




# BMJ Open Patient needs and priorities for patient navigator programmes in chronic kidney disease: a workshop report

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## ABSTRACT

**Background and objective** Patients with early chronic kidney disease (CKD) face challenges in accessing healthcare, including delays in diagnosis, fragmented speciality care and lack of tailored education and psychosocial support. Patient navigator programmes have the potential to improve the process of care and outcomes. The objective of this study is to describe the experiences of patients on communication, access of care and self-management and their perspectives on patient navigator programmes in early CKD.

**Design, setting and participants** We convened a workshop in Australia with 19 patients with CKD (all stages including CKD Stage 1 to 5 not on dialysis, 5D (dialysis), and 5T (transplant)) and five caregivers. All of them were over 18 years and English-speaking. Transcripts from the workshop were analysed thematically.

**Results** Four themes that captured discussions were: lost in the ambiguity of symptoms and management, battling roadblocks while accessing care, emotionally isolated after diagnosis and re-establishing lifestyle and forward planning. Five themes that focussed on patient navigator programmes were: trust and credibility, respecting patient choices and readiness to accept the programme, using accessible language to promote the programme, offering multiple ways to engage and communicate and maintaining confidentiality and privacy. Of the 17 features identified as important for a patient navigator programme, the top five were delivery of education, psychosocial support, lifestyle modification, communication and decision-making support and facilitating care.

**Conclusion** Patient navigator services can address gaps in services around health literacy, communication, psychosocial support and coordination across multiple healthcare settings. In comparison to the existing navigator programmes, and other services that are aimed at addressing these gaps, credible, accessible and flexible patient navigator programmes for patients with early CKD, that support education, decision-making, access to care and self-management designed in partnership with patients, may be more acceptable to patients.

## Strengths and limitations of this study

- We elicited a range of patient and caregiver perspectives on self-management and access to care.
- We included patients across the spectrum of chronic kidney disease to capture a broader range of perspectives.
- The participants were all English-speaking and from Australia.

## BACKGROUND

Guidelines on the management of early chronic kidney disease (CKD) recommend pharmacological, lifestyle and psychosocial interventions to minimise the risk of complications and disease progression.<sup>1 2</sup> This requires a collaborative and multidisciplinary approach.<sup>3</sup> However, patients with early CKD face substantial barriers in accessing and coordinating appropriate healthcare. Healthcare delivery is often fragmented into speciality silos and resources are predominantly invested in treatment rather than prevention. Other challenges include delays in the diagnosis of CKD and referral to nephrologists, poor follow-up, a lack of psychosocial support and education and difficulties navigating the complex treatment plans.<sup>4 5</sup> This is particularly problematic in early CKD because patients can be asymptomatic with an uncertain prognosis.<sup>6</sup> Barriers to follow-up after diagnosis may include costs, difficulties with travelling to clinic for testing and fear and confusion about laboratory results.<sup>5</sup> There is also a lack of awareness of CKD among patients and the general public.<sup>7–9</sup> These reasons may explain, to some extent, why access to education and multidisciplinary care to prevent the



progression of CKD has been consistently identified as the top research priority among patients with early CKD.<sup>8 10 11</sup>

Patient navigator programmes have the potential to improve the process of care and outcomes and are increasingly implemented in the context of chronic disease, particularly for patients with cancer<sup>12</sup> and diabetes.<sup>13 14</sup> Patient navigator programmes facilitate access and manage care through education, care coordination and advocacy to reduce health disparities.<sup>15 16</sup> Patient navigators are trained non-medical personnel (who may be patients, or other members from community, including individuals with a background in a health-related discipline) who assist patients with complex and/or chronic conditions journey through the continuum of care and transit across different care settings.<sup>12 17</sup> They help underserved populations with chronic illness to better understand their diagnoses, treatment options and available resources, assist with navigating complex medical systems, overcoming barriers to healthcare access and bridging gaps in transitions of care.<sup>18</sup>

In the context of cancer, patient navigator programmes have improved patients' satisfaction with care and treatment adherence.<sup>19–21</sup> The navigators in these programmes have included healthcare professionals (eg, nurses and community workers) and respected individuals including community leaders (including cancer survivors). Navigators involved in such programmes needed to have an understanding of the range of services available, an ability to communicate with professionals and assist with obtaining or coordinating referrals to services.<sup>22 23</sup>

Patient navigator programmes for cancer and diabetes patients may not directly apply to patients with early CKD. The difference in disease symptoms, manifestations and treatments between these diseases (cancer and diabetes) and CKD lead us to question the transferability of the navigator programmes. Additionally, the evidence for patient navigator programmes for patients with early CKD remains uncertain and the ability to precisely outline successful components in patient navigator programmes across all chronic diseases remains limited.<sup>16 20 24 25</sup> Studies show that patients are rarely involved in the design of patient navigator programmes meaning they may not address the priorities of patients and their carers.<sup>15</sup>

## CONTEXT AND SCOPE

We conducted a workshop to discuss patient perspectives on access to care and self-management, to ascertain their perspectives on a patient navigator programme that can address barriers and challenges they may have encountered, to identify and prioritise features of such a patient navigator programme in early CKD (all stages of CKD before the need for kidney replacement therapy) and to discuss the acceptability and feasibility of implementation. In the workshop we also included patients on dialysis and kidney transplant recipients, who were able to reflect on their experiences prior to the need for kidney replacement therapy, and thus could provide relevant

perspectives. The intent of the workshop was to inform a trial of a patient navigator programme for patients with early CKD (PAVE-CKD). The half-day workshop was conducted in a hotel meeting room in Sydney in May 2019.

## ATTENDEES AND CONTRIBUTORS

In total, 19 adult patients aged 18 years and over with CKD (not on kidney replacement therapy n=11, receiving dialysis n=6, kidney transplant recipients n=2) and five caregivers (family members) attended the workshop. The participants were from three cities (Sydney, Adelaide and Armidale) in Australia. The characteristics of the participants are provided in [table 1](#). Invitations were sent to patients and caregivers by email through the Better Evidence and Translation in Chronic Kidney Diseases (BEAT-CKD) network. The full list of the PAVE-CKD workshop attendees and contributors is provided in the Acknowledgements.

## WORKSHOP PROGRAMME AND MATERIALS

The workshop programme outline and facilitator guide are provided in the online supplemental file 1 (Item S1 and Item S2, respectively). Participants received a printed copy of the project aims and a list of potential features (eg, facilitating care, delivery of education) of the navigator programme (Item S3 in the online supplemental file 1). The workshop had three phases: introduction, breakout discussions and plenary discussion.

Participants were pre-assigned to one of four facilitated breakout discussion groups of six to seven participants. To encourage an exchange of diverse perspectives, each group included a mix of caregivers and patients with early CKD, patients on dialysis and transplant recipients. Each group had one trained facilitator (PL-V, AT, AB and TG) and a co-facilitator (AJ, CG, NJS-R and RK). To guide the discussions, all facilitators used a standardised run sheet (Item S2 in the online supplemental file 1). The questions were developed based on a literature review on patient navigator programmes<sup>16 26</sup> and discussion among the investigator team, which included multidisciplinary clinicians, patients and researchers.

During the first session participants discussed their experiences and perspectives of self-management, communication and education and access to care in CKD prior to the need for kidney replacement therapy.

In the second session, the concept of a navigator was explained, and participants in each group were given a copy of the list of 11 features of the navigator programme (Item S3 in the online supplemental file 1), identified from systematic reviews of patient navigator programmes.<sup>16 26</sup> The role of the navigator was outlined against each feature. Participants were asked to review the 11 features of the navigator programme, add additional features to the list if required and explain the reasons for additional features and discuss how each feature of the

**Table 1** Participant characteristics (n=24)

Characteristics	N	%
<b>Participant status</b>		
Patients	19	79
Family/caregivers	5	21
<b>Sex</b>		
Male	13	54
Female	11	46
<b>Age group</b>		
18–30	5	21
31–40	4	17
41–50	2	8
51–60	4	17
61–70	4	17
>70	5	21
<b>Highest level of education</b>		
Primary school (<year 10 level)	1	4
School certificate (year 10 level)	5	21
High school certificate (year 12 level)	4	17
Technical and Further Education (TAFE)	5	21
University (Bachelor degree)	4	17
Postgraduate degree	5	21
<b>Employment</b>		
Full-time	7	29
Part-time or casual	6	25
Unemployed	5	21
Retired	6	25
<b>Marital status</b>		
Married	11	46
Single	6	25
Partner (living/not living with partner)	4	17
Widowed/divorced	3	13
<b>Cause/diagnosis</b>		
Polycystic kidney disease	6	32
Glomerulonephritis	5	26
Diabetes	1	5
Hypertension	1	5
Infection	1	5
Immune system	1	5
Other	2	11
Don't know	2	11
<b>Kidney replacement therapy (KRT)</b>		
None	11	46
Peritoneal dialysis	4	17
Haemodialysis	2	8
Kidney transplantation	2	8
<b>Time on KRT</b>		

Continued

**Table 1** Continued

Characteristics	N	%
<6 months	1	13
1–3 years	5	62
4–6 years	1	13
>6 years	1	13

programme might relate to their challenges identified during the first session. They were provided with three sticker dots of different colours to vote for the top three features that they thought were most important. The green sticker dot indicated rank '1' (most important) and was given a weighting of 3 points, the orange sticker dot indicated rank '2' (second most important) and was given 2 points and the red sticker dot indicated rank '3' (third most important) and was given 1 point. They discussed the reasons for their choices. Each group came up with a list of features with the top three prioritised features marked with the stickers. The scores (based on the sticker dots) of each group reflected the combined experiences and opinions of the members of the group. Following this, the participants discussed considerations for implementing the navigator programmes and identified outcomes that were relevant in evaluating the 'success' of patient navigator programmes.

After the session, the scores for each feature of the navigator programme were summed across the breakout groups and presented to the other groups in the plenary session. During the final plenary discussions, the Chair (AT) asked a nominated speaker from each breakout group to summarise their discussion. Each group provided a summary about the important features of patient navigator programmes, impacts, outcomes and critical success factors for uptake and implementation into patient care.

All breakout and plenary discussions were audiotaped and transcribed verbatim. Transcripts were entered into HyperResearch (ResearchWare Inc, V.3.0) to enable coding and analysis of the data. CG reviewed the transcripts line-by-line and identified and coded concepts into themes reflecting the perspectives of patients at the time of the diagnosis of early CKD and their views on the usability and acceptability of a patient navigator programme for early CKD patients. The themes were discussed among the facilitators and investigators to ensure that they captured the full range and depth of the discussions.

### Patient and public involvement

Patients were directly involved in the study. Authors NJS-R and VC are patients with CKD involved as co-investigators. CG (a caregiver) and NJS-R were involved with the facilitation of the workshop. As results emerged, we reviewed the results with patient co-investigators to obtain their feedback to ensure that we presented the findings in the most effective way beyond the research community to general populations. We also shared a summary of findings to the

workshop participants and gave them an opportunity to review the findings.

## SUMMARY OF WORKSHOP FINDINGS

### Workshop discussions

We identified themes that reflected the experiences of patients with early CKD and their perspectives on the features and acceptability of a patient navigator programme. Four themes related to self-management, communication and access to care during early CKD: lost in the ambiguity of symptoms and management, battling roadblocks while accessing care, emotionally isolated and re-establishing lifestyle and forward planning. Five themes related to the acceptability of the patient navigator programme: trust and credibility, respecting patient choices and readiness, using accessible language, offering multiple ways to engage and communicate and confidentiality and privacy. Selected quotations for each theme are presented in [table 2](#). The themes and respective subthemes are described below.

## THEMES RELATED TO SELF-MANAGEMENT, COMMUNICATION AND ACCESS TO CARE

### Lost in the ambiguity of symptoms and management

#### Not recognising the severity of CKD-related symptoms

Patients did not attribute the symptoms they experienced, such as fatigue, to CKD. Patients who experienced fatigue assumed ‘they probably needed more rest’ or were led to believe they had ‘imagined’ their health problems when they were told they were ‘a hypochondriac’. Others ‘felt fine’ and ‘didn’t particularly feel they had the disease’ and thus were not prompted to seek care. One patient mentioned that her clinician dismissed CKD-related symptoms as being anxiety-related.

#### Delay in diagnosis and treatment

Patients felt that some general practitioners (GPs) were not knowledgeable about CKD and commented that ‘a lot of times they don’t understand’ the symptoms and felt the management of the CKD was ‘beyond’ them. They believed that this caused a delay in their diagnosis and commencement of treatment. One patient reported that they had to ‘collapse before anything was really done about it’. Delays were also caused when patients had to go back and forth between specialists before agreement was made on a management plan.

#### Overwhelming shock and despair at prognosis

Patients unfamiliar with the disease (eg, those with no family history of CKD or who did not experience symptoms related to CKD) felt shocked, overwhelmed and unprepared for decision-making and treatment. One patient went ‘from a matter of not knowing what was happening’ with their body, to being ‘in emergency and then admitted into hospital and receiving treatment’

for a disease they were not aware of. On diagnosis, some patients assumed they were ‘going to die’.

### Battling roadblocks while accessing care

#### Frustrated by inadequate information

Patients felt they received insufficient information from GPs and nephrologists. They felt uncertain about their prognosis. Patients sometimes ‘didn’t fully understand’ their condition, ‘because nobody had actually given them information’ of what they had and ‘why’ they had it. Some resorted to educating themselves and used ‘Google’ to learn more about CKD or spoke with other patients—‘I needed to see another patient to understand what this disease was all about’.

#### Bewildered by fragmented services

Patients consulted different multidisciplinary clinicians, but felt that the services were disjointed, siloed, inconsistent and difficult to access. This made ‘life really difficult.’ Some patients felt that nephrologists did not provide them with adequate information and expressed exasperation about the perceived lack of communication among clinicians—‘get clinicians to communicate with each other or respect the need to re-consult back with each other every so often’. Some were unaware of services available and felt patients would not be referred to these additional services, such as dietitians, ‘unless the patient really asks’. One patient commented that they ‘have never seen a social worker...I didn’t realise we had a designated renal social worker’.

#### Perplexed by medical terminology

Patients found it difficult to understand medical language and were unable to interpret their test results. They felt doctors were ‘so busy and it becomes extremely...technical, very jargonistic’. Patients needed the information provided in a ‘demedicalised and plain English’ language and format.

#### Dismissed, disrespected and disempowered in decision-making

Some patients found it difficult to engage with their clinicians in a constructive way that fostered a partnership approach to managing CKD. They felt disregarded as they were expected to just ‘sit there’ and ‘be told what to do’. Patients felt dismissed when doctors were ‘too busy’ to acknowledge and respond to their queries or concerns regarding the treatment.

#### Blindly trusting clinicians

Some patients ‘didn’t understand enough about the disease’ and thus relied on their nephrologists and nurses to make decisions. They trusted their doctors and did not want to participate in decisions about their treatment—‘I was totally guided by my nephrologist...he knew what he was talking about’.

### Emotionally isolated

#### Forced to cope alone

After being diagnosed with CKD, patients were often not referred to or offered psychosocial support. They felt that they were left to cope on their own—‘there was no



**Table 2** Illustrative quotations for themes identified in the workshop discussions

Themes	Quotations
Self-management, communication and access to care	<p>Lost in the ambiguity of symptoms and management</p> <p>Not recognising the severity of CKD-related symptoms</p> <p>Acknowledging and accepting that it's a real thing. I felt fine, my physical condition had changed with fluid retention, so there was the obvious reaction to having a disease. But aside from not being able to explain those, I didn't particularly feel I had the disease. – Patient</p> <p>I felt tired. I am only just realising now when I see my boys going through it that that's obviously part of the disease that I never realised. – Patient</p> <p>Delay in diagnosis and treatment</p> <p>With two parents as doctors, I had to eventually collapse before anything was done about it. – Patient</p> <p>It took 3 months before she was diagnosed. They [the medical staff] would kind of say it's in her head. – Caregiver</p> <p>Overwhelming shock and despair at catastrophic prognosis</p> <p>It was quite horrifying; it was quite scary. At 16 you're not thinking about the fragility of life, generally, and all of a sudden to feel [the vulnerability of life]. – Patient</p> <p>When the results finally came back, when he [the doctor] finally did all the other tests which was over a period of about 3 weeks it wasn't that long, he said to me, 'there's nothing I can do for you, you've got bad kidneys'. That was it. So I went back home... rang my husband and said, 'I think I'm going to die'. – Patient</p>
Battling roadblocks while accessing care	<p>Frustrated by inadequate information</p> <p>In the early days, the only way I got any information was talking to other patients. I got bugger all from the hospital and bugger all from the doctors. – Patient</p> <p>It was not knowing anything. We went down to the dialysis centre, and I totally wiped it out. We went out of there seeing less and knowing less than I went in. – Patient</p> <p>I actually didn't fully understand because nobody had actually given me the full information of what I had in a way that I could kind of go, 'Well this is what I've got, and this is why I've got it.' – Patient</p> <p>Bewildered by fragmented services</p> <p>At the end have got six specialists that are caring; the rheumatoid, the infectious diseases...Well, you know, it gets your head a bit. – Patient</p> <p>And that makes it hard, say, for example, when my iron goes really low, to make all the appointments, to get something done about that. And to be the advocate and to chase people up. – Patient</p> <p>I went to a social worker and said, 'is there a support group I can go to?' And, the comment that came back to me was that you are getting ahead of yourself...Ok. I went back 6 months later, and I asked the same question again. And I was told there is nothing at the moment, we'll let you know if there is something... And I thought; what am I paying you for? – Patient</p> <p>Perplexed by medical terminology</p> <p>[the clinicians] they can answer those questions, ... but it's all very jargonistic. – Patient</p> <p>I didn't know what it [the disease] meant so I couldn't really share it with other people. – Patient</p> <p>Dismissed disrespected and disempowered in decision-making</p> <p>But the doctors don't treat you like that. You're still treated like you are a patient and you just sit there and we'll tell you what to do. – Patient</p> <p>And the doctor came around with some students, and [name of patient] didn't know the difference between the chronic glomerulonephritis and acute glomerulonephritis. So, when he said 'have I got acute glomerulonephritis?' all these interns laughed. – Patient</p> <p>You're asking a question you want an answer to and you're getting laughing. – Caregiver</p> <p>When the doctors came around with the students, he'd be talking about you as if you weren't there. – Patient</p> <p>Blindly trusting clinicians</p> <p>I went from never taking a tablet to taking 22 tablets. What going on here? I didn't know what they were. But I just number them and that did help me a lot because I realised what was going on but some of them, every time I went there [to see the doctor], I'd get another tablet. I knew that I had to take it because they knew what they were doing, the doctors that I went to see. – Patient</p>

Continued

Table 2 Continued

Themes	Quotations
Emotionally isolated	<p>Forced to cope alone</p> <p>And I went to the car and just bawled ... There was no information, no referrals, no referral to a psychologist to help me through the grieving process. – Patient</p> <p>I had nobody with me so that period of time initially was very hard, because I didn't know what it meant so I couldn't really share it with other people because explaining it to them made me feel guilty, 'was it my fault?'. – Patient</p> <p>Because you are in shock, and then processing, and you had nobody to process with because there was nobody really who understood what was going on. – Patient</p> <p>I was like 'Yeah, I feel crap...' Its more the emotional side, to just have nowhere to go. – Patient</p> <p>Struggling to balance disease burden with family responsibilities</p> <p>It would have been better for the family as a whole to have someone, [to take] some of that load. – Patient</p> <p>You are supporting your kids, ... but what are you getting? – Patient</p>
Re-establishing lifestyle and forward planning	<p>Having to adjust to a restricted way of living</p> <p>It impacted my life initially quite significantly in that I was a very, very keen rugby player. I was told to stop right away... I was quite an active person; I was told to stop a lot of activities I did. – Patient</p> <p>The first was changing diet for me. So cutting out potassium and phosphate and watching unhealthy foods. – Patient</p> <p>Struggling to pursue parenthood</p> <p>She was told she could never have children. – Caregiver</p> <p>So did IVF, plus we went to immunologists and they were like, 'Why do you want to have a baby so bad?' Like, just give up. 'Just why, why do you have to have one?' I want to. – Patient</p>
Acceptability of the patient navigator programme	
Trust and credibility	<p>Like any service, there needs to be proper visibility and advertisement around it. And coming from the doctor is a really good way to do it. – Caregiver</p> <p>Your doctor or your nephrologist would set up the appointment or discuss the programme with you and provide you information on that programme, and then actually make arrangement for someone to contact you, and set up the next stage after that so there is a stiff process that occurs. – Patient</p>
Respecting patient's choices and readiness	<p>You can be contacted and opt in, or you can take away a pamphlet and you can opt in when you are ready. – Patient</p> <p>And there are people who don't want to be in it [in the navigator programme]. Some people don't want other people to now there is something wrong with them... And there's not ever going to be a one size fits all, is there? – Patient</p> <p>You want more frequency early on during diagnosis and individualised and tailored to the patient needs. – Patient</p> <p>You are already in a bit of a fuzz anyhow. Are you going to grab that pamphlet and do something about it? Whereas if they ring you, at least there's been an initial contact. – Patient and caregiver</p>
Using accessible language	<p>If you are going to help him with the patient navigator programme, it's got to be really simple. – Patient</p> <p>Don't call it 'navigator'. Call it 'helper'. If I was sick and I wanted help, I wouldn't look, "Oh navigator". – Patient</p>
Offering multiple ways to engage and communicate	<p>My boys would probably take up [the patient navigator programme] online. – Caregiver</p> <p>I'd prefer to be face-to-face or just on telephone. – Patient</p>
Confidentiality and privacy	<p>This person's role as a counsellor is very much about maintaining your privacy and confidentiality but assisting you in all of this and so much more. – Patient</p>

CKD, chronic kidney disease; IVF, in vitro fertilisation.

information, no referral to a psychologist to help' them through 'the grieving process'. Being 'so unwell', patients did not have the 'emotional energy' to be their 'own advocates'. They believed that 'some sort of mentoring' would have been 'reassuring' to help them 'sleep better at night'.

**Struggling to balance disease burden with family responsibilities**  
Patients emphasised that CKD affected their family, particularly parents with CKD who struggled to care for their children. They felt that assistance, such as having a 'case worker' would help to alleviate the burden on their family.

## Re-establishing lifestyle and forward planning

### Having to adjust to a restricted way of living

Patients were advised to make changes to their lifestyle after diagnosis such as restricting 'potassium and phosphate and watching unhealthy foods'. Patients with polycystic kidney disease were asked to refrain from high impact activities that they enjoyed like 'playing rugby' and 'horse riding'.

### Struggling to pursue parenthood

Some patients who wanted to start a family were aware that CKD and its treatment increased the risk of infertility, pregnancy complications and congenital birth defects. They faced resistance from fertility specialists, and some women 'changed doctors' in an attempt to access better support and management of their pregnancy. One patient experienced a miscarriage after going through several cycles of in vitro fertilisation (IVF), and another mother had to undergo an early delivery due to an increased risk of a cardiovascular event. Patients lacked the confidence to 'ask about specifics' around their management of CKD and the way their medications (eg, appropriate dosage) were to be administered to have a safe pregnancy.

### Acceptability of the patient navigator programme

The themes in this section focus on the acceptability of a patient navigator programme to potentially address some of the issues raised above.

### Trust and credibility

To engage with the patient navigator programme, patients needed to be confident in the credibility of the navigator programme. They suggested that the programme should be promoted through trusted or familiar sources, for example, GPs, nephrologists and patient organisations. Some indicated they would prefer the navigator to have lived experience of CKD so they could 'relate' to them.

### Respecting patient choices and readiness

Patients wanted the programme to be able to meet their individual needs and to have the choice and flexibility around participation in the patient navigator programme. Some felt it was acceptable for patients to be contacted by the navigator programme coordinators, while others felt it may be 'too confronting' and preferred to be informed about the programme before deciding to enrol.

### Using accessible language

Patients felt that it was important to explain the programme using terms that were easily understood by patients with different levels of health literacy and education. They regarded the term 'patient navigator' to be potentially confusing and suggested alternatives including 'helper' or 'support person'.

### Offering multiple ways to engage and communicate

Patients suggested that different modes of communication with the navigator could increase engagement and uptake by diverse groups of patients. Some patients

preferred to communicate online with the navigator while others preferred face-to-face or telephone contact. Some older patients stated that they 'wouldn't be online'.

### Confidentiality and privacy

Protecting confidentiality and privacy during consultations with the navigator was important to patients. Some of the participants felt 'there was no privacy at their clinic'. The discussions on sensitive or personal topics, for example, 'insurance' or 'intimacy issues', should be conducted in private settings.

### Rankings of features of navigator programmes

The top five ranked features of patient navigator programmes were delivery of education (35 points), psychosocial support (35 points), lifestyle modification (16 points), communication and decision-making support (15) and facilitating care (referrals, communication and coordination) (14 points). Six new features were added: maintaining independence and living life, networking, translating medical information into plain language, advocacy and education for family and friends, need for patient navigators with 'lived experience' and caregiver support. Scores for each of the features are provided in [table 3](#).

## DISCUSSION

Patients and caregivers prioritised education, psychosocial support, communication and decision-making as the most important features of the patient navigator programme. An overall low level of awareness of CKD among patients and clinicians was believed to be a main reason for delays in the diagnosis and treatment. Following diagnosis, the immediate needs patients identified were education; to gain a better understanding of their disease and psychological support; to overcome the shock of diagnosis. Patients emphasised the need for adequate information, clarification with medical terminology and help with understanding the implications of their test results. They felt that patient navigators should have a role in providing or facilitating disease and treatment-related education and rated education as the top feature in the navigator programme.

The shock of being diagnosed with CKD along with fear of a severe and life-threatening prognosis was overwhelming and impaired their ability to cope and engage in self-management and healthcare. Without ready access to psychological or social support, some felt isolated and emotionally burdened. Patient navigator programmes could potentially identify and facilitate access to social support networks (family, friends and community groups) and psychological and social services (counsellors, psychologists and social workers). The use of online video conferencing platforms could also be considered and may be a more cost-effective way than in-person sessions.

**Table 3** Prioritised list of features for the patient navigator programme

Features*	Description	Score†
*Delivery of education	Provide basic education about CKD Facilitate access to quality information	35
*Psychosocial support	Identify social support networks (family, friends, community groups) Identify and facilitate access to psychological and social services (counsellors, psychologists, social workers)	35
*Lifestyle modification	Encourage and support behaviour change (diet, exercise)	16
*Communication and decision-making support	Discuss potential questions patients/families can ask at their appointments Clarify goals and value in making treatment decisions	15
*Facilitating care (referrals, communication, coordination)	Facilitate referrals Schedule and coordinate appointments (GP, specialist care, allied health) Help in completing complex medical forms Provide support (to address concerns, fears) Provide reminders	14
*Medication	Encourage and support appropriate medicine-taking	13
‡Maintaining independence and living life	Assist with continuing their lifestyle. Focus on activities patients can continue to do rather than limit	5
‡Networking	Connect with other patients (peer support) support mentors	5
‡Translating medical information into plain language	Assist with simplifying medical terminology and jargon	5
‡Advocacy and education for family and friends	Education to support family and friends	4
'Lived experience'‡	Navigators with lived experience would act as motivators for participating in the programme	4
*Appointment schedule	Schedule appointments	3
*Practical support	Explain the logistics (venue, parking) Arrange transportation Arrange childcare as needed Ask about the barriers and address them	1
*Cultural and language support	Arrange interpretation services	1
*Accompaniment	Accompany patients/caregivers at appointments	0
*Financial support	Identify needs and support for financial support (completing applications)	0
‡Caregiver support	Support caregivers to balance burden of care with family responsibilities	0

\*Adapted from existing models and frameworks,<sup>16 26</sup> and not mutually exclusive.

†Points calculated by adding the votes with their weighting where 1=3 points, 2=2 points and 3=1 point.

‡New features identified.

CKD, chronic kidney disease; GP, general practitioner.

Along with education and communication, patients emphasised the need for advocacy to support their choices and help them make informed decisions regarding their care. Patients reported that GPs lacked awareness about CKD and dismissed their symptoms or felt ridiculed and disempowered while asking questions and making decisions about their treatment. They wanted an advocate to help speak on their behalf when they needed clarity around their treatment, and a liaison to facilitate communication (eg, when patients were unable to explain their symptoms, felt unheard or disregarded by doctors, or when they had to manage conflicting advice from specialists). Patients who wanted information and support with regards to family planning (including pregnancy), needed assistance with coordinating services across multiple care

settings (GPs, nephrologists and fertility specialists). The multifaceted and pervasive impact of CKD placed additional demands on the patients and families that navigators could assist with, for example, support for siblings of patients who felt neglected by their parents or managing ongoing stress among family members. Patients suggested that navigators could help to identify and coordinate services (eg, access to social workers to organise for practical assistance at home, or to liaise with the school or employers for extra support). They felt that the navigator programme must address these issues relating to lifestyle, communication, coordination and advocacy.

Overall, the needs of patients centred around education, communication, coordination and psychosocial support. Differences among patients were around life



stages (eg, younger patients were more comfortable with online communication) and disease type. For example, patients with polycystic kidney disease were familiar with their disease and experienced less shock on diagnosis. They were influenced by family members' experiences with the disease and were unfamiliar with the most up to date information on available treatment and services.

The role of a patient navigator may also focus on providing specific information to address vulnerable points in the patient's disease trajectory. For example, assisting transition to dialysis by advocating for patient's choice of dialysis modality; during transplantation by organising psychosocial support for caregivers; by liaising between nephrologists and other healthcare providers including fertility specialists and initiating discussions with female patients on fertility preservation and IVF.

While we generated diverse and relevant insights about self-management, access and priorities for patient navigator programmes for CKD, we recognise that some of the patients were receiving kidney replacement therapy at the time of the workshop. However, through prompting, participants were asked to reflect and focus on their diagnosis of CKD prior to the need for kidney replacement therapy. Patients who had commenced dialysis or received a kidney transplant had the benefit of hindsight and they could recognise various symptoms attributed to CKD only after they received treatment. We acknowledge that participants were all English-speaking, resided in Australia including some who were highly educated. Thus, there is some uncertainty about the transferability of the findings to other populations. This was conducted as a patient workshop with patients involved as co-investigators, therefore we did not collect detailed demographic and clinical characteristics and thus could not compare the data based on these characteristics including age, ethnicity, type of disease or treatment stage. Also, this was conducted as a single workshop with breakout group discussions, and we did not seek to achieve data saturation. However, we noted similar priorities and themes across the breakout groups. Future detailed work is suggested to understand the specific needs of patient populations including non-English speaking patients, Indigenous groups, and culturally and linguistically diverse groups to understand the unique barriers and challenges these groups face.

Based on the evidence for patients with chronic diseases other than CKD, patient navigator programmes can be seen to improve timely access to care and support self-management.<sup>11</sup> Specifically patient navigator programmes have been shown to improve health literacy, build trust, reduce fear and improve patient-provider communication.<sup>12</sup> In patients with cancer, trials have demonstrated that patient navigator programmes are associated with earlier initiation of treatment.<sup>27</sup> One study conducted in patients with abnormal cancer screening results found that the patient navigator programme resulted in earlier diagnosis and treatment.<sup>27</sup> Patient navigator programmes have also been shown to

increase satisfaction with clinician-related interactions (eg, doctors availability, interpersonal skills, information, technical skills and psychosocial support) and to reduce hospitalisation in patients with head and neck cancers.<sup>28</sup> Studies reveal positive feedback from patients with type 2 diabetes and healthcare providers when patient navigators were used for promoting lifestyle modifications.<sup>14</sup> One study revealed that youths with type 1 diabetes found the navigator programme valuable as they transitioned from paediatric to adult care.<sup>13</sup>

However, patient navigator programmes for cancer and diabetes patients may not extrapolate to patients with early CKD due to the differences in the disease trajectory (progression to kidney failure requiring kidney replacement therapy) and treatments. Most of the information on patient navigation programmes relate to screening studies in cancer and a small number of studies pertain to kidney replacement treatment, including transplant education, accessing transplant waiting lists and living donation.<sup>18 29</sup>

There is little evidence for the effectiveness of navigator programmes among patients with early CKD. One trial compared the effect of a navigator programme for patients (with CKD stage 3 to 4) with enhanced personal health record to usual care. No difference was reported in clinical measures (estimated glomerular filtration rate, appropriate CKD-related laboratory measures and referrals to specialists) or hospitalisation.<sup>30</sup> Nevertheless, the acceptance of the programme was high, although the study population comprised of patients with high literacy levels who were actively engaged in their own care. Another study in patients with advanced CKD close to the need for kidney replacement therapy reported that patient navigators increased access to psychological support.<sup>31</sup> However, to date navigator programmes have had minimal involvement of patients in the design which may limit the uptake and effect on outcomes.<sup>15 30</sup>

Our workshop identified new and unique barriers and challenges that patients with early CKD encountered in accessing and navigating healthcare and described specific preferences for designing and implementing navigator programmes. Patients in our workshop identified some features that included support with maintaining their lifestyle, fulfilling their daily activities and responsibilities, facilitating networking and connecting with other patients for support and educating family and friends about CKD. Recommendations on various aspects of the programme included preferences in the way navigator programme could be promoted, implemented and the specific roles of a patient navigator. Patients identified preferred channels for promoting patient navigator programmes (eg, through trusted sources like their healthcare providers, promotional material including fliers, mobile applications and credible websites), options for recruitment (eg, choice to opt in) and mode of contact (through telephone, email, online or face-to-face). Patients indicated a preference for navigators that they could readily identify or establish rapport with (eg,

### Box 1 Summary of recommendations to consider while developing patient navigator programmes for chronic kidney disease (CKD) patients

Implications for interventions of a patient navigator programme for patients with CKD

- ▶ Promote patient navigator programmes through trusted and credible sources (eg, general practitioner or specialist).
- ▶ Provide flexible options for patients to enrol in the programme.
- ▶ Use a range of terms and language that can be easily understood, for example, alternative terms such as ‘helper’ rather than the term ‘navigator’.
- ▶ Allow different modes of contact with the patient navigator (online, email, in-person meetings, telephone).
- ▶ Protect confidentiality and privacy when communication with patient navigators.

navigators with lived experience of chronic conditions, or of similar age) and a flexible multimode delivery of navigator services (through applications, online and in person) with a focus on individualised tailored programmes. Privacy and confidentiality were highlighted as important. The role of a navigator included provision of information around logistics (eg, parking, childcare and transport), education (eg, information on their disease and treatment, discussions around fertility preservation and IVF) and coordination of care (eg, arranging appointments). Clarifying patient goals and assisting in making treatment decisions, providing social support (identifying social networks, facilitating access to psychologists and counsellors), encouraging and supporting appropriate medicine taking, assisting with lifestyle changes (eg, connecting with dietitian) were also deemed important. **Box 1** provides a summary of recommendations for developing and implementing navigator programmes for patients with early CKD, derived from the workshop discussion.

Findings from this workshop will inform the design and implementation of a patient navigator programme for adults with CKD not yet requiring kidney replacement therapy. The programme will include features (eg, education, communication, coordination and advocacy) that have been identified as important to patients. In partnership with patients, we will calibrate the programme to best suit the target patient group. The findings will also be implemented in the development of the training programme and resources for navigators.

Patient navigator programmes should include features of high priority and relevance to patients including the delivery of education, identification of social support networks, advocacy of patient views and concerns, guidance in making lifestyle changes and assistance with communication and accessing services. In so doing the acceptability and uptake of patient navigator programme would be strengthened increasing the likelihood of improved treatment outcomes in patients with early CKD.

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