Supporting equitable access to kidney transplant in remote Western Australia using continuous quality improvement

Contributorship

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Header:

Kimberley Kidney Transplant

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Abstract

Background

Despite an epidemic of End-Stage Kidney Disease in the Australian Aboriginal and Torres Strait Islander population, disparities in access to kidney transplantation persist. The journey to successful kidney transplant is long, with an initial suitability assessment required before waitlist-specific activities begin. In an Aboriginal Community Controlled renal service, we aimed to:

1.) Design and implement a continuous quality improvement (CQI) approach to transplant suitability assessment

2.) Provide transplant suitability assessments for all patients of the service

3.) Describe what temporary contraindications to kidney transplantation should be the focus of health service improvements

4.) Explore participant experiences with the suitability assessment process and:

5.) Use our findings to inform pre-and post-transplant model of care development within Kimberley Renal Services

Methods

Mixed methods design with file review. Transplant suitability assessment results with descriptive analysis, semi-structured interview with thematic analysis.

Results:

Of completed assessments, 20/66 (30%) had no contraindications and were cleared for workup with median time on dialysis prior to assessment of 2.9 years, 42/66 (64%) had temporary contraindications, and 4/66 (6%) had permanent contraindications. Eighty-five temporary contraindications were identified in 46 individuals: 17/46 had both medical and non-medical contraindications, 5/46 had medical contraindications only, and 24/46 had non-medical contraindications only. The most common temporary contraindications were smoking (23/46), treatment adherence (17/46) and high body mass index (BMI) (11/46). Patients wanted more information on the transplant process, and interviewers noted the importance of providing information in an appropriate way. Patients wanted more support to address modifiable health risk factors to improve their chances of future transplantation

Conclusions:

In the first stages of our CQI approach to improving access to kidney transplants for Kimberley Aboriginal people we achieved substantial catch-up in suitability assessments, and a comprehensive summary of factors impacting successful waitlisting. Our results are consistent with, and build upon other work in this space, highlighting the importance of involving Aboriginal staff and patients in education and support for prospective recipients.

Keywords:

Aboriginal health, kidney transplant, renal, equity, CQI

Introduction

An epidemic of end-stage kidney disease (ESKD) has been observed amongst Aboriginal and Torres Strait Islander peoples in remote areas of Australia. Rates of renal replacement therapy (RRT) use is 8 – 9 times higher and ESKD occurs on average about 30 years earlier (1). Given the existing burden of early chronic kidney disease (1), and risk factors for progressive disease (2), effective and culturally safe renal care(3) for Aboriginal and Torres Strait Islander people will need to be a health services priority for years to come.

For many patients across remote Australia accessing haemodialysis entails forced relocation from family and Country with negative impacts on physical and mental health (4). Kidney transplants can help some patients return to their preferred place of residence with a better quality of life and increased life expectancy (5, 6). In the Kimberley region, as in the rest of the country, Aboriginal and Torres Strait Islander patients experience more delays in care that impact on access to transplantation (7, 8). As a result, the percentage of First Nations people with kidney failure who receive a transplant is very low relative to the number receiving dialysis (9). Access to the waitlist itself presents the main barrier to transplantation for Aboriginal people, rather than access to a transplant once waitlisted (10).

The journey to successful transplant is long, and the root causes of access inequity are complex and multifactorial. Before a patient even begins waitlist-specific activities, many factors are considered

by the treating nephrologist to determine whether a patient is a suitable candidate (10). In Australia, only patients who have commenced dialysis are eligible to be listed to receive a deceased donor kidney transplant. Exclusion criteria for kidney transplantation are further outlined in the Transplantation Society of Australia and New Zealand (TSANZ) guidelines (11), however, the risks and benefits of transplantation are considered on an individual basis by the practitioners involved in their care. Aboriginal and Torres Strait Islander patients on RRT have higher rates of medical comorbidities, which may impact suitability, however data have suggested that this does not fully explain the transplant equity gap (12). Other factors considered include those known to increase the likelihood of complications in transplant outcomes (such as smoking or obesity) and those associated with a risk of "non-adherence to complex medical management" such as limited social support, missed medications or missed dialysis sessions.

The National Indigenous Kidney Transplant Taskforce (NIKTT) was established in 2019 by the Commonwealth of Australia Department of Health to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander people. The Taskforce recommended the development of programs to facilitate better access to transplantation, with a particular focus on improving the health of Aboriginal and Torres Strait Islander people so they can be waitlisted (13). Kimberley Renal Services (KRS) is an Aboriginal Community Controlled renal service that provides pre- and post-transplant support to Aboriginal people. This report describes the first results of a real-world, continuous quality improvement (CQI) project aiming to ensure all patients were formally assessed for transplant suitability, in line with the recommendations made by the NIKTT(14) and the National Strategic Action Plan for Kidney Disease(15).

Methods

Setting

The Kimberley region of Western Australia is remote with a large Aboriginal population (2021: 14 408 people, 41% of the total population) (16). Kimberley Renal Services (KRS) provides Aboriginal Community Controlled renal services at four rural and remote sites with 165 satellite haemodialysis positions as of February 2024. The dialysis population in the Kimberley is young, with 78% of patients aged under 65 years compared to 48% in the Australian dialysis population (9). Medical care for dialysis patients is provided in partnership between the visiting nephrology team, local nurses, and general practitioners. Nephrology and transplant services are coordinated from the state capital, more than 2000 km away. The KRS transplant coordinator provides pre- and post-transplant care coordination and delivery of patient education sessions. Education is offered to prospective future transplant candidates. Content is tailored to need and delivered both individually, and in group sessions.

Continuous Quality Improvement (CQI) design:

A plan-do-study-act (PDSA)(17) approach was taken to the design of the CQI program (Figure 1), with the long-term target of achieving transplant suitability assessment for 100% of KRS renal replacement therapy patients within 6 months of their admission to the service and 80% of patients up to date with reassessment as indicated. The PDSA approach was selected due to a history of successful use in the Aboriginal Community Controlled Health Sector, as described in the National Framework for Continuous Quality Improvement in Primary Health Care for Aboriginal and Torres Strait Islander People 2018-2023(18).

At the beginning of the project, the only formal mechanism for recording transplant suitability was via the Australia and New Zealand Dialysis and Transplant (ANZDATA) registry: the "ANZDATA reported status" (19). This reporting activity, which is undertaken annually for all patients

undergoing renal replacement therapy, did not include a systematic assessment or provide recommendations for patient or provider actions to improve suitability. To achieve our target, and to maintain our results over time, we have identified and incorporated into our design the need to:

- Develop, pilot and refine a transplant suitability assessment tool;
- Develop, pilot and refine a tool for reporting against our CQI target;
- Integrate the above into the electronic medical record system used for clinical service delivery (MMEx, ISA technologies).

Participants

Patients were eligible for inclusion in the study if they were an Aboriginal and / or Torres Strait Islander person receiving RRT in the Kimberley region. New patients were added to the list throughout the study on admission. Patients were excluded if they were non-Indigenous, had previously declined transplant workup after a full discussion with the treating nephrologist, had documented permanent contraindications to transplant, were in residential aged care, had an advanced care plan inconsistent with undergoing major surgery or were already waitlisted. Inclusion of suitability assessment data is restricted to eligible patients who provided individual informed consent.

Health staff involved in the CQI elements of this study include nephrologists employed with the visiting specialist services (n = 3), general practitioners employed with KRS who had been caring for haemodialysis patients for many years (n = 2), the KRS transplant coordinator (a registered nurse) and KRS educators and support staff (Aboriginal health workers and non-clinical care co-ordinators) (n = 5). Those health staff completing aspects of the CQI process were those involved in the usual transplant suitability assessment pathways for the patients as per the real-world design of the study.

Data collection and analysis

Transplant suitability

Prior to study commencement there was no transplant suitability assessment tool available at KRS or via the visiting nephrology service. A tool was developed with reference to Australian guidelines (TSANZ(11), CARI(20)) and international guidelines (KDIGO)(21), and with input from the tertiary nephrology service, after a scoping review failed to identify any similar tools in the public domain (Table 1). This was piloted and refined prior to use with consenting patients.

The tool was filled in by the KRS transplant coordinator and KRS general practitioners for all consenting patients, summarising medical history and health risk factors. It was finalised by a visiting nephrologist at the time of their three-monthly face-to-face assessment of the patient. The completing nephrologist was asked to identify any contraindications to transplant workup progression, assign a suitability status and review interval. A contraindication was defined as anything that prevented the nephrologist recommending the patient commence transplant workup. If contraindications to transplant were identified it was noted whether they were permanent (“red” status - without capacity for improvement, review on request only) or temporary (“orange” status – temporary contraindications identified, for later review). If no contraindications to commencement of work-up were identified they were assigned a “green” status.

Time on dialysis was calculated from commencement of any dialysis modality to the day of transplant suitability assessment. Difference in age and time on dialysis between suitability status groups was analysed by a Mann-Whitney test (given not meeting criteria for normality), significance level at p = 0.05. Descriptive quantitative analysis was then performed with data cleaning in Microsoft Excel (©Microsoft Corporation) before analysis in Stata (Release 18, ©Statacorp).

Patient feedback

Consenting patients were given the opportunity to provide feedback on the project via a short, semi-structured interview (Table 1 – interview guide). Interviews were conducted after suitability assessments were complete. All interviews were conducted by KRS staff members (n = 5) who were either Aboriginal or had lived experience of the transplant journey. Thematic analysis of semi-structured interview results was conducted inclusive of research staff (n = 2) and interviewers. Where interview staff consented for their quotes to be included, they are presented verbatim in the results section (Interviewer feedback).

Other related project activities

Transplantation education was delivered to 37 patients during the study period. Concurrent to this project, an outreach assessment clinic project funded by the NIKTT provided three one-week visits of specialist clinical outreach to the region that provided additional specialist nephrology access for components of this project (22). Transplant surgeons and specialised transplant nurses also attended outreach trips.

Results

Suitability status assessments

One hundred and seventy-six patients were considered for inclusion. Seventeen were non-Indigenous, one already waitlisted, and sixteen were excluded (Figure 2), leaving 142 eligible patients.

Seventy-nine patients consented to participate, of which 31 had previously had an ANZDATA reported suitability status. A total of 66 participants completed suitability assessments between January 2021 and January 2022, with 16 participant interviews completed between May and September 2022 (Table 2). Participants came from fourteen different communities from across the Kimberley. Median age was 53.7 (IQR 48.3 – 57.8) and twenty-eight (42%) were male. Median time on dialysis was 4.3 years (IQR 2.0 – 8.2).

The most common medical comorbidity was diabetes (51/66 patients (83%), 30 of whom had extra-renal microvascular complications), followed by cardiovascular disease (34/66, (52%)), chronic infections (15/66, (23%)) and frailty (8/66, (12%)). The most common infectious comorbidity noted was diabetic foot disease with or without osteomyelitis (9/15).

When assessed, 20/66 patients (30%) had no contraindications and were cleared for workup, 42/66 (64%) had temporary contraindications, and 4/66 (6%) had permanent contraindications. There was no statistically significant difference in median age (53 vs 55 years, p = 0.72) or time on dialysis (4.7 years vs 2.9 years, p = 0.15) between those with, or without contraindications. Of the 20 people without identified contraindication to workup, eight had been on dialysis for more than five years, with the longest time being 9.4 years.

Eighty-five temporary contraindications were identified in 46 individuals: 17/46 patients had both medical and non-medical contraindications, 5/46 had medical contraindications only, and 24/46 had non-medical contraindications only. The most common temporary contraindications were smoking (23/46 patients), treatment adherence (17/46) and high body mass index (BMI) (11/46). Only four had permanent contraindications including frailty, and cardiac disease.

Patient feedback

Sixteen patients (62.5% female, median age 51 years (IQR 56 – 63)) provided feedback on their experiences with kidney transplant suitability assessment and workup.

People wanted more information

Participants wanted to know more about the transplant process, especially those who had not attended an education session. They wanted more time with the transplant coordinator and more follow-up from the transplant team. People wanted more positive talk about transplant processes to come from their dialysis service, lists of what needed to be done, and where to get support:

> *"They need to let us know how it works. We need to know… how it work and go about it" (Participant 2).*

Always waiting or forgotten

Patients felt they were always waiting to hear back about their progress. One patient remembered overhearing the doctors discussing transplant with other patients, but not them, which made them feel left out. Several patients expressed having no idea what was happening to them, or not being informed about their care.

> *"… waiting nine years to hear. I didn't know that I wasn't on the waitlist automatically but you are not, you have to go through the process (Participant 7).*

Knowing what, but not how to make changes

Some patients were aware of changes they needed to make to improve their suitability for transplant but found these difficult to action. Several said they needed more support but weren't sure where this could come from. Positive talk, yarning circles and education sessions at dialysis, as well as changes to the home environment to promote health were identified as helpful. More generally, activities that distracted from boredom and facilitated connection to Country were desired.

> *"At this time… the hardest thing for me to do is quit smoking" (Participant 6).*

Interviewer feedback

Interviewers emphasized the great interest from patients in receiving information on the transplant process and the need to deliver it in an appropriate way: consistently and using different modalities such as visual examples. The side effects of dialysis could make patients forgetful (*"dialysis brain", (Patient Care Assistant))* and patients needed to hear things more than once.

> *"It's life-changing… and they need the information in a way they understand … break it down real simple" (Aboriginal Care Coordinator).*

Interviewers noted that Aboriginal involvement was needed throughout, from first assessment of suitability through to assistance navigating the tertiary health system, which scared many of the patients. They described challenges some patients faced balancing health care appointments with other family and cultural commitments:

> *"It's not always the patient's fault… a lot of people have family commitments, they might be waiting and waiting [at their primary care service] … but then they have their granddaughter or daughter with grandkids and they need a hand" (Patient Care Assistant).*

Interviewers recommended regular contact between patients and the transplant support team: *"Just checking in, everyone wants to be checked in on" (Patient Care Assistant).* For those who were displaced from their home Country to access dialysis services, return to Country was a strong motivator, and interview staff identified this as key to supporting positive change: *"once they get home their minds are going to change" (Aboriginal Care Coordinator).*

Discussion

Statement of principal findings

In this article we present the efforts of an Aboriginal Community Controlled Health Service to advance equitable access to transplant suitability assessment. Timely assessment is an important issue for patients of this service: many had spent years without being properly assessed, consistent with the longer median time to transplant experienced by Aboriginal people (23).

A CQI approach achieved a substantial increase in the proportion of patients assessed. The systematic approach to assessment comprehensively identified where actions could be taken to improve their chances of future transplantation, unlike previous approaches to assessment that were driven more by reporting requirements. Future development of the CQI process now requires development of the electronic medical record system to facilitate data entry and real-time reporting.

We described medical comorbidities and contraindications to transplantation in our study group, with the aim of informing health service improvements. As predicted, diabetic nephropathy as a cause of ESKD was more common in our population. Diabetic foot disease was the most common chronic infection identified as a possible concern for transplant, highlighting the importance of podiatry input for ESKD patients on dialysis. Most contraindications preventing commencement of transplant workup were, however, not medical comorbidities, but health risk factors such as smoking, treatment adherence and high BMI. Patients wanted more information on the transplant process, and interviewers noted the importance of providing information in an appropriate way. Feedback from patients and interviewers in this study affirms that any model of care aiming to achieve equitable access to kidney transplant must promote and support effective communication between patient and provider on the background of a trusted relationship.

Strengths and limitations

The strengths of this study were the close integration of the research and clinical teams, the CQI based approach, and a relatively large sample size from a majority Aboriginal patient population. We encountered some challenges in implementing our project. In part due to COVID-19 travel restrictions, half our patients were either not able to be consulted for informed consult or were incompletely assessed (Figure 2), limiting our capacity to present whole-of-service results. Our results are based on the medical information known at the time of patient review – as a patient progresses through transplant work-up, investigations may reveal other contraindications to transplant, and those are not captured here. Our participants were exclusively rural and remote living Aboriginal and / or Torres Strait Islanders, and we would not assume the pattern of suitability or contraindications to be generalisable to other populations. However, the process of transplant suitability assessment could be usefully shared with other centres and adapted to their needs.

Interpretation within the context of the wider literature

The most common contraindications to transplant identified in this study are usually considered modifiable, but without sufficient support change can be hard to achieve. Weight loss is especially difficult to achieve on dialysis. In one study specifically aiming to support weight loss for kidney transplantation, multidisciplinary support without bariatric surgery achieved low rates of waitlisting at 12 months (24). In addition, although overweight is associated with worse outcomes after transplantation, weight loss is also associated with mortality (25), and the evidence to guide safe and effective weight loss for dialysis patients is limited (26).

Appropriate delivery of transplant related education and information was a priority for patients. Effective delivery of these services requires implementation of culturally safe kidney care

recommendations that have been developed in partnership with Aboriginal and Torres Strait Islander people(27) (4, 27, 28). Principles of cultural safety in renal service delivery have been proposed based on a growing body of literature that increasingly prioritises Aboriginal voices(29): in summary: self-reflection, communication, minimisation of power-differential, decolonisation and ensuring individuals are not diminished, demeaned or disempowered. The role of patient navigators in enabling patients to more successfully understand and manage their transplant journey has been demonstrated in recent pilot studies(30, 31), which provide useful frameworks for further development. Additionally, when patients who have received a kidney transplant are included in education delivery as "peer educators", their lived experience can help ensure education content is relevant and culturally appropriate. That lived experience is of particular benefit given the fear many patients feel when anticipating the major surgery required for a transplant(32).

Implications for policy, practice and research

The next phase of this project will focus on implementing required changes to workflow, workforce and the electronic medical record system. Principles of cultural safety will inform ongoing improvements in renal service delivery, including education and support both before and after a kidney transplant. More evidence is required to guide individual goal setting for potential transplant recipients advised to lose weight for surgery, and programs to safely support physical activity and fitness are needed. Pre- and post-transplant outcomes must continue to be monitored transparently with successful initiatives appropriately supported and resourced.

Conclusion

In the first stages of our CQI approach to improving access to kidney transplants for Kimberley Aboriginal people we achieved substantial catch-up in suitability assessments and a comprehensive summary of factors impacting successful waitlisting for our patients. New reporting systems currently in design will provide the infrastructure needed for regular CQI cycles to monitor activity. These results are consistent with and build upon other works in this space, including those highlighting the importance of involving Aboriginal staff and patients in education and support for prospective kidney transplant recipients.

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Figure 1: Continuous Quality Improvement framework for transplant suitability assessment

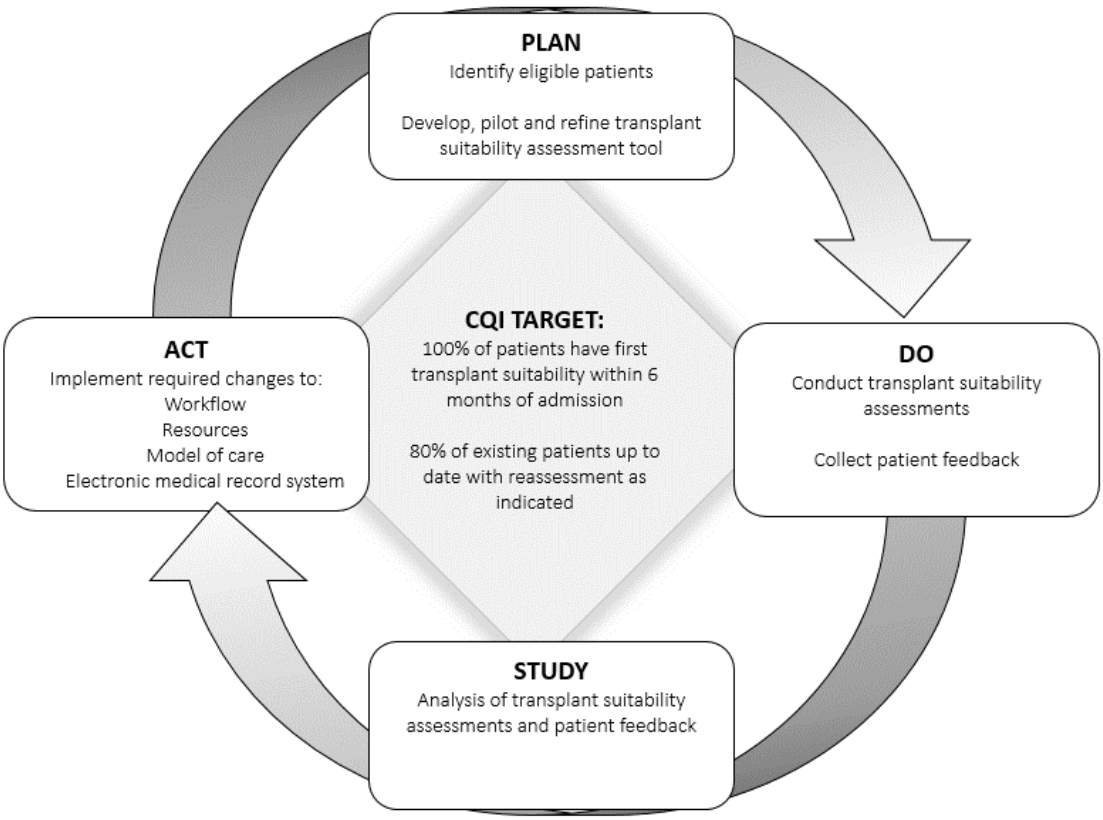

Figure 2: Inclusion and exclusion criteria, with assessment outcome for included patients

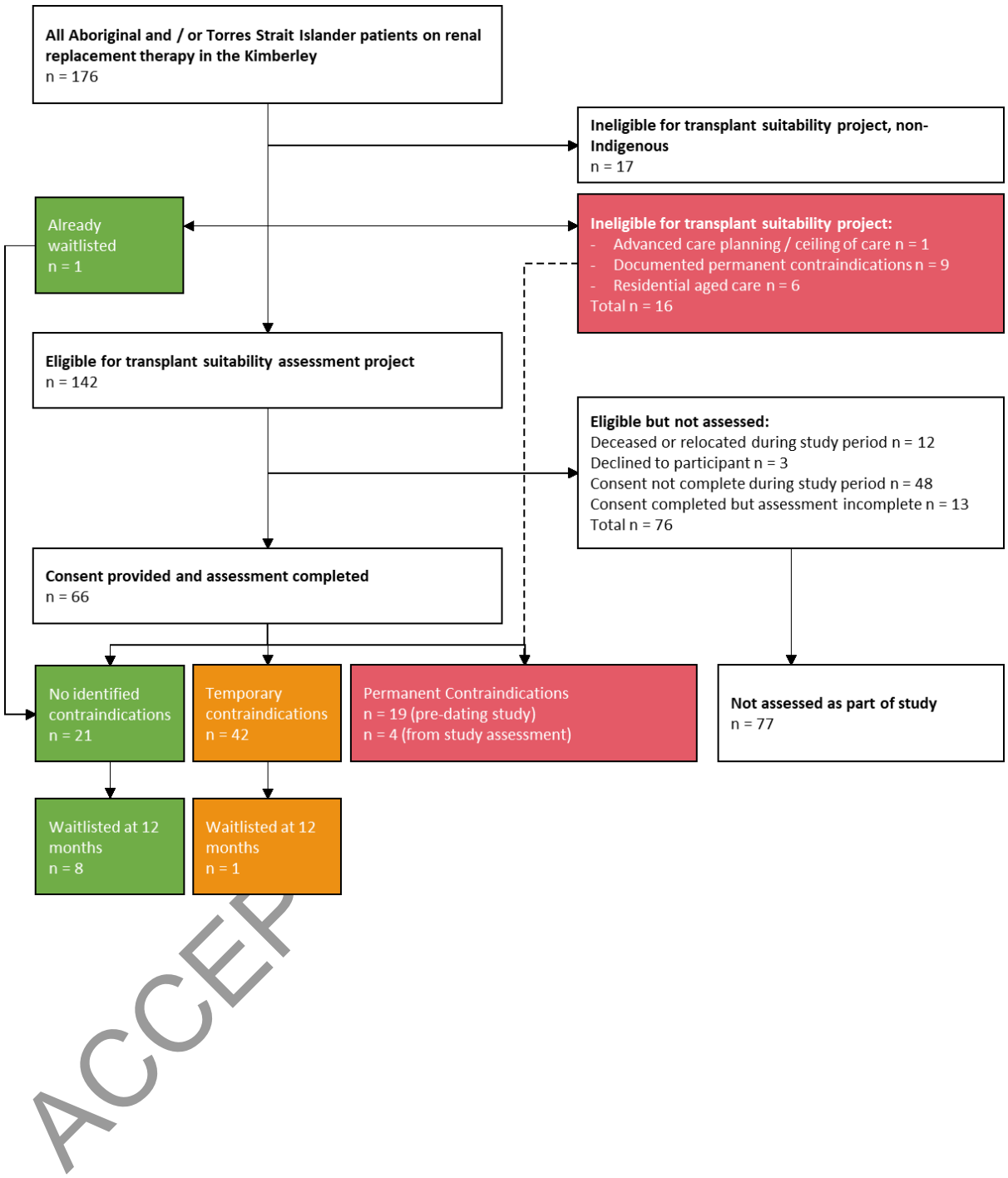

Table 1: Data collection tools: KRS transplant suitability assessment tool and interviewer guide

SECTION	CONTENT	
Transplant suitability assessment		
Cardiac and peripheral vascular disease	History and investigation results	
Malignancy	History and investigation results	
Infection	History and investigation results	
Metabolic	Diabetes: Y/N; type of diabetes; complications; glycaemic control BMI	
Comorbidities	Respiratory / Gastrointestinal / Neurological / Musculoskeletal / Frailty / Other	
Non-medical factors	Substance use: • Current smoker Y/N • Heavy alcohol use Y/N • Illicit drug use Y/N Social supports: Carer identified Y/N Treatment adherence: • Missed dialysis sessions last three months: • Reasons for missed sessions: • Other treatment concerns: Patient interest in transplant: Y/N; Details;	
Contraindications	For any condition identified above: Contraindications: Yes / No, permanent or temporary	
Suitability status	**GREEN:** No contraindication identified, commence work-up **ORANGE:** Temporary contraindication, review at (months): 3 /6 / other **RED**: Permanent contraindication, review only as indicated	
Patient feedback: semi-structured interview guide		
Has anyone ever talked to you about how it works to get a renal transplant / new kidney?		Yes / No / Don't know; Patient comments;
Have you ever been to a group education / yarning session about getting a renal transplant / new kidney?		Yes / No / Don't know; Patient comments;
Are you interested in getting a renal transplant / new kidney?		Yes / No / Don't know; Patient comments;
Do you know whether you are suitable / can have workup for transplant?		Yes / No / Don't know; Patient comments;
Do you know if there is anything you need to change / work on before you can get a renal transplant / new kidney?		Yes / No / Don't know; Patient comments; If Yes: How is it going with [the things the patient is working on]? If DIFFICULT / HAVING PROBLEMS: How can we help you / what would help you with [the things the patient is working on]?
Do you have any other feedback / comments / things to say about the process for getting a renal transplant / new		Patient comments:

kidney?	

Table 2: Participant details:

	n	%
Age at assessment:		
15-24	2	3
25-34	2	3
35-44	8	12
45-54	26	40
55-64	22	33
>=65	6	9
Time on dialysis		
< 1 year	9	14
1 – 2	7	10
2 – 3	9	14
3 – 4	4	6
4 – 5	8	12
>5	29	44
Cause of ESKD		
Diabetic nephropathy	47	71
Hypertensive nephropathy	6	9
FSGS	2	3
Glomerulonephritis	2	3
IgA nephropathy	2	3
Unknown	2	3
Other*	5	8
Suitability status**		
Green (no contraindication identified)	20	30
Orange (temporary contraindication/s identified)	42	64
Red (permanent contraindication/s identified)	4	6
TOTAL	66	100

*Includes congenital and obstructive uropathies, reflex nephropathy and SLE

End-matter: Supporting equitable access to kidney transplant in remote Western Australia using continuous quality improvement

Ethical considerations and consent

A process of informed consent was followed. This project was approved by the Kimberley Aboriginal Health Planning Forum (KAHPF) after receiving letters of support from all Kimberley Aboriginal Community Controlled Health Organisations. Ethics approval was granted by the Western Australian Aboriginal Health Ethics Committee (WAAHEC). Aboriginal staff members were consulted on the suitability of language used in the patient feedback survey and it was revised accordingly. All surveys were administered with at least one Aboriginal staff member present, and these staff members were invited to provide their input into the interpretation of results.

Funding

No funding was allocated specifically for the CQI activities outlined in this manuscript. The National Indigenous Kidney Transplant Taskforce (NIKTT) funded three weeklong outreach clinics to the region during the study period which provided additional availability for the nephrologist to assess patients. Kimberley Renal Services was not the administrator of this grant but did receive some time-limited funds towards the KRS transplant coordinator position (see manuscript references, 17).

Conflict of interests

FS, NC, JS, SC, JB and EG were employees of Kimberley Renal Services during the study period and provided clinical and / or support care to the participants. KP was employed by Royal Perth Hospital visiting the region and provided clinical nephrology services.

Acknowledgements

Johan Rosman (data collection)[2], David Atkinson (project development)[3], Julia Marley (project development)[3], Cohen Dean[1] (data collection and analysis), Sarah Coombes[1] (data collection and analysis).

Data availability statement

In deference to principles of Indigenous Data Sovereignty, access to the data collected as part of this project is available only through processes owned by the Aboriginal Community Controlled Health Services that supported this project. Requests for data access can be directed to the corresponding author.