

# Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia

---

## Performance Report



**TSANZ**

The Transplantation Society of Australia and New Zealand

# Table of Contents

<b>ACKNOWLEDGEMENTS</b> .....	<b>IV</b>
<b>ABBREVIATIONS</b> .....	<b>V</b>
<b>TERMINOLOGY</b> .....	<b>VI</b>
<b>EXECUTIVE SUMMARY</b> .....	<b>VII</b>
<b>1. INTRODUCTION</b> .....	<b>1</b>
1.1 ORGAN DONATION .....	3
1.2 PRE- AND POST-TRANSPLANT BARRIERS .....	4
1.3 AIMS OF THIS REPORT .....	5
1.4 STRUCTURE OF THIS REPORT .....	5
<b>2. CURRENT EVIDENCE</b> .....	<b>6</b>
2.1 CONSUMER ENGAGEMENT.....	6
2.1.1 <i>Catching Some Air – Asserting Indigenous Information Rights in Renal Disease</i> .....	6
2.1.2 <i>Kidney Health Australia’s Indigenous Community Consultations</i> .....	7
2.1.3 <i>Indigenous Patient Voices Symposium</i> .....	7
2.1.4 <i>Indigenous knowledge in health services: a consumer partnership framework</i> .....	8
2.1.5 <i>Patient-led Participatory Action Research (PAR) Project</i> .....	8
2.1.6 <i>IMPAKT</i> .....	9
2.1.7 <i>Managing Two Worlds Together</i> .....	10
2.1.8 <i>Where to next?</i> .....	10
2.2 PRE-TRANSPLANT JOURNEY.....	11
2.2.1 <i>Information sharing and understanding the transplantation process</i> .....	12
2.2.2 <i>Completing transplant workup tests and formal assessment</i> .....	15
2.2.3 <i>Staying healthy on the list</i> .....	19
2.2.4 <i>Surgical assessment</i> .....	19
2.3 POST-TRANSPLANT REQUIREMENTS.....	25
2.3.1 <i>Models of Care</i> .....	26
2.3.2 <i>Immunosuppression</i> .....	33
2.3.3 <i>Infective Prophylaxis</i> .....	38
2.4 CRITIQUE OF CURRENT EVIDENCE.....	39
2.5 ENHANCING DATA COLLECTION & REPORTING .....	40
2.5.1 <i>Facility selection</i> .....	41
2.5.2 <i>Patient selection</i> .....	42
2.5.3 <i>Data collection</i> .....	42
2.5.4 <i>Feasibility and resourcing</i> .....	43
2.5.5 <i>Other data linkage and research projects</i> .....	44
<b>3. PRE-TRANSPLANT KNOWLEDGE GAPS AND RECOMMENDATIONS</b> .....	<b>45</b>
3.1 KNOWLEDGE AND DATA GAPS .....	45
3.1.1 <i>Informing patients</i> .....	45
3.1.2 <i>Completing workup and assessment</i> .....	45
3.1.3 <i>Surgical assessment</i> .....	46
3.2 NEXT STEPS AND RECOMMENDATIONS FOR RESEARCH, PRACTICE AND POLICY .....	47
3.2.1 <i>Consumer Engagement and Education</i> .....	47
3.2.2 <i>Improving Equity and Access to Transplant Services</i> .....	48
3.2.3 <i>Researching, Developing and Implementing Clinical Guidelines and Protocols</i> .....	51
3.2.4 <i>Workforce Training and Development</i> .....	52
<b>4. POST-TRANSPLANT KNOWLEDGE GAPS AND RECOMMENDATIONS</b> .....	<b>53</b>

4.1	KNOWLEDGE AND DATA GAPS .....	53
4.1.1	<i>Models of Care</i> .....	53
4.1.2	<i>Immunosuppression</i> .....	54
4.1.3	<i>Infective Prophylaxis</i> .....	54
4.2	NEXT STEPS AND RECOMMENDATIONS FOR RESEARCH, PRACTICE AND POLICY .....	56
4.2.1	<i>Consumer Engagement and Education</i> .....	56
4.2.2	<i>Improving Equity and Access to Transplant Services</i> .....	57
4.2.3	<i>Researching, Developing and Implementing Clinical Guidelines and Protocols</i> .....	59
	.....	60
<b>5.</b>	<b>SUMMARY</b> .....	<b>62</b>
<b>APPENDIX A</b>	<b>TABLE OF SYSTEMIC BIASES</b> .....	<b>66</b>
<b>APPENDIX B</b>	<b>BELATACEPT TRIALS</b> .....	<b>69</b>
<b>APPENDIX C</b>	<b>PROPHYLAXIS PROTOCOL</b> .....	<b>70</b>
<b>REFERENCES</b>	.....	<b>72</b>

# Acknowledgements

In June 2018, the Minister for Indigenous Health, the Hon Ken Wyatt MP, commissioned an expert panel, led by the Transplantation Society of Australia and New Zealand (TSANZ), to undertake a comprehensive review into the hurdles, service gaps and practical challenges faced by Aboriginal and Torres Strait Islander patients receiving treatment for kidney disease. A number of expert panel members served on pre- and post-transplant Aboriginal and Torres Strait Islander working groups and contributed to this report, including: Stephen McDonald (Convener), Toby Coates (TSANZ President Elect), Peter Boan, Alan Cass, Steve Chadban, Ross Francis, David Goodman, Jaquelyne Hughes, Ashley Irish, Sarah Jones, Wai Lim, William Majoni, Murty Mantha, Olivia O'Donoghue, Greg Perry, Christine Russell, Cherian Sajiv and Paul Snelling. Other expert panel members provided constructive comments and review, including: Stephen Alexander, Lucinda Barry, Shilpa Jesudason and Lisa Murphy.

Beyond the expert panel, a number of health professionals from clinical and research settings provided valuable advice that shaped the development of the report. The authors would like to thank Asanga Abeyaratne, Kerry Dole, Janet Kelly, Namrata Khanal and Paul Lawton for their significant contributions. The authors would also like to thank Svetlana Andrienko from Studio Elevesens for designing the recommendation mapping and consolidated list of recommendations graphic, which features in the report's summary section.

The report was written by Eleanor Garrard and Stephen McDonald. Gill Gorham, Athira Rohit and Charles Triggs undertook extensive work in reviewing the evidence base and investigating current practices of renal units. Kim Rawson managed the project for TSANZ.

This report was funded by the Federal Department of Health under the Indigenous Australians' Health Programme. The authors appreciate the guidance provided by the Department, and particularly the ongoing support from Angela Donovan, Penny Jones and Anna Osland.

# Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
ANZSN	Australian and New Zealand Society of Nephrology
CKD	chronic kidney disease
CVD	cardiovascular disease
DoH	Commonwealth Department of Health
ESKD	end-stage kidney disease
eGFR	estimated glomerular filtration rate
HD	haemodialysis
HLA	human leukocyte antigen
KHA	Kidney Health Australia
MBS	Medicare Benefits Schedule
NRHA	National Rural Health Alliance
OTA	Organ and Tissue Authority
PBS	Pharmaceutical Benefits Scheme
PD	peritoneal dialysis
PNP	patient navigator program
POCT	point of care testing
RRT	renal replacement therapy

# Terminology

**Bariatric surgery:** Comprises a variety of procedures that reduces the size of the stomach and is performed on people who have obesity to achieve weight loss.

**Comorbidity:** The co-occurrence of one or more disorders in the same individual, either at the same time or in some causal sequence.

**Culturally appropriate care:** Involves the delivery of patient-centred care that is tailored to meet the social, cultural and linguistic needs of the patient.

**Diabetes:** A group of diseases that result in too much sugar in the blood (high blood glucose). Type 2 diabetes accounts for 85% of all diabetes and is increasing at the fastest rate, primarily due to the obesity epidemic.

**Dialysis:** An artificial method of removing waste substances from the blood and regulating levels of circulating chemicals—functions normally performed by the kidneys.

**End-stage kidney disease (CKD stage 5):** The most severe form of CKD and requires RRT to survive (defined as eGFR <15 mL/min/1.73 m<sup>2</sup> or on dialysis). Symptoms include nausea, itching skin, restless legs and shortness of breath. Additional common complications include inflammation of the tissue layers surrounding the heart, bleeding in the gastrointestinal tract, altered brain function and structure, and disturbances or structural or functional changes in the peripheral nervous system.

**Health literacy:** The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.

**HLA matching:** HLA molecules are expressed on almost all nucleated cells, and they are the major molecules that initiate graft rejection in organ transplant recipients. HLA matching involves blood or tissue samples being tested before a donor stem cell or organ transplant to find out if tissues are immunologically compatible between the donor and the recipient.

**HLA sensitisation:** Occurs when patients develop anti-HLA antibodies, primarily via pregnancy, transfusion and/or prior transplant. If not adequately suppressed, the presence of such antibodies can lead to early graft loss in kidney transplant recipients.

**Kidney transplant:** A healthy kidney is taken from one person and surgically placed into someone with ESKD. The kidney can come from a live or deceased donor. Transplantation is widely regarded as the preferred treatment for people with ESKD.

**Immunosuppression:** a reduction of the activation or efficacy of the immune system to prevent the rejection of a transplant.

**Pharmacogenetics:** The study of inherited genetic differences in drug metabolic pathways that can affect individual responses to drugs, both in terms of therapeutic and adverse effects.

**Prophylaxis:** Measures designed to preserve health and prevent the spread of disease or infection.

# Executive Summary

End-stage kidney disease (ESKD) is a serious and increasingly common health problem in Australia. Indigenous people, especially those who live in remote communities, have a much greater risk of developing ESKD and requiring dialysis treatment, but their likelihood of receiving a kidney transplant is substantially lower than that of non-Indigenous patients. For those who are fortunate enough to receive a kidney transplant, a disparity between Indigenous and non-Indigenous patients persists, with Indigenous kidney transplant recipients experiencing significantly worse post-transplant outcomes compared to non-Indigenous recipients. In June 2018, the Minister for Indigenous Health, the Hon Ken Wyatt MP, established an expert panel, comprised of people working in clinical settings, research and public policy, to investigate and identify barriers faced by Indigenous people in accessing and maintaining a kidney transplant. This Performance Report constitutes the first piece of work produced by the expert panel, as commissioned by the Commonwealth Department of Health (DoH). The Report complements the EY Review of the Australian organ donation, retrieval and transplantation system and provides a detailed analysis of available evidence around:

1. Evidence and gaps around steps to waitlisting and to long term transplant function;
2. Improving Indigenous dialysis patients' health to improve their capacity to be listed; and
3. Measures to address these gaps.

## **Box 1: Priority recommendations for immediate implementation**

Of the report's 35 evidence-based recommendations, the expert panel has identified three key areas that should receive prioritisation for funding and immediate action. These include:

1. **Establishing a resourced National Indigenous Kidney Transplantation Taskforce**, with representations from DoH, TSANZ, ANZDATA, ANZSN, OTA and invited subject experts, to drive the implementation of the report's recommendations, consult the Indigenous and health care communities, and advocate for equitable access to transplantation for Indigenous patients.
2. **Enhancing data collection and reporting** processes on pre- and post-transplant outcomes by:
  - a. Implementing a 12-month pilot project to capture additional pre- and post-kidney transplant data points in an expanded ANZDATA data collection protocol;
  - b. Incorporating a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander people; and
  - c. Undertaking additional data linkage and research projects that target Indigenous patients' post-transplant outcomes, enabling identification of best practice immunosuppression, infective prophylaxis and vascular complication protocols.
3. **Improving the equity and accessibility of transplantation** for Indigenous patients by:
  - a. Establishing an Indigenous reference group in every transplant unit to help design pathways and models of care that are culturally appropriate;
  - b. Trialling the adoption of patient navigators as part of pre-transplant care protocols;
  - c. Evaluating and leveraging existing initiatives that target cultural bias in health services to facilitate the rollout of best practice pre-transplant care and support interventions for Indigenous transplant candidates; and
  - d. Trialling a multidisciplinary pre- and post-transplant clinic in one major regional centre for 12 months, prioritising the availability of dental and cardiac services, as well as travel and accommodation support for rural and remote patients.

## 1. Introduction

The Aboriginal and Torres Strait Islander peoples of Australia (hereafter referred to as Indigenous Australians) are culturally, linguistically and geographically diverse. Over 250 Indigenous Australian cultural and language groups covered the continent at the time of European settlement in 1788, though only an estimated 120 of these survive today (AIATSIS, 2018). While they make up only 3% of the total Australian population, in 2011 45% of people living in very remote areas and 16% of people living in remote areas were Indigenous (AIHW, 2015). A range of sociodemographic factors are linked to health inequalities and poorer health care outcomes for Indigenous peoples, including:

- Lower levels of education, employment, income and poorer quality housing, on average, compared with non-Indigenous Australians;
- Higher rates of behavioural and biomedical risk factors, such as smoking, risky alcohol consumption, poor diet, lack of exercise, and higher rates of high blood pressure; and
- Difficulties in accessing affordable and culturally appropriate health services.

The gap in life expectancy between Indigenous and non-Indigenous Australians remains significant, as shown in Table 1, with around a 10-year discrepancy for both males and females. In 2016, nearly three in four (71%) of Indigenous deaths were from chronic diseases, including cancer, diabetes and chronic kidney disease (CKD) ("Healthy Lives: Life Expectancy Target," 2018).

*Table 1: Life expectancy at birth ("Healthy Lives: Life Expectancy Target," 2018).*

	Indigenous		Non-Indigenous		Gap (years)	
	Males	Females	Males	Females	Males	Females
<b>2005-2007</b>	67.5	73.1	78.9	82.6	11.4	9.6
<b>2010-2012</b>	69.1	73.7	79.7	83.1	10.6	9.5

Chronic kidney disease is a significant and rapidly growing public health problem that manifests in substantial burden of illness and premature mortality worldwide. CKD is gradual and progressive and comprises five recognised stages. Stage 1 is the mildest and typically symptom free, while Stage 5 is the point where kidney function causes very substantial symptoms and complications and ultimately is incompatible with life unless renal replacement therapy (RRT), comprising dialysis or transplantation, is undertaken (AIHW, 2011a). Intervention to avoid or reduce the impact of kidney disease is targeted at all stages, but in the later stages kidney function is severely reduced, requiring more intensive intervention in preparation for Stage 5 (AIHW, 2011a). The five stages of CKD are outlined in Table 2.

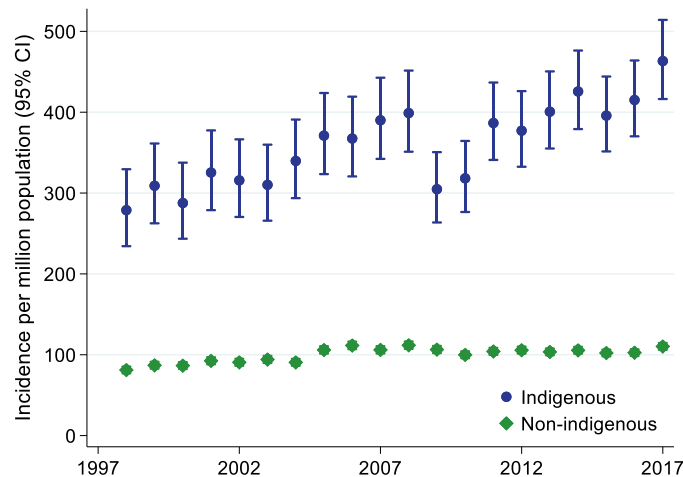
*Table 2: The Five Stages of CKD (AIHW, 2011a).*

The Five Stages of CKD			
Stage	Description	eGFR	Kidney Function Deterioration
<b>1</b>	Kidney damage (protein in urine) and normal GFR	More than 90	50% - 60%
<b>2</b>	Kidney damage and mild decrease in GFR	60 – 88	60% - 70%
<b>3</b>	Moderate decrease in GFR	30 – 59	70% - 77.5%
<b>4</b>	Severe decrease in GFR	15 – 29	77.5% - 85%
<b>5</b>	Kidney failure, including ESKD (dialysis or kidney transplant needed)	Less than 15	85% and above



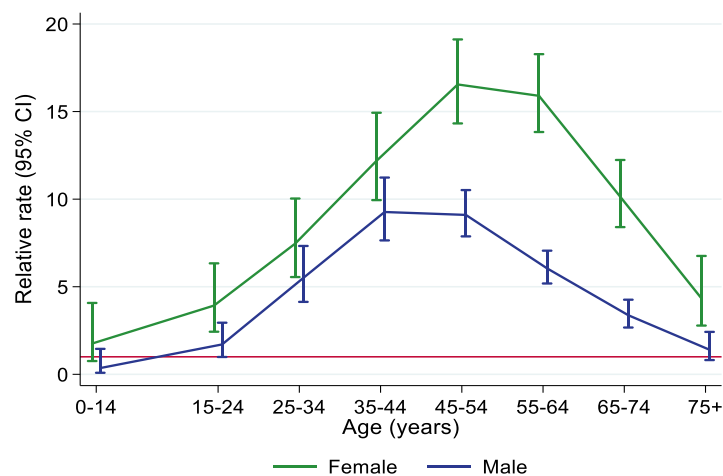
Since the mid-1980s, Indigenous Australians have had a higher incidence of ESKD receiving RRT than non-Indigenous Australians (ANZDATA, 2018; Lawton et al., 2015). ESKD was the underlying or associated cause of death for 15.8% of Indigenous deaths between 2008 and 2012 (AIHW, 2015), contributing 5% of the total disparity between Indigenous and non-Indigenous mortality (AIHW, 2014). The current incidence rates of ESKD for Indigenous patients are markedly and persistently higher than those for non-Indigenous patients, as shown in Figure 1.

Figure 1: Unadjusted incident RRT rate – Australia (ANZDATA, 2018).



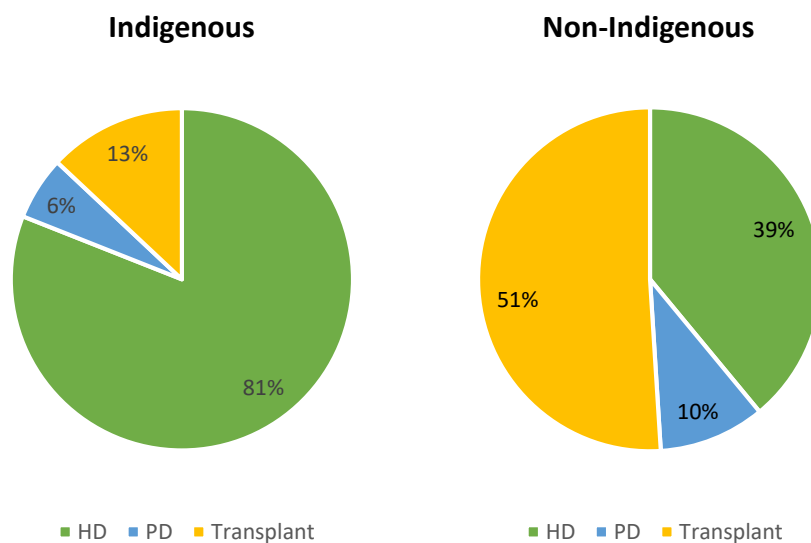
Indigenous patients receiving RRT are generally much younger and live in more remote areas than non-Indigenous patients. The discrepancy in ESKD incidence is most prominent among Indigenous adults aged 25 to 64 where rates are up to 15 times higher than in the non-Indigenous population, as shown in Figure 2 (ANZDATA, 2018), and a 20-fold higher rate of ESKD has been found among Indigenous Australians living in remote compared with urban areas (Cass, Cunningham, Wang, & Hoy, 2001). This reinforces the importance of transplantation as a treatment option for Indigenous patients, who would otherwise be required to undergo dialysis for several years or even decades.

Figure 2: Relative incidence rate of treated ESKD for Indigenous patients by gender Australia 2013-2017 (ANZDATA, 2018).



Kidney transplantation is the optimal treatment for ESKD, but there is a significant and persistent disparity in transplants to Indigenous and non-Indigenous Australians, a situation that is similar to Indigenous patients in New Zealand, Canada and the United States (Yeates et al., 2009). In 2017, there were 2,161 Indigenous Australians registered for RRT. Of these, 87% were reliant on dialysis and 13% had received a kidney transplant (ANZDATA, 2018). In comparison, 49% of non-Indigenous Australians with ESKD were reliant on dialysis and 51% had received a kidney transplant (ANZDATA, 2018), as outlined in Figure 3.

Figure 3: Prevalent Patients by Ethnicity and Treatment Modality 2017 (ANZDATA, 2018). (HD=haemodialysis, PD=peritoneal dialysis).



### 1.1 Organ donation

Over the last ten years the number of Indigenous organ and tissue donors across Australia has steadily increased – primarily due to improved community awareness, and because conversations about organ and tissue donation with Indigenous people are now being conducted in a culturally appropriate manner by expert trained health professionals. In 2008, 1.5% (4/259) of donors were Indigenous, which increased to 3.2% (18/554 donors) in 2018. Culturally appropriate educational materials using pictures, stories and language have been developed with Indigenous people to aid discussions about donation. Previous work undertaken in the Northern Territory identified no cultural barriers that preclude organ donation from being discussed (Stephens, 2007). However, a number of factors continue to impact on the potential for donation from Indigenous people, including:

- Pre-existing comorbidities such as diabetes, hypertension and alcohol misuse, often at a young age, which precludes some Indigenous patients from being considered medically suitable for donation, particularly when coupled with the distance from the potential receiving transplant units.
- A consent rate for donation of approximately 30-40%, which is around half the national rate.
- Indigenous people not being aware of and understanding the link between organ donation and transplantation and how donation may benefit someone in their community.
- Challenges of conducting donation conversations with large Indigenous families split between the community and the hospital often many kilometres away, and the difficulties that sometimes arise in identifying the senior next of kin/community spokesperson.

- Heterogeneity between the different Indigenous communities in terms of health literacy, awareness and the likelihood of giving consent to donation – urban Indigenous people are more likely to give consent to donation than Indigenous people from remote communities.
- Cultural beliefs that preclude organ donation, such as belief in the importance of being buried whole and in the transference of the spirit of the donor with their donated organ to the recipient.
- The time frame over which donation occurs which may be unacceptable for some Indigenous (and non-Indigenous) families, particularly those from remote communities.
- Mistrust of the health system.

There has been considerable debate about the merits of an ‘opt-out’ approach to organ and tissue donation in Australia, but this concept would likely be difficult to explain to Indigenous people, many of whom have low health literacy. Consequently, the main priorities should be:

- 1) Systematically reviewing the evidence on the outcomes of kidney transplantation using a live donor in the Indigenous patient population to inform health service protocols; and
- 2) Educating Indigenous communities about the value of organ donation and how it links to transplantation, ideally in partnership with local transplant recipients and donor families.

## 1.2 Pre- and post-transplant barriers

In addition to donation issues, numerous pre- and post-transplant barriers that may impede Indigenous Australians’ access to a kidney transplant have been identified. Pre-transplant barriers commonly comprise sociocultural and geographic factors, such as a cultural and/or communication divide between the patient and the practitioner, and logistical difficulties in accessing regular assessment and workup tests that are only available in metropolitan areas. Additionally, Indigenous ESKD patients are far more likely to be smokers, diabetic, overweight or obese, and to suffer from cerebrovascular, coronary artery and peripheral vascular disease (Barraclough, Grace, Lawton, & McDonald, 2016; McDonald, 2004; Rogers, Lawton, & Jose, 2006). High comorbidity profiles result in a significant proportion of Indigenous ESKD patients being deemed unsuitable for transplantation.

The poorer post-transplant outcomes experienced by Indigenous patients also presents a significant barrier to transplantation. Indigenous patients are more likely to experience greater sensitisation and human leukocyte antigen (HLA) mismatches, acute rejection, bolus doses of steroids, monoclonal antibody treatment for rejection, hospitalisation with a longer length of stay, and post-transplant infection, particularly bacterial and fungal infections (Boan, Swaminathan, & Irish, 2017; Rogers et al., 2006). The 2017 ANZDATA Annual Report identified a difference in survival after kidney transplantation from a deceased donor between non-Indigenous and Indigenous recipients, evident from 1.5 years post-transplantation. At 5 years post-transplant, 84% of Indigenous recipients and 91% of non-Indigenous recipients were alive, and transplant kidney function was maintained in 71% of Indigenous recipients compared with 83% of non-Indigenous persons (ANZDATA, 2018).

At the end of 2017, 964 patients were active on the Australian kidney transplant waiting list, 31 of whom were Indigenous (ANZDATA, 2018). However, the number of deceased donor kidneys available for transplantation is far lower than the number of patients who might benefit from a transplant, and the average time spent on the waitlist before receiving a transplant is 3 years (KHA, 2019). Prior to 2018, national protocols in Australia required that patients have an anticipated 80% likelihood of survival at 5 years post-transplantation to be eligible for the kidney transplant waitlist (TSANZ, 2018).

This is no longer an absolute requirement, and eligibility for deceased donor kidney transplant waitlisting now requires that kidney transplant candidates have a high likelihood of significant benefit from receiving a kidney transplant (TSANZ, 2018). However, the substantial pre- and post-transplant challenges experienced by Indigenous ESKD patients ultimately means that they have a poorer prospect of successful transplantation compared to non-Indigenous patients, and are thus less likely to be listed for a kidney transplant.

### 1.3 Aims of this report

This report has three interrelated aims, comprising:

- 1) Summarising the literature on Indigenous kidney transplant candidates' barriers to: a) being waitlisted for transplant, b) receiving a transplant, and c) maintaining transplant function.
- 2) Identifying data and knowledge gaps that prevent the attainment of a comprehensive understanding of pre- and post-transplant barriers.
- 3) Proposing a series of recommendations for research, practice and policy to either:
  - a) address data and knowledge gaps, or
  - b) draw upon current knowledge to inform pre- and post-transplant initiatives that are tailored for the Indigenous patient cohort.

It is anticipated that the report will serve as a precursor to a series of projects and health service initiatives that target identified transplantation barriers, practice issues and evidence gaps. The report's findings will also be presented to an international audience at the World Congress of Nephrology Satellite Symposium, "First Nation Kidney Health – a focus on transplantation", in April 2019, which will facilitate an international exchange of ideas on First Nation transplant issues. It is planned that a workshop will be held in the second half of 2019 to engage the local health care sector in Indigenous kidney health issues and enable a diverse range of voices to be heard.

To ensure the momentum generated by this report is not lost, it is proposed that the TSANZ, in partnership with the Australian and New Zealand Society of Nephrology (ANZSN) and Organ and Tissue Authority (OTA), establish a Taskforce to provide oversight and input into Indigenous kidney transplantation issues, consult the Indigenous and health care communities on the report's recommendations, and drive action across research, practice and policy domains.

### 1.4 Structure of this report

The remainder of this report is structured as follows:

- **Chapter 2** describes the work that has been undertaken to date in the consumer engagement space, existing literature on pre- and post-transplant barriers for Indigenous patients, and overarching data issues.
- **Chapter 3** outlines pre-transplant knowledge and data gaps, as well as next steps and recommendations for research, practice and policy.
- **Chapter 4** outlines post-transplant knowledge and data gaps, as well as next steps and recommendations for research, practice and policy.
- **Chapter 5** presents a summary of the report.

## 2. Current Evidence

### 2.1 Consumer Engagement

Historically, much of the focus on the performance of the health care system has been from the perspective of the providers and funders. More recently, the active involvement of consumers and community has become central to both health care service provision and research (ACSQHC, 2017). Over the past decade extensive consumer engagement research has been undertaken within the Indigenous ESKD patient population, and much is now known about the experiences of Indigenous dialysis patients, particularly perceptions of key barriers to treatment and support (Devitt et al., 2008; Dwyer et al., 2011; Hughes, Dembski et al., 2018; Hughes, Kelly, Mick-Ramsamy, & Mills, 2018; Kelly et al., 2015; KHA, 2018; Kirkham et al., 2018; Togni et al., 2017). A clear and consistent message from these research activities has been a high degree of interest in kidney transplantation among Indigenous dialysis patients and their families.

This chapter outlines seven consumer engagement projects that focus on the subjective experiences of Indigenous ESKD patients, their families and communities. While these projects utilise disparate methodologies and explore different issues and themes, they all share one commonality: the experiences and insights of the consumer (i.e. patients, families and carers) are prioritised and harnessed to guide the direction of the research and subsequent recommendations for policy and practice.

#### 2.1.1 Catching Some Air – Asserting Indigenous Information Rights in Renal Disease

The Catching Some Air project, led by the Menzies School of Health Research, is due to be completed in May 2019. This project's primary focus is consulting with the Indigenous CKD/ESKD community to obtain guidance on:

- 1) The development of an Indigenous data governance framework and implementation processes within the ANZDATA Registry; and
- 2) How to create effective, safe, culturally appropriate health systems for patients and communities most impacted by kidney disease. These recommendations will feed into the Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guideline for Management of CKD in Aboriginal and Torres Strait Islander and Maori peoples (Duff, Jesudason, Howell, & Hughes, 2018; Hughes, Kelly, Mick-Ramsamy, & Mills, 2018).

Consultation meetings in three main sites, Darwin, Alice Springs and Thursday Island, comprise the main method of gathering evidence to inform the aforementioned initiatives (Hughes, Kelly, et al., 2018). A number of secondary consultation sites will also be used to test the consolidated recommendations provided by the three main sites (Hughes, Kelly, et al., 2018).

#### **Box 2: Catching Some Air transplant-related recommendations**

- Community-based education is important, not only to prevent ESKD, but to learn about the available treatment options, including the transplantation pathway.
- Transplant care guidelines need to adopt a holistic approach that reflects Indigenous patients, families and communities' world view.
- Indigenous ESKD patients should be supported to receive post-transplant care and treatment in their community, in a way that supports them to 'live with culture'.

### 2.1.2 Kidney Health Australia's Indigenous Community Consultations

Complementing the Catching Some Air project in the Northern Territory, Kidney Health Australia (KHA) is currently conducting a series of community consultations in 16-18 non-Northern Territory Indigenous communities around Australia to further inform the development of the KHA-CARI Guideline for Management of CKD in Aboriginal and Torres Strait Islander peoples. These community consultations, also referred to as 'yarning circles', are part of a 2-year federally-funded program, supported by the office of the Indigenous Health Minister, the Hon Ken Wyatt MP. The consultations have two specific aims:

- To seek feedback and advice on the focus and content of the proposed KHA-CARI clinical guideline for the Management of CKD among Aboriginal and Torres Strait Islander Peoples; and
- To seek feedback and advice on the opportunities for translation of the new clinical guideline into culturally-safe consumer information, tools and education materials (KHA, 2018).

The methodology for this project is outlined in Duff et al. (2018), and is underpinned by local Indigenous governance and clear pathways for feedback to community. Local Aboriginal and Torres Strait Islander Reference Groups will be identified and established in the selected urban and regional communities (KHA, 2018a). The Reference Groups' role will be to provide input on the questions and format of the consultation in each site, inform Elders and other relevant community members about the consultation and invite them to be involved, and provide feedback on draft consultation reports which will be developed for each site based on specific needs at that site (KHA, 2018a). Consultations will be co-convened by a lead clinical contact or researcher in partnership with a local Indigenous community contact (KHA, 2018a). Consultations will include discussions around the scope, content and implementation of the KHA-CARI CKD management guidelines, in addition to general discussions about renal care including transplantation.

### 2.1.3 Indigenous Patient Voices Symposium

Experts in kidney health, including Indigenous people living with kidney disease (i.e. patients with CKD, ESKD, kidney transplants and carers), clinicians from primary, secondary and tertiary care, researchers and policy leaders, gathered in Darwin on 6 September 2017 for the inaugural Indigenous Patient Voices Symposium. This was linked with the 53<sup>rd</sup> Annual Scientific Meeting of the Australia and New Zealand Society of Nephrology (Hughes, Dembski, et al., 2018). Patients and carers described key historical events and milestones that shaped the way they lived their lives, and discussed the specific challenges they faced in accessing appropriate information and education, primary care and specialist services (Hughes, Dembski, et al., 2018). Patients' lived experiences were then used to inform an action plan, performance indicators for renal care, and a series of recommendations for state and federal governments to consider and address as part of future policy initiatives (Hughes, Dembski, et al., 2018).

### **Box 3: Indigenous Patient Voices Symposium – key issues raised by consumers**

- The tyranny of distance presents significant social, financial and logistical burdens.
  - Dialysis and transplant services need to be available close to home so that patients can stay connected to community and country, and subsequently maintain psychosocial wellbeing, whilst undergoing assessment and treatment.
  - Patients reported issues in accessing suitable accommodation services when required to relocate from their community for treatment services, such as assessment for transplantation.
  - In many cases, patients' employment was jeopardised by the travel demands associated with their treatment regimen. As a result, many patients were unemployed and subjected to Centrelink's punitive reporting framework.
- The health workforce's level of cultural awareness and respect for cultural matters.
  - The way in which health care professionals communicate with Indigenous patients was recalled with hurt and distress by some expert-patient delegates.
- Inequalities associated with the Australian health care system's centralised care model.
  - Patients who cannot dialyse in their home communities reported feeling that they were forced to choose between their physical health and maintaining psychosocial wellbeing by remaining on country.
  - The lack of information and education services around access to deceased and living donor transplant in regional and remote communities impedes Indigenous patients' likelihood of being waitlisted for or receiving a transplant.

#### 2.1.4 Indigenous knowledge in health services: a consumer partnership framework

In 2018, the Menzies School of Health Research published the findings from a qualitative research framework that enabled Indigenous renal patients' expectations and satisfaction of care in the Northern Territory to guide recommendations for health care policy and planning. The Indigenous reference group (IRG) was comprised of six Darwin-based haemodialysis patients, who met on a bimonthly basis between April and November 2017 (Kirkham et al., 2018). The key takeaway message from the IRG was that ESKD patients desire opportunities to positively influence dialysis and transplant care policies, and the consumer partnership framework employed by this study provided an appropriate model through which to do so (Kirkham et al., 2018).

The IRG's discussions and recommendations led to the adoption of several new initiatives, including the 'Kidney Yarning Circle-Pathways to My Home' education program. This program provides Indigenous patients and families with more appropriate information and orientation to services, including education about the transplantation journey (Kirkham et al., 2018). Both IRG members and project investigators recommended that a similar consumer partnership framework be embedded into the Top End Health Service's operational structures (Kirkham et al., 2018).

#### 2.1.5 Patient-led Participatory Action Research (PAR) Project

The patient-led PAR project, run by the Menzies School of Health Research between July 2016 and May 2017, involved the development of patient-led cultural awareness training for renal nurses and was catalysed by the Central Australian Renal Voice (CARV) consumer group. Members from the CARV consumer group expressed an interest in teaching renal nurses about Indigenous culture and in building better relationships between Indigenous people on dialysis and the nurses who deliver their

care (Togni et al., 2017). Nurses were recruited from each of the Alice Springs renal units and Purple House (WDNWPT), and participated in a series of workshops that provided information on language, living on country, bush foods and medicines, hunting, cultural and family obligations, and how to make Indigenous people feel comfortable in dialysis units (Togni et al., 2017). Nurses who participated in the project reported that the workshops strengthened their relationships with co-researchers and patients and influenced their practice, thus improving the delivery of culturally sensitive and patient-centred care to Indigenous dialysis patients (Togni et al., 2017).

#### 2.1.6 IMPAKT

The IMPAKT project, coordinated by the Menzies School of Health Research between 2004 and 2008, investigated the disparity in access to kidney transplants between Indigenous and non-Indigenous Australians. The team of IMPAKT researchers visited and worked in 26 locations across South Australia, New South Wales, Queensland, Western Australia and the Northern Territory, including urban centres, regional towns and remote communities (Devitt et al., 2008). The project involved an in-depth exploration of patients' and health care providers' perceptions and attitudes toward transplant services, and specifically focussed on the following key objectives:

- 1) To assess the impact of medical and socio-demographic variables, especially Indigenous status, on the likelihood of being deemed medically suitable for renal transplant;
- 2) To evaluate the appropriateness, accessibility and effectiveness of patient education programs about renal transplant for Indigenous patients;
- 3) To identify systemic barriers to completing the essential steps towards transplant;
- 4) To examine the effect of current deceased-organ allocation algorithms upon Indigenous patients' access to transplant, and to model alternative allocations; and
- 5) To collaborate with health service providers to investigate current practices and to improve the efficiency and equity of transplant services (Devitt et al., 2008).

#### **Box 4: Core themes identified by IMPAKT**

- Indigenous patients' interest in transplant:
  - Indigenous patients are interested in transplant but unclear about the process. They also wish to be better informed about their treatment plans.
  - Patient education is not culturally tailored for Indigenous people.
- Clinical uncertainties:
  - Many key transplant decision-makers are uncertain about the benefits of transplant for Indigenous patients.
  - There is a widespread perception among health service providers that Indigenous patients are less likely to adhere to treatment requirements.
- Systemic issues:
  - Communication issues profoundly affect patient/provider interactions at all levels in ways that disadvantage Indigenous patients.
  - Under-resourcing and systems deficits, especially in regional areas, reduce capacity to address the needs of Indigenous patients.
  - Distance and remoteness have a profound impact on patient care ("IMPAKT ", 2013).

The IMPAKT study team has published a number of peer-reviewed publications that speak not only to transplantation access, but more general experiences of accessing and utilising treatment for ESKD,



providing key insights from patients regarding how services might be delivered to meet their needs (Anderson, Cunningham, Devitt, & Cass, 2013; Anderson, Cunningham, Devitt, Preece, & Cass, 2012; Anderson, Devitt, Cunningham, Preece, & Cass, 2008; Devitt et al., 2017).

### 2.1.7 Managing Two Worlds Together

While the Managing Two Worlds Together project, led by Flinders University between 2008 and 2015, did not exclusively focus on kidney disease, it did explore a range of issues relevant to Indigenous ESKD patients. The overarching goal of the project was to improve knowledge of what works well and what needs improvement in the broader health care system for Indigenous patients from rural and remote areas of South Australia and parts of the Northern Territory (Dwyer et al., 2011). To achieve this, the researchers explored patients' journeys and staff experiences, which unearthed five factors that inhibit Indigenous patients' access to health services (outlined in Table 3). While many Australians are likely to identify with one or two of these factors, Indigenous patients commonly experience all five concurrently, and interactions between these factors further exacerbates the complexity of navigating the Australian health care system (Dwyer et al., 2011).

*Table 3: Five factors that affect access and quality of care (Kelly et al., 2015).*

<b>Issue</b>	<b>Explanation</b>
<b>Rural and remote/city</b>	Some of the problems facing country Indigenous patients and their health care providers are common to all country patients.
<b>Impact of illness or injury</b>	People with chronic or complex conditions are affected more by systemic health care problems, especially across hospital/non-hospital sectors, although any patient may experience care problems.
<b>Language and communication</b>	Some communication challenges that patients and staff encounter are common to all population groups for whom English is not a first language.
<b>Financial resources</b>	It is harder for all people who have little or no extra money to meet the costs of transport, treatment, being admitted for health care, and time off work or away from home and family.
<b>Cultural safety</b>	There are ways in which Indigenous people experience unique disadvantage in their interactions with the mainstream health system (and other social systems); and mainstream worldviews and beliefs about health and health care are often different from those held by Indigenous people.

### 2.1.8 Where to next?

#### **Box 5: Summary of Recommendations**

1. Undertake consumer engagement projects that specifically explore Indigenous transplant candidates' and recipients' preferred models of care.
2. Deliver consumer engagement training to renal unit and transplant centre staff.
3. Establish an Indigenous reference group in every transplant unit to help design pathways and models of care that are culturally appropriate.

Capturing patients' lived experiences, and using these stories to drive meaningful health care reform, is arguably one of the most effective ways in which to address health care inequalities. Consumer engagement frameworks have proven to be a practical and effective methodology in health and medical research, but few health care services have drawn upon these frameworks to improve models of care in practice. For example, recent interviews with renal units revealed that no units had formally established an Indigenous consumer reference group to inform the care of Indigenous kidney

transplant candidates and recipients. Future consumer engagement projects should specifically explore the journeys and experiences of Indigenous transplant candidates and recipients and be designed to achieve effective research translation, informing patient-centred interventions.

Much of the work that has been undertaken in the ESKD consumer engagement space to date has explored how we can achieve better health outcomes for Indigenous Australians. This has generated a number of clear messages that cut across both pre- and post-transplant domains, all of which are addressed in latter chapters of this report, including:

- Health services and practitioners must improve the **accessibility, appropriateness and quality of information** about the causes, prevention, management, progression and treatment of kidney disease. Such information must take into account regional differences in culture, language, patterns of kidney health and illness, and service provision.
- The **renal health workforce must be trained and supported to deliver culturally appropriate and patient-centred care** for Indigenous patients. This includes identifying new employment pathways for Indigenous Australians to support the needs of people with ESKD including personal care attendants for people needing dialysis, health service navigator roles, health promotion and renal-equipped primary health care staff, nursing and nephrologist positions.
- **More renal care services need to be delivered in regional and remote communities** to address accessibility issues, and stronger transport networks and infrastructure should be established so that the Indigenous renal patient community can travel safely between metropolitan treatment services and their home community safely, without exorbitant costs.
- Dialysis and transplant **models of care need to be tailored** to cater for the unique needs of Indigenous patients, such as having separate spaces for men's care and women's care, and recognising the importance of family support.

While these issues have been known for some time, in many cases over several decades, practical responses from health care services and governments in the transplantation context have been few and far between. From a health service policy perspective, it is recommended that every Australian transplant unit managing Indigenous transplant patients explicitly convene an Indigenous reference group to allow Indigenous consumers to drive health care enhancements and improve patient-centred outcomes for Indigenous kidney transplant candidates and recipients. This is consistent with the National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander Health, Action 2.13, which outlines the importance of health service organisations building effective and ongoing relationships with Indigenous communities, organisations and groups to identify service gaps, understand cultural beliefs and practices, and involve Indigenous people in determining their own health priorities (ACSQHC, 2017). In order to maximise the value of Indigenous reference groups, renal care providers need to be trained in consumer engagement practices to enable them to establish effective partnerships with Indigenous consumers and groups and drive the implementation of preferred models of care.

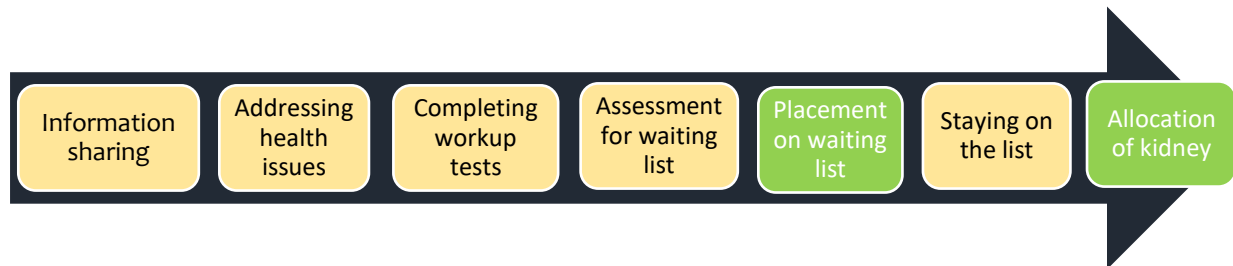
## 2.2 Pre-Transplant Journey

Indigenous Australians are less likely to receive a kidney transplant than other Australians, primarily because they are less likely to be waitlisted (Khanal, Lawton, Cass, & McDonald, 2018). At the end of 2015, only 1.9% of all Indigenous dialysis patients were waitlisted, compared to 9.5% of non-

Indigenous patients (Lawton, McDonald, Snelling, Hughes, & Cass, 2017), which is similar to rates in the United States, Canada and New Zealand (Yeates et al., 2009).

Placement on the transplant waiting list is the culmination of a series of steps and assessments, including information sharing and patient education, addressing underlying health issues and referral for consideration for transplantation, as outlined in Figure 4. If not managed appropriately, these steps can quickly become barriers to waitlisting, particularly for rural and remote Indigenous patients (Khanal et al., 2018). Waitlisting cannot occur until the transplant assessment is successfully completed, with the patient being deemed medically suitable for a kidney transplant.

Figure 4: Steps to receiving a kidney transplantation.



Indigenous patients face multiple challenges in successfully completing work-up, and practitioners have acknowledged that patients are required to navigate a system that has been described as “fragmented, confusing, isolating and burdensome” (Devitt et al., 2017).

### 2.2.1 Information sharing and understanding the transplantation process

Qualitative research has repeatedly documented concerns about poor communication between Indigenous ESKD patients and non-Indigenous health professionals (Anderson et al., 2008; Cass et al., 2002; Hughes, Dembski, et al., 2017; Rix, Barclay, Stirling, Tong, & Wilson, 2015). Poorer outcomes for Indigenous patients, including confusion and frustration (Anderson et al., 2008; Cass et al., 2002), discharge against medical advice (Einsiedel et al., 2013) and distrust of health care providers (Swain & Barclay, 2013; Tonelli et al., 2005) have been attributed to culturally inappropriate and ineffective communication practices. Indigenous patients’ lower levels of understanding of both their illness and its treatments have been linked to reduced active engagement in critical decision-making junctures and long-term management of their condition (Devitt & McMasters, 1998). The engagement of interpreters to assist Indigenous patients in health care settings has also been identified as grossly underutilised (Amery, 2017), primarily due to structural and process barriers (Ralph et al., 2017). These barriers comprise: limited interpreter availability, complexity in booking interpreters, health care provider time constraints, inadequate delivery of tools and training in cultural competence and working with interpreters, low knowledge and documentation of which language patients speak, and preferential use of unofficial interpreters (i.e. family members) for convenience (Ralph et al., 2017).

In a large and diverse cohort study of Indigenous dialysis patients, Devitt et al. (2017) found that the vast majority expressed a positive, in some cases intense, interest in receiving a kidney transplant. While many patients viewed it as their only hope of re-establishing a normal life in their homeland with their family, only half of the respondents reported feeling sufficiently informed about their transplant status and prospects (Devitt et al., 2017). Devitt et al. (2017) also noted that most patients only had a rudimentary knowledge of transplantation and an extremely limited understanding of eligibility criteria, the pathway to being listed and the risks/benefits associated with transplantation. Of the 146 Indigenous patients interviewed, one in four were either mistaken or uncertain about their

current listing status (Devitt et al., 2017). These issues have been reinforced by repeated anecdotes from staff and patients in dialysis units who have reported that education and discussions about transplantation are commonly misinterpreted by Indigenous patients as automatic acceptance and placement on the waitlist.

The multiple communication barriers faced by Indigenous patients not only undermines their engagement in treatment decision-making, but also promotes a sense of disempowerment at the individual, family and community level (Devitt et al., 2017; Sypek et al., 2018).

#### 2.2.1.1 *Culturally appropriate communication and education resources*

Research has noted several common difficulties experienced by the predominantly non-Indigenous health workforce in effectively communicating with Indigenous people and providing appropriate advice. In many cases, these difficulties drive a misperception that Indigenous patients have limited capacity to understand and adhere to strict medical regimes (Anderson, Devitt, et al., 2012; Cass et al., 2002). Factors contributing to poor communication between health professionals and Indigenous patients include: multiple linguistic, social and cultural communication barriers; perceptions of systematic exclusion from critical knowledge (Lowell et al., 2012); a lack of culturally appropriate, user-friendly information and patient education strategies; and failing to assess and cater for patients' level of health literacy (Devitt et al., 2017). Health literacy competencies apply to both the seeker and provider of information, and there is a growing emphasis on the need for renal care providers to rigorously assess Indigenous patients' health literacy and tailor communication accordingly.

Indigenous patients and their families have also repeatedly raised concerns about the quality of transplant education resources. Indigenous patients' feedback suggests that: current transplant information formats are poor facilitators of emotional engagement; the volume of information is often overwhelming; not all of it is relevant to the individual; and it is commonly complicated with the use of medical jargon, requiring practitioners' assistance to decode the message (Cass, Cunningham, Snelling, Wang, & Hoy, 2003; Dole, 2013; Hayes, 2008; Liaw et al., 2011; Yeates et al., 2009). Despite these concerns, most transplant education resources continue to focus on the non-Indigenous population, and the small percentage that have been tailored for the Indigenous patient cohort are primarily developed by clinical nursing staff, who have limited capacity to address the resource gap. Importantly, few Australian transplant resources or education programs to date have been developed with Indigenous consumer input or independently evaluated.

An evaluation of a transplant education program in the United States tailored to meet the unique cultural and linguistic needs of Hispanic patients found that it empowered both patients and their families by addressing specific cultural concerns and improving attitudes about kidney transplantation, thus facilitating increased access to the transplant waiting list (Gordon et al., 2014). While no comparable program has been trialled for the Indigenous Australian population, the need for culturally competent pre-transplant education programs is indisputable and has been identified by both patients and health professionals in numerous studies (Anderson et al., 2008; Cass et al., 2002; Lambert, Mullan, Mansfield, & Lonergan, 2015).

#### 2.2.1.2 *Differing spiritual beliefs and decision-making processes*

For many Indigenous people, the kidney holds special importance in relation to spiritual and physical wellbeing. A sick kidney represents more than physical ill health in some cultures, and accepting a kidney from another person has ramifications beyond the release from maintenance dialysis. As a

result, some Indigenous people may distrust transplantation and disregard it as a viable treatment option for themselves or family members (Anderson, Yeates, Cunningham, Devitt, & Cass, 2009). While there is some literature and anecdotal evidence to suggest this is primarily a view held by older family members with a lesser impact on younger generations, the relationship, influence and authority of elder family members in the decision-making process must be fully appreciated by practitioners.

For many Indigenous communities, important decisions are not made by the individual in isolation, and consultation with extended family over a period of several months or longer are considered essential. This is a process that must run its course, but the significant delays it causes in completing informed consent, transplant assessment and work-up supports the case for education and discussions on treatment options to commence early, ideally before dialysis is initiated.

#### 2.2.1.3 Late referral to dialysis

Late referral (defined as being first seen by a nephrologist less than 3 months prior to starting dialysis) is now less prevalent among Indigenous patients than non-Indigenous patients, as shown in Table 4. These rates show that 83% of Indigenous ESKD patients are assessed by a nephrologist well in advance of commencing dialysis, providing an opportunity for early discussions about treatment pathways.

Table 4: Percentage of Late Referral by Ethnicity 2013-2017 (ANZDATA, 2018).

Year	Non-Indigenous	Indigenous
2013	19%	18%
2014	18%	15%
2015	18%	17%
2016	19%	14%
2017	18%	17%

Late referral manifests in poorer physical condition at commencement of treatment and negatively impacts ensuing treatment phases (Cass, Cunningham, Snelling, & Ayanian, 2003). The development of user-friendly, culturally-informed methods to educate Indigenous patients and their families is still needed to combat late referral and promote early transplant and organ donation decision making.

#### 2.2.1.4 The role of patient navigator programs (PNPs)

In the past decade, there has been considerable interest in the role of patient navigators in addressing systematic problems in access to health care for Indigenous patients. The first PNP was established in New York in 1990 to address perceived barriers stemming from mistrust, fatalistic views and system complexity experienced by medically underserved, generally African American women, with breast cancer (H. P. Freeman, 2006). The objective of PNPs is to train lay individuals to provide one-on-one support during assessment, treatment and beyond for individuals who may have a limited understanding of Western health care systems (Whop et al., 2012). In recent years, PNPs have become more widely used, particularly in the Canadian Indigenous population, and have expanded to not only inform patients about treatment options and available services, but also to address cultural, educational and language barriers through community outreach (Whop et al., 2012).

While the efficacy of PNPs in the Indigenous kidney transplant candidate and recipient population remains unclear, feedback from consumer engagement activities suggests that this is a potentially valuable initiative worth evaluating in Australian renal units and transplant centres.

## 2.2.2 Completing transplant workup tests and formal assessment

### 2.2.2.1 Personal agency and competing priorities

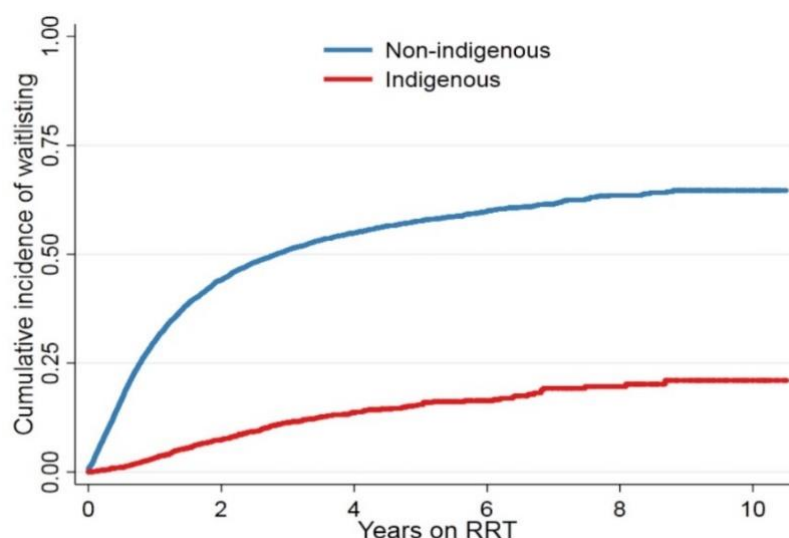
Competing family priorities and cultural obligations, a personally resource intense treatment regime and multiple specialist and investigative appointments can lead to poor attendance at transplant workup and assessment appointments. This can manifest in further delays with regard to the completion of transplant assessment, workup and admittance to the waitlist. Practitioners may also associate poor attendance with non-adherence, which influences expectations of future behaviour, including how the patient would manage and respond to the demands of kidney transplantation, promoting unconscious bias and institutional racism (Majoni & Abeyaratne, 2013; Rix et al., 2015; Tonelli et al., 2005; Tonelli et al., 2004; Yeates et al., 2009).

### 2.2.2.2 Geographical barriers

While there is great diversity among the Indigenous Australian population, many Indigenous patients share social and environmental factors that are likely to affect how they respond to the demands of pre-transplant assessments (Anderson et al., 2013). One particularly prevalent factor is remoteness, with two-thirds of Australia's Indigenous population living in rural and remote communities, often with populations between 50 and 3000 people (Anderson et al., 2013). The prevalence and burden of ESKD is significantly greater in remote compared to urban areas (ANZDATA, 2018; Cass et al., 2001), and the need to relocate to access treatment has a strong negative impact on individuals, families and entire communities (Preston-Thomas, Cass, & O'Rourke, 2007).

Geographical variation in transplant rates has been reported in North America, Canada, Europe and Australia (Yeates et al., 2009). Recent research has reaffirmed that Indigenous patients undergoing dialysis are substantially less likely than non-Indigenous patients to be placed on the transplant waitlist, as shown in Figure 5, with this disparity increasing with remoteness (Khanal et al., 2018).

Figure 5: Unadjusted Kaplan Meier (K-M) curve showing cumulative incidence of waitlisting (time to placement on the waitlist after initiation of RRT) by ethnicity (Khanal et al., 2018).



### 2.2.2.3 Requirement to travel long distances and coordinate multidisciplinary services

Access to health-related infrastructure in remote communities is generally poor, and in 2005-06 approximately half of Indigenous ESKD patients resided in areas with neither dialysis nor transplant facilities (Anderson et al., 2013). However, even when renal services are available within the local

community, certain basic investigative tests required for pre-transplant workup are commonly only performed in urban areas, including:

- Cardiac investigations (i.e. echocardiography, coronary angiogram and stress test)
- Radiology investigations (i.e. chest x-ray, abdominal/renal ultrasound, bone density studies)
- Dental examination
- Dermatology review
- Lung function
- Infective screening (i.e. MRSA, VRE)

Undertaking regular day or overnight trips to tertiary facilities hundreds of kilometres away, or even interstate, is time consuming and logistically challenging. In addition to travel related stressors, coordinating specialist appointments, transport operators, community clinics, accommodation providers and dialysis units requires extensive planning. Failure to secure all of the required bookings or capacity issues with any one operator can derail the process, making the completion of tests a lengthy and frustrating process for rural and remote patients. Additionally, in some instances Indigenous patients' reluctance to leave their community to complete pre-transplant assessment and workup, or a need to return to community during the assessment process for family and cultural obligations, manifests in further delays and reduces their likelihood of achieving waitlisting status.

#### **Box 6: Case study of a waitlisting journey delayed due to family obligations**

A 62-year-old male patient from the Tiwi Islands commenced dialysis in May 2014. He received transplant education in July 2015, was assessed for transplantation in July 2016 and then referred for transplant workup in August 2016. Since then, his workup journey has comprised:

- In September 2016, dental outreach in the Tiwi Islands was undertaken.
- In May 2017, the patient travelled to Darwin for a week of workup, but left halfway through to attend a funeral back home.
- In October 2017, the patient returned to Darwin to complete cardiac testing but failed to attend a follow up dental appointment.
- In November 2017, the Royal Adelaide Hospital reviewed the patient for transplant waitlisting, but needed the patient to complete Mantoux, dental and HLA tests.
- In August 2018, the patient travelled to Darwin for further workup testing but developed chest pain and could not complete the scheduled appointments.
- In December 2018, the patient failed to attend cardiology and dental appointments in Darwin due to a funeral in the Tiwi Islands.
- As of January 2019, the patient is still yet to complete cardiology and dental consultations.

This case study highlights the difficulties faced by rural and remote patients in completing workup and achieving waitlisting. In many cases, these patients are required to put their lives on hold in order to complete testing in an urban centre that is hundreds or thousands of kilometres from their home community. Those who prioritise family and cultural obligations are likely to be negatively affected by workup delays, as most tests cannot be performed in the home community.

Patient assisted travel schemes (PATS) are managed by the states and territories, and all jurisdictions subsidise accommodation and private vehicle travel for eligible patients (NRHA, 2014). While eligibility varies between jurisdictions, PATS is typically available to patients travelling more than 100km one

way for specialist medical services. Fuel allowances are generally only intended to cover a portion of the cost of fuel on a cents per kilometre basis, and commercial accommodation subsidies are limited, ranging from \$40 to \$60 per person per night. Some schemes also provide support for ground and air transport, which is vital for jurisdictions such as the Northern Territory where distances to specialist services can be vast. Over the past decade, a number of PATS schemes have been reviewed at federal state and territory government levels. Recurring recommendations have centred around increasing subsidies for accommodation and travel; streamlining the process for claiming reimbursements; and expanding the schemes to capture a range of essential non-medical specialist services such as allied health and dentistry, which are particularly important for kidney transplant candidates (NRHA, 2014).

Multidisciplinary pre-transplant teams comprise a health care network devoted to identifying, preventing and managing the complications that arise in a patient’s journey to transplantation. A variety of medical and allied health staff, including nephrologists, nurses, dentists, pharmacists, social workers and Indigenous health workers, form part of pre-transplant teams, which work with and improve coordination between the primary and tertiary health care sectors. These teams also deliver accurate and culturally appropriate education, information and clinical care to kidney transplant candidates. Multidisciplinary outreach clinics should be made available to patients in rural and remote areas every 3 months, and an example of a patient’s appointment schedule is outlined in Table 5.

Table 5: Example of a patient’s schedule for a multidisciplinary pre-transplant clinic.

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
<b>Transplant coordinator</b>	X			X			X			X
<b>Nephrologist</b>	X						X			X
<b>Nurse practitioner</b>	X			X						X
<b>Cardiothoracic surgeon</b>	X									
<b>Vascular surgeon</b>							X			
<b>Dentist</b>				X						X
<b>Dermatologist</b>				X			X			
<b>Pharmacist</b>	X						X			
<b>Endocrinologist</b>				X						
<b>Dietitian</b>				X						X
<b>Social worker</b>	X									X
<b>Aboriginal Liaison Officer</b>	X			X			X			X

**Box 7: Primary objectives of multidisciplinary pre-transplant care**

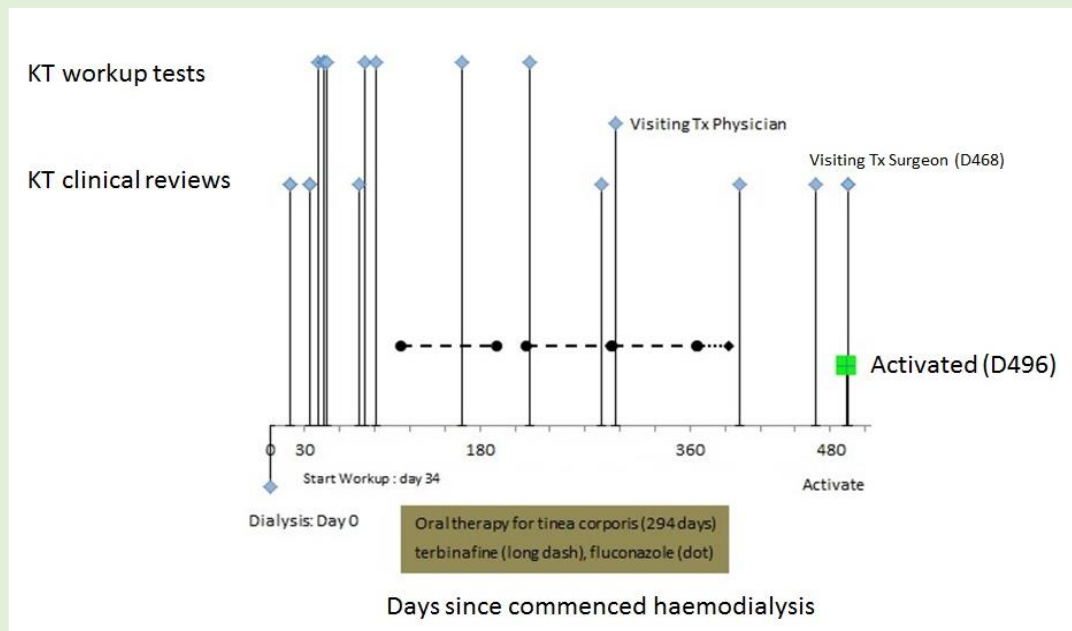
- To evaluate and manage comorbid conditions (i.e. diabetes, hypertension, infections);
- To prevent and manage cardiovascular disease;
- To identify, prevent and manage ESKD specific complications (i.e. management of nutrition, anaemia, renal bone disease as well as fluid, electrolyte and acid-base problems); and
- To help patients and their families prepare for the demands of transplantation.



### Box 8: Case study of a waitlisting journey delayed due to dermatological treatment

A 41-year-old female with presumed diabetic nephropathy commenced dialysis (Day 0) following rapid declining kidney function in the preceding 2 years. She had previously documented chronic tinea corporis (a dermatophyte infection of the skin), which was again microbiologically confirmed on Day 61. As shown in Figure 6, complete resolution of tinea corporis was eventually achieved on Day 396 following 294 days of targeted treatment. Throughout this journey, the patient never experienced a serious soft-tissue infection or bacteraemia, and was engaged in her renal care, including participating in numerous appointments (Hughes, Aye-Min, et al., 2017). In order to complete the assessments, the patient opted to relocate to the urban centre for chronic maintenance dialysis, as she recognised that she may not have completed the assessments and achieved waitlisting if she remained in her home community.

Figure 6: Timeline to activation to the transplant waitlist (Hughes, Aye-Min, et al., 2017).



The delayed cure of chronic and extensive tinea corporis was responsible for 59% of the time taken to achieve active kidney transplant waitlisting (294 days of 496 days). Timeliness to achieve complete resolution of the infection and subsequent waitlisting failed to meet the expectations of both the patient and clinicians. A combination of systemic and individual factors contributed to the delayed resolution, including: disjointed communication, lack of access to medication, normalisation of skin conditions in the Indigenous population, and the clients' competing priorities (Hughes, Aye-Min, et al., 2017).

#### 2.2.2.4 Access to transplant acceptance team delaying entry to waitlist

The majority of dialysis units caring for Indigenous patients in Australia are distant from the tertiary transplant service. While teleconferences may keep communication channels open, patient review and acceptance onto the waitlist is dependent on visits from the tertiary centre and transplant acceptance team and assessment by transplant physician and surgeon. The availability of these visits varies nationally; renal unit staff from Adelaide travel to Alice Springs, Darwin and Katherine to provide

services, while patients in Queensland, Western Australia and New South Wales must travel to major metropolitan centres (i.e. Brisbane, Perth, Sydney or Newcastle) to access transplant assessment.

As part of this project, structured interviews were conducted with all transplant units throughout Australia. These interviews revealed that infrequent visits and logistics of coordinating patient attendance with transplant team visits can delay admission to the waitlist. As a result, geographical distance is an issue not only for those residing in remote and very remote areas (i.e. Kalgoorlie, Broome, Mt Isa, Alice Springs), but also applies to tertiary facilities with large catchment areas such as Cairns, Townsville, Darwin.

### 2.2.3 Staying healthy on the list

Once placed on the transplant waitlist, it is vital that the patient stay as healthy as possible to ensure they remain on the waitlist and are medically fit for the transplant operation to reduce the risk of complications in the recovery phase (KHA, 2019). The national clinical guidelines for organ transplantation indicate that in order to remain active on the waitlist, patients should undergo annual reassessment by the transplant unit to ensure they continue to fulfil the inclusion criteria (TSANZ, 2018). Common factors that may result in the removal of a patient from the active waitlist include cardiovascular disease, uncontrolled diabetes, worsening comorbid diseases, systemic or skin infections, inability to maintain recommended diet and fluid intake, weight gain/obesity and evidence of poor adherence to prescribed medications and treatments (TSANZ, 2018). Evidence suggests that the likelihood of transplantation during the first year of waitlisting is similar for Indigenous and non-Indigenous patients, but significantly lower for Indigenous patients in subsequent years, which may be linked to issues associated with the management of comorbidities and removal from the waiting list (Khanal et al., 2018).

It is well documented that the burden of comorbidities is significantly higher among Indigenous dialysis patients and kidney transplant candidates, particularly diabetes. Diabetes heightens the risk of post-transplant complications, including cardiovascular events and mortality, and past research has shown that the 5-year post-transplant survival rate for diabetic patients is significantly lower than for non-diabetics' (70% vs 93%) (Cosio, Hickson, Griffin, Stegall, & Kudva, 2008). Indigenous patients' comorbidity burden is further exacerbated by socio-economic factors such as access to accommodation, quality and quantity of food and appropriate clothing (particularly footwear) (Dole, 2013; Majoni & Abeyaratne, 2013; Tong et al., 2011). The longer patients remain on dialysis and the transplant waitlist, the greater the probability that these conditions will take their toll, reducing the chance of receiving a kidney transplant.

Fulfilling requirements to stay on the waitlist can be particularly challenging for rural and remote Indigenous patients. Following the initial transplant assessment, waitlisted patients are required to undertake annual reassessments (TSANZ, 2018). For rural and remote patients, this commonly necessitates extensive logistical planning given the number of assessments that need to be completed and the lack of essential services in close proximity. Difficulties associated with maintaining currency of tests means patients may find themselves in a constant cycle of examinations, rather than a single set of tests that roll around once a year.

### 2.2.4 Surgical assessment

Despite improved operative techniques and immunosuppressive regimens, surgical complications following a kidney transplant remain an important challenge that can increase morbidity,

hospitalisation and costs. Surgical complications occurring in the general population after a kidney transplant are well described, including surgical site infections (occurring in 4% - 7.5% of patients), wound healing disorders (occurring in around 20% of patients), urologic complications (occurring in 2.4% - 14% of patients) and arterial and venous thrombosis (occurring in less than 5% of patients), (Di Carlo & Darras, 2015; Katz et al., 2003; Pourmand et al., 2012). Very little is known about the prevalence and antecedents of these complications in the Indigenous patient population. However, anecdotal evidence suggests that Indigenous recipients are at greater risk of wound healing disorders and urologic complications due to higher rates of overweight and obesity and cultural rituals that involve the circumcision and subincision of the penis and urethra. Further research is needed to determine whether tailored pre-transplant surgical assessment and post-transplant monitoring and management protocols are required to reduce the occurrence of surgical complications and adverse outcomes in Indigenous transplant recipients.

One of the few studies to explore the burden and pattern of infection following renal transplantation in Indigenous ( $n = 57$ ) compared to non-Indigenous ( $n = 84$ ) patients found that there was a non-significant trend of more admission days because of infection in the first year in the Indigenous compared to non-Indigenous group, and pneumonia and cryptosporidium were more frequent causes of infectious admission in the Indigenous group, as outlined in Table 6 (Boan et al., 2017).

*Table 6: Admission days in the first year post-transplant according to site of infection in Indigenous versus non-Indigenous kidney transplant recipients (Boan et al., 2017).*

	<b>Indigenous patient admission days (<math>n = 568</math>) <math>n</math> (%)</b>	<b>Non-Indigenous patient admission days (<math>n = 458</math>) <math>n</math> (%)</b>	<b><i>P</i>- value</b>
<b>Urine</b>	116 (20)	174 (38)	<0.001
<b>Bacteraemia</b>	92 (16)	82 (18)	0.503
<b>Wound</b>	88 (15)	26 (6)	<0.001
<b>Invasive Fungal Infection</b>	58 (10)	46 (10)	1.000
<b>Pneumonia</b>	56 (10)	10 (2)	<0.001
<b>Skin and Soft Tissue Infection</b>	11 (2)	18 (4)	0.060
<b>Cryptosporidium</b>	90 (16)	0 (0)	<0.001
<b>Other</b>	57 (10)	102 (22)	<0.001

An ANZDATA analysis of first deceased donor recipients in Australia from 2001 – 2017 found that the rate of technical graft loss within 30 days post-transplant is low for both non-Indigenous and Indigenous kidney transplant recipients (1.4% and 1.6% respectively). An expansive definition of technical graft loss was used, comprising renal artery stenosis and thrombosis, renal vein thrombosis, haemorrhage (primary and secondary), embolus (thrombo and cholesterol), non-viable kidney (due to pre-transplant cortical necrosis), cortical necrosis (not due to rejection), and ureteric and bladder problems. No clear relationship between technical graft loss and BMI was identified, which may reflect current waitlisting practices that prevent people with ‘unsafe’ BMI ranges from being listed for a kidney transplant. However, Indigenous recipients were significantly more likely to be in the upper BMI ranges compared to non-Indigenous recipients; 20.5% of Indigenous patients had a BMI greater than 30 compared to 16.9% of non-Indigenous patients, and 13.8% of Indigenous patients had a BMI greater than 35 compared to 8.4% of non-Indigenous patients.

Multiple risk factors for surgical complications have been identified in kidney transplant recipients, including: obesity, diabetes, cardiovascular disease, acute cellular rejection, delayed graft function, and prolonged cold ischemia time (Harris et al., 2015). Obesity serves as both a direct and indirect risk factor for adverse short- and long-term effects, as outlined in Table 7. Given these associated technical difficulties, surgical site complications and outcome-related concerns, many transplant programs impose a maximum BMI eligibility threshold for kidney transplant candidates, though this is not formally recommended in the national eligibility guidelines (TSANZ, 2018).

Table 7: Direct and indirect effects of obesity (Gill, 2008).

Short-term direct effects	Long-term direct effects	Long-term indirect effects
Wound complications: delayed healing, infection & sepsis	Increased risk of rejection	Diabetes
Lymphocele	Increased risk of graft loss	Vascular disease
Hematoma		Cardiovascular disease
Prolonged cold ischemia time & delayed graft function		
Increased risk of hospital readmission		

The relationship between body composition and body weight has been found to differ significantly between Indigenous and non-Indigenous Australians, suggesting that the currently recommended classification of weight status, based on BMI, may be inappropriate for use in the Indigenous patient population (Maple-Brown et al., 2015; Piers, Rowley, Soares, & O'Dea, 2003). While other measures (i.e. waist circumference, waist hip-ratio and bioelectrical impedance analysis) are not currently collected on a national basis, surgeons typically do not rely on these measures to assess whether patients' obesity poses an unacceptable technical challenge for surgery, opting instead for a thorough clinical examination to determine suitability.

#### 2.2.4.1 Prevalence of surgical risk factors in Indigenous kidney transplant recipients

An observational cohort study of all adult patients registered with ANZDATA who commenced RRT in Australia between 28 June 2006 and 31 December 2016 found that 61.3% of Indigenous patients had comorbid conditions compared to 35.6% of non-Indigenous patients (Khanal et al., 2018). Surgical risk factor discrepancies are also evident among the kidney transplant recipient cohort, with Indigenous recipients more likely to have a higher BMI, be classified as smokers and experience comorbidities such as diabetes and coronary artery disease. They also experience longer total ischaemic time and greater delayed graft function, as outlined in Table 8.

*Table 8: Cohort description of primary deceased donor kidney transplants performed in Australia between 2001 and 2016, based on a de-identified extract from the ANZDATA Registry (McDonald, Jose, Lawton, & Cass, 2018).*

<b>Surgical risk factors</b>	<b>Non-Indigenous (n = 6003)</b>	<b>Indigenous (n = 336)</b>	<b>Significance</b>
<b>BMI (median IQR kg/m<sup>2</sup>)</b>	26.1	27.7	<0.001
<b>Current smokers (at commencement of RRT)</b>	11%	26%	<0.001
<b>Diabetes</b>	17%	46%	<0.001
<b>Coronary artery disease</b>	12%	18%	<0.001
<b>Peripheral vascular disease</b>	7%	10%	0.04
<b>Total ischaemic time (hours, median IQR)</b>	12	14	<0.001
<b>Delayed graft function</b>	29%	38%	<0.001

#### 2.2.4.2 *Weight loss approaches for the general kidney transplant candidate population*

For many people on the transplant waiting list, weight loss is likely to be beneficial in reducing the peri-operative and longer-term post-transplant risk. Facilitating weight loss is particularly critical for those whose weight prevents waitlisting due to prohibitive surgical risk. A number of studies have shown that it is important to achieve a healthy BMI prior to transplantation due to the poorer post-transplant outcomes associated with significant post-transplant weight loss or gain (S. H. Chang & McDonald, 2008; El-Agroudy, Wafa, Gheith, Shehab El-Dein, & Ghoneim, 2004). While both Indigenous and non-Indigenous recipients experience negative effects from BMI loss following transplantation, the effect is greater amongst Indigenous recipients due to their higher rates of high BMI prior to transplantation (Subramani, Ullah, Majoni, Hughes, & McDonald, 2018).

Weight loss prior to kidney transplant surgery may have a number of beneficial effects in general for kidney transplant candidates, including reduced operative time and likelihood of acute rejection, and fewer surgical complications (Chan, Garneau, & Hajjar, 2015). Weight loss can also help to reverse the progression of type 2 diabetes and improve glycaemic control, albuminuria, and eGFR (Friedman, 2019; Schauer, Mingrone, Ikramuddin, & Wolfe, 2016). However, the benefits of weight loss in the dialysis patient population are less clear. There is data from observational studies for both HD and PD patients that suggest best survival is associated with BMI in the ‘overweight’ rather than ‘normal’ range (D. Johnson et al., 2000; Kalantar-Zadeh, Abbott, Salahudeen, Kilpatrick, & Horwich, 2005; Park et al., 2014). These studies have not examined the outcomes of people who lose weight as part of a deliberate health-related strategy, and there is currently no data addressing this specific issue among Indigenous dialysis patients.

Kidney transplant candidates who would benefit from losing weight prior to transplant surgery are typically recommended to undertake conservative weight loss methods in the first instance, such as lifestyle, dietary and pharmacologic interventions (Friedman, 2019). Bariatric surgery is still considered a ‘last resort’ and eligibility is typically dependent on patients having made at least one attempt at a structured weight loss program. National Health and Medical Research (NHMRC) Clinical Practice Guidelines suggest patients should only be referred for bariatric surgery if: a) their BMI is 40 or more; b) their BMI is 35 or more with obesity-related comorbidity (i.e. diabetes, cardiovascular disease or sleep apnea); or c) their BMI is 30 or more with poorly controlled type 2 diabetes and increased cardiovascular risk (NHMRC, 2013)

#### 2.2.4.2.1 Conservative approaches to weight loss

Despite the importance of weight loss prior to transplantation, little is known about the best methods through which to achieve this, particularly in the setting of Indigenous dialysis patients (including low-energy diets and various community and health supports). However, cohort studies have indicated fewer than 10% of potential candidates lose some weight when requested for listing and even fewer (5%) attain the target BMI of less than 30 kg/m<sup>2</sup> (Howard et al., 2002).

To date, only one prospective cohort study has compared outcomes for transplant candidates who undertook a conservative weight loss regime involving a nutrition program, regular exercise, behavioural therapy and Orlistat (an oral lipase inhibitor) with a control group who were solely reliant on self-directed diet and exercise (MacLaughlin et al., 2010). Results after two years showed significantly more patients had achieved weight loss with acceptance to the wait list in the weight loss regime group (35%) compared to the self-directed diet and exercise control group (6%) (MacLaughlin et al., 2010). However, weight loss within the weight loss regime group was modest; on average, participants shed less than 10% of their baseline bodyweight over the two-year study period (MacLaughlin et al., 2010).

While it is broadly considered that significant voluntary weight loss in ESKD patients, even with intensive support, is difficult to achieve, the long-term sustainability, widespread applicability and actual benefits of a comprehensive, labour-intensive weight loss program in the kidney transplant population remains largely unknown.

#### 2.2.4.2.2 Surgical approaches to weight loss

In recent years, bariatric surgery has become a safer option for weight loss and has proven to be effective in patients with ESKD, providing a bridge to transplantation for those who were previously ineligible due to morbid obesity. An analysis of United States Medicare billing claims for open bariatric surgical procedures among kidney transplant candidates and recipients in the United States Renal Data System registry from 1991 to 2004 found that of the 188 cases of bariatric surgery identified, 72 surgeries were performed pre-waitlisting, 29 while on the waitlist, and 87 post-transplantation (Modanlou et al., 2009). Of the 29 waitlisted patients, 20 proceeded to kidney transplantation after bariatric surgery (Modanlou et al., 2009). Perioperative mortality (30-day) was 3.5% for both waitlisted and transplanted patients, primarily due to cardiac and infectious complications, comparable to some trials among patients without kidney disease (Modanlou et al., 2009). Mortality between 30 and 90 days after bariatric surgery was 3.5% for transplanted patients and 0% for patients on the waitlist at the time of surgery (Modanlou et al., 2009).

A 2004 retrospective study found that bariatric surgery was safe and effectively facilitated weight loss in 30 morbidly obese patients with CKD or ESKD (Alexander et al., 2004). Of the ten patients who were on dialysis before bariatric surgery, three were waitlisted, four were scheduled for a living donor transplant, and three received a kidney transplant (Alexander et al., 2004). Only one complication was reported (abdominal wound infection). There were no perioperative deaths; the only death reported was due to cardiovascular disease, occurring 7.9 years after bariatric surgery and 6.1 years after transplantation (Alexander et al., 2004).

The same group of researchers conducted a prospective study from 2011 to 2014, during which time all kidney transplant candidates meeting National Institutes of Health criteria for bariatric surgery were referred to a multi-disciplinary clinic that included a bariatric surgeon, dietician and coordinator

(C. M. Freeman et al., 2015). Of 170 patients deemed eligible for both bariatric surgery and kidney transplantation, 52 (47 of whom were on dialysis) underwent bariatric surgery before the end of 2014 (C. M. Freeman et al., 2015). Among this cohort, the mean BMI decreased from 43.0 to 36.4 following surgery. The majority of patients (55.8%) achieved the 'goal BMI' of less than 35 kg/m<sup>2</sup> and were subsequently placed on the waitlist, with 6 patients receiving kidney transplants after bariatric surgery (C. M. Freeman et al., 2015).

In summary, contemporary bariatric surgery techniques have proven to be effective in achieving sustained weight loss, with total weight loss averaging 20% to 35% of total body weight (A. R. Chang, Grams, & Navaneethan, 2017). In the general population, bariatric surgery has also been found to have a positive impact on type 2 diabetes and kidney function; a systematic review of bariatric surgery studies with long-term follow up reported remission rates for type 2 diabetes of 66.7% for patients who received a Roux-en-y gastric bypass (Puzziferri et al., 2014), and a number of studies have identified decreases in albuminuria and proteinuria after bariatric surgery (Afshinnia, Wilt, Duval, Esmaili, & Ibrahim, 2010; Li et al., 2016). However, bariatric surgery poses a number of substantial perioperative and postoperative risks, including infection, respiratory failure, acute kidney injury and death (A. R. Chang et al., 2017). These risks must be evaluated when considering patients' suitability for bariatric procedures, and balance against the potential health gains following transplantation.

In Australia, bariatric surgery procedures have been listed on the MBS since 1992 (Korda, Joshy, Jorm, Butler, & Banks, 2012). Admissions for this surgery rose from 9,300 to around 22,700 between 2005-06 and 2014-15 (AIHW, 2017). In 2014-15, more than 124,600 weight loss surgery-related procedures were billed to Medicare, including those provided in public and private hospitals and in non-hospital settings (AIHW, 2017). However, most of this surgery (around 89%) is carried out in private hospitals and incurs substantial out-of-pocket costs, resulting in large socioeconomic inequalities (AIHW, 2017). Around 344 Indigenous weight loss surgery procedures were performed in 2014-15, with 259 of these occurring in private hospitals (AIHW, 2017). Indigenous Australians had a higher rate of weight loss surgery in public hospitals than other Australians (1.6 and 1.2 procedures per 10,000 population, respectively), with the median waiting time for all elective bariatric surgery procedures being 73 days (AIHW, 2017). In private hospitals, other Australians had higher rates for weight loss surgery than Indigenous Australians (8.7 and 4.7 procedures per 10,000 population, respectively) (AIHW, 2017). Increasing the accessibility of publicly-funded bariatric surgery is an important step in reducing health inequality and ensuring Indigenous patients, who experience higher rates of obesity and financial disadvantage, are able to undergo essential weight loss surgery when required.

#### 2.2.4.3 *Targeted weight loss strategies for Indigenous kidney transplant candidates*

##### 2.2.4.3.1 *Culturally appropriate conservative approaches*

To be successful, conservative weight loss programs that seek to treat obesity in the Indigenous patient population must be culturally appropriate, geographically accessible and offer goal attainment that is realistic (Canuto, McDermott, Cargo, & Esterman, 2011). Indigenous patients' uptake and adherence to health programs is improved when Indigenous health services and practitioners are responsible for their delivery (McDermott, Campbell, Li, & McCulloch, 2009). Recent trials have explored programmed medical yarn ups (PMYUs) in weight control as an innovative and culturally appropriate approach to obesity and chronic disease management among the Indigenous patient population (Stevens, Egger, & Morgan, 2018). PMYU weight control programs are facilitated by a trained Indigenous health worker who leads and manages a group of six to 12 participants during six

90-minute sessions in a convenient location every two weeks for two to three months (Stevens et al., 2018). Each session is attended by a GP, and facilitators are trained to deliver a specific weight control program whilst encouraging participants to consult the GP about aspects of their health related to weight control and associated comorbidities (Stevens et al., 2018). While the PMYU model is still being trialled to gather more evidence on its utility, it is anticipated that it will be applicable to Indigenous dialysis patients. Given the critical role of obesity as a barrier to access for transplantation, it is important to evaluate the efficacy of this program and other models already successful in the broader Indigenous patient population among kidney transplant candidates to determine if this culturally tailored approach should be adopted in mainstream renal care.

#### 2.2.4.3.2 Regionalised bariatric surgery models of care

Very few studies to date have evaluated the feasibility of achieving significant and sustained weight loss in obese Indigenous Australians through the use of bariatric surgery procedures. In 2016, a prospective cohort study of 30 obese Indigenous adults from the Rumbalara Aboriginal Co-operative in Central Victoria was undertaken, with inclusion criteria including Aboriginality, BMI > 30kg/m<sup>2</sup> and diabetes diagnosed within the last 10 years (O'Brien et al., 2016). Participants were treated in their community (at the regional hospital) with laparoscopic adjustable gastric banding (LAGB) and were subsequently tracked for two years. Outcomes were compared with those of non-Indigenous Australians from an earlier randomized control trial using a similar protocol, and comparable results were identified for both weight loss and diabetes remission (O'Brien et al., 2016). Of the 30 participants, 26 completed a diabetes assessment at two years follow-up, which showed diabetes remission in 20 of the 26 participants and a mean weight loss of 26.0 kilograms (O'Brien et al., 2016). While 13 adverse events were recorded (one early and 12 late), the regionalised model of care centred on the LAGB was found to be feasible and acceptable to the participant cohort, improving quality of life and significantly reducing the prevalence of both obesity and diabetes (O'Brien et al., 2016). While this study did not specifically target kidney transplant candidates, the findings suggest that the use of regionalised bariatric surgery models of care to reduce weight, comorbidities and other surgical risk factors may improve access to the transplant waitlist and postoperative outcomes for the Indigenous ESKD patient population.

### 2.3 Post-Transplant Requirements

Kidney transplantation is considered the best form of treatment for most patients with ESKD, but patients face post-transplant challenges including the necessity of lifelong immunosuppression, regular clinic visits and medication side effects such as infections and cancer. The care of the kidney transplant recipient is a complex task, requiring many interactions between the patient, family, primary care provider, and multidisciplinary renal care team, including transplant physicians, infectious disease physicians, pharmacists, nurses, social workers and community health workers. Renal teams are typically spread across multiple services, including primary care services in local communities, dialysis units and hospitals in regional hubs, and major transplant centres in capital cities; levels of expertise and resource availability often differ greatly across these services.

The current Australian health workforce situation is characterised by an undersupply of health care providers in rural and remote areas, and an imbalance of specialist skills. Similarly, while a multi-disciplinary health care team is essential to delivering holistic care to Indigenous ESKD patients, their contribution is hampered by the limited availability of Indigenous health workers, translators and cultural educators (Gorham, Cass, Howard, & Evans, 2016). This results in poor history-taking,

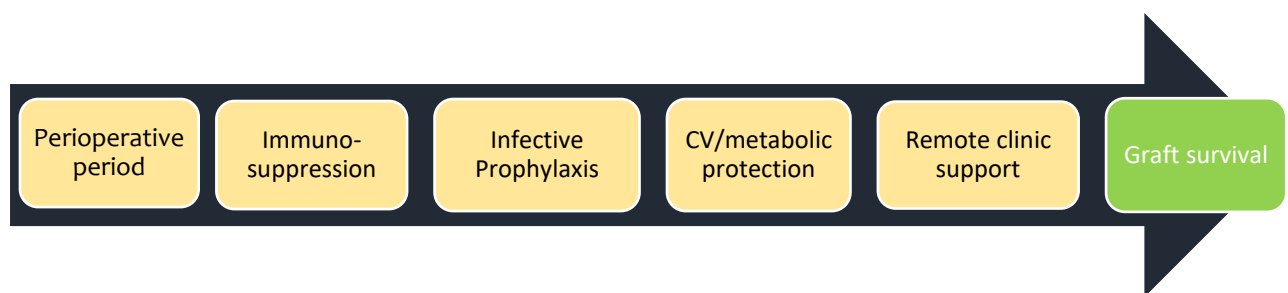


frequent miscommunications, client misunderstanding, poor adherence, lack of informed consent and ineffective service delivery (Gorham et al., 2016), all of which can imperil transplant function and prove fatal in the post-transplant context. Provision of post-transplant care is relatively ad hoc, particularly in remote communities, and models of service delivery continue to be inequitable, insufficiently planned and lack rigorous evaluation processes.

Similar to the pre-transplant journey, post-transplant assessment and treatment regimens comprise several steps, as outlined in Figure 7. Completing these steps can be demanding, especially for patients in rural and remote areas, where logistical planning and travel requirements can become all-consuming and a barrier to successful outcomes. Models of care, immunosuppression and infective prophylaxis regimens can be adapted to reduce this burden by:

- Accounting for patients' residential location and the travel required to access assessment and treatment; and
- Linking all levels of the health care system, including primary care services, local renal units and transplant centres, to ensure patients receive consistent and holistic care.

Figure 7: Getting and staying home after transplantation.



### 2.3.1 Models of Care

Transplant models of care have commonly been designed to cater for non-Indigenous recipients (Lawton, 2015). Qualitative studies have found that Indigenous ESKD patients do not feel adequately supported by the health care system to either: a) pursue and receive a kidney transplant, or b) maintain rigorous post-transplant care requirements (Anderson et al., 2008; Devitt et al., 2017; Hughes, Dembski, et al., 2018). This suggests that tailored models of care that acknowledge the heterogeneity of the kidney transplant recipient population are needed to overcome persistent systemic biases, which are further explored in [Appendix A](#).

While many health care providers want to improve the delivery of health care to Indigenous patients, competing demands - particularly competing organisational demands in a resource-constrained environment - restrict the time and resources needed to understand the complex medical, social and psychological issues that impact Indigenous patients and their experiences of the health care system (Durey & Thompson, 2012). 'Victim blaming' manifests when health care systems and providers do not acknowledge or address social and cultural differences, which deflects accountability for the negative effects of 'one size fits all' practices. These effects can result in the exclusion of cultural understandings and meanings of health that deviate from established norms, as advocated by western medicine (Durey & Thompson, 2012). A common focus of victim blaming is Indigenous patients' non-adherence with treatment regimens - an issue that commonly arises when health care providers do not tailor their communication approach to cater for patients' health literacy, social and

environmental circumstances and cultural beliefs (Durey & Thompson, 2012). This inequity has been observed in the Australian kidney transplant referral system, with one study finding that nephrologists' willingness to recommend Indigenous patients for transplantation was negatively affected by the perceived immutability of 'cultural' causes of non-adherence (Anderson, Devitt, et al., 2012). Recognising and dealing appropriately with cultural differences is crucial to improving management of Indigenous kidney transplant recipients, and the possibility of systemic stigmatisation of patients from minority groups must be monitored and managed (Anderson, Devitt, et al., 2012).

Workforce shortages in rural and remote Australia constitute the most significant barrier in implementing effective models of care for Indigenous transplant recipients, who require specialised follow-up and regular consultations with a multidisciplinary post-transplant team. Ideally, these consultations need to be made available in rural and remote areas; the onus should not be on the patient to travel great distances on a regular basis for essential post-transplant care. Improving the coordination and delivery of care in rural and remote areas should involve a multifaceted approach, comprising: multidisciplinary post-transplant clinics, point-of-care testing, telenephrology and telepharmacy, coordinated clinical pharmacy outreach services, and consistent protocols for the use of dose administration aids.

#### 2.3.1.1 *Current Practice*

Current renal unit and transplant centre models of care tend to be historical and have evolved differentially, with individual transplant units relying on the availability of resources rather than patient and community need. As part of this report, a series of structured interviews with transplant services from the Northern Territory, Western Australia, Queensland, Victoria, New South Wales and South Australia was undertaken. These interviews identified a number of common elements in models of care:

- Most units had an Indigenous Liaison Officer, and many used patient mentors in an organised manner, which commonly involved prior transplant patients being asked to attend education sessions and seminars to help educate future transplant patients.
- Most units offered a variety of allied health services, including pharmacist, dietician, social worker and psychologist services.
- Most units used transplant educational materials that were adapted from existing Kidney Health Australia or industry-based resources.
- Patients are usually informed about transplant as a treatment option as soon as they are diagnosed with CKD, and usually before commencing dialysis treatment.
- Most units reported that transplant workup did not typically commence before dialysis as recommended, but usually within the first 6 months of dialysis treatment.
- Most units reported that transplant workup typically takes between 3-6 months, but that Indigenous patients may take anywhere between 12-18 months to complete workup.
- Once a transplant becomes available, it is usually the local GP or nephrologist who calls the patient to inform them of its availability.
- Travel arrangements to receive the transplant are typically organised by renal transplant coordinators.
- Immediately following surgery, recipients typically spend 5-7 days in hospital.
  - Recipients typically then spend a further 4-12 weeks in the city where the transplant centre is located.

- In some areas, this may be followed by a period of 4-8 weeks in a regional centre (i.e. Alice Springs, Darwin, Cairns or Townsville), prior to returning to their home community.
- Following a transplant, most units provided dosettes to recipients and assessed recipients' understanding of each drug. Units then supported medication adherence by checking recipients' dosettes and Webster Paks and providing regular medication education via pharmacists in the immediate post-transplant period.
- Once recipients' medications, drug doses and clinical situation are stable, they are discharged and returned to their community, often between 3-6 months post-transplant (depending on remoteness and individual unit preferences).
- Most units offered onsite post-transplant education to kidney transplant recipients, but very few units provided outreach education sessions and telehealth options due to lack of funding and/or staff availability.
- Most units had standard immunosuppression and infective prophylaxis protocols that were applied to all patients.

A number of service provision gaps were also identified by the interviews, including:

- Most units indicated that services such as Indigenous Liaison Officers and patient mentors are only offered to patients if requested or clearly required.
- No renal units developed or provided tailored educational materials for Indigenous patients, though a handful of units gave Indigenous patients simple drawings, booklets developed by NT renal services, or videos of Indigenous patient experiences.
- No units had specific processes in place for evaluating a potential Indigenous living kidney donor, and most units expressed reluctance to engage Indigenous donors due to the prevalence of CKD and other comorbidities amongst this population.
- Very few units had specific measures in place for follow-up care after recipients returned to their home community.
- Very few units utilised telehealth to liaise with satellite sites, primary health services, outreach clinics and transplant recipients.
- Most of the units did not have a protocol in place with regard to partnering and collaborating with primary health care services, including Aboriginal Community Controlled Health Services (ACCHS), in the delivery of post-transplant care.

These findings suggest that, for the most part, current models of care are inadequate and lack a specific focus on the Indigenous patient population, particularly for those from rural and remote areas.

### **Box 9: Case study of an Indigenous patients' post-transplant journey**

A 48-year-old Indigenous man from a remote area, who had been on HD since 2010, was transplanted in August 2018. He was discharged on Day 4 post-transplantation, and was reviewed in the outpatient department on Day 5, when it was discovered that he had not taken some of his medications, including tacrolimus. The patient's care progressed with multiple readmissions for ureteric complications. He was reviewed by pharmacists three times to Day 21 - on the first two occasions there were no errors, but errors in dosette packing were noted during the final review. On Day 32, he was discharged back to the regional hospital, and the transplant centre's registrar provided a phone handover to the treating nephrologist in the regional centre. In addition to his medication dosette, the patient was provided with a typed sheet outlining his medication regime.

In the regional centre, the patient's dose aid was changed to a Webster Pak, but the number of medications was such that the breakfast medications were packed into two columns that were clearly marked as 'morning' medications.

Four weeks later he was readmitted to the regional centre with rejection. On investigation, there had been a medication mix-up due to the change in format of medication, which led to the patient not taking some immunosuppressive tablets. He was then transferred to the transplanting centre, returning two months later.

The poor post-transplant outcomes that have been described can be attributed, in part, to standardised, inappropriate models of care, manifesting in numerous health system oversights, including:

- The transplant unit provided written education literature to this patient, who could not read English and had poor eyesight.
- The regional renal unit provided the patient with drug management information as part of his pre-transplant education, but this took place 2 years prior to transplantation.
- There was no ongoing education while the patient was on the transplant waitlist.
- The next time the patient received education was when he was at the transplant hospital shortly after transplant surgery, in an unfamiliar environment, separated from his social supports and usual routines.
- Despite demonstrating difficulty with medication management, the patient did not receive ongoing post-transplant pharmacy input after discharge from hospital.
- When the patient returned to his home community, he needed to commute 100km per day to attend post-transplant review.

#### *2.3.1.2 Acknowledging and addressing social and cultural health determinants*

Recent literature has identified a series of social and cultural determinants that hamper Indigenous patients' uptake of post-transplant support and maintenance of treatment regimens (Aspin, Brown, Jowsey, Yen, & Leeder, 2012; Davy, Harfield, McArthur, Munn, & Brown, 2016; Gibson et al., 2015; Harfield et al., 2015). Low health literacy, different cultural understandings of health, remoteness, poverty, overcrowding, poor sanitation, and a lack of basic household infrastructure, such as facilities for storage of medicines and access to clean water, have been linked to high levels of morbidity and mortality from infection (Davy et al., 2016). Similarly, a lack of communication infrastructure, such as phone and internet connection, prevents access to timely health care guidance and advice,

manifesting in poorer health outcomes (Davy et al., 2016). Even in cases where such infrastructure is available, the money needed to sustain it and issues associated with sharing the phone with multiple family members and keeping mobile phones charged and functional may mean that contact between patients and health services remains problematic.

The delivery of culturally appropriate care is dependent on the health care service's capacity to understand, respect and accommodate these social and cultural health determinants (Browne et al., 2009). However, the majority of health services do not have the resources required to respond to the needs of minority groups (Davy et al., 2016). These services also tend to operate within a set of socially constructed values and norms that are influenced by the biomedical model, which is at odds with the more holistic perspective of health commonly embraced by Indigenous peoples (Olafsdottir, 2013). The association between culturally appropriate models of care and increased engagement from Indigenous patients in the management of their own treatment has been demonstrated, and is further strengthened when care and support services are delivered by ACCHS and Indigenous health practitioners (Davy et al., 2016).

The current Kidney Health Australia Caring for Australians with Renal Impairment (KHA-CARI) Care of Kidney Transplant Recipients Guideline includes recommendations for induction therapy, immunosuppressive medications, treatment of acute rejection, monitoring kidney allograft function, preventing and treating non-adherence, and many other post-transplant care considerations (Chadban et al., 2012). While this guideline is designed to address issues relevant to the care of all kidney transplant recipients in Australia and New Zealand, it does not capture any of the aforementioned social and cultural determinants that may impact Indigenous patients' post-transplant outcomes. The Catching Some Air project and Kidney Health Australia Indigenous Community Consultations are currently underway, comprising a series of consumer consultations across Australia (Hughes, Kelly, et al., 2018). These initiatives will help inform the inaugural KHA-CARI Guideline for the Management of CKD in Aboriginal and Torres Strait Islander Peoples to address relevant social and cultural health determinants that affect the Indigenous ESKD patient cohort (Hughes, Kelly, et al., 2018).

In addition to the development of tailored ESKD management guidelines, there are a number of other areas in which post-transplant models of care can be strengthened for Indigenous kidney transplant recipients, particularly for those in rural and remote communities.

#### 2.3.1.3 *Point-of-care testing*

A barrier to effective post-transplant services in rural and remote Indigenous communities is limited access to pathology services. Community health services and patients may be very distant from the nearest pathology service, and it may take several days for blood samples to be transported, processed and results returned, particularly if air transport is limited. Point-of-care testing (POCT) overcomes the 'tyranny of distance', provides a more convenient, timely and cost effective service for the patient, and increases treatment adherence (Shephard, 2003). POCT also has other advantages specific to the Indigenous health care setting; through appropriate training, Indigenous health workers can perform POCT, thereby empowering them to take greater responsibility for the health of their own community members. For chronic care, POCT has proven to be an effective tool for improving control of chronic conditions either by reductions in HB A1c (for diabetes management) or increased time in therapeutic or target ranges for anticoagulants (Shephard, 2010). A range of POCT tests for the management of chronic illness are available in remote communities, as outlined in Table 9;

crucially, these do not currently include blood tacrolimus concentrations, which is a key factor in regular post-transplant monitoring.

Table 9: POCT tests for chronic care (Shephard, 2010).

Parameters	Test
<b>Carbohydrate metabolism</b>	Glucose
<b>Lipids</b>	Glycated haemoglobin
	Triglyceride
	Total cholesterol
	High-density lipoprotein cholesterol
	Low-density lipoprotein cholesterol (calculated)
<b>Kidney function</b>	Urea
	Creatine (eGFR)
	Urine albumin
	Urine albumin-creatinine ratio
<b>Haematological/coagulation</b>	Haemoglobin
<b>Liver function</b>	INR
	Total protein
	Albumin
	Alanine aminotransferase
	Aspartate aminotransferase
	Gamma-glutamyl transpeptidase
	Alkaline phosphatase
	Bilirubin

The challenges faced in providing an effective POCT service in Indigenous communities are considerable. Many rural and remote Indigenous medical services experience difficult working conditions such as dust, excessive heat and/or humidity, power fluctuations, and inadequate lighting and refrigerator space, together with high rates of staff turnover (Shephard, 2013). Additionally, at present there is no Medicare rebate for POCT in general practice (other than a small group of tests, such as a pregnancy test). This limits the potential uptake of POCT technology and means a thorough cost–benefit analysis is needed before making the decision to implement POCT. While there are clear opportunities to potentially improve post-transplant care by harnessing POCT, the lack of a tacrolimus assay and issues concerning the reliability of total white cell count POC tests means it is currently of limited value in this context. There are also a range of issues associated with cost, health infrastructure and staff resourcing that need to be addressed to improve POCT’s availability and sustainability in rural and remote communities (Shephard, 2013).

#### 2.3.1.4 Engaging ACCHS and Primary Care

ACCHS are run by an Indigenous Board and deliver a range of services, including CKD prevention, detection and education, within a culturally sensitive health model that promotes health, treats illness, fosters community development, and provides educational resources for health professionals (Panaretto, Wenitong, Button, & Ring, 2014). Many Indigenous patients place great trust in ACCHS (Baba, Brolan, & Hill, 2014), and establishing stronger partnerships and improved coordination between renal units, transplant centres and ACCHS would help to facilitate the delivery of culturally and clinically safe post-transplant care to Indigenous patients and communities. Through Primary Health Networks (PHNs), renal units should also commit to regular liaison with primary care providers

more broadly, including government and mainstream GPs, to ensure post-transplant support and monitoring continues after patients have returned to their community.

In communities where ACCHS are not available, telehealth options should be explored so that patients can still communicate with trusted ACCHS practitioners, either via telephone or videoconferencing. These strategies will help to redress the ongoing disadvantages faced by Indigenous patients within mainstream health care settings, which dominate funding, coverage and delivery of complex treatments (Chapman & Berggren, 2005).

#### 2.3.1.5 *Telenephrology and telepharmacy*

Videoconferencing enables health care professionals to overcome the tyranny of distance, and nephrologists throughout Australia are now using 'telenephrology' to manage remote patients with ESKD (either direct to patient, or with "far end" support from clinic nursing or medical staff). Recent improvements in internet connections to remote areas, and the inclusion of telehealth among Medicare-funded health care services, has enabled the expansion of videoconferencing-based telenephrology. This is proving particularly beneficial in Northern Australia, where distances between major health care centres and communities are vast (Rohatgi, Ross, & Majoni, 2017). A retrospective audit of paediatric videoconferencing-based telenephrology in Queensland over a 10-year period (2004-2013) found that telenephrology services provided patients and their families with improved access to information and treatment support, and regional medical teams benefited from additional educational opportunities (Rohatgi et al., 2017). The use of telenephrology also led to a cost saving of \$31,837 in 2013, equating to \$505 saved per consultation (Rohatgi et al., 2017).

Similarly, patients in rural and remote areas have reduced access to prescribed and non-prescribed medicines, advice about the use of these medicines, and professional pharmacy services in general (Poudel & Nissen, 2016). Telepharmacy involves the provision of pharmaceutical care through the use of telecommunications and information technologies to patients at a distant location, and is already being rolled out in remote Queensland communities (Poulson, Nissen, & Coombes, 2010). In 2013, Queensland Health established the CKD Pharmacist initiative, which provides telepharmacy services to CKD patients living in rural and remote areas within the Cairns Hospital and Hinterland Health Service and the Torres and Cape Hospital and Health Service areas (Johnstone, 2017). The service is delivered by a clinical nurse, clinical pharmacist and administration officer, all of whom are based at the Cairns Hospital Renal Unit (Johnstone, 2017). The aims of the renal telepharmacy service include:

1. Increasing access to a clinical pharmacy service for geographically isolated clients.
2. Contributing to reducing the burden of chronic disease by using an intensive case management approach to support patients in self-managing their condition by adhering to medication management regimes, preventing secondary complications by improving access to screening and routine tests, and delaying the progression of CKD and the need for RRT.
3. Improving clinical outcomes from hospitals and hospital-related services by delivering tailored and community-based CKD management education, and preparing patients for RRT.
4. Reducing preventable hospitalisation rates for Indigenous people with CKD (Johnstone, 2017).

The CKD Pharmacist Telehealth Service has had continual growth since its commencement, with demand for the service rising year on year resulting in more patients receiving interventions related to their medication management regimes (Johnstone, 2017). Patient survey results suggest that the service has reduced the disruption and cost associated with travelling to tertiary health services for

face-to-face appointments, and that most patients felt more comfortable receiving telepharmacy services in their community with familiar doctors, nurses or health care workers on hand to provide support if needed (Johnstone, 2017).

The current uptake of telehealth to deliver nephrology and pharmacy services is not clear, but anecdotal evidence suggests that the use of telehealth initiatives has been very limited in both pre-transplant assessment and post-transplant management contexts. While some telehealth models have reportedly enhanced the provision of medical services to ESKD patients and are likely applicable to the Indigenous kidney transplant recipient population, their long-term viability as post-transplant models of care is dependent on the availability of appropriate infrastructure and a stable funding source.

### 2.3.2 Immunosuppression

Kidney transplant rejection occurs when a patient's body recognises that a transplant kidney is not 'its own' and subsequently attacks the new kidney. Rejection is more prevalent among Indigenous kidney transplant recipients compared to non-Indigenous recipients (Rogers et al., 2006). In part, this reflects differences between the donor and recipient populations, which lead to lesser levels of immunological 'matching'. Immunosuppressive medications comprise an essential component of post-transplant care, allowing the transplantation of a kidney from a genetically non-identical person. The optimal level of immunosuppression in kidney transplant recipients is a delicate balance between the benefit of preventing rejection and the harm of adverse effects. Following transplantation, patients require immunosuppressive medication for the duration of transplant function. Critical to this is intake of multiple different medications several times every day. A key side effect is susceptibility to infection and other complications (particularly cancer).

Graft and patient survival rates of over 80% at 5 years depending on the donor source (i.e. living or deceased) are reported worldwide, however, international differences have been identified with long-term adjusted graft failure risk significantly higher in the United States compared to Australia, New Zealand and the United Kingdom (Merion et al., 2018). Despite Australia having one of the best kidney transplant systems in the world, Indigenous recipients typically do not experience the same benefits, with graft survival rates of around 71% at 5 years post-transplant (ANZDATA, 2018) and substantially increased mortality rates, as shown in Figures 8 and 9.



Figure 8: Primary deceased donor graft patient survival 2008-2017 – Australia (ANZDATA, 2018).

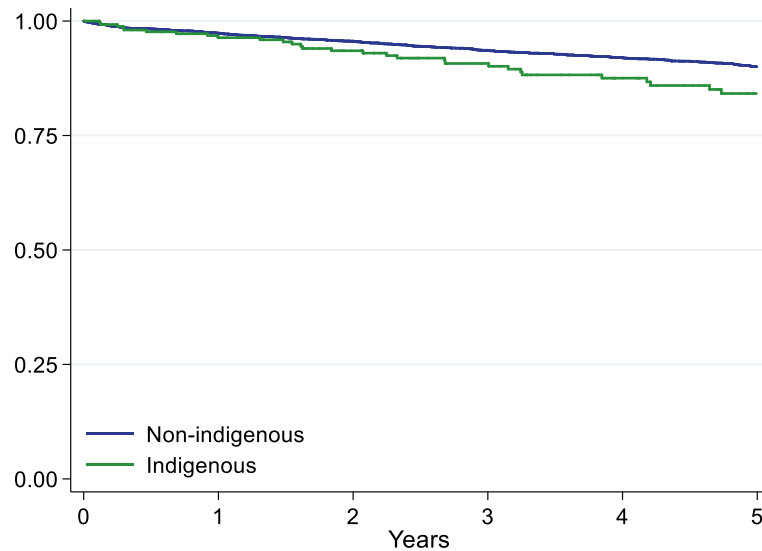
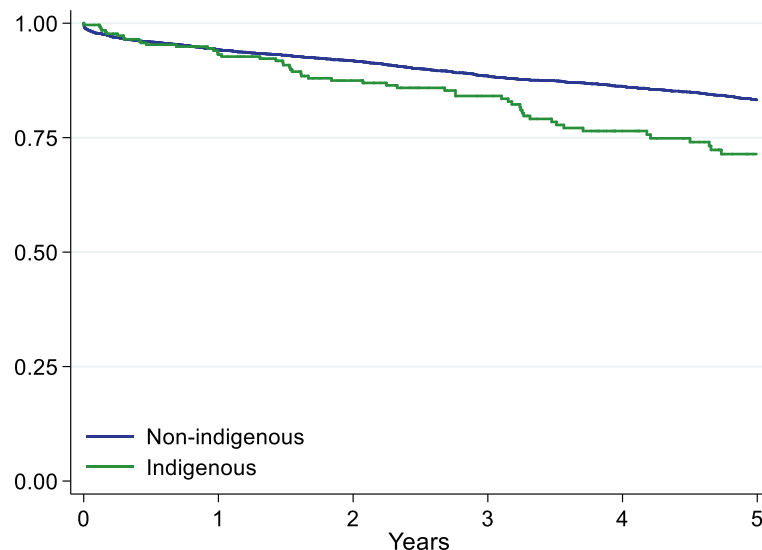


Figure 9: Primary deceased donor overall graft survival 2008-2017 – Australia (ANZDATA, 2018).



Indigenous recipients' increased rate of rejection is commonly attributed to greater human leukocyte antigen (HLA) mismatching, greater sensitisation and longer waiting time from the start of dialysis treatment. The leading cause of death among Indigenous kidney transplant recipients is infection (Boan et al., 2017). Identifying the right level of immunosuppression to prevent rejection is a major challenge when treating Indigenous patients, especially those who return to environments with high exposure to and underlying prevalence of infections (Majoni, Dole, Jabbar, Sundram, & Perry, 2012). Even with optimal immunosuppression-strategies, maintaining immunosuppression levels is reliant on patient adherence to the medication regimen.

### 2.3.2.1 Barriers to medication adherence

Medication adherence can be defined as the extent to which people follow the instructions they are given for prescribed treatments (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008). Nonadherence to medication may be either an intentional decision (i.e. missing or altering doses without consulting

healthcare professionals) or unintentional interruption to a patient's routine (i.e. forgetting to take medications) (M. J. Johnson, 2002). As categorized by the World Health Organization, five main risk factors can influence adherent behaviour: socioeconomic factors (i.e. financial difficulty, lack of transportation), health care organisational barriers (i.e. staff rotation, limited time allocated to each patient), disease-related factors (i.e. the presence of chronic disease), therapy-related factors (i.e. the presence of debilitating side effects, complex dosing regimens) and patient-related factors (i.e. communication barriers, busy work schedules, health beliefs and attitudes) (De Geest & Sabate, 2003).

Pinsky et al. (2009) undertook a retrospective cohort study of data from the United States Renal Data System to investigate the impact of nonadherence on kidney transplant outcomes using a medication possession ratio (MPR) for maintenance immunosuppression drugs. MPR is defined as the number of days medication is supplied over a 1-year time interval; for example, if a patient receives a 30-day supply of immunosuppression, but consistently refills their medication after 35 days, they would have had medication for 320 days out of 360, equating to an MPR of 89%. This study found that kidney transplant recipients with low overall adherence in taking prescribed immunosuppressive medications (defined by fair or poor MPR rankings in the first, second and third year post-transplant) had a 60% increased risk of graft failure (Pinsky et al., 2009). Despite this, nonadherence remains prevalent, with about 22% to 28% of kidney transplant recipients demonstrating poor immunosuppression adherence (Butler, Roderick, Mullee, Mason, & Peveler, 2004; Denhaerynck et al., 2005). A consistent predictor of nonadherence is adolescence, particularly those of an older age and more years post-transplantation (Berquist et al., 2008). Other risk factors include: inadequate regimen knowledge, poor mental health and health-related quality of life, low social support, substance abuse, barriers to medication adherence and poor physician-patient relationship (Fredericks & Dore-Stites, 2010).

Many Indigenous Australians share contextual factors that may detrimentally affect their engagement with the health system and their response to the significant personal demands imposed by post-transplant maintenance. As a group, Indigenous Australians have higher levels of socioeconomic disadvantage, lower educational attainment and poorer health literacy (Anderson, Devitt, et al., 2012). A significant proportion of Indigenous transplant patients also experience isolation and reduced engagement in treatment management, particularly those who return to rural and remote communities following transplantation (Anderson, Devitt, et al., 2012). However, the majority of data on adherence rates are based on anecdotal evidence. For example, Anderson, Devitt, et al. (2012) interviewed 19 Australian nephrologists to investigate how adherence affects specialists' decision-making with regard to referral for transplant. The findings indicated that while nephrologists perceived Indigenous patients as being 'risky' due to dialysis nonadherence, conflated by social and cultural factors, adherence was not systematically measured making it impossible to substantiate these claims. Additionally, very few studies have employed standard measures such as electronic monitoring and medication dispensing data to examine the association between adherence and clinical outcomes for Indigenous Australians.

While no research to date has specifically explored medication adherence among Indigenous kidney transplant recipients, a meta-analysis of rates and risk factors for nonadherence to immunosuppression after adult solid organ transplantation found that demographic factors (i.e. sex, age and ethnicity) showed little correlation with adherence (Dew et al., 2007). This is consistent with the findings of a systematic review of chronic condition management adherence in Indigenous Australians, which found no evidence that Indigenous patients' medication adherence is lower than

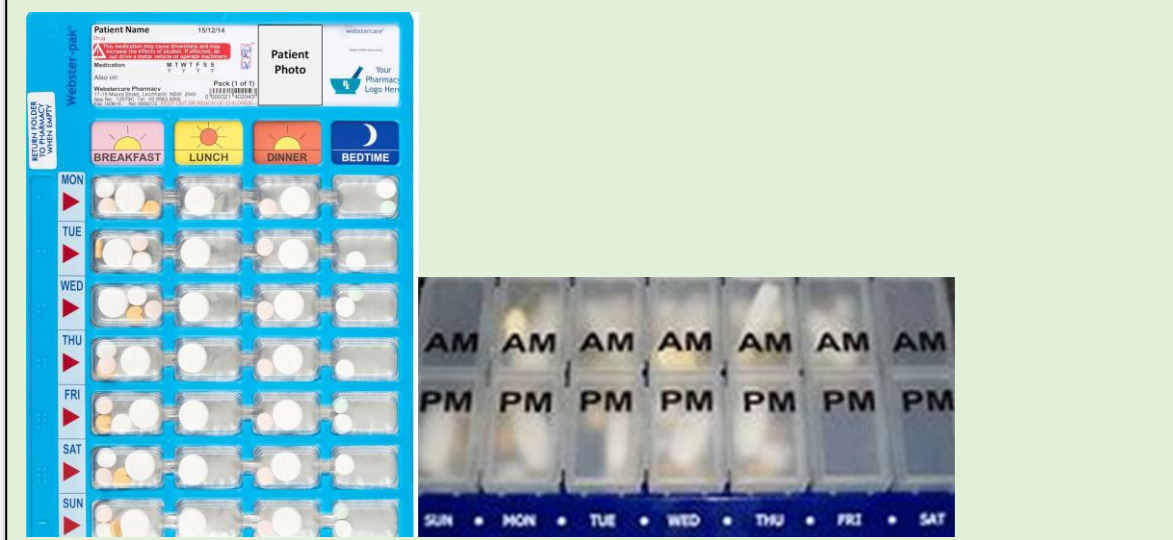
for the general population (de Dassel, Ralph, & Cass, 2017). Nonetheless, de Dassel et al. (2017) identified numerous challenges experienced by Indigenous Australians requiring long-term medicines, which were raised by both providers and patients. These included: conflicting sociocultural obligations that were more important than taking medicines and often involved travelling away from one's home community; affordability; sharing or swapping medicines; stopping medicines once feeling better; and difficulties obtaining medicines while away from home (de Dassel et al., 2017).

Indigenous patients have also reported that forgetting to take doses is a barrier to adherence, while health professionals have suggested that inadequate safe storage for medicines at home impairs adherence (de Dassel et al., 2017). Both providers and patients have called for the development and delivery of culturally appropriate resources, designed to enhance the provision of patient education about medicines and increase adherence (de Dassel et al., 2017). Additionally, health professionals have identified various potential adherence support strategies, including increased involvement of Aboriginal Health Practitioners in medication management, and simplification of dose regimens, including dose administration aids (DAAs) and once-daily dosing (de Dassel et al., 2017).

**Box 10: Dose administration aids**

Webster Paks and dosettes, depicted in Figure 10, are examples of DAAs that help remind patients when to take their medication. This is particularly useful for kidney transplant recipients, as the complexity of immunosuppression regimens increases the risk of nonadherence, and skipping or forgetting to take a dose can quickly result in cellular rejection, appearance of donor-specific antibodies and chronic rejection (Moreso, Torres, Costa-Requena, & Serón, 2015). It is important that transplant centres adopt consistent DAA protocols and promote the use of DAAs to ensure patients are equipped to self-manage the demands of immunosuppressive medications.

Figure 10: Image of a Webster Pak (left) and dosette (right).



2.3.2.2 Simplifying immunosuppressive formulations

Advances in immunosuppressive strategies over the past decades have led to significant improvements in the field of kidney transplantation. Currently available immunosuppressive agents are separated into three categories: 'induction agents', 'maintenance therapy' and 'treatment for

rejection' (Kalluri & Hardinger, 2012). Induction and rejection treatment is undertaken in major centres, often as an inpatient, with regimes that change frequently from day to day and are typically managed under direct oversight. In contrast, maintenance treatment needs to be undertaken at home over months and years with intermittent follow-up. This creates challenges of medical supply and oversight in remote environments, often with limited primary care support. Maintenance regimens typically include a combination of 3 different anti-rejection drugs from different classes: calcineurin inhibitors (cyclosporine and tacrolimus, known as CNIs), antiproliferative agents (azathioprine and mycophenolic acid) or mTOR inhibitors (sirolimus and everolimus), and corticosteroids (Kalluri & Hardinger, 2012). Most of these agents are twice daily formulations. In addition, patients are typically also on anti-infective prophylactic drugs, together with other medications to manage comorbidities, particularly hypertension and diabetes. An active area of development concerns the adoption of prolonged release tacrolimus formulations, which require less frequent doses and helps to address pill burden and nonadherence in kidney transplant recipients.

### 2.3.2.3 *Once daily and novel, long acting immunosuppressive medication*

Past research has identified a significant relationship between more frequent immunosuppressive medication dosing and decreased adherence (Ichimaru et al., 2008; Morales, Varo, & Lázaro, 2012; Weng et al., 2005). Given tacrolimus is the mainstay of immunosuppressive regimens after a kidney transplant (Matas et al., 2015), optimising adherence to tacrolimus-based regimens post-transplantation is vital to achieving good graft and patient outcomes (Abedini, Goransson, Cockburn, Kilany, & Holdaas, 2018). Tacrolimus is available as both twice-daily (immediate-release) and once-daily (prolonged-release) formulations (Abedini et al., 2018). The latter has been approved for use in many countries worldwide, including Australia, for the prophylaxis of transplant rejection in adult liver, kidney, lung and heart transplant recipients. A number of phase III trials have supported the widespread use of the prolonged-release formula, having found it to be noninferior to the immediate-release product with a similar tolerability profile (Garnock-Jones, 2015).

The prolonged-release formulation offers a simpler regimen comprising a single daily morning dose, and therefore has the potential to improve adherence to immunosuppressive therapy. A randomized controlled multicentre trial using electronic monitoring of medication intake found that adherence to the immunosuppressive regimen was significantly higher with once-daily, prolonged-release tacrolimus vs twice-daily, immediate-release tacrolimus (88.2% vs 78.8%) (Kuypers et al., 2013). Furthermore, a recent study that examined self-reported nonadherence using the Basel Assessment of Adherence with Immunosuppressive Medication Scale (BAASIS) identified a significant impact on nonadherence following patient conversion from a twice-daily to once-daily tacrolimus regimen; nonadherence declined from 66.4% (immediate-release tacrolimus) at study entry to 30.9% (prolonged-release tacrolimus) at 1 year post-conversion (Lehner et al., 2018).

### **Box 11: Belatacept**

The Australian nephrology community is also considering the merits of trialling a novel, long acting immunosuppressive agent called belatacept – a once monthly infusion that has been approved by the US Food and Drug Administration and the European Medicines Agency. A possible advantage of belatacept is the ease in which adherence can be tracked, as administration involves an intravenous infusion requiring attendance at an outpatient clinic or hospital (James & Mannon, 2015). Its longer acting formula also simplifies dosage requirements and reduces the number of daily pills patients must consume. Further information on the clinical advantages of belatacept, as well as knowledge and data gaps, are provided in [Appendix B](#).

#### *2.3.2.4 Pharmacogenetic differences*

Immunosuppression is of fundamental importance to the long-term survival of kidney transplant recipients. However, the immunosuppressive medications that are administered to prevent rejection in transplant recipients have a narrow therapeutic index. Under-immunosuppression results in episodes of rejection leading to either damage or loss of the kidney. Conversely, over immunosuppression increases the risk of infection and malignancy, as well as drug specific complications including diabetes mellitus and nephrotoxicity. Currently, immunosuppressive drug treatment tends to only be tailored in accordance with a clinical assessment of the patients' risk of rejection or toxicity and blood drug concentrations, rather than on the basis of pharmacokinetic and pharmacogenetic profiling (Abboudi & Macphee, 2012).

While there is limited data on the pharmacogenetics of Australian Indigenous populations, there is some data to suggest that genotypes of key enzymes that metabolise immunosuppressive drugs differ between the Indigenous and Caucasian populations (Griese et al., 2001; Tucci, 2011). An Australian study is currently comparing immunosuppressant drug pharmacokinetic parameters and patient dosing requirements in Indigenous and non-Indigenous adult kidney transplant recipients ("The PK Study," 2018). These findings will determine whether changes to immunosuppressive protocols are required to reduce immunosuppressant drug inefficacy, susceptibility to infection and toxicities in Indigenous Australians.

#### *2.3.3 Infective Prophylaxis*

Kidney transplantation necessitates long-term immunosuppression, which increases the risk of contracting viral, bacterial, parasitic and fungal infections (Boan et al., 2017). Analyses of ANZDATA data indicate Indigenous kidney transplant recipients experience significantly higher rates of graft loss and death compared to non-Indigenous recipients, primarily due to infection (McDonald, 2004). The administration of greater immunosuppression in response to Indigenous patients' higher rejection rates is a probable antecedent to infective complications in Indigenous patients, though in most cases the causes are likely multifactorial (Barracough et al., 2016). Other factors that influence the risk of infection include environmental exposure, clinical risk factors such as diabetes, substandard housing, inadequate infrastructure for sanitation and geographical location (Rogers et al., 2006).

The underlying risk of infective deaths among the broader Australian Indigenous population is substantially higher than for the non-Indigenous population. This risk increases with remoteness, indicating that environmental factors (including housing conditions and access to health services) play a key role in the manifestation of infection (Cass et al., 2001; Dey, Knox, Wang, Beard, & McIntyre,

2016). Standardised mortality rates for infective deaths in the Indigenous community compared to the general population are 4.5-fold and 3.1-fold for males and females respectively (AIHW, 2011b). Indigenous Australians also have an increased incidence of 3.6-fold for invasive pneumococcal disease, 4-fold for sepsis and 4.6-fold for influenza compared to non-Indigenous Australians (Davis et al., 2011; Dey et al., 2016). Against this background, the immunosuppression required for successful transplantation will magnify existing infection rate discrepancies, manifesting in poorer post-transplant outcomes for Indigenous patients (Boan et al., 2017).

Past research has highlighted the important differences in kidney transplant outcomes between Indigenous and non-Indigenous Australians. The 40<sup>th</sup> Annual ANZDATA Report (2017) found that there are markedly higher rates of transplant loss in Indigenous Australians, particularly evident 3 years after transplantation. Indigenous Australians also experience higher mortality rates throughout the first five years after transplantation, with the difference in survival worsening over time (ANZDATA, 2018).

A retrospective review of all kidney transplants from the Northern Territory between 1984 and 2004 found that Indigenous patients were more likely to have a transplant biopsy, acute rejection, bolus doses of steroids, monoclonal antibody treatment for rejection, longer hospitalisation stays and infection post-transplant (Rogers et al., 2006). Infection was found to be the dominant cause of death for Indigenous patients (17 of 23 deaths); in stark contrast, no non-Indigenous patients died during the study period. It was also reported that Indigenous patients had higher infection rates of skin, respiratory tract, gastrointestinal tract and blood-stream, in addition to higher rates of infection due to bacteria and fungi (Rogers et al., 2006).

In a retrospective review of 141 consecutive adult kidney transplant recipients in Western Australia between 2005 and 2011, Boan et al. (2017) found that Indigenous patients were more likely to test positive for Hepatitis B core antibody (100% vs 13.3%,  $P < 0.001$ ) and Cytomegalovirus (98.2% vs 73.2%,  $P < 0.001$ ) at pre-transplant screening and had a higher rate of pneumonia (17.9% vs 3.6%,  $P < 0.006$ ) and death in the first year after transplantation due to infection. There was also a non-significant trend of a higher rate of gastrointestinal parasitic infection, invasive fungal infection and infectious hospital admission. Of the 47 Indigenous participants included in the study, 26% died within 3 years of kidney transplantation, with infection being the attributable cause in two-thirds of cases (Boan et al., 2017).

## 2.4 Critique of current evidence

The evidence outlined in this chapter is diverse and comprehensive, encompassing qualitative and quantitative studies, academic and “grey” literature and anecdotal evidence from experts in the field. However, the strength of this evidence is hampered by several factors, including:

- The **age** of the research. Many of the cited studies date back to over 5 years ago, and some greater than a decade ago. This may mean that some of the findings reported throughout this chapter are of limited relevance to current practice, particularly given the rapid rate at which medical research advances, and changes in models of care and practices over that time.
- The **specificity** of the research. Very few studies have specifically explored the pre- and post-transplant barriers that affect the Indigenous Australian patient population. Where reasonable, extrapolations have been drawn. Some sections of the current evidence chapter cite research that has been undertaken with international Indigenous populations or rural and

remote Australian cohorts, which is then used to illustrate issues that may affect some Indigenous Australian patients.

- The **reliance on a relatively small group of ‘researcher voices’**. There are relative few experts and groups who specialise and publish in this area of inquiry. This means that the ideas and views presented throughout the current evidence chapter may be narrower than in reality/practice, as these findings have been generated by a group of researchers who are well known to each other, rather than a diverse cohort of consumers, families and clinicians.
- The **ad-hoc nature** of the research. In the absence of a clear national focus on this area, the nature and extent of issues examined has been determined by the availability and interest of appropriately skilled researchers, research funding, and an appropriate and supportive environment. The outcome of this is that the amount of evidence available is uneven, and not all areas are addressed.

These limitations are best addressed by:

- Instigating national conversations on this issue to engage record and document a wide spectrum of voices,
- Supporting and funding targeted research priorities,
- Undertaking further research and expanding national data collection protocols, targeting identified pre- and post-transplant knowledge and data gaps, and
- In the longer term, training and forming a more diverse environment of researchers.

## 2.5 Enhancing data collection & reporting

### **Box 12: Summary of Recommendations**

1. Implement a 12-month pilot project to capture additional pre- and post-kidney transplant data points in an expanded ANZDATA data collection protocol.
2. Incorporate a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander people.
3. Undertake additional data linkage and research projects that target Indigenous patients’ post-transplant outcomes, enabling identification of best practice immunosuppression, infective prophylaxis and vascular complication protocols.

The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) collects information about all people with ESKD in Australia and New Zealand who are being treated with either dialysis or a kidney transplant. It is funded by the Australian Organ and Tissue Donation and Transplantation Authority, the New Zealand Ministry of Health and Kidney Health Australia. All dialysis and transplant units throughout Australia and New Zealand provide a variety of patient data across two basic streams to ANZDATA. First and foremost, the registry is notified in ‘real-time’ (in reality, within 30 days) of key events (dialysis, transplantation, death, and loss of transplant function). In addition, a cross-sectional survey is conducted of all patients at 31 December each year.

The survey includes substantial amounts of process information about the treatment modality. For those receiving haemodialysis, this includes dialyser type, dialysis prescription, dry weight, and type of dialysis access; for peritoneal dialysis patients, episodes of peritonitis are collected, as are PET results and fluids used. Basic biochemistry (haemoglobin, calcium and phosphate) are collected for all dialysis patients. For transplant recipients, graft function, rejection episodes and immunosuppressive

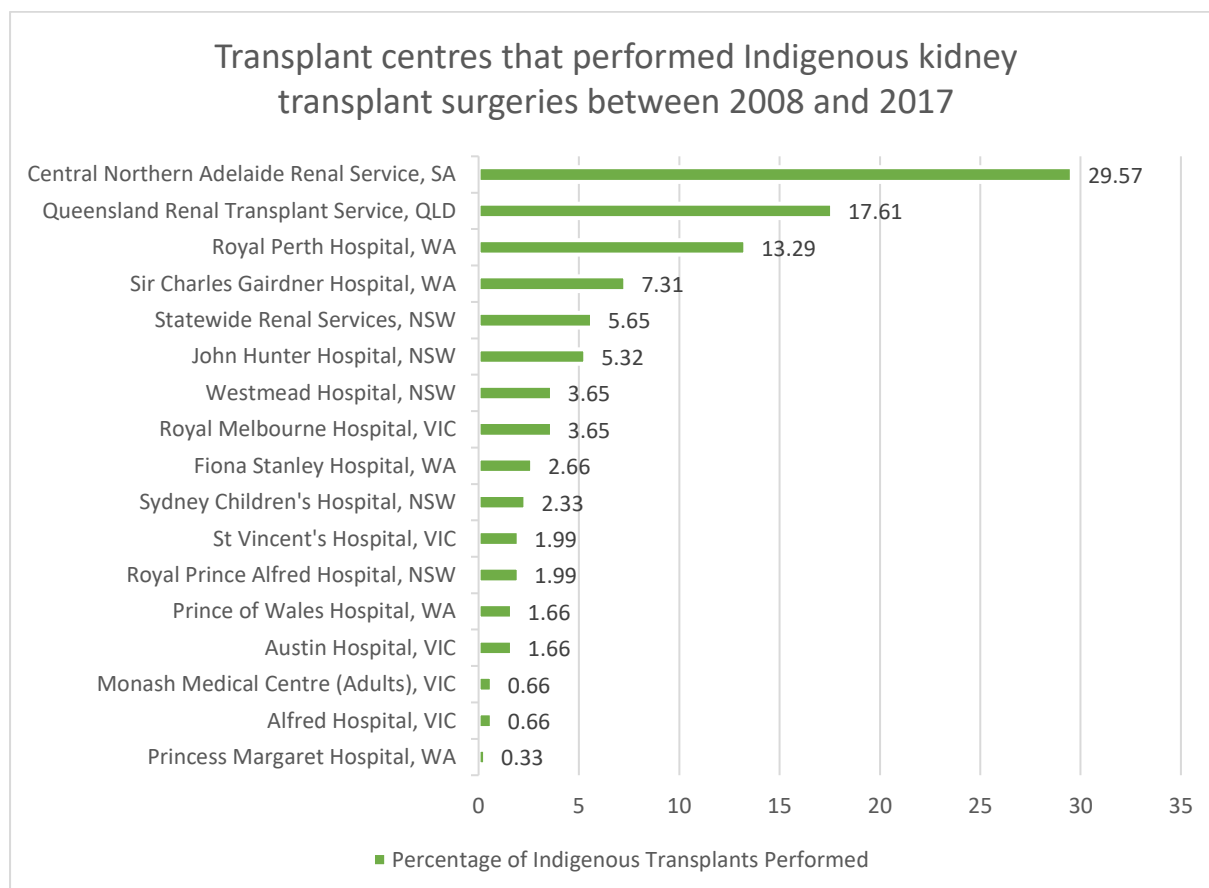
drug use and dosage are recorded. This information has been critical in documenting and highlighting the problems this report seeks to address.

However, ANZDATA does not currently capture a number of critical pre- and post-transplant milestones and outcomes, which are of relevance to assessing progress and changes in this area. A 12-month pilot project involving a select group of tertiary renal health services will enable the identification of measurable and modifiable targets at both the individual and health service level that influence transplant outcomes. This is an important first step in establishing a consistent framework for collecting and reporting data on access to transplantation, which will significantly improve our understanding of the inequities that affect Indigenous patients throughout the pre- and post-transplant journey.

### 2.5.1 Facility selection

Of more than eighty tertiary renal health services coordinating care for Australians receiving RRT, fourteen services coordinate care for approximately 88% of Indigenous Australian patients starting RRT nationally each year. Four services (Royal Darwin Hospital, Alice Springs Hospital, Royal Perth Hospital and Cairns Hospital) care for 62% of all incident Indigenous RRT patients, and a further four (Fiona Stanley Hospital Perth, Royal Adelaide Hospital, Townsville Hospital and Sir Charles Gairdner Hospital Perth) care for an additional 17% of incident Indigenous RRT patients. Another six services, predominantly across NSW, care for a further 9% of incident Indigenous RRT patients. Similarly, only a small proportion of services are responsible for performing transplant surgeries on Indigenous patients, as outlined in Figure 11.

*Figure 11: Transplant centres that performed Indigenous kidney transplant surgeries between 2008 and 2017.*





It is recommended that all renal health services in Australia be invited to participate in a voluntary 12-month trial of an enhanced and expanded ANZDATA data collection protocol, which would require units to capture a number of additional pre- and post-transplant data points. However, it is anticipated that centres that are individually responsible for the care of a very small number of Indigenous RRT patients may choose to not participate. This will not have a negative effect on the trial, given the inclusion of these centres is expected to increase cost and complexity without significantly increasing the ability to explore pre- and post-transplant barriers for Indigenous RRT patients.

### 2.5.2 Patient selection

All Indigenous and non-Indigenous patients receiving RRT from participating renal health services who are covered under existing ANZDATA consent arrangements will be captured as part of the expanded data collection framework. The inclusion of non-Indigenous patients is critical, as this cohort will serve as a comparator for the Indigenous patient population, enabling meaningful conclusions to be drawn.

### 2.5.3 Data collection

Currently, ANZDATA requires all dialysis and transplant units in Australia and New Zealand to complete an annual survey at 31 December. This survey encompasses all patient events that have occurred in the previous twelve months as well as a ‘snapshot’ of all dialysis and transplant patients on those dates.

Following consultations between ANZDATA, hospitals and other data contributors, data ‘users’, consumers and relevant stakeholders, an expanded survey will be provided to transplant coordinators from participating renal units to complete. It is envisaged that the expanded survey will capture additional pre- and post-transplant data points, as outlined in Figures 12 and 13.

Figure 12: Additional pre-transplant data points.

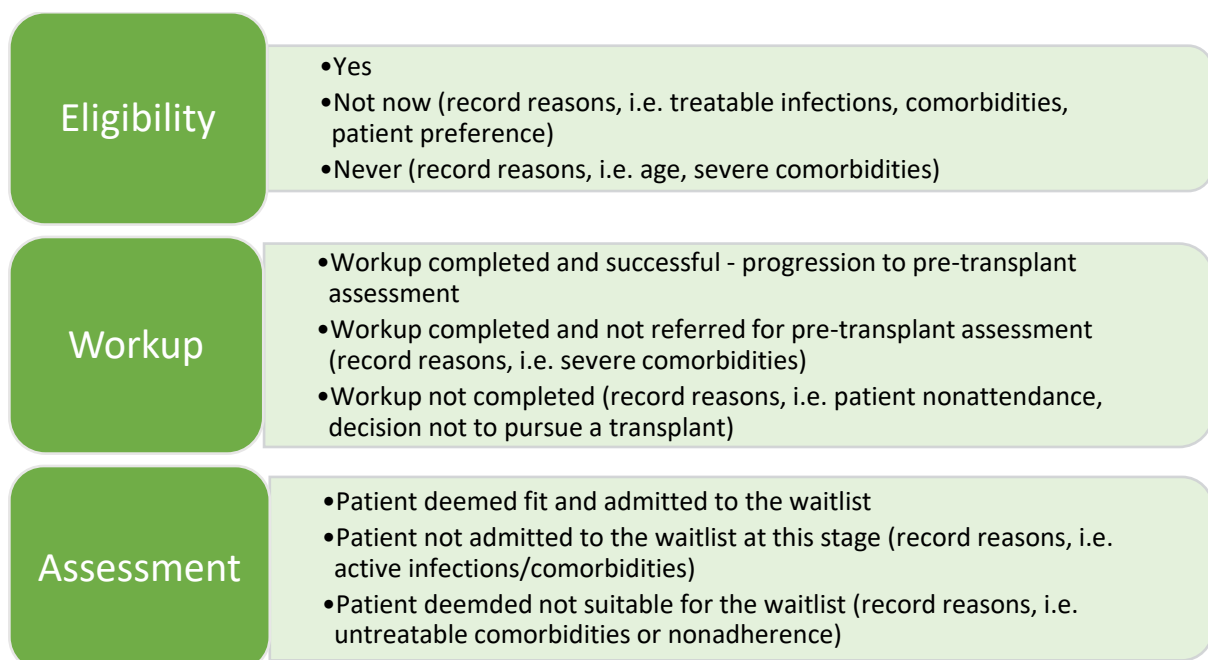
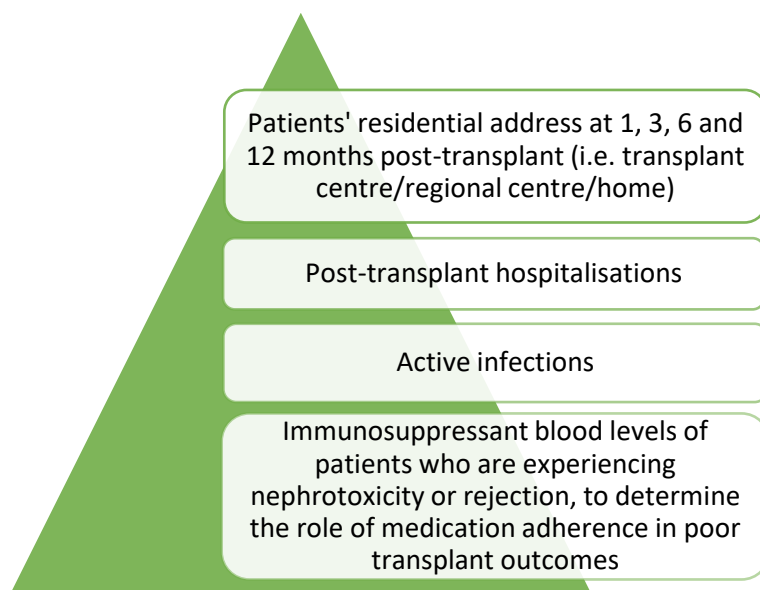


Figure 13: Additional post-transplant data points.



The burden associated with collecting and reporting additional pre- and post-transplant data points will be reduced by incorporating drop-down list boxes, where applicable, as part of the online survey. This will improve the efficiency of the process for transplant coordinators, who will simply be required to select the appropriate option for each patient (i.e. workup completed - awaiting assessment). The survey will also include date fields where applicable, to improve the monitoring of patients' pre- and post-transplant trajectories.

To accommodate the additional pre-transplant data points, a new section will be incorporated into the ANZDATA survey titled 'transplant eligibility and assessment'. The additional post-transplant data points will be incorporated into the existing 'current graft' section of the survey. Once data collection, validation, entry and analysis has been completed, it is critical that this information be made available to patients, carers and community members in appropriate formats.

Other post-transplant variables, such as socioeconomic, housing and health-related infrastructure factors, also affect post-transplant outcomes. While these variables are difficult to measure on a national scale, work is underway to determine which of these factors contribute to poorer post-transplant outcomes among Indigenous recipients and identify possible solutions.

#### 2.5.4 Feasibility and resourcing

ANZDATA has the infrastructure and expertise to manage an expanded national data collection protocol, which would enable the inclusion of a separate Indigenous transplant chapter in the ANZDATA annual report. However, the scope of the additional data collection may prove to be a burdensome undertaking for some units without additional resourcing. It is also anticipated that software modifications and more rigorous data submission requirements will create additional costs. The proposed 12-month pilot project will enable participating renal units to determine whether it is a sustainable undertaking and identify what additional resourcing they require to maintain enhanced data capture.

The risks associated with this multijurisdictional project include low renal health service recruitment rates and delays in the collection, validation, entry and analysis of additional data points. These risks

are expected to be balanced by: a) interest and support in this area from the Australian Government, b) the involvement and support of centres caring for the majority of Indigenous Australian RRT patients nationally, c) the coordinating role of the ANZDATA registry, which has a reputation for data fidelity and completeness, with 'real-time, on-line' data entry now the norm for almost all contributing renal services.

#### 2.5.5 Other data linkage and research projects

The expansion of ANZDATA's data collection protocol should be complemented by a number of discrete projects that specifically target identified transplantation barriers for Indigenous patients. Additional funding is required to facilitate the implementation of proposed projects, which include:

- Linking national hospital separations data to the ANZDATA database to allow examination of episodes of admitted patient care, including post-transplant hospitalisations due to infective complications.
  - This would facilitate a comprehensive comparison of Indigenous and non-Indigenous patients' post-transplant outcomes and would enable a longitudinal examination of the frequency of complications for both patient populations.
- A 24-month multicentre prospective cohort study of Indigenous Australian kidney transplant recipients to investigate the occurrence of and antecedents to post-transplant infective complications and vascular events.
  - This study would also facilitate an examination of the efficacy of infective prophylaxis and vascular complication protocols for Indigenous kidney transplant recipients.
- An adaptive national platform trial to study the best immunosuppression, antibiotic, antiviral and antifungal therapies for Indigenous kidney transplant recipients.
  - This would enable a simultaneous study of multiple therapies for Indigenous kidney transplant recipients, resulting in the identification of the most effective therapies for this patient population.

### 3. Pre-Transplant Knowledge Gaps and Recommendations

#### **Box 13: Summary of pre-transplant barriers**

Indigenous patients face multiple, complex barriers to accessing pre-transplant information and education, assessment and workup. Many of these barriers also impede Indigenous patients' ability to stay healthy on the waitlist, reducing their chances of receiving a transplant. Pre-transplant barriers include:

- Low health literacy and challenges in understanding the transplantation process;
- Lack of access to culturally appropriate information and education programs;
- Lengthy cultural processes for making important health care decisions;
- Lack of appropriate structures for patient and community involvement in the patient's journey to transplantation;
- Competing family priorities and cultural obligations;
- Late referral to dialysis negatively impacting ensuing treatment phases;
- Geographical barriers, which pose numerous social, cultural and economic challenges that have the potential to significantly delay access to support, assessment, workup and treatment; and
- Higher prevalence of surgical risk factors, including obesity and diabetes.

#### 3.1 Knowledge and data gaps

##### 3.1.1 Informing patients

Patient education in general does not currently have a strong disciplinary focus in Australia, with literature describing best practice transplant education and information sharing processes primarily originating from the United States. In particular, there is a dearth of published research on PNP for Australian Indigenous populations, and no studies to date have explored the impact of PNPs in the Indigenous kidney transplant candidate population. As a result, the most effective and appropriate methods and timing of transplant education initiatives for Indigenous ESKD patients remains largely unknown.

Similarly, while past research has advocated for culturally tailored pre-transplant education programs for Indigenous patients, there are some significant knowledge and data gaps around whether culturally informed health service-level interventions are able to effectively reduce cultural biases in the Australian context. Priority gaps that need to be addressed include:

- Determining the relationship between existing cultural awareness programs and the extent to which health services deliver culturally informed care;
- Exploring whether health service-level interventions (such as those that seek to improve patient-practitioner communication) improve either patient perceptions of bias, practitioner biases, or both; and
- Analysing whether these interventions are able to improve patient-centred outcomes (such as patients' sense of empowerment in making informed health care decisions).

##### 3.1.2 Completing workup and assessment

Although recent studies have described differences between Indigenous and non-Indigenous patients' likelihood of being placed on the transplant waitlist, this did not extend to a description of the barriers

to waitlisting. Currently, the only data available across units is the final stage of the process – placement on the waiting list. Consistent information on the proportion and characteristics of the patients with ESKD who may be suitable for transplant waitlisting, and barriers resulting in delays in the identification and workup processes of suitable patients, is not available. Further research is required to investigate the potential causative role of socio-demographic factors, including first language spoken, education level, health literacy, housing status and remoteness. There is also limited data on the most prevalent reasons for non-completion of pre-transplant requirements, including attendance at assessment and workup appointments. Improved data collection processes are needed to monitor progress in this area, and inform future interventions that specifically target those variables found to impede Indigenous patients' ability to be successfully waitlisted.

### 3.1.3 Surgical assessment

Very little is known about the antecedents and prevalence of surgical complications in the Indigenous kidney transplant recipient cohort, and further research is required to identify:

- The best obesity metrics for the Indigenous ESKD patient population;
- The most prevalent surgical risk factors for the Indigenous ESKD patient population, and the best strategies to address these prior to surgery; and
- The most prevalent surgical complications among Indigenous kidney transplant recipients, and the best approaches to prevent and treat their occurrence.

There also remains a paucity of data on the benefits and risks associated with both conservative weight loss strategies and bariatric surgery for Indigenous kidney transplant candidates. Specific knowledge and data gaps include:

- No weight loss programs to date have been tailored for Indigenous patients with ESKD.
  - Evaluations of culturally informed health and weight loss initiatives that are delivered to the broader Indigenous population (such as the PMYU model and NSW Aboriginal Knockout Health Challenge) should be used to guide the development of targeted pilot projects for the Indigenous ESKD patient cohort.
- No studies to date have specifically explored the health potential of bariatric surgery for the Indigenous ESKD patient population.
  - Given the prevalence of obesity is significantly higher among Indigenous Australians compared to the non-Indigenous population, it is critical that future research examine the impacts of bariatric surgery on this cohort to determine whether it is safe and effective in facilitating access to kidney transplantation.

## 3.2 Next steps and recommendations for research, practice and policy

### **Box 14: Summary of recommendations**

#### **Consumer Engagement and Education**

1. Trial and evaluate the adoption of patient navigator programs and yarning circles in pre-transplant protocols.
2. Pilot culturally informed transplant education interventions, including remote language centres.

#### **Improving Equity and Access to Transplant Services**

3. Evaluate and leverage existing initiatives that target cultural bias in health services to facilitate the rollout of best practice pre-transplant care and support interventions for Indigenous transplant candidates.
4. Ensure Indigenous transplant candidates are connected with primary care services earlier in the ESKD treatment continuum, to enable health issues to be addressed prior to workup.
5. Trial and evaluate weight loss strategies for Indigenous kidney transplant candidates, including conservative, culturally tailored weight loss programs and bariatric surgery.
6. If an empirical evidence base supports the use of bariatric surgery for Indigenous kidney transplant candidates, increase funding for bariatric surgery procedures in public hospitals.
7. Trial a multidisciplinary pre-transplant clinic in one major regional centre for 12 months, prioritising the availability of dental and cardiac services, as well as travel and accommodation support for rural and remote patients.
8. Fund relevant medical and allied health services and positions in regional centres to facilitate the delivery of specialist transplant support outreach services, complementing regional pre-transplant clinics and improving coordination of appointments and services.

#### **Researching, Developing and Implementing Clinical Guidelines and Protocols**

9. Evaluate the impact of immunological matching at the epitope (eplet) level for allocation of deceased donor kidneys.

#### **Workforce Training and Development**

10. Implement recruitment and training strategies for the renal workforce, particularly in remote areas, to improve the delivery of culturally appropriate pre-transplant care.
11. Implement transplant-specific 'train the trainer' workshops for Indigenous health workers.

### 3.2.1 Consumer Engagement and Education

It is recommended that renal units, transplant centres and local treatment providers jointly develop culturally informed and region-specific health literacy assessments and education programs, which will require dedicated staff resourcing. Appropriate educational programs and material will, by necessity, take many forms and require input from a variety of personnel including consumers, clinicians, communication and media specialists.

A general information program should be developed for the Indigenous dialysis patient population and community more broadly, with more specific education resources available for Indigenous kidney transplant candidates undergoing assessment. Information should be articulated in the most appropriate language and format, using accessible technologies, and covering the following topics:

- Donor and recipient medical suitability criteria;
- The processes to be wait-listed for transplantation;
- The expected timeframe to achieve a decision for transplant suitability;
- The role of local renal and transplant units in kidney transplant assessment and care; and
- Operative and post-transplant care.

#### 3.2.1.1 *Patient navigator programs*

Models of care with similar characteristics to PNPs have proven effective in other areas of Indigenous health, and early indications from Canadian trials suggest that PNPs can reduce the disparities in health outcomes for Indigenous people. In accordance with insights from recent consumer engagement research (Hughes, Dembski, et al., 2018), Australian transplant centres should trial and evaluate the adoption of PNPs to determine: a) their impact on improving access to the transplant waitlist for Indigenous patients, b) their impact on improving medication adherence and post-transplant outcomes, and c) what navigator characteristics have the greatest influence on outcomes (i.e. Indigenous background, lay person, practical or emotional support).

#### 3.2.1.2 *Yarning circles*

'Yarning circles' may prove to be a valuable addition to transplant education programs, as they provide a more effective and culturally appropriate communication platform for Indigenous patients. In Australia, Indigenous peoples recognise yarning as a conversational process that involves a meeting of peers or participants of similar status for discussion and exchange of views. To date, health and research organisations, including Kidney Health Australia, the Menzies School of Health Research and the Australian National University, have primarily used yarning circles as part of consumer engagement research projects. Very few health services have trialled yarning circle programs as a way to provide more culturally appropriate education and support to Indigenous patients. It is recommended that transplant centres trial the use of yarning circles amongst the Indigenous kidney transplant candidate population, which will necessitate resourcing of yarning circle facilitators, such as Indigenous health workers and interpreters. A rigorous analysis will be required to determine whether this communication method improves the facilitation of kidney transplant knowledge and offers any further insights into Indigenous patients' perceived barriers to accessing a transplant.

#### 3.2.1.3 *Remote language centres*

The delivery of culturally appropriate health services in remote Indigenous communities would be aided by the establishment of 'language centres', particularly in areas where English is a second or even less commonly spoken language for the local Indigenous population. These centres would comprise a team of Indigenous translators and interpreters trained in the transplant treatment pathway. Working in remote communities across Australia, their main responsibilities would include:

- Establishing a set of bridging terms and concepts for contemporary medical terms and concepts, from the Indigenous language of the region to English; and
- Developing word dictionaries and other resources to aid health professionals in delivering culturally appropriate transplant support and care.

### 3.2.2 Improving Equity and Access to Transplant Services

#### 3.2.2.1 *Evaluating and leveraging health service-level interventions that target cultural biases*

While cultural capability training has been advocated in previous research, no applied research has been undertaken to understand the effect of this training on health service delivery in the context of

pre-transplant workup, assessment and referral. Further investigation is required to assess the efficacy of health service-level interventions in reducing cultural biases among renal unit and transplant centre staff for the Indigenous kidney transplant candidate cohort. This research will feed into the development of cultural safety resources and programs that have been proven to address underlying cultural biases in health service providers.

#### 3.2.2.2 *Earlier engagement of primary care services*

In light of the barriers faced by Indigenous patients to accessing pre-transplant assessment and workup tests, particularly those located in rural and remote areas, alternative service delivery models need to be developed and tested. It is critical that these models are regionally specific to account for the great diversity in settings and contexts across the country.

One possible intervention involves the earlier engagement of primary care services, such as dental check-ups and women's health assessments, to improve patients' general health prior to commencing dialysis. Indigenous transplant candidates present with significant comorbidities at a much higher rate than non-Indigenous patients. These comorbidities, including skin, respiratory and urinary tract infections, cardiac disease and poor oral health, commonly require further investigation and multi-specialty treatment, which complicate and delay the pre-transplant workup process. As a result, connecting patients with relevant primary health care services as early in the CKD/ESKD treatment continuum as possible may help to eliminate one of the major causes of delay in the pre-transplant workup process.

#### 3.2.2.3 *Implementing and evaluating conservative prevention and weight loss initiatives for overweight and obese Indigenous kidney transplant candidates*

While Australia's Closing the Gap strategy is heavily focussed on the prevention of chronic disease in the Indigenous population, the adoption of healthy lifestyle choices is equally important for those who have already developed a chronic condition. As such, holistic weight loss projects tailored for Indigenous patients with ESKD should be piloted to determine whether conservative strategies, including nutrition education, exercise and behavioural therapy, can effectively reduce weight and comorbidities, and thus facilitate improved access to the transplant waitlist. The time, cost, adverse events and benefits of these pilot projects must be thoroughly evaluated to determine whether the rollout of a tailored, full-scale weight loss program for the Indigenous kidney transplant candidate population is feasible and worth pursuing.

#### 3.2.2.4 *Investigating the efficacy of surgical approaches for Indigenous patients who are ineligible for waitlisting primarily due to weight*

Further research is required to thoroughly evaluate both the peri-operative safety and long-term outcomes of bariatric surgery in kidney transplant candidates, particularly in the high-risk Indigenous ESKD patient population. Given past research has primarily explored open bariatric surgery procedures, additional investigation is required to determine the safety and efficacy of laparoscopic methods, which is now commonly considered to be the approach of choice. Another area for future exploration concerns whether the pharmacokinetics of immunosuppressive drugs are altered in the setting of bariatric surgery, which may impact kidney transplant recipients who are required to maintain an intensive immunosuppressive regimen.

#### 3.2.2.5 *Prospective, clinical study of the effect of bariatric surgery in Indigenous transplant candidates*

An interventional clinical trial is needed to determine the effects of bariatric surgery in adult Indigenous kidney transplant candidates who are unable to be waitlisted, or are at risk of poorer



transplant outcomes, due to obesity and/or associated comorbidities. Effects of interest comprise the pharmacokinetics of immunosuppressive medication, height, weight, BMI, abdominal circumference, blood pressure, glycosylated haemoglobin, average daily insulin requirements, lipid profile, thyroid-stimulating hormone levels, 24-hour urine creatinine clearance and quality of life.

Proposed primary outcome measures include:

- Placement on the transplant waitlist.
- Weight loss achieved after bariatric surgery in the ESKD patient.
  - Time frame: baseline and every 3 months.
- Changes in health-related quality of life score.
  - Time frame: baseline and 1 year after bariatric surgery.

Proposed secondary outcome measures include:

- Changes in the pharmacokinetics of oral immunosuppressive medications due to bariatric surgery, comparing pre-bariatric surgery to 12 months post-operative.
  - Time frame: pre-bariatric surgery and 1 year after bariatric surgery.
- Changes in blood glucose levels.
  - Time frame: baseline and 1 year after bariatric surgery.
- Changes in the number and dose of medications required to treat co-morbidities including hypertension, hyperlipidaemia and diabetes mellitus.
  - Time frame: baseline and 1 year after bariatric surgery.
- Incidence of complications following bariatric surgery.
  - Time frame: 1, 6 and 12 months after bariatric surgery.

To be eligible for inclusion, it is proposed that participants must: be over 18 years of age, identify as Aboriginal or Torres Strait Islander, have a BMI greater than 35, be currently receiving dialysis and have no major comorbidities that would prevent waitlisting. Proposed exclusion criteria include: medically unfit for surgical intervention, previous gastric or intestinal surgery, active gastric disease, pregnancy or lactation, and active infection.

#### 3.2.2.6 *Increasing funding for bariatric surgery procedures in public hospitals*

The heavy economic burden of obesity and its comorbid conditions may be alleviated in the long term by surgical management, despite upfront resource costs. Severely obese individuals incur twofold higher mean annual health care costs (\$2788 v \$1472) and use double the number of medications annually (11.4 v 5.3 per person) compared with the general population (Lukas et al., 2014). Weight loss surgery can reduce the number of medications required and lower individual health care costs by 26%, a direct saving of \$506 per person annually (Lukas et al., 2014). In the context of ESKD, bariatric surgery may provide the only opportunity for obese transplant candidates to be waitlisted for a kidney, which is more likely to be an issue among Indigenous patients. However, bariatric surgery is least accessible to those who are likely to be in the greatest need, due to the lack of funded bariatric surgery procedures in the public sector. It is thus recommended that the Federal, state and territory governments consider increasing the supply of publicly funded bariatric surgery in Australia.

#### 3.2.2.7 *Establishing multidisciplinary pre-transplant clinics in major regional centres*

Multidisciplinary pre-transplant clinics offer an efficient and effective way to provide care for kidney transplant candidates and improve coordination between the tertiary and primary care sectors. The establishment of 'one-stop shop' multidisciplinary pre-transplant clinics in major regional centres

would improve rural and remote patients' access to essential pre-transplant workup and assessments. However, the successful implementation of these clinics is dependent on:

- Funding for additional medical and allied health positions in regional areas;
- Travel and accommodation allowances for remote patients, who will still be required to travel substantial distances to reach their nearest regional centre; and
- Rigorous, nationally standardised evaluations, to determine each regional clinic's effectiveness in facilitating improved access to transplantation for Indigenous patients.

#### 3.2.2.8 *Improving the design of specialist transplant outreach services*

Maintaining active waitlist status is dependent on patients' ability to access relevant specialist services regularly. Past research has comprehensively described barriers to accessing specialist services for Indigenous patients, particularly those in rural and remote areas, as well as issues around specialist outreach program design, sustainability and impact. Evidence shows that specialist outreach services enable up to 90% of specialist consultations to be delivered in the community setting within 12 months of referral, without patients needing to travel to hospital outpatient clinics (Gruen, Bailie, Wang, Heard, & Rourke, 2006) . However, a number of changes should be made to the design and implementation of future specialist outreach services to ensure their sustainability and effectiveness for kidney transplant candidates, including:

- Outreach services should be delivered by a multidisciplinary team of specialists rather than one or two practitioners in isolation. This will require the recruitment of more specialists to commit to the delivery of regular outreach, and efforts should be made to ensure that outreach activities are valued within health care organisations and systems.
- The coordination of outreach services can be improved by implementing long-term planning of visits that are scheduled in accordance with community need, rather than scheduling visits only a few weeks in advance when transplant candidates may already have made plans to travel to regional or metropolitan hubs for specialist appointments.
- In addition to responding to community needs, outreach visits should be accountable to the referring practitioner and community, provide an appropriate mix of clinical services, education and support, utilise education and training opportunities, and deliver reliable correspondence and good communication.
- To maximise the efficacy of specialist outreach, primary care services must be adequately resourced and staffed. It is critical that specialist outreach be integrated with primary care services to prevent disruptions to the provision of transplant care.
- Specialist outreach services should be complemented by the use of telenephrology to fill service gaps between scheduled community visits.

### 3.2.3 Researching, Developing and Implementing Clinical Guidelines and Protocols

#### 3.2.3.1 *Determining immunological compatibility using both broad antigen and eplet HLA matching*

Indigenous patients' longer waiting times for transplantation are in part attributed to the HLA-antigen mismatch between donors and potential Indigenous transplant candidates. Previous research has found that structural matching at the epitope level (i.e. polymorphic amino acid sequences such as eplets that bind to anti-HLA antibody) may provide a more accurate assessment of immunological risk compared to HLA matching at the broad antigen level. One study that compared the benefits and costs of incorporating an eplet-based matching algorithm to the current allocation of deceased donor

kidneys to Indigenous Australians found that the average waiting time for transplantation for 5 recipients (15% of the participant cohort) was reduced by an average of 23 months (Do et al., 2015). In addition, the study identified an average incremental gain in 0.004 quality-adjusted life years, with average savings of \$3860 using this allocation compared to the current (Do et al., 2015). Further research is required to more precisely define the epitopes of each HLA allele in Indigenous people, which are dissimilar to those of non-Indigenous people and are critical in the future application of HLA eplet-based matching in this population.

### 3.2.4 Workforce Training and Development

#### 3.2.4.1 *Engaging and training a culturally capable renal workforce*

In order to improve transplant centres' ability to address the unique needs of culturally diverse kidney transplant recipients, a range of workforce training and development strategies should be explored, particularly in rural and remote communities. These include:

- Integrating cultural awareness training as part of curriculum and continuous professional development for all renal unit and transplant centre staff;
- Diversifying the spread of specialist training positions across rural and remote Australia, and encouraging all renal registrars to undertake an Indigenous community rotation; and
- Increasing the recruitment, training and utility of Indigenous health workers, patient navigators and interpreters nationally, and equipping them with renal knowledge so they can support Indigenous kidney transplant recipients in fulfilling pre-transplant requirements.
- Establishing stronger partnerships with ACCHS and primary care services more broadly to improve the delivery of culturally appropriate transplant care and support services.
- Upskilling primary care providers, including GPs, nurses, and Indigenous health workers, in the delivery of transplant education and care.

#### 3.2.4.2 *Implementing 'train the trainer' workshops for the Indigenous health workforce*

'Train the trainer' workshops for Indigenous interpreters, health care navigators and health workers need to be implemented across Australia, in metropolitan areas, regional hubs and remote communities, to ensure the Indigenous health workforce is appropriately trained in transplant knowledge and practice before engaging directly with transplant candidates and recipients. While growing the Indigenous health workforce is an important step in facilitating culturally capable education and communication for Indigenous patients, high quality education, support and care can only be provided if the workforce is equipped with a detailed knowledge of kidney issues and the dialysis/transplant journey. In addition to the workshops, new or less experienced Indigenous health workers should be paired with a more senior and experienced Indigenous 'mentor', who can provide ongoing support and guidance beyond the workshop setting.

## 4. Post-Transplant Knowledge Gaps and Recommendations

### **Box 15: Summary of post-transplant barriers**

Indigenous transplant recipients experience significantly poorer post-transplant outcomes compared to non-Indigenous recipients. Standardised models of care, including 'one size fits all' immunosuppression and infective prophylaxis protocols, is thought to contribute to this disparity. Specific post-transplant barriers include:

- Low health literacy and sociocultural challenges that impede adherence to complex post-transplant care and maintenance requirements;
- Limited access to post-transplant treatment, assessment and support services, including pathology and pharmacy services; and
- Higher risk of exposure to infection, particularly in remote communities where substandard housing and inadequate infrastructure for sanitation is more common.

### 4.1 Knowledge and data gaps

#### 4.1.1 Models of Care

The Menzies School of Health Research recently investigated how different dialysis treatment models impact on patients, families and other service providers, however, no such work on transplant models of care has been done in Australia. While this chapter has provided a brief overview of current practice and strategies that may facilitate improved post-transplant outcomes, specifically for the Indigenous patient population, it is important that further research be undertaken to comprehensively address this evidence gap.

The need to tailor models of care for Indigenous patients with chronic disease rather than simply apply existing models has been comprehensively documented in the literature, but the majority of research in the Indigenous health field to date has adopted a descriptive approach. While descriptive research provides valuable information on health patterns and determinants, it does not produce change nor provide any direct evidence on how to best create change (Sanson-Fisher, Campbell, Perkins, Blunden, & Davis, 2006). It is therefore critical that future efforts prioritise intervention research to facilitate effective change in models of care and improve post-transplant outcomes for Indigenous patients.

One intervention that has been frequently proposed in the setting of care for chronic disease in remote areas is POCT. Actual clinical trials or large-scale reviews to assess the effectiveness of POCT are much less numerous than publications that describe the potential risks associated with POCT, issues with specific tests or with specific devices. A systematic review of current models of POCT in Australia, including the Quality Assurance for Aboriginal and Torres Strait Islander Medical Services Program, State-wide i-STAT network, and Integrated Cardiovascular Clinical Network SA, should be undertaken to inform the development of new models that are specifically designed to enhance post-transplant pathology testing and the quality of clinical care in remote Indigenous communities.

Previous research has posited that telepharmacy has the potential to improve health outcomes for patients requiring chronic disease management and improve quality of service delivery in the primary care setting, particularly for patients based in rural and remote areas (Johnstone, 2017). However, while telepharmacy offers potential benefits and efficiencies, evidence of its effectiveness and economic impact is far from extensive. Pharmacy regulation laws, operational difficulties, start-up

costs, data security issues, and patients' reluctance to use technology all pose significant barriers that may inhibit the successful uptake of telepharmacy in remote communities (Poudel & Nissen, 2016). A rigorous analysis of telepharmacy's pros and cons is needed to justify an extended rollout across rural and remote Australian communities to aid post-transplant medication management. Furthermore, a systematic review or meta-analysis would help to strengthen the telepharmacy literature by providing a more precise measurement of telepharmacy's effects (i.e. increased access to pharmacist advice and medicines).

#### 4.1.2 Immunosuppression

Despite anecdote and opinion (Anderson, Devitt, et al., 2012), there is a paucity of data that accurately identifies rates and causes of nonadherence in Indigenous kidney transplant recipients. Therefore, the role nonadherence plays in poor health outcomes in Indigenous recipients remains largely unknown although often debated. Similarly, while past research has advocated for a range of targeted adherence support strategies for Indigenous Australians, the efficacy of these strategies has not been evaluated. Additional evidence on the activities that effectively support Indigenous Australians requiring long-term medication, including immunosuppressant drugs, is needed to aid the development and implementation of culturally appropriate adherence education and support resources.

There is evidence in the general population that once-daily medication dosing is associated with better uptake and adherence. The use of this strategy post-transplantation is erratic, and there is no current evidence about the best implementation approach. While prolonged-release tacrolimus has demonstrated good efficacy and tolerability in clinical studies, adherence data after conversion from immediate-release tacrolimus are limited in kidney transplant patients, and no studies have specifically investigated its impact in the Indigenous patient population. These knowledge gaps also apply to novel approaches, such as immunosuppressive agents that require intermittent administration from a clinic base (i.e. belatacept).

Previous research has found that Indigenous kidney transplant recipients suffer poorer post-transplant outcomes compared to non-Indigenous recipients, driven in large part by higher rates of infective complications. Although this observation supports the development of tailored immunosuppressive regimens for this patient population, in current clinical practice Indigenous patients are still treated with similar immunosuppressive protocols, at similar doses and target concentrations to those administered to non-Indigenous patients. It is critical that future research comprehensively assess Indigenous Australians' immunosuppression burden through pharmacokinetic and pharmacogenetic profiling to facilitate the development of tailored immunosuppressive protocols for this cohort.

#### 4.1.3 Infective Prophylaxis

Previous studies have demonstrated that Indigenous Australians suffer markedly higher rates of morbidity and mortality due to infective causes, however, the scope of these studies was limited to two individual jurisdictions (i.e. exclusively analysing patients from the Northern Territory and Western Australia). It is important that future work involves a nationwide exploration of the antecedents to serious infection in Indigenous kidney transplant patients, including an analysis of jurisdictional and regional differences, to enable the introduction of regionally specific infective prophylaxis strategies in Australian renal units. The establishment of a national prophylactic protocol

for Indigenous kidney transplant recipients is also critical to improve consistency of care across jurisdictions and aid coordination between renal units and primary care providers.

While a range of social and environmental factors have been theorised to promote infection risk in Indigenous recipients, particularly those returning to a rural or remote community, few studies have explored this association in depth. Future research should seek to identify the specific challenges that pose a risk to the health of Indigenous transplant recipients and evaluate the efficacy of initiatives and modifications that target either behaviour or the environment. A greater focus on Indigenous patients' health literacy is also critical to reduce the disparity in post-transplant outcomes. The development and evaluation of culturally informed and region-specific patient education programs and practices is needed to ensure Indigenous transplant recipients fully understand post-transplant care recommendations and relevant maintenance responsibilities. Evaluation of region-specific programs could then serve to inform the establishment of national guidelines for Indigenous patient education.

For all transplant recipients, various methods to prevent infection post-transplantation are in use. However, little is known about the efficacy of various prophylaxis approaches among the Indigenous kidney transplant recipient cohort. Gaps include: pre-transplant screening and vaccination measures; environmental initiatives, such as educating patients about the importance of sanitation and good dietary habits; and the best peri- and post-transplant antimicrobial regimes to prevent the manifestation of common bacterial, fungal and viral infections (such as CMV). The identification and ongoing monitoring of key data points, including baseline immunological screening, post-transplant hospitalisations and active infections, is needed to determine the success of infective prophylaxis protocols, particularly those that are tailored for Indigenous kidney transplant recipients.

## 4.2 Next steps and recommendations for research, practice and policy

### **Box 16: Summary of recommendations**

#### **Consumer Engagement and Education**

1. Pilot culturally informed transplant education interventions, including culturally tailored immunosuppression adherence education videos.

#### **Improving Equity and Access to Transplant Services**

2. Trial a multidisciplinary post-transplant clinic in one major regional centre for 12 months, prioritising the availability of dental and cardiac services, as well as travel and accommodation support for rural and remote patients.
3. Conduct a study on transplant models of care to quantify the costs for rural and remote Indigenous patients to inform the development of a needs-based funding model.
4. Undertake a systematic review of Australian POCT models to guide the development of a post-transplant care POCT program, comprising new POCT measures that enable the monitoring of renal function and immunosuppressive drug levels in kidney transplant recipients.
5. Subsidise POCT tests that have been validated by empirical evidence.
6. Investigate the value of telenephrology and telepharmacy programs for kidney transplant recipients living in rural and regional areas.
7. Design and implement a remote community pharmacist trial to facilitate improved awareness and knowledge of transplant related maintenance requirements among Indigenous kidney transplant candidates and recipients.
8. Subsidise clinical pharmacy outpatient consults for Indigenous transplant recipients.
9. Broaden the list of eligible prescribers for the Closing the Gap (CTG) PBS Co-payment Measure to include transplant centres.

#### **Researching, Developing and Implementing Clinical Guidelines and Protocols**

10. Establish a national dose administration aid protocol and a consistent format for drug information.
11. Implement and evaluate novel, long acting immunosuppressive agents in Indigenous transplant recipients.
12. Adopt prolonged-release tacrolimus-based regimens in immunosuppressive protocols.
13. Revise immunosuppressive protocols based on relevant findings from the pharmacokinetic study of immunosuppressives in Indigenous transplant recipients.
14. Design and undertake research projects to identify the antecedents to infective episodes.
15. Test and evaluate novel infective prophylaxis interventions for Indigenous transplant recipients.
16. Adopt coordinated, nationally consistent clinical data collection, analysis and reporting protocols of infective complications across renal units.
17. Implement a tailored prophylactic protocol for Indigenous transplant recipients.

### 4.2.1 Consumer Engagement and Education

#### 4.2.1.1 *Trialling the use of culturally tailored immunosuppression adherence education videos*

Past research has found that Indigenous Australians with chronic conditions are inadequately supported by health professionals to comply with post-transplant care recommendations, particularly

with regard to taking medication. Confusion over medicines, perceived lack of advice from health professionals to patients about medicines, and challenges in having effective interactions with medical practitioners and pharmacists all contribute to the manifestation of nonadherence. While tailoring the therapeutic regimen to the needs of the patient (including through prolonged release formulations) is a step in the right direction, these efforts need to be bolstered by complementary educational measures that address cultural, social and geographic barriers.

Indigenous ESKD patients have reported that they value hearing about other Indigenous patients' stories in order to understand the dialysis and transplant journey and its associated demands. Kidney Health Australia and the Menzies School of Health Research have produced a number of educational videos that showcase Indigenous patients' experiences, but none to date have specifically focussed on the importance of adherence and strategies to ensure the immunosuppression regimen is maintained. As such, culturally tailored immunosuppression adherence education videos should be developed and trialled using a number of platforms, including YouTube, Vimeo and DVD. The success of these videos will be dependent on promotion from health care professionals and patient navigators to ensure patients are aware of the video's existence and can easily access the relevant content.

#### 4.2.2 Improving Equity and Access to Transplant Services

##### 4.2.2.1 *Establishing multidisciplinary post-transplant clinics in all major regional centres*

Following a kidney transplant, recipients are educated by a multidisciplinary health care team to self-manage their complex medical therapy. However, continued involvement from specialists and allied health providers is vital to ensure recipients are appropriately supported to maintain their transplant. A number of strategies have been identified to mitigate workforce shortages in rural and remote areas and improve the coordination and delivery of post-transplant care for Indigenous recipients.

It is important that multidisciplinary post-transplant clinics, comprising nephrologists, nurses, pharmacists, dieticians, social workers and Indigenous health workers, be made available in major regional centres to assist Indigenous recipients in managing their post-transplant care and facilitate improved coordination between transplant centres and primary care services. Similar to pre-transplant clinics, the successful implementation of post-transplant clinics is dependent on:

- Funding for additional medical and allied health positions in regional areas;
- Travel and accommodation allowances for remote patients, who will still be required to travel substantial distances to reach their nearest regional centre; and
- Rigorous, nationally standardised evaluations, to determine each regional clinic's effectiveness in facilitating improved post-transplant outcomes for Indigenous patients.

##### 4.2.2.2 *Developing a needs-based funding model for relocation*

The consequences of relocation for kidney transplant treatment and post-transplant care are pervasive. Families are often separated or whole families relocate, sometimes interstate, in order to access transplant centres. For some, the need to relocate from family and country may lead to a decision to forego treatment. In almost all people, the impact of kidney failure on the patient and their family is severe with prolonged ill health, a heavy symptomatic burden, loss of job opportunities and ability to work, financial hardship and very real social disruption (KHA, 2018b). There are major challenges in the health and social support area for Indigenous patients undergoing kidney transplantation away from home, and recent literature has identified a need for improved social and



financial support services when relocating Indigenous patients and their families to urban centres for transplant assessment, treatment and extended post-transplant monitoring (Gorham et al., 2017).

As a first step, further analysis is required to accurately quantify the cost of relocation for Indigenous transplant patients, covering urban housing, social support and transport expenses. This research should then be used to inform a needs-based funding model to help combat the multifaceted economic and social challenges that impede the pursuit of transplantation for Indigenous patients.

#### 4.2.2.3 *Facilitating the broader rollout of sustainable post-transplant POCT*

Given the cost of POCT to the community is considered to be the most significant barrier to its wider implementation, POCT measures that have been found to be non-inferior to pathology laboratory testing (i.e. tests for measuring glycated haemoglobin, urine albumin, albumin-creatinine ratio, total cholesterol and triglyceride levels) should be added to the MBS so that they are covered under Medicare. Furthermore, new POCT measures that enable ACCHS and other community health services to monitor kidney function and immunosuppressive drug levels in remote transplant recipients should be developed and trialled to maximise the value of POCT in the post-transplant context.

It is also critical that future POCT trials and programs establish a system of progressive knowledge transfer and capacity building, so that as a POCT program is implemented, the community is empowered with the resources to manage and sustain the program in the long term. Existing POCT programs that have successfully implemented a sustainable approach have:

- Systematically embedded a functional clinical governance structure for the organisation and accountability of POCT;
- Developed a tailored, continuing program for training and competency assessment of POCT device operators;
- Implemented sustainable quality management practices fit for purpose and relevant and appropriate for the device(s) being used; and
- Documented policies and procedures in flexible formats, depending on the clinical, cultural and geographic settings where community-based POCT is practiced.

It is recommended that a systematic review of well-established Australian POCT models be undertaken to guide the development of a new POCT program that is tailored to cater for the unique needs of remote Indigenous kidney transplant recipients.

#### 4.2.2.4 *Adopting telenephrology and telepharmacy as models of care for rural and remote Indigenous kidney transplant recipients*

While telenephrology and telepharmacy have been found to deliver effective clinical care for geographically distant dialysis patients, to date there has been no analysis of their impact on transplant-related outcomes, including medication adherence. Consequently, it is proposed that telenephrology and telepharmacy services be trialled among remote Indigenous kidney transplant recipients to determine their efficacy as models of care in the post-transplant context. Key performance indicators should include:

- Patient-centred outcomes, including transport distance, costs, convenience, comfort, and perceived quality of video-conferencing sound and picture, clinician communication, and overall experience;
- Rates of medication nonadherence;

- Rates of post-transplant hospitalisation; and
- Health service cost-benefit analyses.

In addition, it is critical that clinical pharmacy outpatient consults be recognised, endorsed and Medicare funded to ensure equity for patients living in rural and remote communities, and further funding should be allocated to establish and maintain telehealth infrastructure in remote and very remote communities that do not currently have the required setup in place.

#### 4.2.2.5 *Implementing a remote clinical pharmacist trial*

A remote clinical pharmacist trial could be implemented by supporting pharmacists based in regional hubs to travel to remote community health centres on a part time basis (i.e. 2 days per week) as part of a 'hub and spoke' model. Deploying pharmacists on a regular basis to remote communities is expected to facilitate improved awareness and knowledge of transplant related maintenance requirements, specifically immunosuppressive medication adherence, among Indigenous kidney transplant candidates and recipients. To be involved in the trial, pharmacists would need to undertake training in cultural safety and demonstrate a willingness to work collaboratively with ACCHS and Indigenous health workers.

#### 4.2.2.6 *Enabling transplant centres to provide patients with a CTG annotated script*

Indigenous patients with chronic disease have identified medication affordability as one of the key barriers to adherence. Eligible Indigenous patients living with or at risk of chronic diseases have access to low cost or free PBS medicines through the CTG PBS Co-payment Measure. However, transplant centres are currently unable to provide kidney transplant recipients with CTG annotated prescriptions, as eligible prescribers are limited to:

- Medical practitioners working in a practice that's participating in the Indigenous Health Incentive under the Practice Incentives Program (PIP);
- Any medical practitioner working in an Indigenous Health Service; and
- Any medical specialist provided the patient is: a) eligible for the measure, and b) referred by a clinician working in a practice participating in the Indigenous Health Incentive under PIP.

Enabling transplant centres to provide patients with CTG PBS prescriptions would have a significant impact on the affordability of post-transplant medications, and thus improve Indigenous transplant recipients' medication adherence

### 4.2.3 Researching, Developing and Implementing Clinical Guidelines and Protocols

#### 4.2.3.1 *Adopting consistent dose administration aid protocols*

DAA's have proven to be a successful adherence support strategy for kidney transplant recipients, and the provision of DAA's is a standard model of care in Australian transplant centres and renal units. However, there isn't a national DAA protocol for kidney transplant recipients, which can create confusion and reduce adherence for recipients who are required to transition between transplant centres; for example, a patient in the Northern Territory who receives their pre-transplant care in Darwin, has the transplant procedure in Adelaide, and then returns to Darwin for post-transplant monitoring. While dosettes and Webster Paks are similar, their layouts differ slightly. As a result, patients who have been trained to use Webster Paks during their immediate post-transplant care, but are then provided with a dosette upon returning to their home state may end up taking doses at the wrong time of day or skipping doses altogether due to the unfamiliar layout. It is thus recommended

that Australian transplant centres and renal units establish a national DAA protocol to ensure all patients receive the same post-transplant care regardless of where they are receiving treatment.

#### 4.2.3.2 *Trialling novel, long acting immunosuppressive agents*

New immunosuppressive agents are being developed to reduce acute rejection, improve long-term outcomes, minimise nephrotoxicity, reduce infections, cardiovascular, and malignancy-related complications, and promote adherence. Many of these agents, including belatacept, are yet to be trialled in the Australian context. Interventional clinical trials are needed to determine the safety and efficacy of novel, long acting immunosuppressive agents in adult kidney transplant recipients in Australia, particularly Indigenous recipients and those returning to rural and remote communities

#### **Box 17: Outline of an interventional clinical trial of belatacept**

##### **Proposed intervention groups:**

- Experimental – Belatacept Immunosuppression
  - Kidney transplant recipients will receive steroids (Methylprednisolone), rATG, Belatacept and Mycophenolate.
- Active Comparator – Standard Immunosuppression (Tacrolimus)
  - Kidney transplant recipients will receive standard immunosuppressive therapy, including steroids (Methylprednisolone), rATG, Tacrolimus and Mycophenolate.

##### **Proposed outcome measures:**

- Graft survival rates
- Number of graft rejection and infective complication episodes
- Renal function (on the basis of eGFR)
- Development of donor-specific antibodies
- Drug tolerability
- Medication adherence
- Rates of reintegration into the home community

#### 4.2.3.3 *Simplifying existing immunosuppressive regimens*

Past research has found that reducing immunosuppressive dosing frequency for kidney transplant recipients improves their adherence to the treatment regimen and overall quality of life (Obi et al., 2013). One way in which to achieve this is adopting prolonged-release tacrolimus-based regimens in Australian immunosuppressive protocols, as this simplifies patients' post-transplant care requirements and reduces the likelihood of accidentally missing doses.

#### 4.2.3.4 *Reducing immunosuppressant drug inefficacy and toxicities in Indigenous patients*

The PK Study is currently exploring genetic targets that may aid the development of tailored immunosuppressive protocols for the Indigenous patient population. Renal units may be able to harness relevant findings from this study to adjust immunosuppressive protocols for Indigenous kidney transplant recipients, reducing immunosuppressant drug inefficacy and toxicities and improving post-transplant outcomes.

#### 4.2.3.5 *Identifying nationwide antecedents and predictors to severe infective episodes in Indigenous patients*

Nationwide research is required to further explore the post-transplant infection rate disparity between Indigenous and non-Indigenous patients. However, due to the small number of transplants provided to Indigenous recipients, an appropriately powered randomised controlled trial is unlikely to be feasible in many areas. Instead, future research should endeavour to identify key medical, health service and environmental factors that promote or protect against recurrent or severe infective episodes that may drive the high risk of graft failure post-transplantation. An analysis of jurisdictional and regional differences should also be undertaken to enable renal units across Australia to introduce regionally specific infective prophylaxis protocols.

#### 4.2.3.6 *Adopting consistent clinical data collection protocols of infective complications*

From a clinical perspective, it is vital that those renal units responsible for providing care to Indigenous transplant patients cooperate to implement consistent clinical data collection protocols of infective complications. This will facilitate evaluation of uptake and effectiveness of prophylactic protocols for viral, bacterial and fungal infections.

#### 4.2.3.7 *Implementing a tailored prophylactic protocol for Indigenous kidney transplant recipients, based on current evidence*

Currently, no national protocol for infective prophylaxis in Indigenous kidney transplant recipients exists; instead, individual clinical units develop and apply their own protocols. The development of a national protocol has a range of benefits, including: improved consistency of care; enhanced coordination between clinical units and primary care providers, particularly in remote areas; and acknowledgement on a nationwide scale of the importance of tailoring post-transplant care for Indigenous patients. As such, it is recommended that a national working group be established to develop, monitor and evaluate a standardised prophylactic protocol for all Australian renal units.

Appendix C outlines recommendation for a prophylactic protocol to prevent infection in Indigenous kidney transplant recipients, covering pretransplant screening, vaccination, antimicrobial prophylaxis and education. The majority of these recommendations draw from and build upon the findings of previous research, while others need to be evaluated as part of clinical trials before broader implementation. For some conditions, regionally specific approaches will need to be implemented to reflect differences in infection prevalence, such as prevalence and causative organisms of invasive fungal infection, gastrointestinal helminth infection, and skin and soft tissue infection.

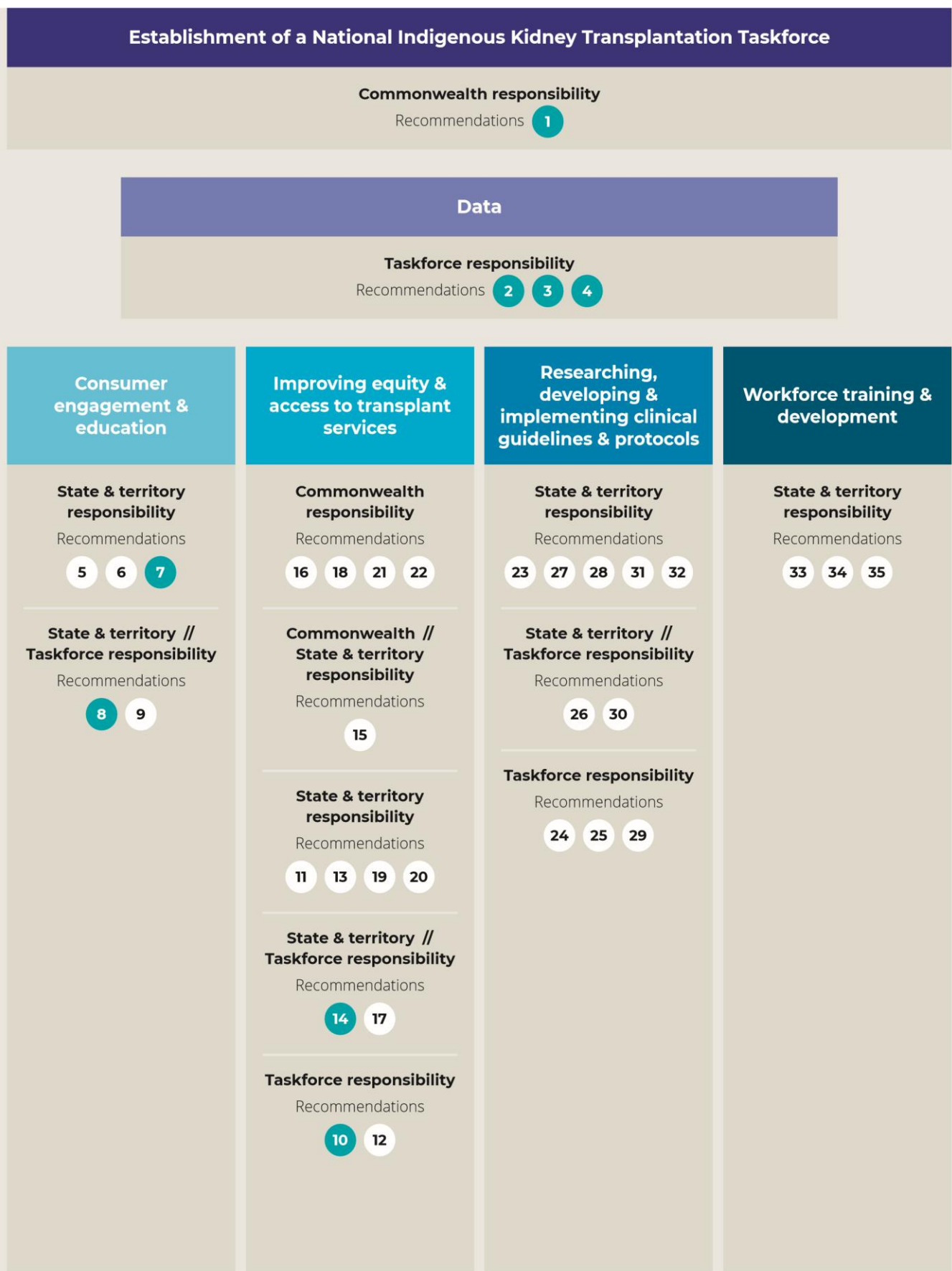
## 5. Summary

This report has outlined the various reasons contributing to Indigenous patients' under-representation on the kidney transplant waitlist and in receiving a transplant, including:

- The challenges in delivering appropriate health services to people living in remote areas, who might also have low health literacy and not speak English as a first language.
- The greater burden of comorbid illness among Indigenous dialysis patients, leading to fewer patients being deemed medically suitable.
- The shortage of living and deceased donors from within Indigenous communities.
- The length of time on the waiting list and the allocation system based primarily on HLA matching.
- The dislocation that follows from moving to transplant centres in distant capital cities.
- The high complication rate, particularly in terms of early infectious complications, leading to poor transplant outcomes (i.e. higher death and graft loss rates).

The scope of these barriers, covering cultural, social, psychological, biological and genetic areas, makes improving transplant outcomes for Indigenous candidates an incredibly challenging and complex task. There is no easy fix – achieving progress will require a multifaceted approach that targets identified pre- and post-transplant barriers. As outlined in Figure 14, further research, changes to the delivery of health services, and new policies are needed. This will require close collaboration between consumers, research organisations, health services, peak bodies and state, territory and federal governments to enable comprehensive and holistic solutions to be identified and implemented.

Figure 14: Recommendation mapping and consolidated list of recommendations.



## CONSOLIDATED LIST OF RECOMMENDATIONS - Total: 35 recommendations

**00** Highlight = Priority recommendation

### **Establishment of a National Indigenous Kidney Transplantation Taskforce**

- 1** Establish a resourced National Indigenous Kidney Transplantation Taskforce, with representations from DoH, TSANZ, ANZDATA, ANZSN, OTA and invited subject experts to drive the implementation of the report's recommendations, consult the Indigenous and health care communities on all relevant initiatives, and advocate for equitable access to transplantation for Indigenous patients.

### **Data**

- 2** Implement a 12-month pilot project to capture additional pre- and post-kidney transplant data points in an expanded ANZDATA data collection protocol.
- 3** Incorporate a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander people.
- 4** Undertake additional data linkage and research projects that target Indigenous patients' post-transplant outcomes, enabling identification of best practice immunosuppression, infective prophylaxis and vascular complication protocols.

### **Consumer engagement & education**

- 5** Deliver education programs to Indigenous communities about the value of organ donation and how it links to transplantation, in partnership with local transplant recipients and donor families.
- 6** Undertake consumer engagement projects that specifically explore Indigenous transplant candidates' and recipients' preferred models of care.
- 7** Establish an Indigenous reference group in every transplant unit to help design pathways and models of care that are culturally appropriate.
- 8** Trial and evaluate the adoption of patient navigator programs and yarning circles in pre-transplant protocols.
- 9** Pilot culturally informed transplant education interventions, including remote language centres and culturally tailored immunosuppression adherence education videos.

### **Improving equity & access to transplant services**

- 10** Evaluate and leverage existing initiatives that target cultural bias in health services to facilitate the rollout of best practice pre-transplant care and support interventions for Indigenous transplant candidates.
- 11** Ensure Indigenous transplant candidates are connected with primary care services earlier in the ESKD treatment continuum, to enable health issues to be addressed prior to workup.
- 12** Trial and evaluate weight loss strategies for Indigenous kidney transplant candidates, including conservative, culturally tailored weight loss programs and bariatric surgery.
- 13** If an empirical evidence base supports the use of bariatric surgery for Indigenous kidney transplant candidates, increase funding for bariatric surgery procedures in public hospitals.
- 14** Trial a multidisciplinary pre- and post-transplant clinic in one major regional centre for 12 months, prioritising the availability of dental and cardiac services, as well as travel and accommodation support for rural and remote patients.
- 15** Fund relevant medical and allied health services and positions in regional centres to facilitate the delivery of specialist transplant support outreach services, complementing regional pre- and post-transplant clinics and improving coordination of appointments and services.

- 16 Conduct a study on transplant models of care to quantify the costs for rural and remote Indigenous patients to inform the development of a needs-based funding model.
- 17 Undertake a systematic review of Australian POCT models to guide the development of a post-transplant care POCT program, comprising new POCT measures that enable the monitoring of renal function and immunosuppressive drug levels in kidney transplant recipients.
- 18 Subsidise POCT tests that have been validated by empirical evidence.
- 19 Investigate the value of telenephrology and telepharmacy programs for kidney transplant recipients living in rural and regional areas.
- 20 Design and implement a remote community pharmacist trial to facilitate improved awareness and knowledge of transplant related maintenance requirements among Indigenous kidney transplant candidates and recipients.
- 21 Subsidise clinical pharmacy outpatient consults for Indigenous transplant recipients.
- 22 Broaden the list of eligible prescribers for the Closing the Gap (CTG) PBS Co-payment Measure to include transplant centres.

### **Researching, developing & implementing clinical guidelines & protocols**

- 23 Systematically review the evidence on the outcomes of kidney transplantation with a live donor in the Indigenous patient population to inform health service protocols.
- 24 Evaluate the impact of immunological matching at the epitope (eplet) level for allocation of deceased donor kidneys.
- 25 Establish a national dose administration aid protocol and a consistent format for drug information.
- 26 Implement and evaluate novel, long acting immunosuppressive agents in Indigenous transplant recipients.
- 27 Adopt prolonged-release tacrolimus-based regimens in immunosuppressive protocols.
- 28 Revise immunosuppressive protocols based on relevant findings from the pharmacokinetic study of immunosuppressives in Indigenous transplant recipients.
- 29 Design and undertake research projects to identify the antecedents to infective episodes.
- 30 Test and evaluate novel infective prophylaxis interventions for Indigenous transplant recipients.
- 31 Adopt coordinated, nationally consistent clinical data collection, analysis and reporting protocols of infective complications across renal units.
- 32 Implement a tailored prophylactic protocol for Indigenous transplant recipients.

### **Workforce training & development**

- 33 Deliver consumer engagement training to renal unit and transplant centre staff.
- 34 Implement recruitment and training strategies for the renal workforce, particularly in remote areas, to improve the delivery of culturally appropriate pre-transplant care.
- 35 Implement transplant-specific 'train the trainer' workshops for Indigenous health workers.



## Appendix A Table of Systemic Biases

Systemic Biases and Effect	Mitigating Strategies
<ul style="list-style-type: none"> <li>• Australia’s kidney transplant system has been designed to cater for the needs of non-Indigenous patients.               <ul style="list-style-type: none"> <li>○ This promotes inequity in pre- and post-transplant outcomes.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Processes and systems that support equity in transplant outcomes and organ allocation need to be identified and integrated into renal units and transplant centres.</li> <li>• Possible actions that involve change at the health system, rather than personal, level include:               <ul style="list-style-type: none"> <li>○ committing additional funding to Indigenous specific transplant initiatives, such as delivering outreach services in remote areas,</li> <li>○ incorporating Indigenous paradigms within service specifications, and</li> <li>○ increasing Indigenous representation on advisory boards and steering groups.</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• A number of criteria used by renal units and transplant centres to determine patients’ suitability for kidney transplantation are standardised across Indigenous and non-Indigenous populations, despite the significant biological, cultural, genetic and social differences that exist between these patient groups.               <ul style="list-style-type: none"> <li>○ Applying standardised contraindication criteria to Indigenous patients may not be appropriate and could unjustly limit their access to the waitlist.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• A solid evidence base around criteria to determine transplant suitability needs to be developed and made available to patients and families so that they can understand the rationale underpinning medical decision making.               <ul style="list-style-type: none"> <li>○ The evidence base should then be harnessed to determine if certain criteria should include caveats in certain circumstances/individuals.</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• The higher rates of diabetes and CKD in the Indigenous population may mean that nephrologists adopt a more cautious approach in allowing Indigenous people to donate a kidney to a family member. However, very little is known about how renal unit and transplant centre protocols address this issue, and what evidence has informed the development of these protocols.</li> </ul>	<ul style="list-style-type: none"> <li>• Evidence on the outcomes of kidney transplantation using a live Indigenous donor (for both donor and recipient) needs to be systematically reviewed to inform health service protocols.</li> <li>• The findings of this review should be disseminated to Indigenous transplant candidates and the community more broadly to ensure transparency around decision making processes.</li> </ul>

<ul style="list-style-type: none"> <li>○ While the intention is to ensure donors are not put at future risk for ESKD, current donation and transplant protocols may limit the accessibility of kidney transplantation for Indigenous transplant candidates.</li> </ul>	
<ul style="list-style-type: none"> <li>● Indigenous ESKD patients are more likely to be overweight or obese compared to non-Indigenous patients, but renal units and transplant centres currently offer very little assistance in helping Indigenous patients to lose weight in order to access a kidney transplant. <ul style="list-style-type: none"> <li>○ This limits Indigenous patients' access to the waitlist.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Renal units and transplant centres must engage and work alongside Primary Health Networks to develop, implement and support effective weight loss strategies for the Indigenous kidney transplant candidate population.</li> <li>● Further evidence is also needed to determine the safest body composition for kidney transplantation, given that Indigenous patients tend to have a very different fat distribution compared to non-Indigenous patients.</li> </ul>
<ul style="list-style-type: none"> <li>● Indigenous patients who delay assessment and workup tests due to conflicting family and cultural obligations may be perceived to be nonadherent by renal units and transplant centres. <ul style="list-style-type: none"> <li>○ This detrimentally affects Indigenous patients' likelihood of being waitlisted.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● The health care system needs to accommodate Indigenous patients' family and cultural obligations by delivering care close to home wherever possible. <ul style="list-style-type: none"> <li>○ This necessitates the establishment and funding of multidisciplinary pre- and post-transplant teams and outreach services in regional, rural and remote areas.</li> </ul> </li> <li>● When travel to a renal unit or transplant centre in a regional or metropolitan area is unavoidable, a holistic system of support should be made available to rural and remote Indigenous patients, encompassing accommodation, transport and Indigenous interpreters and patient navigators.</li> </ul>
<ul style="list-style-type: none"> <li>● Issues associated with Indigenous kidney health continue to be insufficiently recognised and prioritised by health care services and governments. <ul style="list-style-type: none"> <li>○ Until it is appropriately recognised, inequitable models of care will continue to detrimentally affect Indigenous patients' pre- and post-transplant outcomes.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● A national agenda to achieve optimal and equitable kidney health for all Australians should be established and supported across all levels of the health care system and government.</li> <li>● In particular, renal health should be prioritised as part of the Australian Government's Closing the Gap targets, with</li> </ul>

	<p>progress monitored and reported on annually.</p> <ul style="list-style-type: none"> <li>• Within the nephrology community, a formal, nationally recognised advocacy group should be established to champion equitable access to transplantation and post-transplant outcomes for Indigenous patients.</li> </ul>
<ul style="list-style-type: none"> <li>• The extent of inequity in the transplant system is currently difficult to assess, due to a lack of collection and understanding of metrics that identify influencers to pre- and post-transplant outcomes for Indigenous patients. <ul style="list-style-type: none"> <li>○ This makes it difficult to pinpoint exactly where the system is failing Indigenous patients, and what antecedents lead to poor pre- and post-transplant outcomes.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Expand national data collection and reporting processes to enable granular and transparent reporting of key pre- and post-transplant outcomes for Indigenous people.</li> <li>• Expanded data collection and reporting needs to be accompanied by an Indigenous data governance framework to support the communication and use of findings within the Indigenous community.</li> </ul>
<ul style="list-style-type: none"> <li>• There are few resources available to engage interpreters and patient navigators in the health care system; in most cases, Indigenous patients who do not speak English as a first language are required to make do with 'broken English'. <ul style="list-style-type: none"> <li>○ This results in frequent misinterpretations, confusion and frustration, ultimately leading to poorer health service engagement and treatment outcomes.</li> <li>○ The situation is further complicated by transplants often being performed hundreds or thousands of kilometres away from home, limiting the availability of interpreters.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Equity cannot be achieved without establishing a language competent health workforce who can support timely and quality knowledge exchange with Indigenous patients.</li> <li>• This requires increased funding for interpreter and patient navigator roles in renal units, transplant centres and health services more broadly.</li> <li>• With improved communication comes improved knowledge, and health care providers must harness the knowledge provided by patients (via interpreters and patient navigators) to incorporate patient preferences into clinical decisions and health action plans.</li> </ul>

## Appendix B Belatacept Trials

Trialling the efficacy of belatacept as a novel addition to Australian immunosuppression protocols is supported by the findings of two phase 3 studies: Belatacept Evaluation of Nephroprotection and Efficacy as First-line Immunosuppression Trial (BENEFIT) and BENEFIT-Extended Criteria Donors Trial (BENEFIT-EXT) (Vincenti et al., 2016).

The BENEFIT trial found belatacept reduced the risk of death or graft loss by 43% at 7 years post-transplant, compared with patients randomly assigned to a CNI known as cyclosporine (Vincenti et al., 2016). Similarly, a post hoc analysis of BENEFIT-EXT data showed a 41% reduction in the risk of death, graft loss or a mean eGFR that was less than 30ml per minute per 1.73m<sup>2</sup> 7 years after transplantation among patients randomly assigned to belatacept compared to those assigned to cyclosporine (Vincenti et al., 2016). However, the trials also revealed some cautionary signals; belatacept-treated patients experienced higher acute rejection rates and were at greater risk of developing post-transplant lymphoproliferative disorder (PTLD) (Siddiqui, Tedesco-Silva, & Riella, 2017).

To combat the high rate of rejection, belatacept trial protocols have been adjusted by adding tacrolimus in the first 11 months post-transplant (Siddiqui et al., 2017). A retrospective study using registry data from the Scientific Registry of Transplant Recipients found that of the 875 kidney transplant recipients receiving belatacept in the United States in 2011, around half (n = 417) were on concomitant tacrolimus (Adams et al., 2016). This strategy was associated with lower rejection rates when compared to belatacept alone (Adams et al., 2016). With regard to PTLD, the BENEFIT trial showed that recipients who developed PTLD in the belatacept group were primarily Epstein-Barr virus (EBV) seronegative, and it was posited that a lack of immunity to EBV and potent suppression of T cells by belatacept enabled early EBV infections to manifest unchecked (Vincenti et al., 2012). Subsequently, it has been recommended that belatacept not be administered to patients who are EBV-negative.

### Box 18: Criticisms of the BENEFIT and BENEFIT-EXT Trials

- The lack of a contemporary control group has been scrutinised, as control patients received cyclosporine, an outdated CNI, rather than tacrolimus that is typically the first choice in current practice (Ekberg et al., 2007).
  - Although the authors suggested that graft survival should not differ among CNIs (Vincenti et al., 2016), a randomised trial comparing the standard dose of cyclosporine with low dose tacrolimus showed that graft survival in the group using tacrolimus was higher than the survival rate of the cyclosporine group (94% vs. 89%,  $p = 0.01$ ) (Ekberg et al., 2007).
  - Furthermore, eGFR was higher in the tacrolimus group than the cyclosporine group, indicating belatacept may not have as great of an advantage over tacrolimus.
- Measurement of long-term patient adherence posed an additional limitation, as this was not assessed beyond month 36 of the 84-month study period (Vincenti et al., 2016).
  - While it was theorised that adherence would differ between the two groups, this is yet to be validated by data.

## Appendix C Prophylaxis Protocol

Recommendations for a tailored prophylactic protocol for Indigenous kidney transplant recipients, based on current evidence	
Pre-transplant screening	<ol style="list-style-type: none"> <li>1. Undertake standard screening for HIV, HBV (HBsAg, HBcAb, HBsAb), HCV Ab, CMV IgG, EBV IgG, Toxoplasma IgG, HepA IgG, Quantiferon TB GOLD (or equivalent TB Elispot, Mantoux) and HTLV Ab to ensure effective treatment is undertaken, if necessary, prior to transplantation.</li> <li>2. Test for Melioidosis and Strongyloides serology, and if positive, treat as appropriate.</li> <li>3. Screen patients' stool for parasites (ideally three samples, but at least one), specifically Cryptosporidium.               <ol style="list-style-type: none"> <li>a) Repeat testing on the transplant waiting list is required if there is ongoing risk of exposure.</li> </ol> </li> <li>4. Test for scabies, and if present, treat as appropriate.</li> </ol>
Pre-transplant vaccination	<ol style="list-style-type: none"> <li>1. Administer one dose of pneumococcal vaccination with 13v PCV prior to transplantation, followed by 23vPPV 8 weeks later. Repeat 23vPPV at 5 years and finally at 10 years of age 50, whichever is later.</li> <li>2. Administer Haemophilus influenzae B vaccination single dose, as well as HBV and HAV vaccination if the patient is not immune.</li> <li>3. Ensure the patient receives an annual influenza vaccine.</li> <li>4. dTPa vaccination if last dose was administered longer than 10 years ago.</li> <li>5. Administer Varicella (live vaccine), MMR (live vaccine), Zoster (live vaccine), and HPV vaccination according to unit policy. Note – live vaccines are contraindicated in most immunosuppressed patients, and patients should not be immunosuppressed for 1 month after live vaccination.</li> </ol>
Antimicrobial prophylaxis	<ol style="list-style-type: none"> <li>1. Administer usual IV antibiotic prophylaxis peritransplant.</li> <li>2. Administer usual PJP prophylaxis with cotrimoxazole for durations according to unit policy. Consider increasing the dose of cotrimoxazole to double strength (160mg/800mg) one tablet once daily for 1 year to provide better protection against Staphylococcus aureus skin and soft tissue infections (including MRSA).</li> <li>3. For those with positive melioidosis serology, administer indefinite prophylaxis with cotrimoxazole 160mg/800mg once daily.</li> <li>4. Administer usual CMV prophylaxis with valganciclovir.</li> </ol>
Education	<ol style="list-style-type: none"> <li>1. Develop and deliver culturally appropriate information-sharing processes and resources to ensure Indigenous patients have a comprehensive understanding of post-transplant care and maintenance considerations, including the role good hygiene and nutrition has in staving off infection.</li> </ol>

- a) Education about post-transplant requirements must begin in the pre-transplant phase, and be reinforced regularly throughout patients' time on the waitlist and following transplantation.
- 2. In order to develop improved education processes and resources, consideration should be given to:
  - a) Integrating cultural awareness training and continuous professional development into the non-Indigenous health workforce curriculum; and
  - b) Increasing the training, recruitment and utility of Indigenous health workers and interpreters to aid the transmission of medical information and facilitate informed decision-making.
- 3. Advise Indigenous patients returning to high-risk remote areas without a safe drinking water supply to consume only bottled water.

**Recommendations for novel pre-transplant screening and antimicrobial prophylaxis initiatives for Indigenous kidney transplant recipients, which need to be trialled prior to being incorporated into a tailored prophylactic protocol**

Pre-transplant screening	<ol style="list-style-type: none"> <li>1. Implement routine comprehensive baseline immunological screening for both Indigenous and non-Indigenous patients to facilitate a direct comparison of the data and improve knowledge of underlying immune deficiencies that may influence post-transplant outcomes.           <ul style="list-style-type: none"> <li>a) This data could shed light on how increased exposure and underlying immune deficiencies contribute to the heightened incidence of graft loss and infectious death in Indigenous patients.</li> </ul> </li> </ol>
Antimicrobial prophylaxis	<ol style="list-style-type: none"> <li>1. Administer Amoxicillin 250mg once daily for 1 year for bacterial pneumonia prophylaxis (a reasonable percentage of Streptococcus pneumoniae are cotrimoxazole resistant). If hypersensitive to penicillin, use roxithromycin 150mg once daily.           <ul style="list-style-type: none"> <li>a) Data on rates of treatment for bacterial pneumonia among Indigenous kidney transplant recipients should be assessed to determine the efficacy of this approach.</li> </ul> </li> <li>2. Administer Lozanoc (itraconazole) 100mg once daily for 3-6 months to treat antifungal prophylaxis.           <ul style="list-style-type: none"> <li>a) Data on rates of treatment for fungal infections among Indigenous kidney transplant recipients should be assessed to determine the efficacy of this approach.</li> </ul> </li> </ol>

## References

- Abboudi, H., & Macphee, I. A. (2012). Individualized immunosuppression in transplant patients: potential role of pharmacogenetics. *Pharmacogenomics Pers Med*, 5, 63-72. doi:10.2147/PGPM.S21743
- Abedini, S., Goransson, L., Cockburn, E., Kilany, S., & Holdaas, H. (2018). Immunosuppression Adherence in Stable Kidney Transplant Patients Converted From Immediate- to Prolonged-Release Tacrolimus in Clinical Practice: A Norwegian Study. *Transplant Direct*, 4(2), e338. doi:10.1097/TXD.0000000000000755
- ACSQHC. (2017). *National Safety and Quality Health Service Standards: User Guide for Aboriginal and Torres Strait Islander Health*. Sydney, Australia: Australian Commission on Safety and Quality in Health Care. Retrieved from <https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/improving-care-for-aboriginal-and-torres-strait-islander-people/>
- Adams, A. B., Garrett, C., Goldstein, J., Zhang, R., Guasch, A., Pastan, S., . . . Larsen, C. (2016). *Post-Trial Experience with Belatacept: A Large Single Center Experience*. Paper presented at the 2016 American Transplant Congress, Emory Transplant Center, Atlanta.
- Afshinnia, F., Wilt, T. J., Duval, S., Esmaili, A., & Ibrahim, H. N. (2010). Weight loss and proteinuria: systematic review of clinical trials and comparative cohorts. *Nephrol Dial Transplant*, 25(4), 1173-1183. doi:10.1093/ndt/gfp640
- AIATSIS. (2018). Indigenous Australian Languages. Retrieved from <https://aiatsis.gov.au/explore/articles/indigenous-australian-languages>
- AIHW. (2011a). *End-stage kidney disease in Australia: Total incidence, 2003-2007*. Canberra, Australia: Australian Institute of Health and Welfare. Retrieved from <https://www.aihw.gov.au/getmedia/0b59410e-c277-4bde-8bd8-31054c51ee68/12787.pdf.aspx?inline=true>
- AIHW. (2011b). *Life expectancy and mortality of Aboriginal and Torres Strait Islander people*. Canberra, Australia: Australian Institute of Health and Welfare. Retrieved from <https://www.aihw.gov.au/reports/indigenous-australians/life-expectancy-and-mortality-of-aboriginal-and-to/contents/table-of-contents>
- AIHW. (2014). *Mortality and life expectancy of Indigenous Australians 2008 to 2012*. Canberra, Australia: Australian Institute of Health and Welfare. Retrieved from <https://www.aihw.gov.au/reports/indigenous-australians/mortality-life-expectancy-2008-2012/contents/summary>
- AIHW. (2015). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*. Canberra, Australia: Australian Institute of Health and Welfare. Retrieved from <https://www.aihw.gov.au/reports/indigenous-health-welfare/indigenous-health-welfare-2015/contents/table-of-contents>
- AIHW. (2017). *Weight loss surgery in Australia 2014-15: Australian hospital statistics* Canberra, Australia: Australian Institute of Health and Welfare. Retrieved from <https://www.aihw.gov.au/reports/hospitals/ahs-2014-15-weight-loss-surgery/contents/table-of-contents>
- Alexander, J. W., Goodman, H. R., Gersin, K., Cardi, M., Austin, J., Goel, S., . . . Woodle, E. S. (2004). Gastric bypass in morbidly obese patients with chronic renal failure and kidney transplant. *Transplantation*, 78(3), 469-474. doi:10.1097/01.Tp.0000128858.84976.27
- Amery, R. (2017). Recognising the communication gap in Indigenous health care. *Med J Aust*, 207(1), 13-15. doi:10.5694/mja17.00042
- Anderson, K., Cunningham, J., Devitt, J., & Cass, A. (2013). The IMPAKT study: using qualitative research to explore the impact of end-stage kidney disease and its treatments on aboriginal and Torres Strait Islander Australians. *Kidney Int Suppl (2011)*, 3(2), 223-226. doi:10.1038/kisup.2013.19

- Anderson, K., Cunningham, J., Devitt, J., Preece, C., & Cass, A. (2012). "Looking back to my family": Indigenous Australian patients' experience of hemodialysis. *BMC Nephrol*, *13*. doi:10.1186/1471-2369-13-114
- Anderson, K., Devitt, J., Cunningham, J., Preece, C., & Cass, A. (2008). "All they said was my kidneys were dead": Indigenous Australian patients' understanding of their chronic kidney disease. *Med J Aust*, *189*(9), 499-503.
- Anderson, K., Devitt, J., Cunningham, J., Preece, C., Jardine, M., & Cass, A. (2012). If you can't comply with dialysis, how do you expect me to trust you with transplantation? Australian nephrologists' views on indigenous Australians' 'non-compliance' and their suitability for kidney transplantation. *Int J Equity Health*, *11*(1), 21. doi:10.1186/1475-9276-11-21
- Anderson, K., Yeates, K., Cunningham, J., Devitt, J., & Cass, A. (2009). They really want to go back home, they hate it here: the importance of place in Canadian health professionals' views on the barriers facing Aboriginal patients accessing kidney transplants. *Health Place*, *15*(1), 390-393. doi:10.1016/j.healthplace.2008.03.002
- ANZDATA. (2018). *Chapter 10: ESKD in Indigenous Peoples of Australia and Aotearoa/New Zealand*. Adelaide, Australia: ANZDATA Registry.
- Aspin, C., Brown, N., Jowsey, T., Yen, L., & Leeder, S. (2012). Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: A qualitative study. *BMC Health Serv Res*, *12*. doi:10.1186/1472-6963-12-143
- Baba, J. T., Brolan, C. E., & Hill, P. S. (2014). Aboriginal medical services cure more than illness: a qualitative study of how Indigenous services address the health impacts of discrimination in Brisbane communities. *Int J Equity Health*, *13*(1), 56. doi:10.1186/1475-9276-13-56
- Barracough, K. A., Grace, B. S., Lawton, P., & McDonald, S. P. (2016). Residential location and kidney transplant outcomes in indigenous compared with non-Indigenous Australians. *Transplantation*, *100*. doi:10.1097/tp.0000000000001007
- Berquist, R. K., Berquist, W. E., Esquivel, C. O., Cox, K. L., Wayman, K. I., & Litt, I. F. (2008). Non-adherence to post-transplant care: Prevalence, risk factors and outcomes in adolescent liver transplant recipients. *Pediatric Transplantation*, *12*(2), 194-200. doi:10.1111/j.1399-3046.2007.00809.x
- Boan, P., Swaminathan, R., & Irish, A. (2017). Infectious complications in indigenous renal transplant recipients in Western Australia. *Intern Med J*, *47*(6), 648-655. doi:10.1111/imj.13450
- Browne, A. J., Varcoe, C., Smye, V., Reimer-Kirkham, S., Lynam, M. J., & Wong, S. (2009). Cultural safety and the challenges of translating critically oriented knowledge in practice. *Nurs Philos*, *10*. doi:10.1111/j.1466-769X.2009.00406.x
- Butler, J. A., Roderick, P., Mullee, M., Mason, J., & Peveler, R. C. (2004). Frequency and impact of nonadherence to immunosuppressants after renal transplantation: A systematic review. *77*, 769-776. doi:10.1097/01.TP.0000110408.83054.88
- Canuto, K. J., McDermott, R. A., Cargo, M., & Esterman, A. J. (2011). Study protocol: a pragmatic randomised controlled trial of a 12-week physical activity and nutritional education program for overweight Aboriginal and Torres Strait Islander women. *BMC Public Health*, *11*, 655. doi:10.1186/1471-2458-11-655
- Cass, A., Cunningham, J., Snelling, P., & Ayanian, J. Z. (2003). Late referral to a nephrologist reduces access to renal transplantation. *Am J Kidney Dis*, *42*. doi:10.1016/j.ajkd.2003.07.006
- Cass, A., Cunningham, J., Snelling, P., Wang, Z., & Hoy, W. (2003). Renal transplantation for Indigenous Australians: identifying the barriers to equitable access. *Ethn Health*, *8*(2), 111-119. doi:10.1080/13557850303562
- Cass, A., Cunningham, J., Wang, Z., & Hoy, W. (2001). Regional variation in the incidence of end-stage renal disease in Indigenous Australians. *Med J Aust*, *175*(1), 24-27.
- Cass, A., Lowell, A., Christie, M., Snelling, P. L., Flack, M., Marrnganyin, B., & Brown, I. (2002). Sharing the true stories: improving communication between Aboriginal patients and healthcare workers. *Med J Aust*, *176*(10), 466-470.



- Chadban, S. J., Barraclough, K. A., Campbell, S. B., Clark, C. J., Coates, P. T., Cohney, S. J., . . . Kidney Health Australia Caring for Australians with Renal, I. (2012). KHA-CARI guideline: KHA-CARI adaptation of the KDIGO Clinical Practice Guideline for the Care of Kidney Transplant Recipients. *Nephrology (Carlton)*, *17*(3), 204-214. doi:10.1111/j.1440-1797.2011.01559.x
- Chan, G., Garneau, P., & Hajjar, R. (2015). The impact and treatment of obesity in kidney transplant candidates and recipients. *Can J Kidney Health Dis*, *2*, 26. doi:10.1186/s40697-015-0059-4
- Chang, A. R., Grams, M. E., & Navaneethan, S. D. (2017). Bariatric Surgery and Kidney-Related Outcomes. *Kidney Int Rep*, *2*(2), 261-270. doi:10.1016/j.ekir.2017.01.010
- Chang, S. H., & McDonald, S. P. (2008). Post-kidney transplant weight change as marker of poor survival outcomes. *Transplantation*, *85*(10), 1443-1448. doi:10.1097/TP.0b013e31816f1cd3
- Chapman, R. R., & Berggren, J. R. (2005). Radical contextualization: contributions to an anthropology of racial/ethnic health disparities. *Health (London)*, *9*(2), 145-167. doi:10.1177/1363459305050583
- Cosio, F. G., Hickson, L. J., Griffin, M. D., Stegall, M. D., & Kudva, Y. (2008). Patient survival and cardiovascular risk after kidney transplantation: the challenge of diabetes. *Am J Transplant*, *8*(3), 593-599. doi:10.1111/j.1600-6143.2007.02101.x
- Davis, J. S., Cheng, A. C., McMillan, M., Humphrey, A. B., Stephens, D. P., & Anstey, N. M. (2011). Sepsis in the tropical Top End of Australia's Northern Territory: disease burden and impact on Indigenous Australians. *Med J Aust*, *194*(10), 519-524.
- Davy, C., Harfield, S., McArthur, A., Munn, Z., & Brown, A. (2016). Access to primary health care services for Indigenous peoples: A framework synthesis. *International Journal for Equity in Health*, *15*(1), 163. doi:10.1186/s12939-016-0450-5
- de Dassel, J. L., Ralph, A. P., & Cass, A. (2017). A systematic review of adherence in Indigenous Australians: an opportunity to improve chronic condition management. *BMC Health Services Research*, *17*(1), 845. doi:10.1186/s12913-017-2794-y
- De Geest, S., & Sabate, E. (2003). Adherence to long-term therapies: evidence for action. *Eur J Cardiovasc Nurs*, *2*(4), 323. doi:10.1016/S1474-5151(03)00091-4
- Denhaerynck, K., Dobbels, F., Cleemput, I., Desmyttere, A., Schafer-Keller, P., Schaub, S., & De Geest, S. (2005). Prevalence, consequences, and determinants of nonadherence in adult renal transplant patients: a literature review. *Transpl Int*, *18*(10), 1121-1133. doi:10.1111/j.1432-2277.2005.00176.x
- Devitt, J., Anderson, K., Cunningham, J., Preece, C., Snelling, P., & Cass, A. (2017). Difficult conversations: Australian Indigenous patients' views on kidney transplantation. *BMC Nephrol*, *18*(1), 310. doi:10.1186/s12882-017-0726-z
- Devitt, J., Cass, A., Cunningham, J., Preece, C., Anderson, K., & Snelling, P. (2008). Study Protocol - Improving Access to Kidney Transplants (IMPAKT): a detailed account of a qualitative study investigating barriers to transplant for Australian Indigenous people with end-stage kidney disease. *BMC Health Serv Res*, *8*. doi:10.1186/1472-6963-8-31
- Devitt, J., & McMasters, A. (1998). *Living on Medicine: A Cultural Study of End-stage Renal Failure in Aboriginal People*: IAD Press.
- Dew, M. A., DiMartini, A. F., De Vito Dabbs, A., Myaskovsky, L., Steel, J., Unruh, M., . . . Greenhouse, J. B. (2007). Rates and risk factors for nonadherence to the medical regimen after adult solid organ transplantation. *Transplantation*, *83*(7), 858-873. doi:10.1097/01.tp.0000258599.65257.a6
- Dey, A., Knox, S., Wang, H., Beard, F., & McIntyre, P. (2016). Summary of National Surveillance Data on Vaccine Preventable Diseases in Australia, 2008–2011. *Communicable diseases intelligence quarterly report*, *40*, S1-70.
- Di Carlo, H. N., & Darras, F. S. (2015). Urologic considerations and complications in kidney transplant recipients. *Adv Chronic Kidney Dis*, *22*(4), 306-311. doi:10.1053/j.ackd.2015.04.003
- Do, H., Wong, G., Chapman, J., Craig, J. C., D'Orsogna, L., & Lim, W. (2015). Comparative survival benefits and costs of an eplet and broad antigen based matching system in deceased donor

- kidney transplant allocation among Indigenous Australians [abstract]. *Am J Transplant*, 15(suppl 3).
- Dole, K. (2013). Breaking down the barriers: Indigenous transplantation in the northern territory. *Transplant Journal of Australasia*, 22(2), 17-23.
- Duff, D., Jesudason, S., Howell, M., & Hughes, J. T. (2018). A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease. *Renal Society of Australasia Journal*, 14, 84-88.
- Durey, A., & Thompson, S. C. (2012). Reducing the health disparities of Indigenous Australians: time to change focus. *BMC Health Serv Res*, 12(1), 151. doi:10.1186/1472-6963-12-151
- Dwyer, J., Kelly, J., Willis, E., Glover, J., Mackean, T., Pekarsky, B., & Battersby, M. (2011). *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People - Project Report*. Melbourne: The Lowitja Institute.
- Einsiedel, L. J., van Iersel, E., Macnamara, R., Spelman, T., Heffernan, M., Bray, L., . . . Davis, A. (2013). Self-discharge by adult Aboriginal patients at Alice Springs Hospital, Central Australia: insights from a prospective cohort study. *Aust Health Rev*, 37(2), 239-245. doi:10.1071/AH11087
- Ekberg, H., Tedesco-Silva, H., Demirbas, A., Vítko, Š., Nashan, B., Gürkan, A., . . . Halloran, P. F. (2007). Reduced Exposure to Calcineurin Inhibitors in Renal Transplantation. *New England Journal of Medicine*, 357(25), 2562-2575. doi:10.1056/NEJMoa067411
- El-Agroudy, A. E., Wafa, E. W., Gheith, O. E., Shehab El-Dein, A. B., & Ghoneim, M. A. (2004). Weight Gain after Renal Transplantation Is a Risk Factor for Patient and Graft Outcome. *Transplantation*, 77(9), 1381-1385. doi:10.1097/01.Tp.0000120949.86038.62
- Fredericks, E. M., & Dore-Stites, D. (2010). Adherence to immunosuppressants: how can it be improved in adolescent organ transplant recipients? *Current opinion in organ transplantation*, 15(5), 614-620. doi:10.1097/MOT.0b013e32833d3115
- Freeman, C. M., Woodle, E. S., Shi, J., Alexander, J. W., Leggett, P. L., Shah, S. A., . . . Diwan, T. S. (2015). Addressing morbid obesity as a barrier to renal transplantation with laparoscopic sleeve gastrectomy. *Am J Transplant*, 15(5), 1360-1368. doi:10.1111/ajt.13116
- Freeman, H. P. (2006). Patient navigation: a community based strategy to reduce cancer disparities. *J Urban Health*, 83(2), 139-141. doi:10.1007/s11524-006-9030-0
- Friedman, A. N. (2019). The Case for a Bariatric-Centered Approach to Chronic Kidney Disease Care. *Clinical Journal of the American Society of Nephrology*, CJN.12061018. doi:10.2215/cjn.12061018
- Garnock-Jones, K. P. (2015). Tacrolimus Prolonged Release (Envarsus<sup>®</sup>): A Review of Its Use in Kidney and Liver Transplant Recipients. *Drugs*, 75(3), 309-320. doi:10.1007/s40265-015-0349-2
- Gibson, O., Lisy, K., Davy, C., Aromataris, E., Kite, E., Lockwood, C., . . . Brown, A. (2015). Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. *Implement Sci*, 10. doi:10.1186/s13012-015-0261-x
- Gill, J. S. (2008). Cardiovascular disease in transplant recipients: current and future treatment strategies. *Clin J Am Soc Nephrol*, 3 (Suppl 2), S29-37. doi:10.2215/CJN.02690707
- Gordon, E. J., Reddy, E., Gil, S., Feinglass, J., Rodde, J., Abecassis, M. M., & Caicedo, J. C. (2014). Culturally competent transplant program improves Hispanics' knowledge and attitudes about live kidney donation and transplant. *Prog Transplant (Aliso Viejo, Calif)*, 24. doi:10.7182/pit2014378
- Gorham, G., Cass, A., Howard, K., & Evans, K. (2016). *Central Australia Renal Study: Technical Report Update*. Canberra, Australia: Menzies School of Health Research.
- Griese, E. U., Ilett, K. F., Kitteringham, N. R., Eichelbaum, M., Powell, H., Spargo, R. M., . . . Minchin, R. F. (2001). Allele and genotype frequencies of polymorphic cytochromes P4502D6, 2C19 and 2E1 in aborigines from western Australia. *Pharmacogenetics*, 11(1), 69-76.

- Harfield, S., Davy, C., Kite, E., McArthur, A., Munn, Z., Brown, N., & Brown, A. (2015). Characteristics of Indigenous primary health care models of service delivery: a scoping review protocol. *JBI Database of Systematic Rep Implement Rep*, 13. doi:10.11124/jbisrir-2015-2474
- Harris, A. D., Fleming, B., Bromberg, J. S., Rock, P., Nkonge, G., Emerick, M., . . . Thom, K. A. (2015). Surgical site infection after renal transplantation. *Infect Control Hosp Epidemiol*, 36(4), 417-423. doi:10.1017/ice.2014.77
- Hayes, B. (2008). Renal transplant coordination in the tropics: distance and diversity. *Transplant Nurses' Journal*, 17(1), 18-21.
- Haynes, R. B., Ackloo, E., Sahota, N., McDonald, H. P., & Yao, X. (2008). Interventions for enhancing medication adherence. *Cochrane Database of Systematic Reviews*(2). doi:10.1002/14651858.CD000011.pub3
- Healthy Lives: Life Expectancy Target. (2018). Retrieved from <https://closingthegap.pmc.gov.au/healthy-lives#box1-chapter6>
- Howard, R. J., Patton, P. R., Reed, A. I., Hemming, A. W., Van der Werf, W. J., Pfaff, W. W., . . . Scornik, J. C. (2002). The changing causes of graft loss and death after kidney transplantation. *Transplantation*, 73(12), 1923-1928.
- Hughes, J. T., Aye-Min, O., Majoni, S. W., Currie, B. J., Hall, H., & Kirkham, R. (2017). Delayed resolution of an extensive dermatophyte infection: client and clinician perceptions of treatment response in an adult dependent on haemodialysis. . *Posters. Nephrology*, 22, 51-92. doi:10.1111/nep.13105
- Hughes, J. T., Dembski, L., Kerrigan, V., Majoni, S. W., Lawton, P. D., & Cass, A. (2017). *Indigenous Patient Voices: Gathering Perspectives - Finding Solutions for chronic and end stage kidney disease*. Darwin.
- Hughes, J. T., Dembski, L., Kerrigan, V., Majoni, S. W., Lawton, P. D., & Cass, A. (2018). Gathering Perspectives - Finding Solutions for Chronic and End Stage Kidney Disease. *Nephrology (Carlton)*, 23 Suppl 1(S1), 5-13. doi:10.1111/nep.13233
- Hughes, J. T., Kelly, J., Mick-Ramsamy, L., & Mills, P. (2018). *Summary Report, Thursday Island, Catching Some Air - Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease*. Darwin: Menzies School of Health Research.
- Ichimaru, N., Kakuta, Y., Abe, T., Okumi, M., Imamura, R., Isaka, Y., . . . Takahara, S. (2008). Treatment Adherence in Renal Transplant Recipients: A Questionnaire Survey on Immunosuppressants. *Transplantation Proceedings*, 40(5), 1362-1365. doi:10.1016/j.transproceed.2008.02.083
- IMPAKT (2013). Retrieved from <https://www.lowitja.org.au/impakt>
- James, A., & Mannon, R. B. (2015). The Cost of Transplant Immunosuppressant Therapy: Is This Sustainable? *Curr Transplant Rep*, 2(2), 113-121. doi:10.1007/s40472-015-0052-y
- Johnson, D., Herzig, K. A., Purdie, D., Chang, W., Brown, A. M., Rigby, R. J., . . . Hawley, C. (2000). Is obesity a favorable prognostic factor in peritoneal dialysis patients? *Peritoneal dialysis international: journal of the International Society for Peritoneal Dialysis*, 20.
- Johnson, M. J. (2002). The Medication Adherence Model: a guide for assessing medication taking. *Res Theory Nurs Pract*, 16(3), 179-192. doi:10.1891/rtnp.16.3.179.53008
- Johnstone, L. (2017). *Telepharmacy and chronic kidney disease - a Making Tracks investment strategy*. Paper presented at the 14th National Rural Health Conference, Cairns, Queensland.
- Kalantar-Zadeh, K., Abbott, K. C., Salahudeen, A., Kilpatrick, R., & Horwich, T. (2005). *Survival advantages of obesity in dialysis patients* (Vol. 81).
- Kalluri, H. V., & Hardinger, K. L. (2012). Current state of renal transplant immunosuppression: Present and future. *World journal of transplantation*, 2(4), 51-68. doi:10.5500/wjt.v2.i4.51
- Katz, R., Pode, D., Gofrit, O. N., Shenfeld, O. Z., Landau, E. H., Golijanin, D., & Shapiro, A. (2003). Transurethral incision of ureteroneocystostomy strictures in kidney transplant recipients. *BJU International*, 92(7), 769-771. doi:10.1046/j.1464-410X.2003.04455.x

- Kelly, J., Dwyer, J., Pekarsky, B., Mackean, T., Willis, E., de Crespigny, C., . . . Dixon, K. (2015). *Managing Two Worlds Together. Stage 3: Improving Aboriginal Patient Journeys - Study Report*. Melbourne: The Lowitja Institute.
- KHA. (2018a). *KHA-CARI Indigenous Guidelines: Australian Community Consultation Methodology*. Kidney Health Australia.
- KHA. (2018b). Kidney Health Australia - Indigenous Kidney Health Program. Retrieved from [https://kidney.org.au/cms\\_uploads/docs/kidney-health-australia---indigenous-kidney-health-program-budget-submission.pdf](https://kidney.org.au/cms_uploads/docs/kidney-health-australia---indigenous-kidney-health-program-budget-submission.pdf)
- KHA. (2019). Kidney Transplant. Retrieved from <https://kidney.org.au/your-kidneys/support/kidney-transplant>
- Khanal, N., Lawton, P. D., Cass, A., & McDonald, S. P. (2018). Disparity of access to kidney transplantation by Indigenous and non-Indigenous Australians. *Med J Aust*, 209(6), 261-266. doi:10.5694/mja18.00304
- Kirkham, R., Maple-Brown, L. J., Freeman, N., Beaton, B., Lamilami, R., Hausin, M., . . . Hughes, J. T. (2018). Incorporating indigenous knowledge in health services: a consumer partnership framework. *Public Health*. doi:10.1016/j.puhe.2018.08.009
- Korda, R. J., Joshy, G., Jorm, L. R., Butler, J., & Banks, E. (2012). Inequalities in bariatric surgery in Australia: findings from 49 364 obese participants in a prospective cohort study. *Med J Aust*, 197(11), 631-636. doi:10.5694/mja12.11035
- Kuypers, D. R. J., Peeters, P. C., Sennesael, J. J., Kianda, M. N., Vrijens, B., Kristanto, P., . . . Kanaan, N. (2013). Improved Adherence to Tacrolimus Once-Daily Formulation in Renal Recipients: A Randomized Controlled Trial Using Electronic Monitoring. *Transplantation*, 95(2), 333-340. doi:10.1097/TP.0b013e3182725532
- Lambert, K., Mullan, J., Mansfield, K., & Lonergan, M. (2015). A Cross-Sectional Comparison of Health Literacy Deficits Among Patients With Chronic Kidney Disease. *Journal of Health Communication*, 20(sup2), 16-23. doi:10.1080/10810730.2015.1080329
- Lawton, P. D. (2015). *The Incidence and Outcomes of Chronic Kidney Disease amongst Indigenous Australians*. (Doctor of Philosophy), Charles Darwin University, Darwin.
- Lawton, P. D., Cunningham, J., Zhao, Y., Gray, N. A., Chatfield, M. D., Baade, P. D., . . . Jose, M. D. (2015). Survival of Indigenous Australians receiving renal replacement therapy: closing the gap? *Med J Aust*, 202. doi:10.5694/mja14.00664
- Lawton, P. D., McDonald, S. P., Snelling, P. L., Hughes, J., & Cass, A. (2017). Organ Transplantation in Australia: Inequities in Access and Outcome for Indigenous Australians. *Transplantation*, 101(11), e345-e346. doi:10.1097/tp.0000000000001911
- Lehner, L. J., Reinke, P., Hörstrup, J. H., Rath, T., Suwelack, B., Krämer, B. K., . . . Banas, B. (2018). Evaluation of adherence and tolerability of prolonged-release tacrolimus (Advagraf™) in kidney transplant patients in Germany: A multicenter, noninterventional study. *Clinical Transplantation*, 32(1), e13142. doi:10.1111/ctr.13142
- Li, K., Zou, J., Ye, Z., Di, J., Han, X., Zhang, H., . . . Zhang, P. (2016). Effects of Bariatric Surgery on Renal Function in Obese Patients: A Systematic Review and Meta Analysis. *PloS one*, 11(10), e0163907. doi:10.1371/journal.pone.0163907
- Liaw, S. T., Lau, P., Pyett, P., Furler, J., Burchill, M., Rowley, K., & Kelaher, M. (2011). Successful chronic disease care for Aboriginal Australians requires cultural competence. *Aust N Z J Public Health*, 35(3), 238-248. doi:10.1111/j.1753-6405.2011.00701.x
- Lowell, A., Maypilama, E., Yikaniwuy, S., Rrapa, E., Williams, R., & Dunn, S. (2012). "Hiding the story": indigenous consumer concerns about communication related to chronic disease in one remote region of Australia. *International Journal of Speech-Language Pathology*, 14(3), 200-208. doi:10.3109/17549507.2012.663791
- Lukas, N., Franklin, J., Lee, C. M., Taylor, C. J., Martin, D. J., Kormas, N., . . . Markovic, T. P. (2014). The efficacy of bariatric surgery performed in the public sector for obese patients with comorbid conditions. *Med J Aust*, 201(4), 218-222. doi:10.5694/mja13.00046

- MacLaughlin, H. L., Cook, S. A., Kariyawasam, D., Roseke, M., van Niekerk, M., & Macdougall, I. C. (2010). Nonrandomized trial of weight loss with orlistat, nutrition education, diet, and exercise in obese patients with CKD: 2-year follow-up. *Am J Kidney Dis*, *55*(1), 69-76. doi:10.1053/j.ajkd.2009.09.011
- Majoni, S. W., & Abeyaratne, A. (2013). Renal transplantation in Indigenous Australians of the Northern Territory: closing the gap. *Intern Med J*, *43*. doi:10.1111/imj.12274
- Majoni, S. W., Dole, K., Jabbar, Z., Sundram, M., & Perry, G. (2012). Infections: The Achilles Heel of Immunosuppression for Renal Transplantation and Immunological Renal Disease Management in the Top End of Northern Australia: Case Reports. *Open Journal of Nephrology*, *2*(4), 60-64. doi:10.4236/ojneph.2012.24010
- Maple-Brown, L. J., Hughes, J. T., Chatfield, M. D., Ward, L. C., Piers, L. S., Jones, G. R., . . . Jerums, G. (2015). Adding measures of body composition to the CKD-EPI GFR estimating equation in Indigenous Australians: the eGFR study. *Am J Kidney Dis*, *65*(4), 632-634. doi:10.1053/j.ajkd.2014.11.015
- Matas, A. J., Smith, J. M., Skeans, M. A., Thompson, B., Gustafson, S. K., Stewart, D. E., . . . Kasiske, B. L. (2015). OPTN/SRTR 2013 Annual Data Report: Kidney. *American Journal of Transplantation*, *15*(S2), 1-34. doi:10.1111/ajt.13195
- McDermott, R., Campbell, S., Li, M., & McCulloch, B. (2009). The health and nutrition of young indigenous women in north Queensland - intergenerational implications of poor food quality, obesity, diabetes, tobacco smoking and alcohol use. *Public Health Nutr*, *12*(11), 2143-2149. doi:10.1017/S1368980009005783
- McDonald, S. P. (2004). Indigenous transplant outcomes in Australia: what the ANZDATA Registry tells us. *Nephrology (Carlton)*, *9* (Suppl 4), S138-143. doi:10.1111/j.1440-1797.2004.00350.x
- McDonald, S. P., Jose, M. D., Lawton, P., & Cass, A. (2018). *Kidney Transplant Outcomes among Indigenous compared to Non-Indigenous Australians*. Adelaide, Australia.
- Merion, R. M., Goodrich, N. P., Johnson, R. J., McDonald, S. P., Russ, G. R., Gillespie, B. W., & Collett, D. (2018). Kidney transplant graft outcomes in 379 257 recipients on 3 continents. *Am J Transplant*, *18*(8), 1914-1923. doi:10.1111/ajt.14694
- Modanlou, K. A., Muthyala, U., Xiao, H., Schnitzler, M. A., Salvalaggio, P. R., Brennan, D. C., . . . Lentine, K. L. (2009). Bariatric surgery among kidney transplant candidates and recipients: analysis of the United States renal data system and literature review. *Transplantation*, *87*(8), 1167-1173. doi:10.1097/TP.0b013e31819e3f14
- Morales, J. M., Varo, E., & Lázaro, P. (2012). Immunosuppressant treatment adherence, barriers to adherence and quality of life in renal and liver transplant recipients in Spain. *Clinical Transplantation*, *26*(2), 369-376. doi:10.1111/j.1399-0012.2011.01544.x
- Moreso, F., Torres, I., Costa-Requena, G., & Serón, D. (2015). Nonadherence to immunosuppression: Challenges and solutions. *Transplant Research and Risk Management*, *7*. doi:10.2147/TRRM.S50796
- NHMRC. (2013). *Clinical practice guidelines for the management of overweight and obesity in adults, adolescents and children in Australia*. Canberra: Department of Health. Retrieved from <https://nhmrc.gov.au/about-us/publications/clinical-practice-guidelines-management-overweight-and-obesity>
- NRHA. (2014). *Patient Assisted Travel Schemes*. Canberra, Australia: National Rural Health Alliance. Retrieved from <http://ruralhealth.org.au/sites/default/files/publications/nrha-factsheet-pats.pdf>
- O'Brien, P. E., DeWitt, D. E., Laurie, C., Brennan, L., Wentworth, J. M., Anderson, M., . . . Dalton, D. P. (2016). The Effect of Weight Loss on Indigenous Australians with Diabetes: a study of Feasibility, Acceptability and Effectiveness of Laparoscopic Adjustable Gastric Banding. *Obes Surg*, *26*(1), 45-53. doi:10.1007/s11695-015-1733-4
- Obi, Y., Ichimaru, N., Kato, T., Kaimori, J. Y., Okumi, M., Yazawa, K., . . . Takahara, S. (2013). A single daily dose enhances the adherence to immunosuppressive treatment in kidney transplant

- recipients: a cross-sectional study. *Clin Exp Nephrol*, 17(2), 310-315. doi:10.1007/s10157-012-0713-4
- Olafsdottir, S. (2013). Social construction and health. In W. C. Cockerham (Ed.), *Medical sociology on the move*. Dordrecht Heidelberg: Springer Science.
- Panaretto, K. S., Wenitong, M., Button, S., & Ring, I. T. (2014). Aboriginal community controlled health services: leading the way in primary care. *Med J Aust*, 200(11), 649-652. doi:10.5694/mja13.00005
- Park, J., Ahmadi, S. F., Streja, E., Molnar, M. Z., Flegal, K. M., Gillen, D., . . . Kalantar-Zadeh, K. (2014). Obesity paradox in end-stage kidney disease patients. *Prog Cardiovasc Dis*, 56(4), 415-425. doi:10.1016/j.pcad.2013.10.005
- Piers, L. S., Rowley, K. G., Soares, M., & O'Dea, K. (2003). *Relation of adiposity and body fat distribution to body mass index in Australians of Aboriginal and European ancestry* (Vol. 57).
- Pinsky, B. W., Takemoto, S. K., Lentine, K. L., Burroughs, T. E., Schnitzler, M. A., & Salvalaggio, P. R. (2009). Transplant outcomes and economic costs associated with patient noncompliance to immunosuppression. *Am J Transplant*, 9(11), 2597-2606. doi:10.1111/j.1600-6143.2009.02798.x
- The PK Study. (2018). Retrieved from [https://www.menzies.edu.au/page/Research/Projects/Kidney/Comparison\\_of\\_Immunosuppressant\\_Drug\\_Pharmacokinetics\\_in\\_Aboriginal\\_versus\\_non-Aboriginal\\_Australian\\_Kidney\\_Transplant\\_Recipients/](https://www.menzies.edu.au/page/Research/Projects/Kidney/Comparison_of_Immunosuppressant_Drug_Pharmacokinetics_in_Aboriginal_versus_non-Aboriginal_Australian_Kidney_Transplant_Recipients/)
- Poudel, A., & Nissen, L. (2016). *Telepharmacy: a pharmacist's perspective on the clinical benefits and challenges* (Vol. 5).
- Poulson, L. K., Nissen, L., & Coombes, I. (2010). Pharmaceutical review using telemedicine--a before and after feasibility study. *J Telemed Telecare*, 16(2), 95-99. doi:10.1258/jtt.2009.090716
- Pourmand, G. R., Dehghani, S., Saraji, A., Khaki, S., Mortazavi, S. H., Mehraei, A., & Sajadi, H. (2012). Relationship between Post-kidney Transplantation Antithymocyte Globulin Therapy and Wound Healing Complications. *Int J Organ Transplant Med*, 3(2), 79-84.
- Preston-Thomas, A., Cass, A., & O'Rourke, P. (2007). Trends in the incidence of treated end-stage kidney disease among Indigenous Australians and access to treatment. *Aust N Z J Public Health*, 31. doi:10.1111/j.1753-6405.2007.00111.x
- Puzziferri, N., Roshek, T. B., 3rd, Mayo, H. G., Gallagher, R., Belle, S. H., & Livingston, E. H. (2014). Long-term follow-up after bariatric surgery: a systematic review. *JAMA*, 312(9), 934-942. doi:10.1001/jama.2014.10706
- Ralph, A. P., Lowell, A., Murphy, J., Dias, T., Butler, D., Spain, B., . . . Cass, A. (2017). Low uptake of Aboriginal interpreters in healthcare: exploration of current use in Australia's Northern Territory. *BMC Health Serv Res*, 17(1), 733. doi:10.1186/s12913-017-2689-y
- Rix, E. F., Barclay, L., Stirling, J., Tong, A., & Wilson, S. (2015). The perspectives of Aboriginal patients and their health care providers on improving the quality of hemodialysis services: a qualitative study. *Hemodial Int*, 19(1), 80-89. doi:10.1111/hdi.12201
- Rogers, N. M., Lawton, P. D., & Jose, M. D. (2006). Kidney transplant outcomes in the Indigenous population in the Northern Territory of Australia. *Transplantation*, 82. doi:10.1097/01.tp.0000232439.88527.49
- Rohatgi, R., Ross, M. J., & Majoni, S. W. (2017). Telenephrology: current perspectives and future directions. *Kidney Int*, 92(6), 1328-1333. doi:10.1016/j.kint.2017.06.032
- Sanson-Fisher, R., Campbell, E. M., Perkins, J., Blunden, S. V., & Davis, B. B. (2006). *Indigenous health research: A critical review of outputs over time* (Vol. 184).
- Schauer, P. R., Mingrone, G., Ikramuddin, S., & Wolfe, B. (2016). Clinical Outcomes of Metabolic Surgery: Efficacy of Glycemic Control, Weight Loss, and Remission of Diabetes. *Diabetes Care*, 39(6), 902-911. doi:10.2337/dc16-0382
- Shephard, M. (2003). Point-of-care testing in the Aboriginal community. *Australian Journal of Medical Science*, 24, 10-16.

- Shephard, M. (2010). Point-of-care testing comes of age in Australia. *Australian Prescriber*, 33(1), 6-9. doi:10.18773/austprescr.2010.003
- Shephard, M. (2013). Point-of-Care Testing in Australia: The Status, Practical Advantages, and Benefits of Community Resiliency Point of Care. *Point of Care*, 12(1), 41-45. doi:10.1097/POC.0b013e318265f79e
- Siddiqui, Z., Tedesco-Silva, H., & Riella, L. V. (2017). Belatacept in kidney transplantation - past and future perspectives. *J Bras Nefrol*, 39(2), 205-212. doi:10.5935/0101-2800.20170035
- Stephens, D. (2007). Exploring pathways to improve indigenous organ donation. *Internal Medicine Journal*, 37(10), 713-716. doi:doi:10.1111/j.1445-5994.2007.01500.x
- Stevens, J. A., Egger, G., & Morgan, B. (2018). A novel, culturally appropriate approach to weight management in Aboriginal and Torres Strait Islander people. *Med J Aust*, 209(1), 68. doi:10.5694/mja17.01240
- Subramani, P., Ullah, S., Majoni, S. W., Hughes, J. T., & McDonald, S. (2018). *The association of body mass index change one year post kidney transplantation with graft and patient survival: a comparative study between Indigenous and non-Indigenous Australians*. Paper presented at the 54th Australian and New Zealand Society of Nephrology Annual Scientific Meeting, Sydney, Australia.
- Swain, L., & Barclay, L. (2013). They've given me that many tablets, I'm bushed. I don't know where I'm going: Aboriginal and Torres Strait Islander peoples' experiences with medicines. *Aust J Rural Health*, 21(4), 216-219. doi:10.1111/ajr.12053
- Sypek, M. P., Clayton, P. A., Lim, W., Hughes, P., Kanellis, J., Wright, J., . . . McDonald, S. P. (2018). Access to waitlisting for deceased donor kidney transplantation in Australia. *Nephrology (Carlton)*. doi:10.1111/nep.13484
- Togni, S., Nangala, I., Heffernan, M., Bonney, E., Smith, M., Nelson, A., . . . Gorham, G. (2017). *Final Report - Patient-led Participatory Action Research Project: Patient-led pathways to cultural understanding and better patient-nurse relationships in renal care*. Darwin: Menzies School of Health Research
- Tonelli, M., Chou, S., Gourishankar, S., Jhangri, G. S., Bradley, J., & Hemmelgarn, B. (2005). Wait-listing for kidney transplantation among aboriginal hemodialysis patients. *American Journal of Kidney Diseases*, 46(6), 1117-1123. doi:10.1053/j.ajkd.2005.09.005
- Tonelli, M., Hemmelgarn, B., Manns, B., Pylypchuk, G., Bohm, C., Yeates, K., . . . Gill, J. S. (2004). Death and renal transplantation among Aboriginal people undergoing dialysis. *CMAJ*, 171(6), 577-582. doi:10.1503/cmaj.1031859
- Tong, A., Howard, K., Wong, G., Cass, A., Jan, S., Irving, M., & Craig, J. C. (2011). Nephrologists' perspectives on waitlisting and allocation of deceased donor kidneys for transplant. *Am J Kidney Dis*, 58. doi:10.1053/j.ajkd.2011.05.029
- TSANZ. (2018). *Clinical Guidelines for Organ Transplantation from Deceased Donors*. Sydney, Australia: Transplant Society of Australia and New Zealand. Retrieved from <https://www.tsanz.com.au/Clinical%20Guidelines%20-Dec%202018.pdf>
- Tucci, J. D. (2011). Pharmacogenetic screening of Indigenous Australians. *Med J Aust*, 195(7), 386-387. doi:10.5694/mja11.10678
- Vincenti, F., Larsen, C. P., Alberu, J., Bresnahan, B., Garcia, V. D., Kothari, J., . . . Charpentier, B. (2012). Three-Year Outcomes from BENEFIT, a Randomized, Active-Controlled, Parallel-Group Study in Adult Kidney Transplant Recipients. *American Journal of Transplantation*, 12(1), 210-217. doi:10.1111/j.1600-6143.2011.03785.x
- Vincenti, F., Rostaing, L., Grinyo, J., Rice, K., Steinberg, S., Gaitte, L., . . . Larsen, C. P. (2016). Belatacept and Long-Term Outcomes in Kidney Transplantation. *N Engl J Med*, 374(4), 333-343. doi:10.1056/NEJMoa1506027
- Weng, F. L., Israni, A. K., Joffe, M. M., Hoy, T., Gaughan, C. A., Newman, M., . . . Feldman, H. I. (2005). Race and Electronically Measured Adherence to Immunosuppressive Medications after

Deceased Donor Renal Transplantation. *Journal of the American Society of Nephrology*, 16(6), 1839-1848. doi:10.1681/asn.2004121059

- Whop, L. J., Valery, P. C., Beesley, V. L., Moore, S. P., Lokuge, K., Jacka, C., & Garvey, G. (2012). Navigating the cancer journey: A review of patient navigator programs for Indigenous cancer patients. *Asia Pac J Clin Oncol*, 8. doi:10.1111/j.1743-7563.2012.01532.x
- Yeates, K. E., Cass, A., Sequist, T. D., McDonald, S. P., Jardine, M. J., Trpeski, L., & Ayanian, J. Z. (2009). Indigenous people in Australia, Canada, New Zealand and the United States are less likely to receive renal transplantation. *Kidney Int*, 76. doi:10.1038/ki.2009.236