

# Review of current pathways to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander peoples with end-stage kidney disease in the Top End of Northern Australia

Sandawana W. Majoni<sup>1,2,3,5</sup> MBChB, MRCP, FRACP, MMedStats, MClinicalMed, FRCP, Honorary Clinical Fellow, Consultant Nephrologist

Kerry Dole<sup>1</sup> DN, PostGradDip, MNurs, Transplant Coordinator, Clinical Nurse Consultant

Jaquelyne T. Hughes<sup>1,2</sup> BMed, FRACP, PhD, Senior Research Fellow, Consultant Nephrologist

Charles Pain<sup>4</sup> LRCP, MRCS, MSc, FFPH, FAFPHM, FACHSM, FISQua, Executive Director Medical Services, Director Clinical Governance

<sup>1</sup>Department of Nephrology, Division of Medicine, Royal Darwin Hospital, Top End Health Services, PO Box 41326, Casuarina, NT 0811, Australia. Email: [kerry.dole@nt.gov.au](mailto:kerry.dole@nt.gov.au)

<sup>2</sup>Menzies School of Health Research, Charles Darwin University, PO Box 41096, Casuarina, NT 0811, Australia. Email: [jaqui.hughes@menzies.edu.au](mailto:jaqui.hughes@menzies.edu.au)

<sup>3</sup>Northern Territory Medical Program, Flinders University, PO Box 41326, Casuarina, NT 0815, Australia.

<sup>4</sup>Top End Health Services, Executive Suite Royal Darwin Hospital, PO Box 41326, Casuarina, NT 0811, Australia. Email: [charles.pain@nt.gov.au](mailto:charles.pain@nt.gov.au)

<sup>5</sup>Corresponding author. Email: [william.majoni@nt.gov.au](mailto:william.majoni@nt.gov.au)

**Abstract.** Published evidence confirms poor access to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander Australians from the Northern Territory. This study aimed to identify the practical causes and recommend improvement. Pathways to wait-listing for a kidney transplant were reviewed to identify potential barriers. Processes were mapped to identify potential problem areas, provide comparison of the actual versus the ideal, identify where data needed collecting and provide clear presentation of the processes. Staff involved in the work-up of patients going for wait-listing were asked to list the barriers. Data were collected for patients from the transplant database between 1 January 2017 to 31 August 2018. Quality improvement statistical processes and charts were used to analyse and present the results. There were 102 patients in the transplant work-up process; 81.4% were Aboriginal and Torres Strait Islander, 71.6% were progressing with the work-up, 28.4% were on-hold. Of the 29 patients on hold, 92.9% were Aboriginal and Torres Strait Islander. Causes of delays to wait-listing included: failure to attend appointments due to competing priorities and communication barriers, access and navigating complex pathways to specialist services, transport, co-morbidities requiring multiple tests and multiple specialty services, and pressures on dialysis and hospital bed capacity. In conclusion, barriers to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander Australians are complex and can be addressed by redesigning healthcare provision, including increasing the Aboriginal and Torres Strait Islander workforce to provide education and patient navigation of the healthcare system and improve communication, streamlining investigations and coordinating specialist services.

**What is known about the topic?** Access to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander Australians from the Northern Territory is poor. Barriers to wait-listing for kidney transplantation can occur anywhere along the pathway of care from a patient's first contact with the renal service to wait-listing.

**What does this paper add?** Identified barriers to wait-listing for kidney transplantation include health service workforce and resources shortages, patient and health service barriers such as patients' competing priorities, poor communication between the health service and patients, transport and accommodation for patients from remote communities, complex comorbidities, and access to specialist services.

**What are the implications for practitioners?** Recruitment and retention of Aboriginal and Torres Strait Islander mentors, healthcare workers and patient navigators should be prioritised to provide an effective culturally appropriate service. Effective communication strategies with patients and improved access to streamlined appropriate investigations and collaboration among specialist services will invariably improve access to wait-listing for kidney transplantation.

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## Introduction

Over 70% of patients requiring renal replacement therapy in the Top End of Northern Australia are Aboriginal and Torres Strait Islander peoples. Most must relocate from remote communities to urban areas for dialysis, thus leaving their families, culture and way of life.<sup>1</sup> In general, kidney transplantation provides better quality of life and survival, and would be a good option for most of these patients, if suitable, but access to kidney transplantation for this group is very low.<sup>2–4</sup> Published literature has demonstrated barriers to wait-listing for kidney transplantation.<sup>5–8</sup> Barriers can occur anywhere along the pathway of care from a patient's first contact with the renal service to wait-listing. This was demonstrated by a recent case of severe dermatophyte infection requiring 394 days to achieve cure, leading to wait-listing 496 days after the patient started dialysis.<sup>9</sup> As part of an ongoing quality improvement project, we reviewed the pathways to wait-listing for a kidney transplantation for Aboriginal and Torres Strait Islander Australians.

## Objectives

The aims of this study were to: (1) detail the current pathways to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander patients; (2) identify the practical causes of barriers to wait-listing; (3) recommend and implement improved processes to wait-listing; and (4) recommend and develop ongoing strategies for continuous improvement to improve the care for patients preparing for wait-listing.

## Methods

### Setting

The Department of Nephrology at a tertiary hospital in the Top End of Northern Australia is the hub of the Top End Renal Service (TERS), providing care, including renal replacement treatments, to people with kidney disease. The transplant service is coordinated by a lead nephrologist, transplant coordinator and up to two other nurses. There are nine nephrologists, most of whom work part-time. All are involved in the preparation and care of patients undergoing kidney transplantation. The Department runs a multidisciplinary service including one psychologist, two renal dietitians, two social workers and four Aboriginal Liaison Officers, all involved in the preparation of patients for kidney transplantation.

Kidney transplantation is performed in South Australia, approximately 3000 km away or 3.5 h travel by air. Patients spend approximately 4 weeks in South Australia after transplantation before being transferred to the tertiary hospital in the Top End.

Pretransplant assessments are performed by the patients' primary nephrologists and the transplant team, consisting of a surgeon and physician, from South Australia. The team travels to the Top End three to four times yearly, but used to travel according to demand until 2017.

All clinicians proactively discuss transplantation as an option with all new patients referred to the renal service and refer all suitable patients for kidney transplantation.

### The project team

The present study was supported and endorsed by members of the multidisciplinary, leadership and management teams within

the Department after consultations. The project team consisted of the Executive Director of Medical Services (the lead for Clinical Governance and Quality and Safety for the Top End Health Service), the lead nephrologist for transplantation, the transplant coordinator and one other nephrologist with interest in quality improvement. We used standard methods of performing quality and continuous improvements projects.<sup>10</sup>

### Participants and data collection

Data from medical notes and electronic medical records of patients referred to the renal transplant services were collected over the 20 months from 1 January 2017 to 31 August 2018. Data collected included demographic information, date of referral to the transplant service, when the transplant work-up started and all documented steps through the work-up process. Using Microsoft (Bellevue, WA, USA) Excel spreadsheets, data were entered on every step, including reasons for each decision made during the work-up process to either wait-listing for a transplant, holding off the process or being considered unsuitable for wait-listing.

Emails were sent to all four nursing staff, available nephrologists and other staff involved in the work-up process to list all the reasons identified as potential causes of the barriers to wait-listing.

### Key measures of improvement

No guidelines exist on what proportion of patients in a renal program should be wait-listed for kidney transplantation. In order to improve access to the waiting list for patients, TERS aims that at least 20% of all prevalent dialysis patients are on the waiting list. In order to achieve this, the work-up and assessment for wait-listing needs to be completed within 6–12 months for at least 80% of all incident dialysis patients. With over 350 prevalent patients on dialysis and another 40–60 incident patients annually, 70 patients should be on the waiting list and the work-up process should be completed for 32–48 new patients within 12 months of starting dialysis. However, only 15 patients (4%) are currently on the waiting list and 18–24 are undergoing transplantation assessment within 12 months of dialysis initiation.

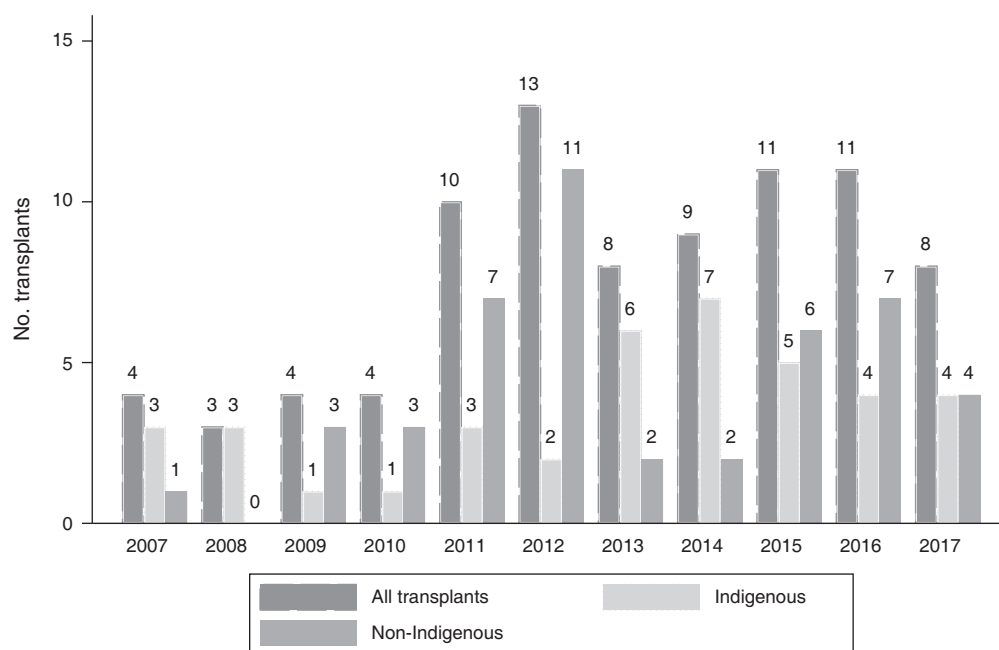
### Summary review of transplant activities from 2010 to 2017

In 2010, a new strategy for offering transplantation for all potential and suitable prevalent patients on maintenance dialysis was instituted to improve access to transplantation. A summary review of the kidney transplantation activities from 2010 to 2017 was performed to obtain an overview of the number of transplants performed during this period. We also included the data from 2007 to 2010 for comparison.

### Description of current pathways to wait-listing for kidney transplantation

TERS uses the same transplant work-up and assessment processes regardless of ethnic background. Processes and pathways to wait-listing patients were identified and mapped onto flow charts to: (1) provide a clear visual presentation of the processes; (2) identify potential problem areas; (3) provide an opportunity to compare the actual versus the ideal; and (4) identify where additional data needed to be collected.

Initially, details of all potential causes of barriers were determined to enable: (1) the main causes to be discovered;



**Fig. 1.** Number of transplants by ethnicity in the Top End of Northern Australia: 2007–17. The effects of changes introduced in 2010 started to become evident from 2013, with a small increase in the number of transplants for Indigenous patients. The time taken for the change to be evident is reflective of the long work-up process for Indigenous Australians. A significant number of transplants for non-Indigenous Australians were from living donors.

(2) the problem(s) to be focused on; (3) a snapshot of the collective knowledge to be created for all involved in the project; and (4) analysis and efforts to be focused on the main causes. The main causes were divided into four categories (causes related to staffing; patient-level causes; systems-level causes; and equipment and environmental causes) and plotted onto a cause and effect (Ishikawa/Fishbone) diagram.

#### Statistical analysis

Descriptive analysis of the pathway to listing from a patient's first contact with TERS was performed. Based on the Pareto principle, which states that 20% of the sources cause 80% of any problem,<sup>10</sup> Pareto charts were constructed to: (1) identify the real main causes and develop a clear recommendation for strategies to overcome these problems; (2) focus efforts on the problems that would offer the greatest potential for improvement by showing their relative frequency or size in a descending bar graph; and (3) help prevent 'shifting the problem', whereby the 'solution' removes some causes but worsens others.

Data are presented as the mean  $\pm$  s.d. for normally distributed continuous data and as the median with interquartile range (IQR) for data with a skewed distribution. Frequencies are expressed as percentages. Student *t*-test or Mann–Whitney *U*-tests were used for comparisons as appropriate. Details of reasons for delays as provided by staff were tabulated. All analyses were performed using Stata version 15.1 (StataCorp, College Station, TX, USA) and Microsoft Excel.

#### Ethics approval

This project was approved by the Human Research Ethics Committee (HREC) of the Northern Territory Department

of Health and Menzies School of Health Research (HREC: 2019-3285).

## Results

### *Transplant activities from 2010 to 2018*

The effects of changes introduced in 2010 started to be evident from 2013, with a small increase in the number of transplants among Aboriginal and Torres Strait Islander patients from 2013 to 2017 (Fig. 1). The number of transplants per year increased significantly from a median of 2.5 (IQR 1.3–3) in 2013 to 5 (IQR 4–6) in 2017 ( $P < 0.001$ ). Overall, there was no significant difference in the median number of transplants per year between Aboriginal and Torres Strait Islanders (3.5; 95% confidence interval (CI) 2.3–4.8) and non-Indigenous Australians (4.2; 95% CI 2.0–6.4;  $P = 0.5821$ ).

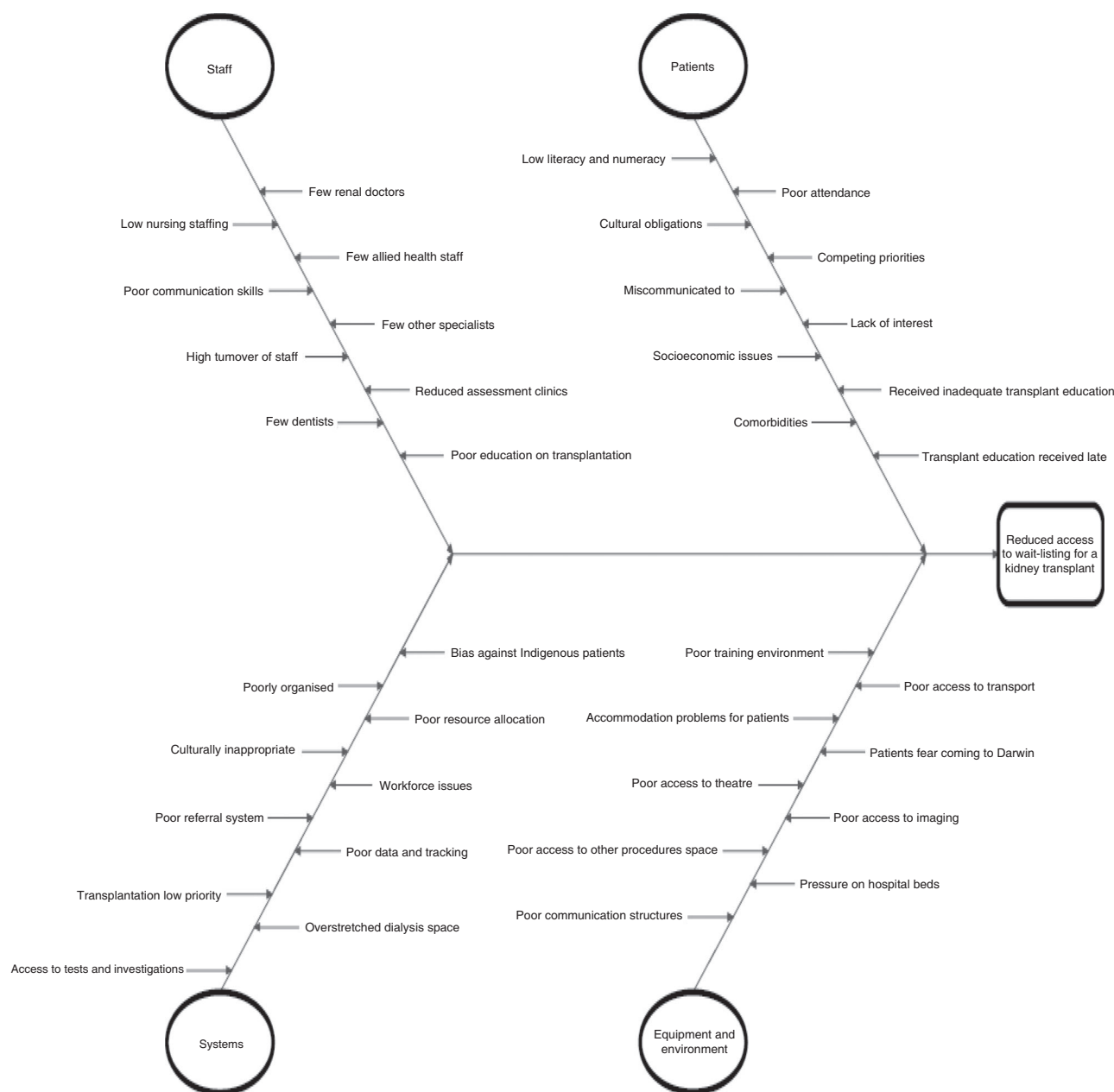
Fig. 2 shows the potential causes of barriers mapped on a Fishbone/Ishikawa diagram, Fig. 3 details the current pathway from contact with the renal services to starting the work-up and Fig. 4 shows the current processes from starting work-up to wait-listing.

Of 102 patients who commenced the transplant work-up process, 83 (81.4%) were Aboriginal and Torres Strait Islanders. The mean age was  $50.1 \pm 8.1$  years, work-up was progressing in 73 (71.6%) but was on hold in 29 (28.4%). Of the 29 patients on hold, 27 (92.9%) were Aboriginal and Torres Strait Islanders.

### *Identified barriers to listing for kidney transplantation*

#### *Health service workforce and staff*

One major barrier to listing for kidney transplantation was health service workforce resourcing for the transplant program, with only one full-time nurse position and one other position



**Fig. 2.** Fishbone (Ishikawa) diagram of the potential causes of poor access or barriers to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander Australians.

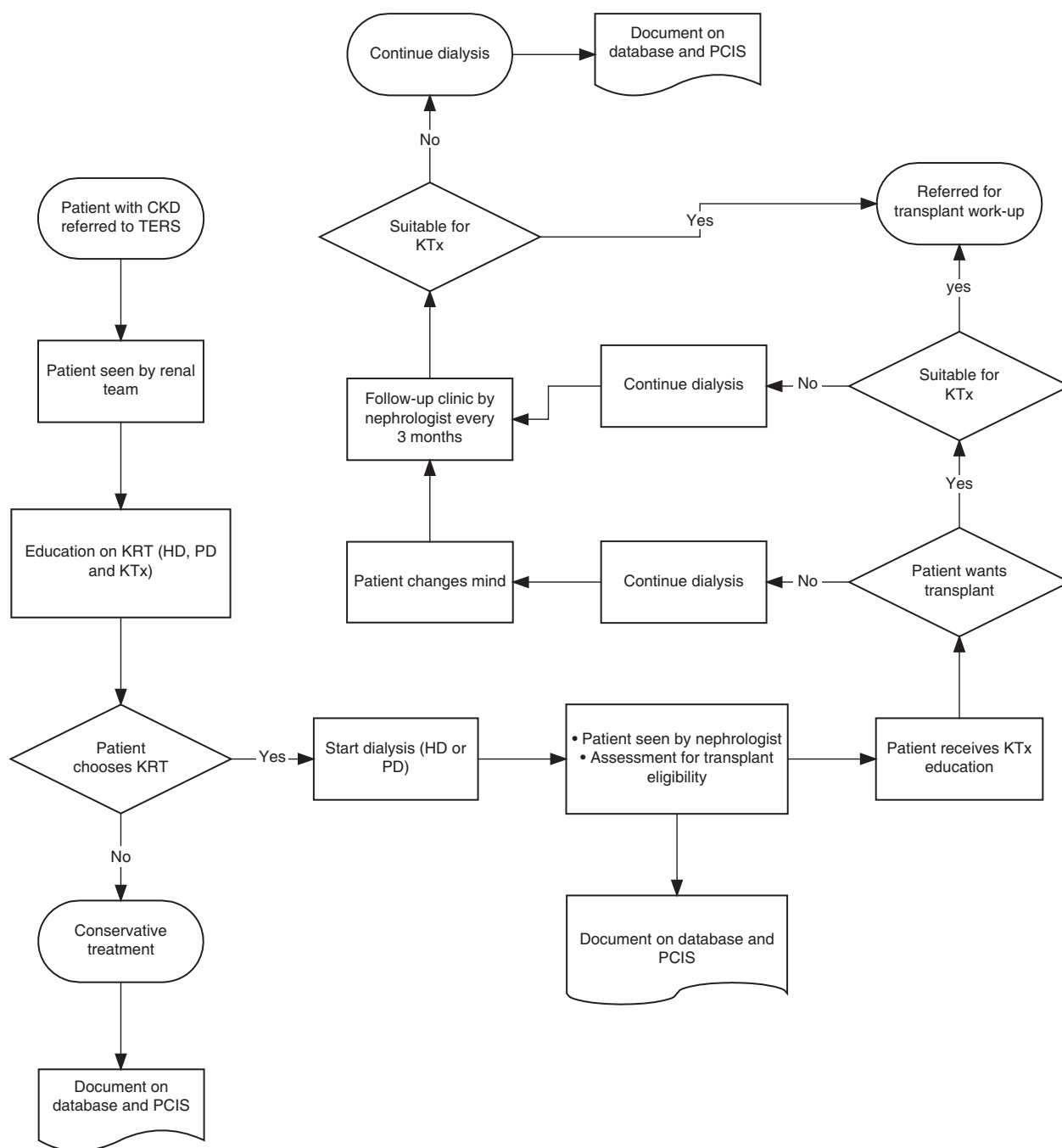
shared by three nurses rotating from the dialysis unit. With no dedicated administration support, the nurses' workload included following-up the results of investigations, reminding patients to attend appointments, arranging clinics and post-transplantation patient care and caring for non-transplant renal patients on immunosuppression.

#### *Patient and health service barriers*

The Pareto chart in Fig. 5 shows the actual causes of barriers among the 102 patients. Patients not attending or missing dental investigations and other specialist appointments was common. The reasons for attending or missing dental investigations were

multifactorial and included competing priorities (e.g. other important engagements such as funerals, important festivals and community commitments), problems with patient transport to appointments, poor communication between health services and patients about their appointments, a lack of patient accommodation, patients being uncontactable and patients losing interest in the whole process.

Significant comorbidities, such as cardiac disease, diabetes and its complications, skin,<sup>9</sup> respiratory and urinary tract infections, poor oral health (a reflection of poor socioeconomic status) and overweight and obesity were also common. All these required more investigations and multispeciality involvement.

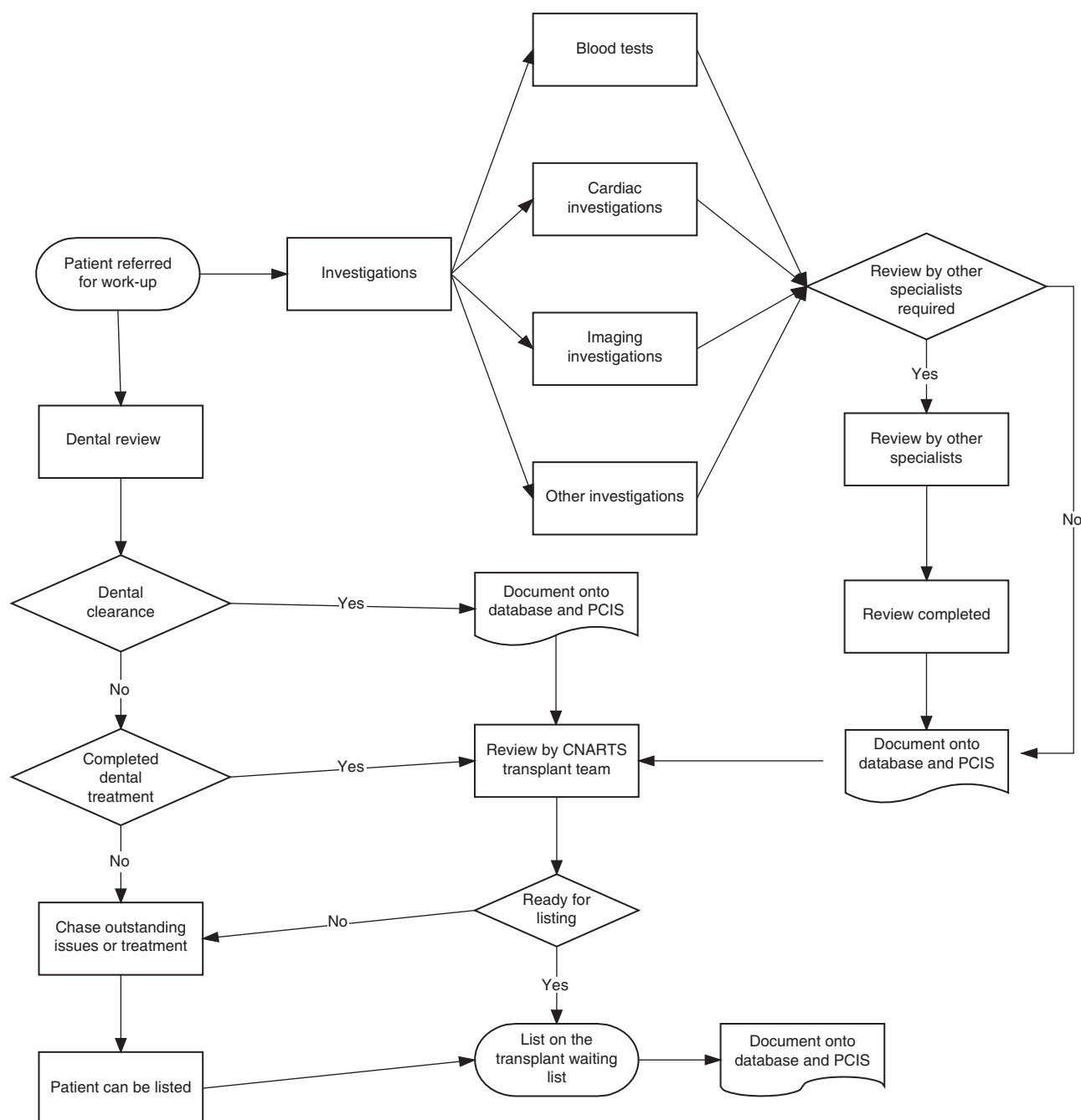


**Fig. 3.** Flow chart showing details of the current pathways from referral to the Top End Renal Service (TERS) to the start of transplant work-up. CKD, chronic kidney disease; HD, haemodialysis; KRT, kidney replacement treatment; KTx, kidney transplantation; PCIS, primary care information system; PD, peritoneal dialysis.

Other health service-level factors included a lack of or delayed appointments, long waiting lists for dental and other specialist services (e.g. surgery, urology, ear nose and throat, psychology), cancellation of appointments, a shortage of dialysis space for patients travelling from remote communities for specialised investigations, a requirement for complex medical or surgical procedures and a shortage of hospital admission beds. Causes identified by staff as barriers were similar (Table 1).

## Discussion

It took 3 years for transplant numbers to increase after implementation of changes in 2010, reflecting the time taken to wait-list patients due to the barriers described above. All Aboriginal and Torres Strait Islander patients received deceased donor transplants. The shortage of donors may affect the rates of transplantation. However, even with the current donor rates, the



**Fig. 4.** Flow chart showing the current pathway from the start of transplant work-up to when patients are wait-listed for kidney transplantation. The pathway is the same for all patients referred to the Top End Renal Service (TERS) regardless of ethnic background. CNARTS, Central and North Adelaide Renal Transplantation Service; PCIS, primary care information system.

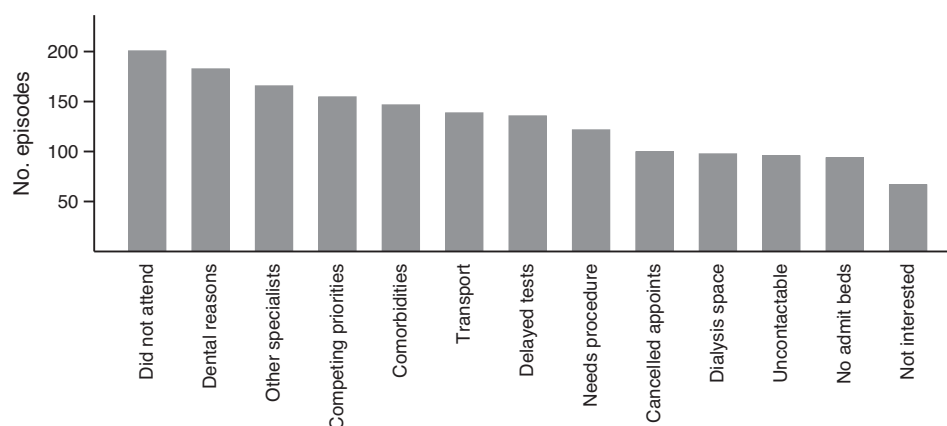
number of Aboriginal and Torres Strait Islander patients on the waiting list is still unacceptably low.

The absence of an overall difference in the transplant numbers between Aboriginal and Torres Strait Islander and non-Indigenous patients suggests that the numbers of deceased donor transplants was higher for the former, because most non-Indigenous patients received transplants from living donors. However, the rates of transplantation for Aboriginal and Torres

Strait Islander patients are too low because these patients account for over 70% of the dialysis cohort.

Changes implemented include improved data capture and recording, improved patient-level communication, strategies for using effective and culturally appropriate communication methods, such as Yarning Circles,<sup>1,11</sup> timely access to specialists and working with patient navigators to assist patients through the work-up process. Other culturally appropriate communication





**Fig. 5.** Pareto chart showing the actual causes of the barriers during the work-up to wait-listing for kidney transplantation among Aboriginal and Torres Strait Islander Australians. 'Did not attend' refers to patients failing to attend expected appointments or investigations. The y-axis shows the number of episodes each cause was recorded for among the 102 patients in this study.

**Table 1. Causes of barriers to wait-listing as identified and reported by staff members**

ENT, ear, nose and throat; TEPTS, Top End Patient Transport System

Cause or barrier category	Description
Staffing	Lack of nursing resources Lack of education in outreach setting for patients awaiting education and commencement of work-up Lack of administration support for transplantation services High turnover of staff in remote communities
Patient travel	Lack of Aboriginal and Torres Strait Islander workforce Patient travel: communities may have forgotten to book and transport (TEPTS needed to get patients to appointments)
Socio economic	Remoteness and logistical complexities of travel for appointments, tests and transplant assessments Lack of social support Low socioeconomic status and poverty Housing problems in remote communities Social isolation or dislocation from families, communities and culture Non-adherence to dialysis due to social isolation or dislocation
Access	Patient education: ability to know whether a patient understands the processes to wait-listing for a transplant Access to other specialist clinics (e.g. urology, respiratory, liver, ENT, gynaecology) Access to dental services in remote communities and, to a lesser extent, in urban areas Access to mammograms (mainly only available in Darwin; limited access in remote communities) Access to Mantoux testing (only done in Darwin and Katherine) Access to bone mineral density testing (only available Darwin) Access to pulmonary function tests (only available in Darwin) Access to other important services in remote communities Main transplanting unit transplant assessment visits need to increase Awaiting visiting team from transplanting unit to review patients and decision making
Communication and other patient factors	Inability to access private health Conflicting patient priorities Cultural commitments Health literacy Language barriers Patients' other commitments Increased comorbidities High body mass index (central obesity) Patient education: ability to know whether a patient understands the processes to wait-listing for a transplant Getting informed consent Communication with patients: either no mobile phone or continuously changing mobile phone number Preparation for stress test: non-adherence to the preparation requests and cessation of beta-blockers etc. Family consent in decision making

**Box 1. Summary of recommendations**

1. Recruitment and retention of Aboriginal and Torres Strait Islander mentors, healthcare workers and patient navigators will improve engagement with patients across the modalities of kidney replacement treatment, which will facilitate the process of work-up for transplantation. Recruiting Aboriginal Health Practitioners (AHP) will consolidate the closure of the cultural and clinical gap, especially with transplant education. This, combined with the dedicated nurse specialist, will make a significant difference to the process of delivering education and information to patients.
2. Increased resources and support to facilitate appropriate communication with patients and communities, such as Yarning circles, will provide effective education and information sharing processes.
3. There is a need to increase the number of nursing staff and administration support resources.
4. Increasing resources for the current new start and transitional program within the Top End Renal Service (TERS) with multidisciplinary resources will help those starting kidney replacement therapy settle into the treatment routines and with timely referral for transplantation.
5. Increased interspeciality and interdisciplinary collaboration with robust administration support will make a huge difference to the process. This will also improve collaboration and communication with primary health care. As with other clinical services, strategies to recruit and retain a specialist workforce are critical to the improvement of the transplant service.
6. We have identified the need for research into innovative ways to improve processes towards wait-listing patients and translating the results into practice. Research needs to be embedded within the service as part of quality improvement.
7. A review of the relevance of the pretransplant tests is needed to streamline the process of work-up. Some of the tests currently required may not be backed up by strong published evidence of clinical value.
8. Because some of the delays were identified as being directly related to time taken for review by the transplant centre from South Australia, increased assessment visits from the team and the use of telehealth will improve the process.

and transplant educational tools to improve engagement are being developed.

Cardiac services now prioritise transplant work-up patients. This change is being broadened to other specialist areas. An agreement has been reached with dental services to prioritise transplant work-up patients.

The results from this project contributed to the national performance report on improving access to transplantation for Aboriginal and Torres Islander patients across Australia submitted to the Commonwealth Department of Health.<sup>12</sup>

Proactive patient and community engagement and increased collaboration with primary health care to improve general health for patients before they start dialysis will eliminate delays. A patient reference group for TERS has been set up.<sup>13</sup>

Performing investigations closer to patients' communities and increasing the use of telehealth will improve access to specialists. The recent appointment of a psychologist within the renal services has closed a significant gap in the service.

Several key recommendations are summarised in [Box 1](#).

**Conclusions**

Barriers to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander Australians are complex and can be addressed by innovative improvements in the provision of health care. This includes increasing the Aboriginal and Torres Strait Islander workforce to provide culturally appropriate patient navigation of the healthcare system and improving communication processes between health services and patients. There is a need for streamlined investigations and coordinated specialist services.

**Competing interests**

The authors declare no competing interests.

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