional	18	43
Workshop type		
Videoconference (Zoom)	30	73
In person	12	27
State/Territory of Australia		
New South Wales	18	43
Northern Territory	6	14
South Australia	6	14
Victoria	4	10
Western Australia	4	10
Queensland	3	7
Tasmania	1	2
Previous experience with/as a patient navigator		
Yes	19	45
No	21	50
Unsure	2	5

RESEARCH (version 4.0.3; ResearchWare Inc.) for thematic analysis and coding. NSR reviewed all transcripts line by line and identified and coded concepts into themes reflecting the perspectives of participants on rural patients access to healthcare. These were then discussed and agreed by all facilitators.

TABLE 2 Illustrative quotations

Theme	Quotation
Themes related to rural access to care	
Overwhelmed by separate and disconnected health systems	
Fear of navigating complex health systems	'I find it a nightmare, and it's a huge thing to navigate when you're actually sick yourself'. (Pt) 'Just the understanding, like if you're having a transplant, you've got to deal with the city hospital and they say, "Okay, I'll book you in 8:00 in the morning, tomorrow morning, can you make it?" Well, I live in XXX. All right, well can you travel? Well, it's six hours away and I've got a family to organize and I'm on dialysis so it's like they don't get it. And then they'll say, "Come back next week and see me." Like, you're kidding. Can't you have the one stop thing?' (Pt) 'One lady in particular has worked here for probably four of her appointments, because the last minute didn't want to go, or we couldn't find her to go and I think from what we gather, just that fear of getting down there and having to get around the hospital by herself'. (Nurse)
Confused by medical jargon	'We need to simplify the jargon because there is a lot of medical terminology that our patients just get dazzled by basically'. (Nephrologist) 'The things they're looking at, they're talking about reduction of fluids, perhaps that could be explained in plain English. Everything should be in plain English'. (Pt) 'I think between a complex health system, which is jargonised and difficult, and patients who are trying their best to live their best lives'. (Nurse)
Frustration at vast amount of information	'Just having differing opinions and different information being provided, is probably the biggest thing that patients I work with identify as an issue'. (Social Worker) 'When you're sick, your brain bloody doesn't work, so sometimes absorbing what told. You walk out and go, 'What'd he say?' (Pt) 'I would have really liked to have sat and talked with somebody who had gone the journey before me, and to give me a heads up on about what I'm going to experience from the importance of taking the medication, understanding what the kidney function is in my body, understanding about my fluids, my nutrition, all of those coming together of the importance, because as a primary school teacher, you're having to say it at least 20 times before it clicks'. (Care partner)
Experience of cultural disconnect	'There are lots of hindrances for our (Aboriginal) patients at Port Augusta. Most of them are very shy, they don't directly ask anything and that journey, that three, three and a half hours journey from Port Augusta to Royal Adelaide Hospital, most of them don't want to do it'. (Pt) 'And it's actually trying to navigate what's happening and being educated about what's happening with their body. Within that system of being off country, away from family and cultural responsibilities, there's so much extra pressure and stress being placed on the patient and the families'. (Nurse) 'And it came down to the lack of support and lack of understanding of a First Nations person and their personal circumstance. So not just their health, but the obligation to family, the obligation to country, and how all of that comes into play when it comes to looking after their health'. (Nurse)
Unprepared for emotional toll and isolation	
Left alone to manage	'If you've got no one to take it's a lot on your own'. (Pt) 'They come a long distance from the Kimberley's down to the tertiary center in Perth, and oftentimes, they're unable to bring their support person along, whether that be due to financial issues or just not being covered'. (Nurse) 'In a rural community feeling like you're the only person who's going through this problem, you're the only person with a transplant That's really hard', (Caregiver)
Experiencing geographical and emotional remoteness	'We are obviously isolated by distance to meet other renal patients, other than those that share your dialysis unit but pre-dialysis patients and transplant patients, sort of get a bit lost with making connections with other people that understand their experiences'. (Nurse) 'It's quite important to know that there are other people, your peers that you can lean on' (Pt)
Shocked at new circumstances	'Sitting down in that chair the first time, it's terrifying'. (Pt) 'You're coming from the country into a city. It's all overwhelming in the beginning. Then you add multiple appointments with different people. For someone who's new, and who's not been in the system for that long, it can be quite overwhelming. I feel like it can be detrimental to other parts of your health' (Pt) 'So, when they're going through their assessments, they got to get in personal. Put up their shirts, showing that, you may have the tummy in whatever played and poked and prodded, and they had their weight questioned. That is personal, and it can be a bit embarrassing for them to talk about and feel like they're being told off or scolded for the way that they've been thinking or where their weights at, or their health situation'. (Pt)
Disoriented family and care partners	'Well, no one told me nothing, I just went in with XX and that would have been good-if someone explained it to me'. (Caregiver) 'I think caregivers are given short shift very often'. (Nephrologist) 'This patient's husband is so fearful of having to come to terms with what's actually happening'. (Nurse)

(Continues)

TABLE 2 (Continued)

Theme	Quotation
Lack of practical support	
Difficulty negotiating logistical and geographical barriers	'It's really difficult. I know our social worker, spends a lot of time trying to chase our transport but there's limited transport options'. (Pt) 'If you're catching public transport, if you're anything like me, I always end up getting off about a mile before. I get worried about going past the place I'm supposed to be. To compensate, I get off about three blocks before, or three stops before'. (Pt) 'It's three or four planes from Thursday Island to get down to Brisbane or helicopter all and hoping to get down to Brisbane, same as I was in Kununurra last month with the Royal Perth team and Sir Charles Gairdner team, and just seeing the whole day it took to travel. If we're reversing that, some of these patients have never been on a plane before, so there's so many other obstacles that they're facing on top of their health'. (Nephrologist)
Uncertainty of financial options and impacts	'It's not just IPTAAS. Yeah, they might get the money back, but if you haven't got the money to start with your buggered'. (Pt) 'there's a whole minefield in there, that doesn't help you with transition. And then there are benefits with superannuation. Like you can take two years off, work on a sort of just modified pension scheme. But when you're sick and you're thinking, 'I can't work any longer'. (Pt) 'We need financial support not only for the patient, but also the caregiver?' (Nurse)
Changing and complex needs	'They're quite isolated. And a lot of them find challenges with depression, anxiety. Some have substance abuse and if you're smoking, you may not get access to transplant. So, it's huge, the psychological burden on our patients it's massive' (Nurse) 'We see so many different Drs in different hospitals that it is hard to keep up with where we need to be' (Pt) 'So multiple issues arise that are transplant related from medications. Skin cancers, other cancers, other digestive problems that happen with our medications. But you go to different specialists, and then getting that information. Often the GP isn't updated adequately or hasn't read that information when you go back. There's that, and then there's the problem with who to be referred to when you have to go outside of XXX'. (Pt)
Inability to develop trust and rapport	
Broken communication channels	'Especially where communication and especially with our patients coming from rural to metro. Firstly, it's a big city that they don't want to be in. The language that's spoken there, they don't understand, so they need someone to help them translate'. (Nephrologist) 'We have a lot of patients from the APY Lands come down, and it's language barriers'. (Nurse) 'I've found that it's hard to get all of the information back to the GP'. (Pt) 'Feedback that I get from our patients is they feel that healthcare workers don't talk to each other. They are sent out for appointments in metro hospitals, they get there, and nobody knows who they are, where they're supposed to be, what they're there for. Then they end up seeing other nephrologists and other doctors, and not their primary nephrologist, and they come and change their medications. It's very confusing for them'. (Nurse)
Obstacles to self-advocacy	'At times it can be very difficult for their voice to be heard in these really Patients busy, complex renal departments and services' (Nurse) 'Not everyone is going to be able to advocate for themselves, or they don't feel confident enough to ask those questions. They're just in this position where they feel like they've got to do something, but they don't know what. They don't know the right questions to ask, or... Not that there's a stupid question, I guess a stupid question is one that you don't ask. For those who aren't able to speak up and to advocate for themselves'. (Pt) 'When you're new to it, you assume your interests are being fully looked after, and considered with the time and concern required, but that's not the case. When I see no new patients, I'm like you have to get on the phone, hassle, squeaky wheel, that's how you navigate it, basically'. (Pt)
Themes related to role and acceptability of a rural patient navigator	
Valuing lived experience	'All the patient navigators that I've met, have been on dialysis and going through transplant and their second transplant. They know exactly what it's like to sit in that chair, and have treatment for hours on end, the restrictions that you're on, the medications that your body must handle after transplant. And although someone can sit and tell you about this importance, I think it comes at another level with someone else who's experienced that and been successful, and that you can draw on and build a relationship with, and it's kind of upskilling'. (Pt) 'Bridging that health literacy gap, hearing it from another person that's been through that journey, sometimes help to bridge that gap because they think oh yeah, I can actually do this, because that's how they're managing to do it and they've been on dialysis'. (Nephrologist)

TABLE 2 (Continued)

Theme	Quotation
Offering cultural expertise	'I can talk to the teenagers, but actually getting older 20-year-olds to actually come up long and talk to them, that slightly older age group where they've been through as a teenager, they'll listen to them much more than they will me and actually that peer-to-peer is really critical'. (Nephrologist)
	'First of all, we show respect for our tribal group and acknowledgement. When we talk about that sort of thing, she would understand. Same with They're a group, different groups, and everyone speaks for each group, different tribes. We speak different languages. We try and make sure we get the everybody's system'. (Pt)
	'Cultural understanding, cultural education, whatever you want to call it. As you know, Indigenous people make up the highest percentage of renal patients, so especially in those remote communities, rural, remote. So, I think that understanding and cultural awareness, I think that will go a long way'. (Pt)
Requiring a conduit for communication	'With regards to us who are nonpatients, education with support that happens when you're working together of that Indigenous cultural role, but also patient roles. We have this privilege of working in the same space'. (Nurse)
	'We need interpreters for all languages' (Pt)
	'It's actually the direct language barrier. It's also the medical language and putting that into real terms of people from community. So, I think they're really important those two aspects of communication'. (Pt)
Flexibility of job description	'So, simplifying the jargon, as in you've got their translator, but not in the language sense in a medical jargon sense'. (Pt)
	'Even knowing the family history and family background of a person is very important, because that will tell you a lot about what support they've got around them. Or even just the people that's around them, and is it healthy relationships or unhealthy relationships and how do we support that? And it's not even about the person, it's about the family unit of that person'. (Nurse)
	'It should be flexible because context is really important. And what you might have in one community, they may have different needs in other community. So, in the end patient mentors are men and women who provide key supportive role and assistance to Aboriginal people as they undertake their kidney care'. (Pt)
	'So, it's a really the local context is critically important'. (Nephrologist)
	'If they're new and acute, and are on that really steep learning curve, and realization and sort of that understanding of what you've lost, and what you're now going to have to do, your needs are different to if you've been doing it all your life'. (Pt)

Abbreviation: Pt, patient.

2.5 | Patient and public involvement

First author NSR lives in rural Australia and has lived experience of dialysis and kidney transplantation, and at the time of writing this paper she is a PhD candidate at The University of Sydney. KO lives in rural Australia and has lived experience of dialysis and kidney transplantation and is the primary caregiver to a relative currently on dialysis. KO is a Kurna, Narungga and Ngarrindjeri woman.

3 | RESULTS

3.1 | Workshop discussions

Four themes were related to rural participants' access to healthcare: overwhelmed by separate and disconnected health systems, unprepared for emotional toll and isolation, lack of practical support and inability to develop trust and rapport. Four themes related to the acceptability and core requirements of the patient navigator role: valuing lived experience, offering cultural expertise, requiring a conduit for communication and flexibility of the job description. Table 2 provides illustrative participant quotations

from the workshop. Further suggestions regarding the potential roles of a rural patient navigator can be seen in Table 3. Table 4 highlights the outcomes that participants believed could be used in assessing the effect of a rural patient navigator on improving access.

4 | THEMES RELATED TO RURAL ACCESS TO HEALTHCARE

4.1 | Overwhelmed by separate and disconnected health systems

Fear of navigating complex health services: Patients found that it is a 'huge thing to navigate' around healthcare services, but particularly 'when you're actually sick' and when you have 'to deal with the city hospital' that may be 'six hours away'. They believed there was a lack of understanding from city-based services as to the long distances and complicated coordination of logistics (e.g., accommodation, travel, childcare) required to attend appointments. Health professionals reported patients had a 'fear of getting down there [city hospital] and having to get around the hospital' by themselves.

TABLE 3 Prioritized list of roles for a rural patient navigator

Roles	Description	Score ^a
Psychosocial support and networking ^b	Identify and facilitate access to psychological and social services (social workers, psychologists, counsellors) Connect with other patients and peer mentors	37
Provide/consolidate education ^b	Provide and consolidate education about dialysis and transplantation Assist to provide access to trustworthy information sources Create visual education resources	29
Provide practical support ^b	Assist in finding transportation Arrange accommodation Explain logistics to access hospital/appointments in different towns/cities Provide maps, public transport routes	25
Attend appointments ^b	Attend medical appointments with patients and caregivers	21
Assist with accessing financial support ^b	Identify needs and options for financial support Assist with lodging for reimbursements for travel Refer to appropriate welfare organizations	18
Assist to build trust and rapport between clinical team and patients ^c		18
Assist with scheduling appointments ^b	Schedule appointments Assist to keep a diary Provide reminders Facilitate referrals (allied health)	17
Initiate contact with Indigenous liaison officer/ALO/AHW/ Indigenous patient navigator, Aboriginal health practitioner ^b	Cultural and/or language support	16
Translation of medical information into plain language ^b	Simplification of jargon Development of visual aides Explaining acronyms	12
Preparation for medical appointments ^b	Assist patients and caregivers with strategies to ask questions (write a list prior to appointment)	11
Orientation to new treatments ^c	Attend Haemodialysis initiation with patients to assist with orientation to new treatment modality	6
Caregiver support ^b	Support family members and caregivers	3

^aPoints calculated by adding votes across participants with their weighting where 1 = 3 points, 2 = 2 points, 3 = 1 point.

^bAdapted from existing models and frameworks.¹⁹

^cNew features identified by participants.

TABLE 4 Suggested outcomes for a clinical trial involving rural patient navigator

Suggested outcome	Related theme/s
Quality of life	Changing and complex needs Left alone to manage
Assessment of unmet needs	Difficulty negotiating logistical and geographical barriers Flexibility of job description
Patient empowerment	Obstacles to self-advocacy
Patient satisfaction	Broken communication channels Experiencing geographical and emotional remoteness
Health literacy levels	Confused by medical jargon Frustration at vast amount of information Requiring a conduit for communication
Levels of anxiety and depression	Fear of navigating complex health systems Shocked at new circumstances
Appointment attendance rates	Disoriented family and care partners Experience of cultural disconnect Changing and complex needs
Time to waitlisting (for transplantation)	Difficulty negotiating logistical and geographical barriers Frustration at vast amount of information
Out-of-pocket costs of patients	Uncertainty of financial options and impacts
Navigator/health teams' feedback on acceptability/feasibility of programme	Difficulty negotiating logistical and geographical barriers Broken communication channels
Health system costs or savings	Difficulty negotiating logistical and geographical barriers

Confused by medical jargon: Patients and caregivers were confused by the large amount of 'medical terminology' and stated that the 'complex health system was jargonised'. They suggested that education about their disease and treatment options should be in 'plain English' and requested more visual aids that could be created to assist with understanding the education, particularly for those with English as a second language.

Experience of cultural disconnect: Aboriginal and Torres Strait Islander participants felt uneasy attending larger hospitals and that 'most of them don't want to do it'. They found it difficult to ask questions of health professionals as 'most of them are very shy', due to their unfamiliarity with the colonized health system, language barriers and lacking trust in the system due to historic, often traumatic, experiences with hospitals.

Frustration at vast information: Patients and were required to see many health professionals and were often confused by the 'differing opinions and different information' that they received. Consequently, they were unable to 'absorb' the vast amount of information they received which was compounded by their feeling 'sick' and that their 'brain bloody doesn't work' due to their CKD.

4.2 | Unprepared for emotional toll and isolation

Shocked at new circumstances: Patients felt that commencing new treatments, particularly 'sitting down in that [Hemodialysis] chair the first time' was terrifying. Attending multiple appointments at the unknown city hospitals with 'different people' resulted in patients and care partners feeling overwhelmed and they felt it was 'detrimental to other parts' of their health, especially their mental health.

Left alone to manage: In some circumstances, patients found it difficult to ask a support person to come with them to the 'tertiary centre' due to an inability to afford it financially or the support persons' other commitments at home or work. If no one was able to accompany them, they felt just getting to appointments at the larger hospital was a lot to do on their own, especially if unwell.

Experiencing geographical and emotional remoteness: Patients wanted to sit and talk 'with somebody who had gone through the journey before' them, believing it would improve their understanding of information. Patients living in small communities expressed feeling 'like you are the only person who's going through this problem', increasing their sense of isolation.

Disoriented family and care partners: Participants felt that caregivers missed out on vital education that would help them support patients, particularly at times such as commencing dialysis when patients' ability to self-manage was compromised. Caregivers felt ostracized and confused, and not a part of the process, particularly if they were inexperienced with the health system, or unable to be at appointments with the patient due to other responsibilities.

4.3 | Lack of practical support

Difficulty negotiating logistical and geographical barriers: Patients identified many logistical issues to accessing healthcare and acknowledged that the health professionals spend 'a lot of time trying to chase... transport but there's limited transport options'. They faced difficulties in unfamiliar cities negotiating public transportation routes and how to find the hospitals. Patients from the remotest parts of Australia endured 'three or four planes' to reach the city hospitals.

Changing and complex needs: Patients had to see different doctors in different clinics and re-explain their issues each time, finding it hard to keep up with attending the right location and appointment. They felt pressure to ensure that their primary healthcare team 'at home' was kept up to date with any changes in their care. Participants felt 'the psychological burden on patients is massive' and co-morbidities, including mental health issues which required specialized health services, were difficult to coordinate.

Uncertainty of financial options and impacts: Caregivers expressed concerns about their ability to maintain work commitments when the patient was unwell, receiving dialysis or relocation for transplantation surgery for extended time periods. They worried about finances and the complicated and delayed process of claiming reimbursements for out-of-pocket expenses placed duress on families. Longer-term financial implications for rural families were of concern.

4.4 | Inability to develop trust and rapport

Broken communication channels: Communication between patients and their health teams could be challenging, especially with patients moving between rural and metropolitan hospitals, where they saw many health professionals. Lack of communication between treating health professionals left patients feeling confused about who they are seeing and why, what changes to medications were needed and felt 'it's hard to get all of the information back to the GP [General Practitioner]'.

Obstacles to self-advocacy: Patients acknowledged that 'not everyone is going to be able to advocate for themselves', due to illness, lack of confidence to ask their healthcare teams, being in a new or unknown hospital and just not knowing what questions to ask, especially with younger patients. Healthcare providers felt it was 'very difficult for their voices (patients and families) to be heard in large busy, complex renal departments'.

5 | THEMES RELATING TO ROLES OF A RURAL PATIENT NAVIGATOR PROGRAMME

Valuing lived experience: For those who had experience with a patient navigator, they valued the lived experience of the navigator, which enabled them to draw on experiences to build relationships, knowledge and trust to assist those going through dialysis and transplantation. Participants felt able to bridge 'the health literacy gap' by hearing from those who had experienced treatments and receiving information that way 'sticks a bit better than something you might read'.

Offering cultural expertise: CKD affects many Aboriginal and Torres Strait Islanders, so cultural understanding and cultural education was noted as an essential part of any navigator role. It showed respect and acknowledgement for different tribal and ethnic groups and helped to make the health system 'everybody's system'. Aboriginal and Torres Strait Islanders patients and care partners would require a designated Aboriginal and Torres Strait Islander patient navigator within any programme embedded within the health service.

Requiring a conduit for communication: Participants reported a need for translation of information and language due to a 'direct language barrier' and in a 'medical jargon sense'. This was important for Aboriginal and Torres Strait Islander people, they identified the 'need for interpreters for all languages' in rural communities. Health professionals identified the need for greater context and support 'of the family unit' to assist the patients and wanted to understand how they could support rural patients more effectively.

Flexibility of job description: Due to the variability of health systems throughout Australia between the States and Territories, but also between towns, participants requested that the role required in-built flexibility to adapt to the specific needs of a community, and this role may vary depending on the community it is based within. Patients also felt that the role would require different levels of support depending on the CKD stage of the patient, with greater support when starting dialysis or working up for transplantation.

6 | RANKING OF RURAL PATIENT NAVIGATOR ROLES

Table 3 provides suggestions for the role of a rural patient navigator for those with CKD requiring dialysis or kidney transplantation, including ranking from workshop participants. The top ranked roles of a rural patient navigator were psychological support and networking (37 points), provide/consolidate education (29 points), provision of practical support (25 points), attending appointments with patients (21 points), and assistance with accessing financial support (18 points). Of importance is cultural support, with initiation of contact with an Aboriginal and Torres Strait Islander liaison officer if the rural patient navigator does not identify as Indigenous (16 points).

7 | OUTCOME MEASURES FOR A TRIAL

Table 4 summarizes the outcome measures suggested by workshop participants for inclusion in a clinical trial regarding the role of rural patient navigator programme to improve access to dialysis and transplantation.

8 | DISCUSSION

Patients living in rural communities felt isolated and disorientated in a complex healthcare system, which when combined with an inability to understand medical 'jargon' contributed to reduced access to health services. The need to access kidney replacement therapy, often in locations requiring many days of travel from their home, left patients feeling alone and requiring psychosocial support, wanting to talk to others who had been down this path before to reduce feelings of isolation but also to gain reassurance regarding their future. Participants prioritized identifying and facilitating access to psychosocial support and networks (psychologists, counsellors, and social workers), provision and consolidation of education, and practical support as the most important features of the rural patient navigator role. They face many stresses including separation from family, financial hardship, grief and loss, and seek to discuss with health professionals or other rural CKD patients.²⁴ Whilst there are some similar themes with a systematic review of patients' and caregivers' perspectives on access to kidney replacement therapy in rural communities, in this workshop we identified and prioritized the roles of a patient navigator with patients, caregivers, experienced peer /patient navigators and clinicians.⁴

Ten (24%) of the participants identified as Australian Aboriginal or Torres Strait Islander, with five having experience as a patient navigator. All reported difficulty negotiating larger hospitals and felt a 'lack of understanding' of their cultural connection to Country, family, and community. They noted a cultural divide existed between the patients and health professionals, but patient navigators had assisted with overcoming this. Disparities in access to kidney replacement therapy in Australia are greatest among Aboriginal and Torres Strait Islander people, due to their increased likelihood of living rurally or

remotely, experiences of socioeconomic disadvantage and the high prevalence of CKD, especially in remote communities.²⁵ There are Aboriginal and Torres Strait Islander patient navigator programmes in place in some locations throughout Australia through the work of National Indigenous Kidney Transplantation Taskforce and The Purple House, but there are many communities without access to navigators, and participants felt that this would assist with access in a culturally safe way throughout rural Australia.^{13,23}

Participants felt overwhelmed by the amount of information they received and the number of decisions they faced when commencing dialysis or transplantation work up. Medical jargon added to their uncertainty regarding what was happening to them. Rural patient navigators have the potential to help patients understand the information provided by multiple healthcare professionals through providing information in a way that is easily understood. Rural patient navigators with lived experience would assist with providing education in a simplified manner in the patient's own language.

Rural patients face many barriers to accessing dialysis and particularly kidney transplantation particularly organizing transport and accommodation.^{1,4,7} Participants felt that rural patient navigators had a role in helping to coordinate the logistics required for them to attend large unfamiliar metropolitan services, where they felt lost and overwhelmed. Providing maps of hospitals and public transport routes would help to reduce the anxiety felt by patients to attend unfamiliar centres.

Patient navigator programmes in other chronic diseases have been shown to improve health literacy, improve access to healthcare, decrease patients' fear and in kidney transplantation support patients through the complex workup required.^{11,26-28} However, there is little evidence regarding the effectiveness of patient navigator for rural patients with CKD that aim to improve access to both dialysis and kidney transplantation.^{26,29-31} Home-based therapies for dialysis are one option for reducing travel burden or the need to relocate for rural patients, but there is little known regarding the use of patient navigators to improve uptake of home dialysis modalities.³²

Outcome measures reported in patient navigator studies in CKD populations to date have included changes in glomerular filtration rates, increased wait listing for transplantation, improved health-related quality of life and increase in potential living donors.^{14,20,28,29,33} Measuring change in a participant's quality of life, health literacy, financial hardship and empowerment were suggested outcomes and some of these outcomes have not been addressed in previous trials of patient navigators.

This study has produced diverse and highly relevant insights regarding the development of a rural patient navigator programme for patients with CKD, however, we acknowledge some limitations. There was limited participation from other culturally and linguistically diverse groups from within Australia such as Maori, Pacific Islanders or Asian. We acknowledge that this study has been conducted in a high-income country with access to universal healthcare for dialysis and transplantation services, which may limit its relevance to low- and middle-income countries without universal health care. We acknowledge that some of the findings may be consistent with people living in

urban areas, but there are some that are not consistent including travel burden, logistical and geographical barriers and negotiating care at multiple health services.

Findings from these workshops will inform the co-design and implementation of a rural patient navigator programme for adults with CKD, with a particular focus on improving access to dialysis and transplantation. The programme will include the features prioritized by the participants including education, cultural safety and connection, communication, valuing of lived experience and being flexible to the differing needs of people from different communities. As the programme is developed further, ongoing patient partnership and consultation will continue to ensure that it aligns with the priorities and needs of the people who will be utilizing the service.

9 | CONCLUSION

Rural patients, caregivers and health professionals believed that programmes that include navigators with lived experience of dialysis and kidney transplantation and cultural expertise, especially for Aboriginal Australians, may have the potential to improve patient experiences in accessing healthcare.

AUTHOR CONTRIBUTIONS

Research idea and study design: Nicole Scholes-Robertson, Martin Howell, Allison Tong, Jonathan C. Craig; data acquisition: Nicole Scholes-Robertson, Martin Howell, Simon A. Carter, Karine E. Manera, Andrea K. Viecegli, Eric Au, Chanel Chong, Andrea Matus-Gonzalez, Anita van Zwieten, Donna Reidlinger, Chad Wright; cultural context: Kelli Owen; data analysis/interpretation: Nicole Scholes-Robertson, Martin Howell, Allison Tong; supervision or mentorship: Martin Howell, Jonathan C. Craig, Allison Tong. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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