

Patient Perspectives of Center-Specific Reporting in Kidney Failure Care: An Australian Qualitative Study



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Introduction: Public reporting of quality of care indicators in healthcare is intended to inform consumer decision-making; however, people may be unaware that such information exists, or it may not capture their priorities. The aim of this study was to understand the views of people with kidney disease about public reporting of dialysis and transplant center outcomes.

Methods: This qualitative study involved 27 patients with lived experience of kidney disease in Australia who participated in 11 online focus groups between August and December 2022. Transcripts were analyzed thematically.

Results: Patients from all Australian states and territories participated, with 22 (81%) having a functioning kidney transplant and 22 (81%) having current or previous experience of dialysis. Five themes were identified as follows: (i) surrendering to the health system, (ii) the complexity of quality, (iii) benefits for patient care and experience, (iv) concerned about risks and unintended consequences, and (v) optimizing the impact of data.

Conclusion: Patients desire choice among kidney services but perceive this as rarely possible in the Australian context. Health professionals are trusted to make decisions about appropriate centers. Public reporting of center outcomes may induce fear and a loss of balanced perspective; however, it was supported by all participants and represents an opportunity for self-advocacy and informed decision-making. Strategies to mitigate potential risks include availability of trusted clinicians and community members to aid in data interpretation, providing context about centers and patients, and framing statistics to promote positivity and hope.

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KEYWORDS: center outcomes; kidney disease; public reporting; qualitative research; quality indicators

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People requiring kidney replacement therapy (KRT) must weigh several decisions about treatment, potentially including choice of dialysis and/or transplant center. One aim of public reporting of quality indicators in healthcare is to inform and improve such decisions, helping consumers to select a service or

provider most likely to achieve a desired outcome.¹ Variations across quality indicators at dialysis and transplant centers exist due to differences in infrastructure, education programs, treatment regimens, and referral processes.² Provider factors such as qualification, experience, and communication skills may also affect patient experience and outcomes. Variation in these factors can therefore result in considerable consequences for patients, depending on which center they attend.

The impact of public reporting of healthcare quality indicator data on consumers' decision-making is unclear.^{3–5} Consumers may not be aware that this

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information exists, may be unable to access it, or the data reported may be different from patient priorities.^{4,6} Other barriers to public reporting influencing consumer decision-making include unclear presentation of data and low health literacy.¹ In kidney transplantation, patients desire increased ease of access to services, but often have limited knowledge about center options and trust providers to make referrals.^{7,8} A perception of limited or unreliable online information relevant to assessing the quality of kidney transplantation programs also inhibits patients from driving these decisions.⁷ In the Australian “public” healthcare system, as in other public health systems such as the UK and Canada, there is universal access for citizens to dialysis treatment. However, in Australia there is no right to choose either treating doctor or hospital location. People with private health insurance (about 40% of the population) managed in private hospitals can choose the provider and location of their treatment; however, only a small proportion of these offer dialysis, and many health insurance policies do not cover dialysis treatment. For people living in rural and remote areas, low population density regions and centralization of health services create logistical, financial, and psychological barriers, which further limit access to and choice of kidney care.^{9–11}

Research in kidney failure has focused on prioritization of quality indicators in specific areas such as primary care,¹² conservative management,¹³ and among critically ill (intensive care) patients requiring KRTs.¹⁴ There is little knowledge of patients’ views of quality indicator outcomes in dialysis and transplantation and public reporting of these, especially in contexts where service access and choice is limited.

The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) is a clinical quality registry that collects and reports quality indicator data of Australian and New Zealand dialysis and transplant centers. ANZDATA reports unit-specific results for quality assurance purposes and includes indicators such as dialysis and transplant patient survival in a publicly available report; however, how these are interpreted and used by audiences is not known.¹⁵ This study explored patients’ views of quality indicator outcomes in KRTs, including advantages, disadvantages, and impacts of knowing center performance on patients’ decision-making and care experience.

METHODS

This study is reported according to the Consolidated Criteria for Reporting Qualitative Research checklist (Supplementary Figure S1).¹⁶

Participants and Setting

Participants were recruited through kidney services and the investigators’ networks. Purposive sampling was applied to obtain a diversity of participant views and characteristics, including age, sex (self-reported), experience of KRTs, and residential location in Australia. Eligible participants were English-speaking people with lived experience of kidney disease of any stage, with or without experience of dialysis and kidney transplant. Potential participants were approached via e-mail or in-person by study investigators or clinical staff. SM and ED followed-up interested participants to provide study information, obtain consent, and arrange the focus groups. Ethical approval was received from the institutional ethics committee (HREC No. 16623). All participants provided written informed consent.

Data Collection

Participants completed a background questionnaire over the phone or Zoom with ED or SM. ED (female health psychologist with experience in conducting interviews and focus groups for qualitative health research), CED (male biostatistician), and SM (male researcher with lived experience of kidney disease) conducted 11 mini focus groups via Zoom (2–4 participants in each) between August and December 2022. Participants were made aware that the researchers were seeking to understand consumers’ perspectives regarding impacts of public reporting of kidney center outcomes, to inform reporting policy and dissemination strategies. Participants were informed of the interviewers’ occupations and any lived experience of kidney disease. Recruitment ceased at thematic saturation, when no new or additional themes were identified when coding transcripts. In focus groups, the facilitators explained background of ANZDATA, defined quality indicators, and presented a hypothetical center’s results for dialysis patient survival, transplant graft survival, access to transplantation, and peritonitis infection rates (Supplementary Figure S2). After each focus group, ED and SM or CED documented field notes of key issues discussed. Focus group questions were informed by the relevant literature regarding consumers’ healthcare service access and decision-making, and the investigators’ experience (including nephrologists, researchers, and consumers). A pilot focus group was conducted with 3 people with experience of kidney disease (EJ, ZT, and MH) to refine the question guide. Focus groups were audio recorded and transcribed verbatim.

Data Analysis

Descriptive statistics of participant characteristics were calculated as numbers and percentages.

Transcripts were imported into NVivo for thematic analysis.¹⁷ ED read transcripts line-by-line to inductively code the data, identifying key phrases and concepts relating to the research question, reviewing against field notes, and monitoring data saturation. Initial codes were grouped and collapsed into preliminary themes and subthemes and refined until agreed upon by ED, CED, SM, and SPM. All authors reviewed the preliminary findings, including theme descriptions and thematic schema. An audit trail documented iteration of themes and analytic decisions made. Member-checking occurred following the development of preliminary themes; all participants were provided with a summary, and their feedback was incorporated.

Consumer Involvement

SM, EJ, KM, MH, and ZT have lived experience of kidney disease and helped to inform the study, develop patient-facing documents and a participant information video, and participated in the pilot focus group. They gave feedback on the results summary provided to study participants as part of the member-checking process, reviewed the final analysis, and contributed to the manuscript.

RESULTS

Forty-four patients were invited to participate. Eleven did not reply or were unable to be contacted after expressing interest and 6 withdrew due to health or personal reasons. Twenty-seven patients from all Australian states and territories participated (Table 1) across 11 mini focus groups (2–4 participants in each). Twenty-two (81%) of the participants had a functioning kidney transplant, 2 (7%) were currently receiving hemodialysis, and 3 (11%) had kidney disease but had not commenced KRT. Twenty-two (81%) had current or previous experience of dialysis. Five (19%) participants had worked with ED or SM in consumer engagement activities previously, the remainder were not known to the researchers. Fifteen (56%) were not aware of ANZDATA prior to the study and 12 (44%) had been involved in ANZDATA research activities previously or learned of ANZDATA when using the internet to research kidney disease. Two participants recalled their nephrologist reviewing ANZDATA data with them. Focus groups lasted between 65 and 100 minutes (mean duration = 79 minutes).

Five themes and 12 subthemes were identified (Figure 1) representing patient perspectives of the reporting and use of center outcome data. In Table 2, we include illustrative quotations.

Table 1. Participant characteristics (*N* = 27)

Characteristic	<i>n</i> (%)
Sex	
Female	13 (48%)
Male	14 (52%)
Age group, y	
20–29	1 (4%)
30–39	4 (15%)
40–49	6 (22%)
50–59	4 (15%)
60–69	7 (26%)
70+	5 (19%)
Aboriginal/Torres Strait Islander	5 (19%)
Education	
Primary school	1 (4%)
Completed 10th grade	1 (4%)
Completed 11th grade	3 (11%)
Completed 12th grade	1 (4%)
Professional certificate	5 (19%)
University degree	16 (59%)
Employment status	
Not employed	2 (7%)
Full time	6 (22%)
Part-time or casual	10 (37%)
Studying	1 (4%)
Retired	8 (30%)
Current KRT	
Hemodialysis	2 (7%)
Kidney Transplant	22 (81%)
Nil (pre-KRT)	3 (11%)
Previous KRT experience	
Peritoneal Dialysis	9 (33%)
Hemodialysis	18 (67%)
Kidney Transplant (failed)	7 (26%)

KRT, kidney replacement therapy

Surrendering to the Health System Lack of Agency in Decision-Making

Participants perceived they had little to no choice in where they received KRTs in Australia. Some passively accepted this, recognizing that decisions were usually determined by service availability, nephrologists' affiliations and centers' distance from their home. Others expressed frustration and "a sense of injustice" (Participant 7) that they could not lead these decisions, particularly people from regional and remote areas, who described multiple barriers to accessing care. Many participants felt unable to choose or change their center.

Most participants received care at centers closest to home. Even where people requiring treatment had multiple center options, some were reluctant to incur greater travel times to attend a center with more favorable outcomes, aiming to minimize the burden of dialysis on their daily lives. A minority of patients had chosen between centers; those with private health insurance (who can public dialysis units but may choose to attend a private facility instead) or from regional

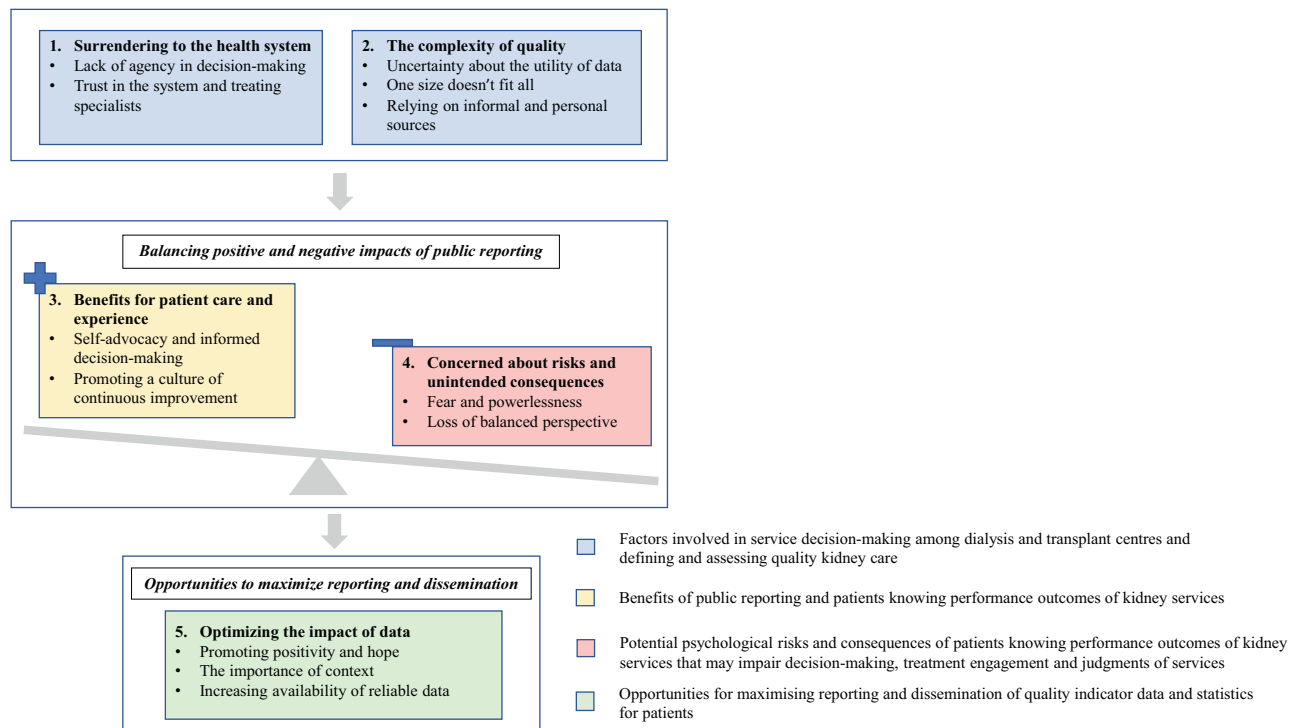


Figure 1. Thematic schema.

areas with 2 transplant centers similar distances from home. Their nephrologist's suggestions, existing relationships with centers, travel distance, and road conditions were equally important to centers' outcomes. One participant recalled reviewing ANZDATA's transplant center performance reports with their nephrologist and considering centers' results in decision-making.

Trust in the System and Treating Specialists

Participants described trusting the decisions and referrals made by primary care physicians and nephrologists, which determined the center they attended. Patients' long-term relationships with nephrologists and "an allegiance" (Participant 23) with care teams would likely take precedence over a center's performance. Younger patients were suspected to be more likely to question referrals and ask for centers' outcomes in making service decisions or requesting to change centers. Perceived seniority and size of transplanting hospitals also influenced patients' judgments of them; those that were larger, had been performing transplants for longer or publicly known as "a pioneer of transplants" (Participant 16) could be trusted more and perceived favorably.

The Complexity of Quality

Uncertainty About the Utility of Data

Quality indicator outcomes currently reported by ANZDATA were seen as relevant for clinicians and hospital administrators, but difficult for patients to

relate to. Those who felt their kidney disease was well-managed did not care to "know negative statistics, I'd rather stay in bliss or ignorance" (Participant 18). Similarly, patients who were satisfied with or had been receiving care at their center since childhood or adolescence were unlikely to be interested in performance data. Some participants described themselves as unequipped to interpret it. Hesitancy was expressed about if performance data would be helpful or a hindrance to patients about to commence dialysis, when people are unwell, adjusting to treatment and "switch to survival mode" (Participant 19).

Differing Priorities and Preferences

Participants acknowledged that quality healthcare was a complex issue, defined and assessed differently by different stakeholders. Clinicians may evaluate the success of treatments by clinical and laboratory measures, whereas participants valued patient-provider communication, availability of parking, choice in dialysis schedule, and center cleanliness in defining quality kidney care. These metrics were reported to be of greater interest to patients.

Preferences also varied for how quality indicator data may be presented and disseminated if made publicly available. Some participants desired to know performance of dialysis and transplant centers across Australia; however, the majority wanted to know comparable results for centers only in their state or close to their residence "in the patient's little world" (Participant 21).

Table 2. Illustrative quotes

Theme & sub-theme	Quote
1) Surrendering to the health system	
Lack of agency in decision-making	"There's not really a great deal of choice of where to go, you are sort of automatically categorized into one place." (Participant 6) "That's a bad statistic, but I don't know whether I would weigh up the inconvenience of having to go somewhere that was much further away. Might just take pot luck and hope for the best." (Participant 27) "Patients suffer under a variety of limitations and often have the choice made for them." (Participant 8)
Trust in the system and treating specialists	"Well, I'm in a long-term relationship with my nephrologist. So, it would be a very strange thing to do to actually make an assessment of the potential outcome based on a consumer's perspective rather than consider the relationship that I already have." (Participant 24) "It's often an allegiance to the renal team that you've been dealing with that guides the decision anyhow." (Participant 23)
2) The complexity of quality	
Uncertainty about the utility of data	"Having the data there available is great. It's just how we're going to use it. I'm not sure. I think it's great for researchers to improve outcomes and improve patient care and things like that. But I think we just have to be very careful of how we present data to consumers." (Participant 9) "I have no interest in researching kidney disease. I think partly because it's a denial thing. I'd rather think I was just as healthy as I feel. In some ways, I don't want to know negative statistics, I certainly don't want bad news. I'd rather stay in bliss, ignorance." (Participant 18) "I don't really know as a consumer, how I could respond to it. Especially as a consumer living in regional New South Wales who isn't like to move to Sydney or a metropolitan area, the lack of choice makes the data not so relevant to me." (Participant 8)
Differing priorities and preferences	"Quality is about being respected and being listened to. That's the most important thing I can pick up on because for me that's the most front facing-, patient facing place where I actually interact with healthcare." (Participant 3) "I think a measure of quality should be based on patient satisfaction, and I would read that." (Participant 16) "Start off with the whole group, then break it down by nationality. We want to know for Indigenous, because Indigenous health up here is a big issue." (Participant 20) "Different people like different things. I really like graphical data, but some people want to watch a video. If you're doing a video it's got to be short and clear." (Participant 2)
Relying on informal and personal sources	"I know I'm not like every patient, but I really used the word of mouth. As [participant] also said, talk to my peers at every service, at every appointment. I really like to gauge what type of quality of care is going on at that service." (Participant 13) "I knew I was going to see [nephrologist] because everybody else in my family had too." (Participant 12)
3) Benefits for patient care and experience	
Self-advocacy and informed decision-making	"It should be provided with really good information and clear pathways on how to deal with it [peritonitis infection], like a patient infographic that tells them a decision-tree type thing." (Participant 14) "Then I'd be asking the question 'Oh well how come that happened there and they got on the list in six months, but I had to wait. So yes, that information could still be helpful – why is my experience different?'" (Participant 20) "And then at least you can start that discussion or talk to them about the fact they're not doing as well on that statistic. You can ask 'Do you have any more information why this clinic looks better for me? Can either a referral to that one or that one be made?'" (Participant 26)
Promoting a culture of continuous improvement	"It's vital for dialysis centers to be aware of their performance. You're not necessarily going to want to move home or go to a place further away from where you live to obtain dialysis, so I don't think for a consumer, I'm not sure that that's something that is useful. But for the people carrying out the dialysis, absolutely vital." (Participant 18) "It's always scary for any institution to look at their failure rates, but when you open the door and have these discussions, there have to be benefits. Maybe those reports should be circulated within the centers including to patients and to the social workers and the nephrologists. And when people have questions about what's going on, it makes the environment more open, more forgiving, comforting is a great word, to the patients. It should be available." (Participant 8) "Why is the death rate higher? It should be addressed to find out why and if its publicly known to patients who are already in there receiving treatment, they need to be comforted to realize that its being addressed, rectified." (Participant 9)
4) Concerned about potential risks and unintended consequences	
Fear and powerlessness	"If I was making a decision between places where one carried a statistically significantly high risk for mortality, I think you may be ethically obligated to inform people of that risk, but then it also depends on what people can do about it. And if they don't have any choice in how to react, uh, or change their treatment center, then you may also be ethically obligated not to stress 'em out about something that's unchangeable. So pretty complex existential dilemma I think you're facing here." (Participant 3) "They're gonna see how many people died at that center and that's gonna be stuck in their mind. That fear will get the better of them." (Participant 20) "But on the flip side of that, when everyone's talking about that data and you letting patients know before they come onto dialysis, you can be frightening them too. They're going to go to a dialysis center and you might frighten the hell out them and they might not know what choice they're gonna have." (Participant 22)
Loss of balanced perspective	"I think it's good to know this where we have choice. I think I'd wanna know this, but how helpful it would be for people who don't really have choice. I don't know if that would help or hinder them, is that too much information when they actually don't have choice or control or any opportunity to choose?" (Participant 10) "I probably wouldn't put this on a poster on a wall. I guess depression and resignation are such a high factor of being on dialysis. This is something that could really just add to the burden of 'what's the point?'. It's always a possibility [death], anything could happen, but it's not something that I wanted to think about [survival rate]." (Participant 15)

(Continued on following page)

Table 2. (Continued) Illustrative quotes

Theme & sub-theme	Quote
	"The risk could be that I'd judge that center falsely. That's where you're sort of in dangerous territory, people won't look at it and go 'Oh yeah there's a reason behind it.' Most people just go, 'Well that means they're bad and they're not doing the right things', and that's not necessarily the truth." (Participant 11)
5) Optimizing the impact of data	
Promoting positivity and hope	"We don't want all the negative stuff. Sometimes we want some of the positive stuff and it might not be achievable or attainable, but sometimes in this disease, you really want some hope and sometimes data can give us a bit of hope. If there are some good scores or if there's good things possible, maybe that's information we wanna know. How far we could live, living rates rather than death rates. It's sometimes in how it's put." (Participant 11) "I'd rather flip it. I'd rather read '97% of people retain their kidney function after they received the transplant.' That's a better figure. You're focusing on the negative, focus on the positive. You want a 100% [not 0%]." (Participant 1)
The importance of context	"I think I'd want the cohorts broken down into ages. I think it clearly puts it more into context. Like technically when you read that, it's like the death rate is one and a half times higher, the national average at this center ... Like, does it matter that I'm probably a lot younger than a lot of the other patients or that I'm female or that I've been on for two years, what are these contributing factors and how am I gonna avoid being this one and a half times higher, is my thought. These pretty blanket statements, even though it is obviously statistically correct, for me reading it as a patient this would be overwhelming for me." (Participant 5) "It is good information and it's real, but it's sensitive. Are there secondary factors, is it diabetes? Is it heart disease? Are there other ailments to this death rather than just the fact that they're on dialysis?" (Participant 16)
Increasing availability of reliable data	"Whether it's the patient advocate or nurse practitioners or the transplant coordinator, whoever that advocate is that spends that time builds that rapport with patients. That's where I feel, especially for me, I'm more receptive to when I've got a rapport and I feel comfortable with someone and I genuinely feel like they're taking an interest and they care, the content is far more relatable." (Participant 5) "I think for someone that's just been newly diagnosed, I think it should be up to the renal team to at least point them in that direction. Because it's a minefield out there and you've been hit with this news that your kidney's failing. And then, all of a sudden you are looking through, whether it's Kidney Health Australia or Transplant Australia, and then it's also the American sites that you get onto as well." (Participant 11) "I think it would be useful for the, the people, the specialists and the practitioners to be able to direct us to relevant sites, um, to try to avoid some of the, the rubbish that you can get on the internet." (Participant 18)

Aboriginal participants desired results by patients' Indigenous status. Suggestions for communicating data to consumers included flyers and posters in dialysis units, infographic summaries, patient videos or a "dashboard page" (Participant 5), including location, characteristics, and outcomes of centers on patient organization websites such as Kidney Health Australia.

Relying on Informal and Personal Sources

Participants described evaluating services based on their interactions with kidney health professionals. Some had sought referrals to alternative nephrologists if they felt theirs was not knowledgeable, not forthcoming with education and information, or dismissive of the patient's concerns. "Word of mouth" (Participant 7) was relied upon to learn about services and individual providers, by talking to peers in clinic waiting rooms and friends or family members with kidney disease. Some had attempted to use the internet to find out about dialysis and transplant centers but could only find centers' locations.

Benefits for Patient Care and Experience

Self-advocacy and Informed Decision-Making

Participants reported that knowing the performance of their center relative to others in their state or territory, or nationally, could be a catalyst for self-advocacy. Data was an important conversation starter and could prompt change to improve a patient's access to and outcomes of treatment. If an individual's experience was different from the center's overall performance, they could initiate discussions with health professionals

and question, for example, why time taken to be placed on the transplant waiting list. This was viewed as a quality improvement opportunity, whereby clinicians listen to patients and reflect on and change practices and processes. For patients who desire detailed statistics and information about treatments, data informed decision-making and helped them to feel "like I'm not the only one with this disease" (Participant 13).

Data-sharing was also seen as an opportunity for education, making population-level data meaningful to an individual. For example, regarding outcomes of peritonitis infection and graft survival rates, patients suggested this information be paired with education about what patients can do to avoid infection or maintain their transplanted kidney.

Promoting a Culture of Continuous Improvement

Public reporting was supported by all participants and was thought to promote service accountability and transparency and encourage all services to strive to improve no matter their ranking in performance, for the betterment of patient outcomes. Important to accountability was public reporting leading to clear actions within services. Reporting without the change processes was considered pointless and an inefficient use of resources.

Concerned About Risks and Unintended Consequences

Fear and Powerlessness

Participants expressed concern about the potential psychological impacts of knowing that their center was

Table 3. Suggestions for public reporting and presentation of center performance data for patients

Domain	Suggestion
Promote hope and patient empowerment	- Communicate prognostic information, risks and treatment outcomes in a way that is realistic but framed positively, describing benefits of dialysis and transplantation (e.g. survival rate – the proportion of patients alive at a particular center after 1 year of starting dialysis, compared to the rest of Australia or at other centers and peritonitis infection – the length of time a proportion of patients received peritoneal dialysis without acquiring peritonitis infection) - Education about what patients can do to promote their kidney health should accompany statistics (for example, measures to minimize risk of peritonitis infection) - Where centers are identified as underperforming in a particular area, include information about quality improvement steps/actions in place to address this
Personalize communication of statistics	- Trusted kidney health professionals should ask patients how much they would like to know about center's performance outcomes - For people who want information, provide time to review data with the patient, contextualize data to the individual's situation and check for understanding
Minimize need for patient interpretation of data	- Avoid medical and statistical jargon - Provide definitions of terms and outcomes - Contextualize 'big data' to patient's individual circumstance, considered alongside other patient preferences and clinical factors - Engage trusted clinicians, community members or other patients to assist in the sharing and explanation of reports and center performance results – consider providing appropriate training and support for such intermediary people
Tailor statistical outputs and presentation methods	- Include consumers in the design of materials/outputs - Create multiple information sources for the presentation of data – flyers/pamphlets, posters, summarized versions of reports, one-page infographics, and brief videos

performing poorly. Fear and a sense of powerlessness may result if patients were unable to choose between or change centers, potentially leading some to avoid or withdraw from therapy if they knew they were receiving care “at a center with a bad name” (Participant 20). Patients also emphasized the importance of sensitive communication of statistics. Knowing a patients' center had a high patient death rate could contribute to feelings of depression and hopelessness. Aboriginal patients emphasized the importance of having trusted community members with experience of kidney disease share and explain this information to others, with support from clinicians.

Loss of Balanced Perspective

Trusted individuals such as transplantation coordinators, nephrologists, or community members were considered vital to assist patients' interpretation of performance data. Without this, participants were concerned that poor performance data could lead patients to disqualify a center or label them as “good or bad” based on one statistic and even assume they will die if attending a center with a high patient death rate. High performance could also result in disappointment if an individual patient's experience was different from this. Performance data could also potentially “overload” (Participant 2) patients, because many viewed it as information that they could not act upon in service decision-making.

Optimizing the Impact of Data

Promoting Positivity and Hope

Participants urged that statistical information be delivered clearly and sensitively, noting that “we are human beings at the other end of these things”

(Participant 5). Patients recalled receiving statistics from health professionals in the past that were ill-timed, irrelevant, or about patient death rates that were distressing and remained in their memory years later. Where consumers are the intended audience, participants expressed that reporting of statistics should promote a realistic yet positive message of living with kidney disease and benefits of dialysis and transplant. Careful consideration was needed to present data in an empowering way, including “wordsmithing and flipping it so it's not all doom and gloom” (Participant 13) and reporting patient-relevant outcomes. For example, participants suggested reporting the length of time patients receive peritoneal dialysis at a center without acquiring peritonitis infection rather than the infection rate.

The Importance of Context

To aid interpretation, participants desired details about centers' characteristics and the patient cohort to accompany analyses and results explanations, such as comorbidities, age, and socioeconomic status. Without these details, inaccurate opinions or unfair judgments of a center may result. Patients also questioned how their individual characteristics and comorbidities influence which center they attend and expected kidney health professionals to assist with this.

Increasing Availability of Reliable Data

Patients desired easier access to reliable statistics about kidney disease and KRTs and were cautious of many sources on the internet. They believed ANZDATA had potential to benefit patients, but that its profile should increase through patient organizations and nephrologists. Participants suggested a dashboard page with

centers' location, characteristics, outcomes, clinicians, and services offered. Nephrologists were considered integral to direct patients to reliable information sources and would be expected to assist with interpretation of statistics.

DISCUSSION

Public reporting of dialysis and transplant center outcomes represents an opportunity for patient empowerment and service improvement; however, it is not without ethical dilemmas. In the Australian healthcare system, there may be little or no choice in selecting treatment location. Many patients experience a lack of control over where they receive dialysis or kidney transplantation, limiting the extent to which quality indicator information can influence service choice. Therefore, there are potential unintended consequences of patients knowing a center's poor performance, including fear, perpetuation of inaccurate beliefs about centers, and even treatment disengagement. Conversely, benefits may include prompting discussions with clinicians to improve dialysis outcomes and access to transplantation and education about therapies. We suggest measures to maximize the impact of public reporting of center-specific information and balance associated potential risks and benefits (Table 3). These measures will require changes from organizations reporting center-specific information, and time with healthcare professionals to discuss this information with patients.

Our participants supported public reporting of center-specific information, but emphasized the position of "the public," or patients, must be carefully considered. The increasing burden of kidney failure and the substantial number of patients without access to treatment for the disease is well known.^{9-11,18} Some patients passively accept being referred to the closest center that has availability; however, others desire greater agency in determining where they receive care, based on factors that are important to them. This desire may lead to some tension in the current Australian context, where dialysis facilities are at capacity, choice is limited, and additional services are urgently required to meet growing demand. In other health systems where patients have greater ability to choose provider this tension may be less, although there are still likely to be various barriers to changing providers.

Our findings highlight the need for organizations to consider the potential impacts of knowing a centers' poor performance on patients. A patient knowing that their center carries a higher risk for infection or mortality compared to another, who does not have the ability to change centers, may experience distress and

information burden. We suggest the reporting of outcomes be altered to convey balanced, and positive messages of length and quality of life offered by dialysis and transplantation; for example, years of patient survival and time spent undergoing peritoneal dialysis without acquiring peritonitis. As suggested elsewhere,¹⁹ patients and patient organizations should be involved in creating such materials to ensure language and messages portrayed are relevant to and understood by patient audiences.

In addition to potential emotional impacts of public reporting, there are cognitive demands in processing comparative data. Attention needs to be paid to how this data is presented and how patients access it, to support interpretation and health-related decision-making. Suggestions to maximize information processing include the removal of confidence intervals, providing data interpretation summaries, and using features including colors and symbols.^{7,20,21} We suggest that additional data about centers and their patient cohorts be clearly explained alongside results to inform interpretations and judgements, such as centers' size, patient comorbidities, and socioeconomic status of the area. Adjusted outcomes with explanation of analysis may address this. Further research is needed to formally evaluate preferences for and comprehension of display options of comparative performance data among patients and how these may influence decisions about healthcare.¹⁹

Equally important to the content of public reports is their promotion and dissemination. Tailored approaches are needed, depending on the intended audience and objective of public reporting.¹ Nephrologists, nurses, or culturally appropriate staff may be the suitable professional to provide center outcomes to patients and contextualize it to their situation. Our findings also suggest that clinical quality registries such as ANZDATA should consider patient organization websites to host and promote reports. This source may also include general information about centers' size, location, and available kidney services to assist patients in accessing care if relocating or travelling. Targeting individuals or groups in dissemination strategies as "information intermediaries" is critical to reaching intended audiences.²¹ These should include people with lived experience of kidney disease in Indigenous communities or rural areas, to help with hands-on promotion and teaching of reports to patients. This has implications for clinical quality registries, hospital administrators, and kidney units to implement targeted distribution strategies and provide support and training for professionals or other patients, in understanding and sharing statistical information.

Quality outcomes in solid organ transplantation, including kidney transplantation, have generally focused on safety and efficacy of treatments and not patient-centeredness, patient-provider communication, or patient experience.^{8,22} Clear and timely communication, center cleanliness, transport, and patient satisfaction were important domains of quality care described by participants. Patient-reported outcome measures and patient-reported experience measures are gaining increasing attention to implement their routine collection into kidney registries and ensure effective and satisfactory care.^{23–27} A formal prioritization process is needed to select patient-important quality metrics and then develop and validate tools, to establish an integrated outcomes set that represents all stakeholders' priorities.

This study has limitations. Our sample consisted predominantly of patients already established with therapy, limiting real-time discussions about upcoming decisions of where patients may receive kidney care. Five participants were known to the focus group facilitators, which may have produced socially desirable responses; however, all participants were encouraged to respond honestly based on their own experiences. Participants were English speaking, and the majority were university educated. Focus groups were also conducted on Zoom, possibly limiting participants without access to internet or those with low technological literacy from participating. The study topic may have recruited individuals with high literacy and an interest in healthcare information, perhaps influencing the majority view of support for public reporting of center outcomes. This is of course not necessarily representative of all patients. Nevertheless, the participants represented all areas of Australia, including regional and remote, and all forms of KRT.

For patients who perceive little choice among dialysis or transplant centers, public reporting of center outcomes represents a challenge in balancing potential risks and benefits. Fear and disempowerment can be mitigated through tailored reporting and presentation approaches and engaging trusted individuals and organizations in sharing of results. There is important work to be pursued, including the development of patient-friendly reports, evaluation of data presentations that consider patients' psychological and informational needs, and collection of patient-important metrics in quality care.

DISCLOSURE

All the authors declared no competing interests.

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AUTHOR CONTRIBUTIONS

Research idea and study design was done by ED, CED, SM, EJ, MH, KM, ZT, NAG, and SPM. Data acquisition was done by ED, SM, and CED. Data analysis was conducted by ED, CED, SM, NAG, and SPM. Data interpretation and manuscript preparation was conducted by ED, CED, SM, EJ, KM, ZT, NAG, and SPM.

SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

Figure S1. Consolidated Criteria for Reporting Qualitative Research Checklist.

Figure S2. Focus Group Question Guide.

REFERENCES

1. Canaway R, Bismark M, Dunt D, Prang KH, Kelahe M. "What is meant by public?": stakeholder views on strengthening impacts of public reporting of hospital performance data. *Soc Sci Med*. 2018;202:143–150. <https://doi.org/10.1016/j.socscimed.2018.02.019>
2. Toussaint ND, McMahon LP, Dowling G, et al. Implementation of renal key performance indicators: promoting improved clinical practice. *Nephrol (Carlton, Vic)*. 2015;20: 184–193. <https://doi.org/10.1111/nep.12366>
3. Totten AM, Wagner J, Tiwari A, O'Haire C, Griffin J, Walker M. Closing the quality gap: revisiting the state of the science (vol. 5: public reporting as a quality improvement strategy). *Evid Rep Technol Assess (Full Rep)*. 2012;5:1–646.
4. Victoor A, Delnoij DMJ, Friele RD, Rademakers JJ. Determinants of patient choice of healthcare providers: a scoping review. *BMC Health Serv Res*. 2012;12:272. <https://doi.org/10.1186/1472-6963-12-272>
5. Fung CH, Lim Y-W, Mattke S, Damberg C, Shekelle PG. Systematic review: the evidence that publishing patient care performance data improves quality of care. *Ann Intern Med*. 2008;148:111–123. <https://doi.org/10.7326/0003-4819-148-2-200801150-00006>
6. Emmert M, Schlesinger M. Patients' awareness, usage and impact of hospital report cards in the US. *Patient*. 2017;10: 729–738. <https://doi.org/10.1007/s40271-017-0243-y>
7. Schaffhausen CR, Bruin MJ, McKinney WT, et al. How patients choose kidney transplant centres: a qualitative study of patient experiences. *Clin Transplant*. 2019;33:e13523. <https://doi.org/10.1111/ctr.13523>
8. Brett KE, Ertel E, Grimshaw J, Knoll GA. Perspectives on quality of care in kidney transplantation: a semistructured

- interview study. *Transplant Direct*. 2018;4:e383–e383. <https://doi.org/10.1097/TXD.0000000000000820>
9. Scholes-Robertson N, Talia G, Howell M, et al. Clinicians' perspectives on equity of access to dialysis and kidney transplantation for rural people in Australia: a semistructured interview study. *BMJ Open*. 2022;12:e.052315. <https://doi.org/10.1136/bmjopen-2021-052315>
 10. Scholes-Robertson N, Gutman T, Dominello A, et al. Australian rural caregivers' experiences in supporting patients with kidney failure to access dialysis and kidney transplantation: a qualitative study. *Am J Kidney Dis*. 2022;80:773–782.e1. <https://doi.org/10.1053/j.ajkd.2022.05.015>
 11. Scholes-Robertson N, Gutman T, Howell M, Craig JC, Chalmers R, Tong A. Patients' perspectives on access to dialysis and kidney transplantation in rural communities in Australia. *Kidney Int Rep*. 2022;7:591–600. <https://doi.org/10.1016/j.ekir.2021.11.010>
 12. Van den Bulck SA, Vankrunkelsven P, Goderis G, et al. Developing quality indicators for Chronic Kidney Disease in primary care, extractable from the Electronic Medical Record. A rand-modified Delphi method. *BMC Nephrol*. 2020;21:161–161. <https://doi.org/10.1186/s12882-020-01788-8>
 13. Harrison TG, Tam-Tham H, Hemmelgarn BR, James MT, Sinnarajah A, Thomas CM. Identification and prioritization of quality indicators for conservative kidney management. *Am J Kidney Dis*. 2019;73:174–183. <https://doi.org/10.1053/j.ajkd.2018.08.014>
 14. Rewa OG, Villeneuve P-M, Lachance P, et al. Quality indicators of continuous renal replacement therapy (CRRT) care in critically ill patients: a systematic review. *Intensive Care Med*. 2016;43:750–763. <https://doi.org/10.1007/s00134-016-4579-x>
 15. McDonald SP, Russ GR. Australian registries—ANZDATA and ANZOD. *Transplant Rev (Philadelphia, PA)*. 2013;27:46–49. <https://doi.org/10.1016/j.trre.2013.01.003>
 16. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–357. <https://doi.org/10.1093/intqhc/mzm042>
 17. Braun V, Clarke V. *Thematic Analysis : a Practical Guide*. SAGE Publications Ltd; 2022.
 18. Liyanage TM, Ninomiya TP, Jha VP, et al. Worldwide access to treatment for end-stage kidney disease: a systematic review. *Lancet*. 2015;385:1975–1982. [https://doi.org/10.1016/S0140-6736\(14\)61601-9](https://doi.org/10.1016/S0140-6736(14)61601-9)
 19. Damberg CL, McNamara P. Postscript: research agenda to guide the next generation of public reports for consumers. *Med Care Res Rev*. 2014;71(5) (suppl):97S–107S. <https://doi.org/10.1177/1077558714535982>
 20. Hibbard J, Sofaer S. Best Practices in Public Reporting No. 1: how to effectively present health care performance data to consumers. Published 2010. Accessed March 3, 2023. <https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/public-reporting/report-1-public-reporting.pdf>
 21. Sofaer S, Hibbard J. Best Practices in Public Reporting No. 3: how to maximise public awareness and use of comparative quality reports through effective promotion and dissemination strategies. Published 2010. Accessed March 13, 2023. <https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/public-reporting/report-3-public-reporting.pdf>
 22. Brett KE, Ritchie LJ, Ertel E, Bennett A, Knoll GA. Quality metrics in solid organ transplantation: a systematic review. *Transplantation*. 2018;102:e308–e330. <https://doi.org/10.1097/TP.0000000000002149>
 23. Morton RL, Lioufas N, Dansie K, et al. Use of patient-reported outcome measures and patient-reported experience measures in renal units in Australia and New Zealand: a cross-sectional survey study. *Nephrol (Carlton, Vic)*. 2020;25:14–21. <https://doi.org/10.1111/nep.13577>
 24. Aiyegbusi OL, Kyte D, Cockwell P, Anderson N, Calvert M. A patient-centred approach to measuring quality in kidney care: patient-reported outcome measures and patient-reported experience measures. *Curr Opin Nephrol Hypertens*. 2017;26:442–449. <https://doi.org/10.1097/MNH.0000000000000357>
 25. Field M, Tullett K, Khawaja A, Jones R, Inston NG. Quality improvement in vascular access: the role of patient-reported outcome measures. *J Vasc Access*. 2020;21:19–25. <https://doi.org/10.1177/1129729819845624>
 26. Parra E, Arenas MD, Fernandez-Reyes Luis MJ, et al. Evaluation of dialysis centres: values and criteria of the stakeholders. *BMC Health Serv Res*. 2020;20:297–297. <https://doi.org/10.1186/s12913-020-05085-w>
 27. Breckenridge K, Bekker HL, Gibbons E, et al. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant*. 2015;30:1605–1614. <https://doi.org/10.1093/ndt/gfv209>