A report for:

CULTURAL BIAS INDIGENOUS KIDNEY CARE AND KIDNEY TRANSPLANTATION REPORT

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Every which way you look at renal disease in Aboriginal people, the only solutions that will work in the long term are those that are Aboriginal–led, culturally responsive, located in Aboriginal organisations and evaluated through an Aboriginal lens.

To our non-Indigenous supporters …, I believe these examples about HOW we want to work together will be inspiring. Please expand your discussions … with a positive acknowledgment of community control, and the rights we have as Aboriginal and Torres Strait Islander peoples to shape our own destiny, to partner with you as equals in service delivery, and to be accountable.

Pat Turner paying tribute to her Uncle Charlie Perkins in speech to the National Indigenous Dialysis and Transplantation Conference (Turner 2019)

Prepared by:

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Terminology

ACCHO/S – Aboriginal Community Controlled Health Organisation/Service: Aboriginal Community Controlled Health Organisations or Services are non-government primary healthcare organisations operated by the local Aboriginal community for the local Aboriginal community to deliver comprehensive and holistic culturally appropriate healthcare (NACCHO 2020).

AMS – Aboriginal Medical Service: An Aboriginal Medical Service is a generally a primary healthcare service that is funded to provide healthcare services mainly to Aboriginal and Torres Strait Islander people. Some AMS's are community controlled and some are government health services run by their respective state or territory government.

Cultural bias: For the purposes of this review cultural bias refers to any action or inaction that contributes to disparate treatment or treatment outcomes for Aboriginal and Torres Strait Islander people.

Cultural safety: a practice philosophy about *how* care is provided not *what* care is provided. It includes recognition of power inequity between practitioner and patient and is a decolonising model of practice based upon reflective practice, dialogue and communication, power sharing and negotiation of white privilege. Cultural safety was first described by Maori nurse educator Irihapeti Ramsden in 1991.[1]

Individual racism: racism at the interpersonal level, usually identifiable by its overt nature in actions or words — interactions between people that maintain and reproduce avoidable and unfair inequalities across ethnic/racial groups.[1]

Institutional racism: the way organisations are governed, staffed, resourced, operated and held accountable which results in the organisation delivering disparities in outcomes for some groups in society. It is often hidden in nature and integrated into governance, policies and practices.[1]

Racial prejudice is the unthinking negative beliefs about people from other racial groups similar to unconscious bias.[1]

Racism: the expression of a person's belief in their racial superiority and their compulsion to maintain the power of their racial group over others. It is not necessarily expressed as hate as racism is fundamentally about power.[1]

Unconscious bias: an unthinking bias against people of a race, culture or ethnicity different to your own.[1]

Whiteness and white privilege: the benefits given to those who resemble the people who dominate the powerful positions in our society. White privilege is like an invisible knapsack of resources and benefits. It can be difficult for those who were born with white privileges to see and understand the mechanisms that consistently redirect resources to them.[1,2]

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[1] Bourke, C. 2019, Presentation to the National Indigenous Dialysis & Transplantation Conference (NIDTC), Alice Springs, 20-22 October 2019. Viewed 3 March 2020 at: https://tsanz.com.au/committees/niktt.htm and https://vimeo.com/379925176

[2] McIntosh, P. 1989, 'White Privilege: Unpacking the Invisible Knapsack', *Peace and Freedom*, July/August, pp. 1–3.

Acronyms

ACCHO	Aboriginal Community Controlled Health Organisation (hence ACCHOs)
ACCHS	Aboriginal Community Controlled Health Service
AHW	Aboriginal Health Workers
AKction	Aboriginal Kidney Care Together – Improving Outcomes Now
AMIC	Aboriginal Maternal Infant Care
AMS	Aboriginal Medical Service (hence AMSs)
AHPRA	Australian Health Practitioner Regulation Agency
APD	Automated peritoneal dialysis
APY Lands	Anangu Pitjantjatjara Yankunytjatjara Lands
ARDAC	Aboriginal Children and Young People (ARDAC) study
C-AIR	Catching Some Air: Asserting Aboriginal and Torres Strait Islander Rights in Renal Disease
CARV	Central Australia Renal Voice
CAPD	continuous ambulatory peritoneal dialysis
CKD	chronic kidney disease
CNARTS	Central Northern Adelaide Renal & Transplantation Service
ED	Emergency Department
eMR	Electronic medical record
HP	Health professionals
ILO	Indigenous Liaison Officers
IMPAKT	Improving Access to Kidney Transplants study
IRG	Indigenous Reference Group (hence IRGs)
KHA-CARI	Kidney Health Australia – Caring for Australasians with Renal Impairment
KPIs	Key performance indicators
KRS	Kimberley Renal Service
MBS	Medical Benefits Schedule
MeSH	Medical Subject Headings
NHMRC	National Health and Medical Research Council
NIKTT	National Indigenous Kidney Transplantation Taskforce
NSQHS	National Safety and Quality Health Service
NSW	New South Wales
NT	Northern Territory
NUM	Nurse Unit Manager
OVHS	Outback Vascular Health Service
QLD	Queensland
RAAC	Renal Advocacy Advisory Committee
SA	South Australia
WA	Western Australia

Acknowledgments

Structure of this report

Section 1 includes an introduction to this project and an explanation of the term cultural bias as it applies to this report. It also explains our method when conducting the overall review.

Section 2 includes a review of the grey literature. It provides an overview of key programs and cultural bias initiatives that have been undertaken in kidney care, from kidney transplantation and dialysis to prevention and early detection.

Section 3 presents the systematic review of the peer reviewed literature regarding cultural bias initiatives for Aboriginal and Torres Strait Islander peoples. The identified publications were analysed using three different approaches to assess:

1. efficacy addressing cultural biases from a patient/family, health professional and administration/clinical perspectives
2. comparison using an identified conceptual framework to address racism and improve healthcare outcomes for Aboriginal and Torres Strait Islander people within chronic kidney disease
3. application across the varying levels of the health system – individual, health service and systems level (micro, meso, macro).

Finally, **Section 4** brings together the synthesis of the kidney specific and peer reviewed literature into a wider discussion and makes recommendations for future action.

This report has been prepared by the Lowitja Institute and the University of Adelaide for the National Indigenous Kidney Transplantation Taskforce.

Preface: Colonised Health Systems

The Australian healthcare system is predominantly based on Western and colonial perspectives, dominated by Western biomedical science and decision making, with economics controlling how and where services are delivered. Western biomedical care is based on numerous cultural assumptions, and a hierarchy of scientific knowledge that values efficiency and evidence and a focus on disease. Indigenous knowledge systems (Indigenous ways of knowing, being and doing) are more collective and connected to people, culture and land.

Colonisation continues to impact negatively on Indigenous peoples in society and cause a disconnect within health care. Indigenous knowledges are often misunderstood, undervalued and overlooked, leading to decreased access to responsive care, and increased levels of ill health.

Decolonisation is an active process of reimaging and restructuring how health services are provided. It involves changing the mechanisms of power and control, and increasing Indigenous community involvement and decision making. An important factor is the extent to which funding, support and resources are available to enable Aboriginal and Torres Strait islander patients and families to engage. Decolonisation involves equitable mechanisms for engagement.

Cultural safety, an Indigenous (Maori) developed concept can also help facilitate and inform the process of decolonisation. Cultural safety focuses on equity, the impact of colonisation and power differentials in health care, and on systemic and individual change through critical self-reflection. Importantly, cultural safety is defined by the recipients of care, not by the care provider.

Self-knowledge and critical self-awareness about the way we view and interpret the world can help us all better understand why we may dismiss things that are presented to us that do not meet our world view and culturally influenced criteria of facts. In the healthcare setting, listening to, and responding to First Nation peoples' experiences, stories and voices and valuing differing perspectives can improve the way our health system functions, and ultimately save lives. Decolonisation is an important concept for all Australians to understand and achieve. It has the potential to benefit our health system and society as a whole.
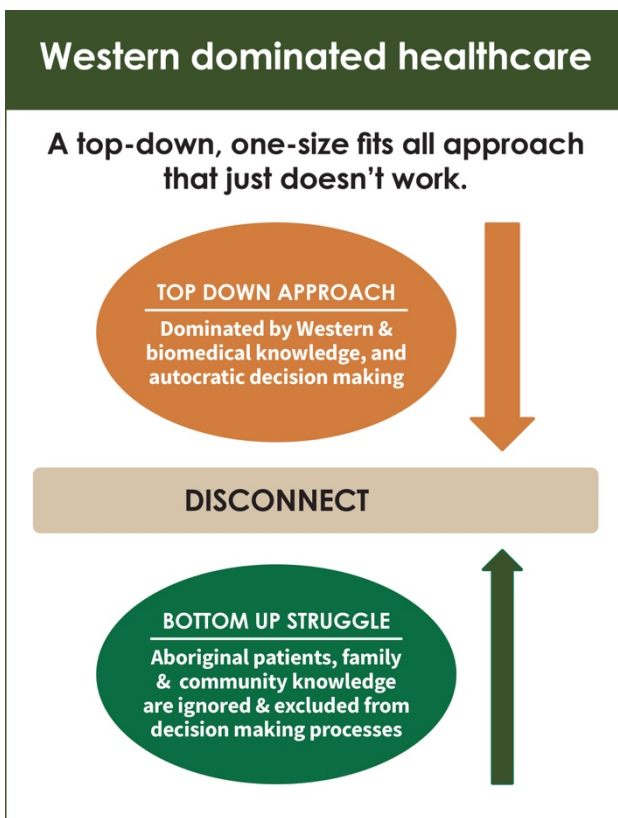
Figure 1: Western dominated healthcare

Figure 2: Bringing together Indigenous and Western knowledge systems

Decolonisation

Resources
Approaches
Connections
Processes
Experiences
Protocols

Resources
Approaches
Structures
Processes
Experiences
Systems
Services

Values & beliefs worldviews

Indigenous health & wellbeing

Collective decision making & governance

Connection to:
- Spirit, spirituality & ancestors
- Family, community & kinship
- Country & culture
- Body, mind and emotions
- Life, death, life cycles

Health and wellbeing is impacted by colonisation, intergenerational trauma, racism, loss & grief

Focus on inclusion

Culturally safe healthcare as defined by Indigenous recipients of care

Built on:
- Trusting relationships between healthcare providers and recipients of care
- Two way communication & respectful sharing of information and perspectives
- Shared decision making
- Critical self reflection on assumptions and bias
- Adequate and long term funding, support and resources to enable meaningful community involvement

Reimagining health care involves:
- *Equitable access*
- *Indigenous governance*
- *Deep collaboration*
- *Brave spaces*

Focus on co-creation & equity

Indigenous experiences of Western healthcare

Autocratic decision making & governance

Disconnection due to:
- Reliance on biomedical, scientific and physical evidence
- Separation of body parts mind & spirit
- Focus on individuals
- City centric, specialisation services
- Short term funding cycles

Collaborative approaches are impacted by timeframes, workload, funding and resource availability

Focus on usual care & equality

Executive Summary

Kidney disease is a serious and increasing health problem for many Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander people are significantly more likely to experience kidney failure compared to other Australians, be diagnosed at an earlier age, and have a higher prevalence of other comorbidities (ANZDATA Registry 2018).

Despite this disparity, Aboriginal and Torres Strait Islander people are much less likely to receive a kidney transplant (Khanal et al. 2018). In 2017, the proportion of Aboriginal and Torres Strait Islander people who had received a kidney transplant for treatment of kidney failure was 13 per cent compared to 51 per cent for non-Indigenous Australians (ANZDATA Registry 2018)

To address these inequities in health outcomes and access to treatment, the National Indigenous Kidney Transplantation Taskforce (NIKTT) was established in July 2019. The taskforce was formed as a result of the report on *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia* (Garrard & McDonald 2019) led by the Transplantation Society of Australia and New Zealand (TSANZ). Amongst other findings, the report identified cultural bias as barrier to Aboriginal and Torres Strait Islander people receiving equitable access to kidney transplantation.

This review represents the first step, under the NIKTT, to identify, understand and address underlying reasons for the gap in transplantation rates related to cultural bias and identify effective initiatives for future improvements.

Racism and cultural bias in healthcare

This project aims to bring understanding to the term cultural bias, how it is founded in racism and colonisation, and how racism occurs across the Australian healthcare system.

Although the causes of the health disparities between non-Indigenous and Aboriginal and Torres Strait Islander people are complex, multiple sources of evidence suggest that racism is a significant factor, even when it is unintended. Racism manifests in various ways in healthcare through inflexible institutional and organisational systems and implicit and explicit bias from health professionals. Data on the experiences of Aboriginal and Torres Strait Islander healthcare users in Australia in regard to racism and cultural safety is limited[i]. This information is critical to reducing racism and the harm it causes.

One national survey found that 32.4 per cent of Aboriginal and Torres Strait Islander patients reported racial discrimination in medical settings most or all of the time[ii] and, in 2012–13, 20 per cent of Aboriginal and Torres Strait Islander Australians reported being treated unfairly by healthcare staff in the last 12 months[iii].

To address racism, culturally safe healthcare systems and practices are needed. Cultural safety, unlike cultural awareness, focuses on equity, systemic and individual behaviour change through critical reflection, and acknowledges the impact of colonisation and power differentials between healthcare providers and patients. Importantly, cultural safety is defined by recipients of care, rather than the care provider.

For the purposes of this work, cultural bias refers to the various mechanisms through which health professionals, organisations and systems perpetuate or deliver inequitable healthcare access and outcomes for Aboriginal and Torres Strait Islander peoples. These mechanisms include, but are not limited to, attitudes, beliefs, behaviours, policies, resourcing, governance and accountability and encompass both institutional and interpersonal racism. While the negative impact is often unintended, it remains incredibly harmful to Aboriginal and Torres Strait Islander people's health and wellbeing.

i. Australian Institute of Health and Welfare (AIHW) 2019, *Cultural Safety in Healthcare for Indigenous Australians: Monitoring framework*, Cat.no. IHW 222, AIHW, Canberra.

ii. Cunningham, J. & Paradies, Y.C. 2013, 'Patterns and Correlates of Self-reported Racial Discrimination among Australian Aboriginal and Torres Strait Islander Adults, 2008–09: Analysis of national survey data', *International Journal of Equity in Health*, vol. 12(47), DOI: https://doi.org/10.1186/1475-9276-12-47

iii. AIHW 2019, op. cit..

Methodology

A mixed methods approach was undertaken to identify, analyse and present the available evidence regarding cultural bias initiatives in renal care for Aboriginal and Torres Strait Islander peoples in Australia. The method aimed to decolonise the data collection and analysis process to ensure that diverse information and voices were not missed. In order to achieve this goal, the scoping review was conducted in two parts:

1. Systematic review of peer reviewed literature.
2. Grey literature review that also included resource recommendations by experts in the field, and information from patient-expert and Aboriginal healthcare professional consultations.

The search for the peer reviewed literature extended beyond renal care in recognition that 1) there was limited information available, and 2) initiatives from other areas of healthcare may offer valuable strategies applicable for renal transplantation. Given the volume of potential grey literature, sources of this material were limited to publicly available documents focused on renal care for Aboriginal and Torres Strait Islander peoples. These documents were identified through an advanced Google search and consultation with NIKTT staff members and the Cultural Bias Working Group. Patient-expert and Aboriginal health professional voices came from community consultation work conducted by the NIKTT National Community Engagement Coordinator.

Results

This scoping review has revealed that there are very few published examples of initiatives to address cultural bias for Aboriginal and Torres Strait Islander Australians in relation to kidney transplantation or renal care that have been formally evaluated and published.

Of the peer reviewed literature, only two papers outlined cultural bias initiatives in renal care that have been evaluated. The first describes the effectiveness of the South Australian Renal Dialysis Bus from the perspective of Aboriginal patients and staff who travelled to rural and remote locations on the bus (Conway et al. 2018). The second focuses on the structure, implementation, and outcomes of telenephrology clinics for the management of patients with chronic kidney disease (CKD) in rural, regional, and remote areas of the Darling Downs region in Queensland, Australia (Venuthurupalli et al. 2018).

A diverse range of initiatives to address cultural bias were identified across a range of other tertiary healthcare settings. Initiatives from other areas of care can provide examples and opportunities to learn from where cultural bias initiatives are more strongly developed. This was particularly the case for maternity care which focused on new or improved models of care which included Aboriginal and Torres Strait Islander roles, extended midwifery practice, working collaboratively with other services, advocating for improvement in women's care and meeting holistic health and access needs of Aboriginal and Torres Strait Islander women.

The review of the grey literature and community consultations found that many small cultural bias initiatives are being undertaken in kidney health and kidney transplantation locations and care settings across Australia, but few have been formally evaluated and published. Over the last two decades, a series of renal focused research projects have

identified issues and problems of access to care for Aboriginal and Torres Strait Islander peoples, with recommendations for improvement from biomedical, health service, healthcare professionals and patient, family and community perspectives. Arguably, the same or similar issues and problems have been identified over the last 20 years. For example, in 2004 the IMPAKT study identified that there was a need to examine and remodel the health system so that kidney transplant services were equitable and effective for all Australians. In 2019, the TSANZ report on *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia* outlined a similar range of barriers for Aboriginal and Torres Strait Islander kidney transplant candidates, highlighting the little progress that has been made. In fact, data shows that the gap in rates of transplantation is widening from one-third the rate in 2008 to one-quarter the rate in 2017 (ANZDATA Registry 2018; Devitt et al. 2008).

To improve kidney transplantation rates, it is necessary to focus on the full spectrum of kidney care to analyse the steps that need to be taken to address cultural bias across the entire patient pathway from diagnosis to transplantation. The steps preceding receiving a kidney transplant are complex and each step represents its own barrier to ultimately receiving a transplant (Cass et al. 2004; Stacey 2019).

Initiatives to improve Aboriginal and Torres Strait Islander people's access to dialysis have occurred for some time, particularly for people living in rural and remote areas. There has also been a focus on improving access to early detection and slowing the progression of kidney disease particularly in primary care and Aboriginal Community Controlled Health Organisations (ACCHOs).

The review also found that there is an increasingly conducive policy environment in Aboriginal and Torres Strait Islander health for further action to address cultural bias in kidney care. Several national initiatives, such as the implementation of National Safety and Quality Health Service (NSQHS) standards and Australian Health Practitioner Regulation Agency's (AHPRA) cultural safety strategy show promise but are yet to be fully felt by Aboriginal and Torres Strait Islander kidney patients and clients on the ground.

A framework for planning, implementing and evaluating cultural bias initiatives

The enablers identified in the grey and peer reviewed literature of this review have been used to create a framework for planning, implementing and evaluating cultural bias initiatives. These enablers combine key elements from 1) the 20 peer reviewed studies across a range of healthcare areas, 2) renal specific examples of transplantation, dialysis and prevention/detection care, projects and priorities from across Australia, and 3) the principles within the Health Care Action Framework for Aboriginal and Torres Strait Islander People (Bourke et al. 2020). This cultural bias framework is informed by an evaluation of effectiveness from a recipient of care, or health professional or administrative and clinical data perspective, and identification of key facilitators and barriers at an individual, service and systems level.

Figure 3: The framework for planning, implementing and evaluating cultural bias initiatives
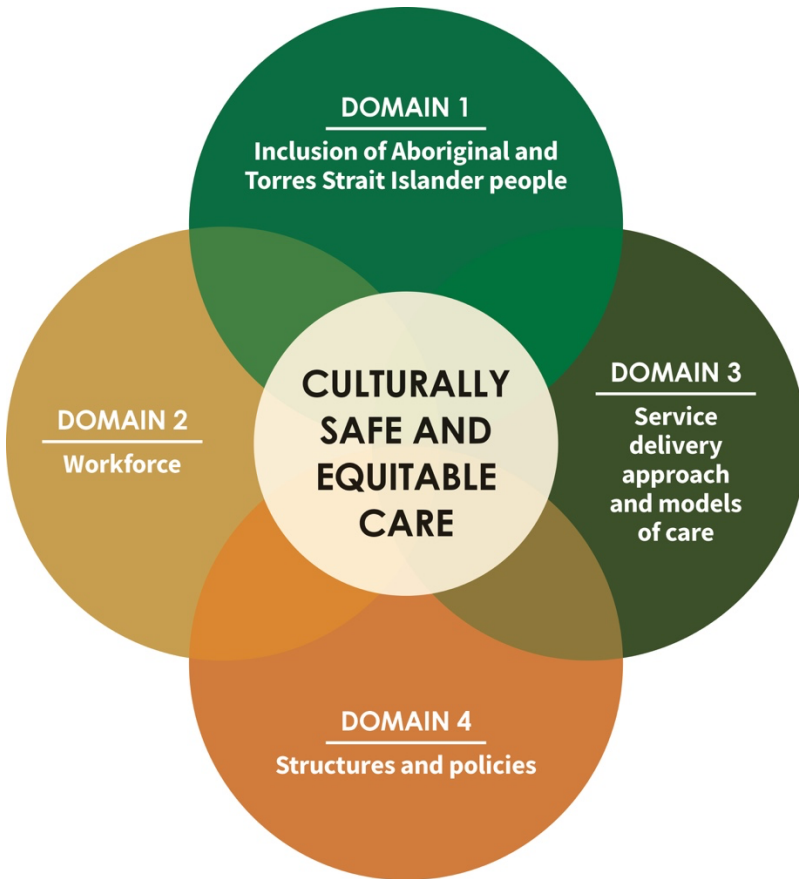
The framework includes four main domains of care: Inclusion of Aboriginal and Torres Strait Islander peoples; Workforce; Service delivery, approach and models of care; and Structures and policies that are necessary to support people on their kidney transplantation journey.

Figure 4: Framework domains and sub-domains

DOMAIN 1 Aboriginal and Torres Strait Islander peoples	DOMAIN 2 Workforce	DOMAIN 3 Service delivery, approach & models of care	DOMAIN 4 Structures and policies
• Inclusion of family in care and decision making • Indigenous governance, community consultations reference groups • Patient perspectives and feedback	• Indigenous workforce • Knowledge and skills of all workforce • 2 way learning	• Advocacy • Case management, referral and follow up • Collaboration • Communication, understanding, trust and transparency • Continuity of care and carer • Cultural safety and responsiveness • Flexibility • Health promotion, education, prevention • Responding to holistic health, wellbeing and socioeconomic needs • Peer support • Quality, safety, evaluation and CQI	• Organisational governance, commitment, leadership and management • Policies, guidelines and standards • Physical environment • Resources and funding

Inclusion of Aboriginal and Torres Strait Islander peoples

There is increasing recognition in Australia of the need for Aboriginal and Torres Strait Islander peoples to be meaningfully involved in all levels of healthcare decision making and governance. This may include, for example, informed consent and decision making, involvement of family in care plans, and co-design of health services. There are significant opportunities currently to address institutional racism and to more effectively de-colonise our healthcare system, thereby enabling more equitable access and outcomes.

Workforce

This review found that initiatives that successfully address cultural bias focused on the roles, support, abilities and training of both Aboriginal and Torres Strait Islander and the non-Indigenous workforce, and supported the development of new roles in peer support and coordination where necessary. These initiatives valued the well-developed cultural skills, knowledge and relational networks of Indigenous staff and the unique perspective and understanding they offer Aboriginal and Torres Strait Islander patients. They also ensured that non-Indigenous staff were well skilled and had a positive and respectful attitude toward Indigenous colleagues, patients and families, recognising both the challenges and strengths experienced by these groups. The most effective initiatives embedded two way learning into training and practice, enabling the combination and enhancement of clinical and cultural skills.

Kidney health and kidney transplantation services delivery and models of care

This review has identified many different components of and ways to addresss cultural bias in primary, secondary and tertiary healthcare settings (as summarised in Figure 4). These offer a range of options for other services seeking to adapt and improve their models of practice, approaches and models of care. We identified 11 key elements or subdomains of successful service delivery, approaches and models of care (Figure 4, Domain 3). The initiatives evaluated as most effective by patients and staff were those that included more of these aspects in all stages of kidney heath and transplantation care (Figure 4). These initiatives also included Aboriginal and Torres Strait Islander peoples in the design, delivery and evaluation of their initiatives, and ensured that the workforce (Indigenous and non-Indigenous) were well trained and supported, with clear roles that were understood by other staff.

One concerning theme that has emerged in this and other studies is that Aboriginal and Torres Strait Islander patients often feel unsafe when providing critical feedback, or highlighting gaps in care, and their experience is that lodging a complaint often leads to negative care responses by staff and is inherently unsafe. This situation counters effective quality and safety and feedback mechanisms, and can lead to patient anxiety and disengagement (Owen 2020).

Policies, standards and guidelines

A series of policies, standards and guidelines have been developed nationally to guide and direct kidney and transplantation care in Australia, some of which focus specifically on the needs of Aboriginal and Torres Strait Islander peoples. There is an increasing trend to include and respond to the voices, perspectives and priorities of Aboriginal and Torres Strait Islander patients and community members, health professionals and services in these documents. The community consultations and health professional consultations for the new national clinical guidelines for Aboriginal and Torres Strait Islander kidney care, combined with Indigenous governance and oversight over the writing of these guidelines, signals an important recognition of and response to cultural bias. The revision of transplantation guidelines regarding eligibility for Aboriginal and Torres Strait Islander peoples is another example. The peer reviewed literature highlights the importance of

reviewing and embedding supportive policies at unit, service and health system levels to effectively support cultural bias initiatives.

Wider healthcare standards have the potential to help address cultural bias that are not kidney health specific. These include the NSQHS six specific actions for Aboriginal and Torres Strait Islander healthcare and the AHPRA cultural safety strategy. Our analysis of the peer reviewed and grey literature and community consultations has identified that while these standards exist, their impact is not being felt or perceived consistently and reliably by Aboriginal and Torres Strait Islander patients and clients. Australia's major healthcare settings are not yet being perceived as a uniformly safe place for care by Indigenous peoples.

Resources and funding, clear leadership and management support are necessary to mobilise policies into practice. The ongoing challenge for many health services is how best to embed and sustain new initiatives.

Recommendations

Recommendation MAPPING (who is responsible?)

	For transplant units and kidney health services:	Recommendations 1, 2, 3, 4, 5, 6, 7, 8, 10, 11
	National peak bodies and organisations (NIKTT):	Recommendations 2, 6, 9, 12, 14
	For governments and funders:	Recommendations 3, 4, 6, 7, 8, 13

Based on the review of the literature and the resulting framework for planning, implementing and evaluating cultural bias initiatives, this report makes the following recommendations to address cultural bias in kidney care and transplantation for Aboriginal and Torres Strait Islander people:

1. Establish Indigenous Reference Groups in every transplantation unit to help co-design culturally appropriate pathways and models of care that are tailored to the needs of Aboriginal and Torres Strait Islander transplant recipients and candidates.

2. Increase Indigenous representation on relevant kidney health advisory boards and steering groups, especially within boards and management of transplant units.

3. Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, including the development of specialised clinical roles such as Aboriginal Regional Transplant Care Coordinators, Case Managers and Health Practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).

4. Establish and fund sustainable kidney patient navigator/peer support roles in transplant units and kidney health services. These roles involve peer support from an Aboriginal and Torres Strait Islander person with lived experience of kidney disease and require long term funding.

5. Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.

6. Fund, design, implement and evaluate tailored models of care for Aboriginal and Torres Strait Islander kidney transplant recipients and candidates that:

i. are client and family centred, and include continuity of care;

ii. are based on the feedback and perspectives of patients and consistently involve family in healthcare discussions, decision making and health education;

iii. are responsive to holistic health and wellbeing and the socioeconomic needs of Aboriginal and Torres Strait Islander peoples, including specific needs around transport, accommodation, social and emotional wellbeing and involvement of traditional healers;

iv. are based on partnerships and collaboration between services, especially with Aboriginal Community Controlled Health Organisations;

v. recognise and include the role of the Aboriginal and Torres Strait Islander workforce, including establishing new roles such as Aboriginal Transplant Coordinators and Patient/Peer navigators;

vi. include multidisciplinary pre and post-transplant teams in urban areas and outreach services in regional, rural and remote areas.

These models of care should be co-developed to address the needs of local communities and may vary across the country. They should be a means of addressing inequities in access to and outcomes from kidney transplantation and will require long term funding.

7. Expand and embed the use of telehealth and videoconferencing services for kidney transplant recipients and candidates and ensure the inclusion of Aboriginal and Torres Strait Islander health workers/practitioners (and interpreters when required) in these consultations.

8. Support and fund the further use of interpreters.

9. Co-develop specific health promotion and health education resources and approaches on kidney transplantation with Aboriginal and Torres Strait Islander people.

10. Review existing CQI processes, policies, protocols and guidelines in transplant units and kidney health services to ensure equity of access for Aboriginal and Torres Strait Islander people and safe feedback channels for Aboriginal and Torres Strait Islander people.

11. Assess institutional racism within transplant units and kidney health services using an institutional racism audit tool.

12. Develop and implement specific clinical guidelines for Aboriginal and Torres Strait Islander kidney care and evaluate their effectiveness in increasing equity of access to kidney transplantation.

13. That the Australian Government Department of Health allocate a dedicated funding stream to implement the recommendations in this report across multiple jurisdictions to increase equity of access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander Australians.

14. That the NIKTT undertake further work to assess the baseline status of these recommendations within transplant units and further develop an evaluation framework and supporting data development to monitor the implementation of the recommendations and provide public reporting.

Future research

Multiple studies conducted over the last 20 years have clearly identified gaps in care for Aboriginal and Torres Strait Islander peoples in kidney care and/or kidney transplantation. Many of these propose specific strategies for improvement. In order to effect change and improve kidney transplantation rates and kidney health outcomes, future research needs

to focus on implementation and evaluation of effectiveness from the perspective of patients, families and communities, and on healthcare services and systems' models of care, quality improvement, guidelines and standards. Co-designed and co-created participative approaches to research, implementation and evaluation offer the greatest opportunities for the development of new models of transplantation care that meet the complex clinical and cultural care needs of Aboriginal and Torres Strait Islander people living with kidney disease.

Increasingly, research that addresses disparities and meets the needs of Aboriginal and Torres Strait Islander people is being led, informed, undertaken and evaluated by First Nations people (APPRISE 2020). If this approach were supported and funded adequately within kidney care and transplantation across Australia, significant and targeted improvements in addressing cultural bias could be achieved.

1. Introduction

1.1. Background and context

Kidney disease is a serious and increasing health problem for many Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander people are significantly more likely to experience kidney failure compared to other Australians and be diagnosed at an earlier age (ANZDATA Registry 2018).

Despite this disparity, Aboriginal and Torres Strait Islander people are much less likely to receive a kidney transplant (Khanal et al. 2018). In 2017, the proportion of Aboriginal and Torres Strait Islander people who had received a kidney transplant for treatment of end stage renal disease was 13 per cent compared to 51 per cent for non-Indigenous Australians (ANZDATA Registry 2018).

To address these inequities in health outcomes and access to treatment, the Minister for Indigenous Health, the Hon Ken Wyatt MP, commissioned an expert panel in June 2018, led by the Transplantation Society of Australia and New Zealand (TSANZ), to undertake a comprehensive review into challenges and services gaps faced by Aboriginal and Torres Strait Islander people receiving treatment for kidney disease. The review, *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia*, made a range of comprehensive findings and recommended the establishment of NIKTT (Garrard & McDonald 2019).

The NIKTT was established in July 2019 to drive initiatives that target knowledge and service delivery gaps and facilitate improved access to the kidney transplant waiting list and better post-transplant outcomes for Aboriginal and Torres Strait Islander people, with a key focus on:

a. designing and implementing data collection and reporting processes on pre and post-transplant outcomes
b. improving the equity and accessibility of transplantation for Indigenous patients by trialling a range of multidisciplinary service models and protocols; and
c. **reviewing existing initiatives that target cultural bias in health services to facilitate best practice care and support.**

This scoping review represents the first step in seeking to identify, understand and address underlying reasons for the gap in transplantation rates related to cultural bias and identify effective initiatives to inform future improvements.

1.2. Purpose

The purpose of this scoping review is to synthesise evidence from peer reviewed publications, grey literature, community consultations and reports, regarding health service cultural bias initiatives for Aboriginal and Torres Strait Islander people. The intention is to inform the design of future initiatives to address cultural bias in health services and improve service delivery for Aboriginal and Torres Strait Islander Australians with kidney disease.

The key questions addressed by the review are:

1. What health service cultural bias initiatives currently exist in kidney health and tertiary care settings?

2. What is the potential effectiveness of these initiatives in relation to outcomes such as (but not limited to) wait listing for kidney transplantation?

3. What do patient, carer/support person and provider experiences and outcomes of these initiatives reveal about the acceptability and effectiveness of existing initiatives, as well as barriers and facilitators of implementation?

1.3. Cultural bias

Although the causes of the health disparities between non-Indigenous and Aboriginal and Torres Strait Islander people are complex, the evidence suggests that racism is a major cause (Berman & Paradies 2010). Racism is described by Berman and Paradies as existing at three levels: internalised (incorporated into one's worldview); interpersonal (interactions between individuals); and institutional (where systems and institutions privilege one ethno-racial group and disadvantage another) (2010). Racism can be direct or indirect. Direct racism refers to unequal treatment leading to unequal outcomes. Indirect racism occurs when equal treatment leads to unequal outcomes. In a colonial society like Australia, where colonial institutions and the dominant culture determine how systems are designed, indirect racism results. Data on the experiences of Aboriginal and Torres Strait Islander healthcare users in Australia in regard to racism and cultural safety is limited (AIHW 2019). This information is critical to reducing racism and the harm it causes. One national survey found that 32.4 per cent of Aboriginal and Torres Strait Islander patients reported racial discrimination in medical settings most or all of the time (Cunningham & Paradies 2013) and in 2012–13, 20 per cent of Aboriginal and Torres Strait Islander people reported being treated unfairly by healthcare staff in the last 12 months (AIHW 2019).

The TSANZ report *on Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia* (Garrard & McDonald 2019) identified a number of existing systemic biases in relation to kidney transplantation for Aboriginal and Torres Strait Islander people (see Appendix A of the report). These include:

- the clinical guidelines used by renal units to assess patients' suitability for kidney transplantation
- clinicians' decision making and perceptions around patient and family suitability for kidney donation and transplantation
- insufficient funding for necessary services such as interpreters
- differing views and understanding of health, and
- the transplant system being designed to cater for non-Indigenous patients.

The report then makes several recommendations to mitigate these factors. In the recommendations and body of the report these biases are broadly referred to as cultural biases.

A range of concepts and terms can be used in relation to cultural bias including systemic bias, racial/ethnic bias, racism, racial prejudice, discrimination, institutional racism, white privilege, unconscious bias, implicit bias, cultural safety, cultural competence and cultural respect (Bond, Macoun & Singh 2019; Bourke 2019). This is reflective of a growing awareness across the health system of the impact of racism, cultural safety and bias on access to healthcare and health outcomes for Aboriginal and Torres Strait Islander peoples. Culturally safe healthcare systems and practices are the goal. Cultural safety, unlike cultural awareness, focuses on equity, systemic and individual change, and acknowledges the impact of colonisation and power differentials between healthcare providers and patients. Importantly, it is determined by the recipient of care, rather than the care provider.

Figure 5: Cultural safety building blocks (National Collaborating Centre for Aboriginal Health 2013)

Several examples of the growing focus on racism and cultural safety in the healthcare system include:

- The new National Agreement on Closing the Gap which prioritises Aboriginal and Torres Strait Islander cultures and commits to identifying and eliminating racism and embedding cultural safety into the way governments work (priority reform 3) (The Coalition of Aboriginal and Torres Strait Islander Peak Organisations & all Australian Governments 2020).

- The vision of the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 for a health system free of racism (Australian Government Department of Health and Ageing 2013).

- Australian Health Ministers Advisory Council's Cultural Respect Framework 2016-2026 which commits all Australian Governments to embed cultural respect within the health system (Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee 2016).

- The second edition of the National Safety and Quality Health Service Standards which includes six actions to specifically meet the needs of Aboriginal and Torres Strait Islander people (The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute 2017).

- The Australian Health Practitioner Regulation Agency which recently adopted a definition of cultural safety and an associated body of work (AHPRA 2020).

- Work in Queensland and more recently South Australia to measure institutional racism in health organisations (Marrie 2017) (Bourke et al. 2020).

While the term 'cultural bias' lacks a formal theoretical basis in the Australian context, it is clear that the ideas embraced within the term may play a strong role in the experiences of Aboriginal and Torres Strait Islander people with kidney disease within the health system. Based on the work of the NIKTT Cultural Bias Working Group, and for the purposes of this review, cultural bias refers to: *anything that institutions or practitioners do or do not do that delivers inequitable outcomes for Aboriginal and Torres Strait Islander peoples*. This definition encompasses both institutional and interpersonal racism. The term cultural bias may also be more acceptable within dominant white culture because work to address the very real experiences of interpersonal racism, institutional racism and systemic bias within the health system for Aboriginal and Torres Strait Islander peoples can make people uncomfortable and challenges current power structures, existing organisational cultures and personal values, beliefs and behaviours. Some people see the term cultural bias as a euphemism for describing racism. Understandably, the use of euphemisms may be frustrating for those who experience racism, or are further along their decolonising and anti-racism journey. However, we also recognise that in Australia there remains a silence about the realities of colonisation and its impacts, leaving people at different points in their

personal journey of understanding racism, including systemic, interpersonal and internalised racism. At the beginning of the journey racism is often a confronting word and concept, and can cause defensiveness, anxiety and guilt, emotions that can prevent people from taking steps forward to deepen their understanding of this complex topic. This reluctance to explore racism conceptually and personally was described by Dwyer et al. (2016) as racism anxiety. In Australia's current context, euphemisms act as tools to encourage more people to walk the path toward real improvements. This review aims to bring understanding to the term cultural bias and how it is founded in racism and colonisation.

Table 1: The elements of cultural bias and ways to address them

Components of cultural bias	Ways to address cultural bias
Colonisation, inequities & unequal access to social and cultural determinants of health and decision making	**Decolonisation & Indigenous governance:** working in partnership, shared decision making and co-created models of care
Interpersonal racism: attitudes, beliefs, unconscious bias, power imbalance	**Cultural safety:** as defined by recipients of care, with staff undertaking critical reflection & training, health service redesign policies that address access and equity, power imbalances and white privilege.
Institutional racism: structures, systems, policies, clinical guidelines, quality & safety standards, workforce and resources	

1.3.1. Cultural Bias definitions in the context of this review

Cultural bias: The various mechanisms through which health professionals, organisations and systems perpetuate or deliver inequitable healthcare access and outcomes for Aboriginal and Torres Strait Islander peoples. These mechanisms include, but are not limited to, attitudes, beliefs, behaviours, policies, resourcing, governance and accountability and encompasses both institutional and interpersonal racism.

Cultural bias initiatives: For the purpose of this review, refers to initiatives that aim to address the presence of cultural biases or racism at an interpersonal or systemic level.

1.4. Methodology

A mixed methods approach was undertaken to identify, analyse and present the available evidence regarding cultural bias initiatives in renal care for Aboriginal and Torres Strait Islander peoples. The method used aimed to decolonise the data collection and analysis process and ensure that diverse information and voices were not missed. In order to achieve this goal, the scoping review was conducted in two parts:

1   Systematic review of peer reviewed literature
2   Grey literature review that also included resource recommendations by experts in the field, and information from patient-expert and Aboriginal healthcare professional consultations

The search for the peer reviewed literature extended beyond renal care in recognition that 1) there was limited information available, and 2) initiatives from other areas of healthcare may offer valuable strategies applicable for renal transplantation care. Given the volume of potential grey literature, sources of this material were limited to publicly available reports, PowerPoint presentations, abstracts, PDFs and government policy documents focused renal care for Aboriginal and Torres Strait Islander peoples. These documents were identified through an advanced Google search and consultation with NIKTT staff members and the Cultural Bias Working Group. Patient-

expert and Aboriginal health professional voices came from community consultation work conducted by the National Community Engagement Coordinator on the NIKTT team.

This combined approach was chosen to purposely flatten and decolonise the hierarchy of knowledges established through peer reviewed publications. Patients who experience care are recognised as experts of their own experience, and experts in how care is provided. They are in a unique position to identify barriers and gaps in care as well as proposing possible solutions. Their voices must be privileged in this and wider discussions in order to achieve real change moving forward.

Members of the NIKTT's Cultural Bias Working Group provided guidance, oversight and feedback on the scoping review methodology. Periodical Zoom meetings enabled discussion to shape the search strategy and inclusion and exclusion criteria. The scoping review writing team, consisting of two Indigenous and three non-Indigenous researchers, shared drafts and discussed key aspects with the group, who then provided electronic comments and feedback.

2. The Context of Kidney Transplantation and Kidney Care for Aboriginal and Torres Strait Islander People

Section 2 presents a summary of key research, projects and reports related to kidney transplantation; dialysis and prevention and early detection of kidney disease for Aboriginal and Torres Strait Islander peoples. This search aimed to find kidney specific cultural bias interventions that had been, or were currently being undertaken to improve kidney care for Aboriginal and Torres Strait Islander peoples. These may or may not have been formally evaluated and published.

2.1. Method

Search strategy

The combined grey literature search included the following sources:

- Google Scholar
- Australian Indigenous Health*Info*Net and Kidney Health Australia websites
- suggestions from expert members of the Cultural Bias Working Group
- consultation notes from Kelli Owen, NIKTT National Community Engagement Coordinator, who met with patient-experts and Aboriginal health professionals in sites across Australia
- any peer reviewed literature that did not meet the criteria of the systematic literature review inclusion criteria, but did discuss a cultural bias innovation.

Data selection

Grey literature was defined as:

- Publicly available reports
- Community consultation and reports available through the following projects that have focused on Aboriginal and Torres Strait islander kidney care and transplantation:
    - Indigenous Patient Voices – Symposium, September 2017, Darwin[1]
    - Catching Some Air – Asserting Indigenous information Rights – Project, December 2017 – May 2109[2]
    - AKction – Aboriginal kidney Care Together – Improving Outcomes now – Project[3]
    - KHA CARI Kidney Health Australia – Caring for Australian and New Zealanders with Kidney Impairment Guidelines (Duff et al. 2019)
    - NIKTT National Indigenous Kidney Transplantation Taskforce, National Community Engagement Coordinator consultations[4]

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[1] Information viewed on 17 December 2020 at:
https://www.menzies.edu.au/page/Research/Projects/Kidney/Indigenous_Patient_Voices/; viewed on 17 December 2020.

[2] Information viewed on 17 December 2020 at: https://www.lowitja.org.au/page/research/research-categories/science-and-health-conditions/health-conditions/projects/catching-some-air;
https://www.menzies.edu.au/page/Research/Projects/Kidney/Catching_Some_Air-_Asserting_Indigenous_Information_Rights_in_Renal_Disease/Latest_news/CSA_-_Catching_Some_Air/

[3] Information viewed on 17 December 2020 at: https://healthtranslationsa.org.au/projects/improving-aboriginal-kidney-care-together/

[4] Information viewed on 17 December 2020 at: https://tsanz.com.au/committees/niktt.htm.

- PowerPoints, conference abstracts
- Government policy documents.

A Google advanced search was undertaken but returned only two relevant results.

Google advanced search strategy

Search criteria:

- an Aboriginal or Torres Strait Islander specific kidney health cultural bias action or initiative that was evaluated and reported in the last 5 years
- a search was undertaken of the first fifty PDF's in English, in Australia, updated within the last 5 years.

Search terms:

Three different searches were undertaken using key words.

1. kidney, cultural; Indigenous OR Aboriginal OR Torres Strait Islander
2. kidney, racism; Indigenous OR Aboriginal OR Torres Strait Islander
3. renal, Indigenous OR Aboriginal OR Torres Strait Islander.

Google advanced search results:

The combined results of this Google advanced search identified only two relevant sources, indicating that very few Aboriginal and Torres Strait islander kidney care cultural bias initiatives had been undertaken, evaluated and reported publicly and were available via Google Scholar.

2.2. Grey literature search results

Over the last two decades, a number of renal-focused research projects have identified issues and problems of access to care for Aboriginal and Torres Strait Islander peoples, with recommendations for improvement from biomedical, health service, healthcare professionals and patient, family and community perspectives. Arguably, the same or similar issues and problems were identified over those 20 years. For example, in 2004 Cass, Devitt, Preece et al. identified that there was a need to examine and remodel the health system so that kidney transplant services were equitable and effective for all Australians (Cass et al. 2004). Fifteen years later, in 2019, Stacey identified that work was needed to address the disparity in transplantation rates and required a focus on, and inclusion of all the steps towards transplantation, and also post-transplant outcomes (Stacey 2019).

To improve kidney transplantation rates, it is necessary to focus on the full spectrum of kidney care to analyse the steps that need to be taken to address cultural bias across the entire patient pathway from diagnosis to transplantation. The steps that precede the receipt of a kidney transplant are complex and each step represents its own barrier (Cass et al. 2004; Stacey 2019).

Initiatives to improve Aboriginal and Torres Strait Islander people's access to dialysis have been implemented by health services over the last fifteen years, particularly in response to the needs of people living in rural and remote areas. There has also been a focus on improving access to early detection and slowing the progression of kidney disease particularly in primary care and by ACCHOs.

However, the documentation and publicly available reporting of these initiatives is limited, and very few have been formally evaluated. This section, therefore, includes information on kidney care-specific initiatives that seek to address cultural bias, but may not yet have been formally evaluated and reported in the peer reviewed literature.

How we have reported on results in this section

The Working Group identified a preference that this section present information related to kidney transplantation first, then dialysis and early detection. Following this, we discuss elements that are relevant across all stages of kidney care under four key domains of kidney care, with related sub-domains, as is shown below in Table 2.

Table 2: Presentation of results – grey literature

Part 1: A focus on specific stages of care	Part 2: Key elements across all stages of care – arranged under the 4 Domains of the Framework
• Transplantation • Dialysis • Early Detection	1. Inclusion of Aboriginal and Torres Strait Islander peoples 2. Workforce 3. Service delivery approach and models of care 4. Structures and policies

2.3. Kidney transplantation

In Australia, Aboriginal and Torres Strait Islander people experience much higher rates of kidney failure than other Australians. However, they are much less likely to receive a kidney transplantation (Department of Health 2018).

Kidney transplantation is the optimal treatment for kidney failure compared to long term dialysis because it results in better quality of life, longer life expectancy, and lower costs of healthcare (Cass et al. 2004). In 2004, it was reported that Aboriginal and Torres Strait Islander people with kidney failure received transplants at approximately one-third the rate of non-Indigenous patients. More recent data from 2017 indicates that the disparity in transplantation rates is increasing, with 13 per cent of Aboriginal and Torres Strait Islander kidney failure patients receiving a transplant compared to 51 per cent of non-indigenous patients (ANZDATA Registry 2018).

One commonly cited reason why Aboriginal and Torres Strait Islander people have lower rates of kidney transplantation is that they are less likely to be waitlisted. In 2015, 1.9 per cent of Aboriginal and Torres Strait Islander dialysis patients were waitlisted for transplantation, compared to 9.5 per cent of non-Indigenous patients (ANZDATA Registry 2018).

Several barriers exist for Aboriginal and Torres Strait Islander patients being waitlisted for transplantation. Prior to waitlisting, patients must complete several steps and assessments. Steps include information sharing, addressing existing health issues and completing work-up tests as pictured in Figure 6. Each of these steps can involve new barriers and challenges for patients.

Figure 6: Steps to receiving kidney transplantation (Garrard & McDonald 2019)

Information sharing → Addressing health issues → Completing workup tests → Assessment for waiting list → Placement on waiting list → Staying on the list → Allocation of kidney
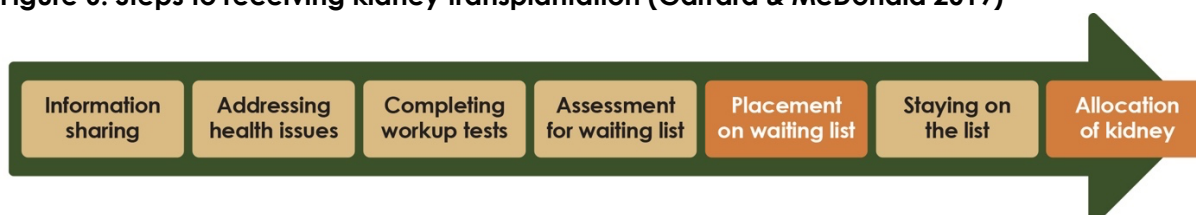
Many steps in the transplantation journey may be relatively straightforward for some patients, but significantly challenging for others. For example, access to information, tests and services may be relatively uncomplicated for non-Indigenous patients who

have a high level of health literacy, speak and read English, can navigate complex health systems, have good access to transport, family and/or carer support, and live in urban areas. However, each step can become a major hurdle for Aboriginal and Torres Strait Islander (and other) people without the same resources, and even more so for those living in rural and remote areas. Health infrastructure is notoriously difficult to access in remote areas.

Only half of Aboriginal and Torres Strait Islander people diagnosed with kidney failure live in areas that have access to dialysis or transplant facilities. Therefore, a significant number of Aboriginal and Torres Strait Islander people are required to relocate to urban areas or larger regional centres to obtain life sustaining treatment (Anderson et al. 2013). This relocation results in significant distress for patients, grief and loss from being separated from family, culture, community and Country, financial and resource challenges and difficulty accessing suitable accommodation and transport (Puszka 2020). One report described the personal impact of this predicament:

> "*It may not be an exaggeration to say that moving to the city to undertake dialysis allows life-continuing treatment but removes people from all that is important in life*". (Mapleson & Australian Resource and Development Services 2018)

In addition, many studies have identified significant communication difficulties between many Aboriginal and Torres Strait Islander people with renal failure and non-Indigenous healthcare staff (Casset al. 2004; Cass et al. 2002; Hughes et al. 2017; Owen 2020). Patients are expected to navigate a complex and confusing health system, and often require the assistance of support services that are not always available (Kelly et al. 2016). A high level of coordination is required to successfully traverse the transplantation work-up journey.

2.3.1. IMPAKT (Improving Access to Kidney Transplants)

Between 2004 and 2008, the IMPAKT project conducted three discrete studies to investigate the disparity in access to kidney transplants between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians (Cass et al. 2004). The project investigated how health systems in different Australian states and territories provided transplant services for patients and documented the experiences of Aboriginal and Torres Strait Islander patients' access to, and use of, transplantation services.

An exploration of patient and staff perceptions and attitudes across 26 locations in the Northern Territory (NT), South Australia (SA), New South Wales (NSW), Queensland (QLD) and Western Australia (WA), found that:

- Aboriginal and Torres Strait Islander patients are interested in kidney transplantation:
  o Indigenous patients are interested in transplant but unclear about the process. They also wish to be better informed about their treatment plans.
  o Patient education is not sufficiently targeted to the cultural, language and literacy needs of Indigenous people.
- There are clinical uncertainties:
  o Many key transplant decision-makers are uncertain about the benefits of transplantation for Indigenous patients.
  o There is a widespread perception among health service providers that Indigenous patients are less likely to fully carry out treatment requirements (i.e. they are seen as less 'compliant').
- There are 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 the regional areas, reduce capacity to address the needs of Indigenous patients.
- Distance and remoteness are critical aspects of the context of patient care. (Cass et al. 2004).

2.3.2. NIKTT (National Indigenous Kidney Transplantation Taskforce)

The NIKTT was formed in July 2019 in response to a review from the Transplant Society of Australia and New Zealand on *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia* (Garrard & McDonald 2019). The review provides a comprehensive summary of the current evidence on barriers to kidney transplantation for Aboriginal and Torres Strait Islander people including consumer engagement and pre and post-transplant care. It identified numerous reasons for the low rates of kidney transplantation for Aboriginal and Torres Strait Islander people including:

- the challenges in delivering appropriate health services to people living in remote areas, who might also have low health literacy and do 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 (human leukocyte antigen) 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) (Garrard & McDonald 2019).

In addition to these reasons, the review also outlined a table of systemic biases, their effect on kidney transplantation for Aboriginal and Torres Strait Islander people and possible mitigating strategies. At a system (macro) level these included:

- Australia's kidney transplant system has been designed to cater for the needs of non-indigenous patients. This creates inequity and actions to address this inequity need to include additional funding for Indigenous specific transplant initiatives such as outreach services; incorporating Indigenous paradigms within service specifications and increasing Indigenous representation on advisory boards and steering groups.
- There is a lack of data on pre and post-transplant outcomes meaning it is difficult to pinpoint exactly where the system is failing Aboriginal and Torres Strait Islander patients.
- Kidney health continues to be insufficiently recognised and prioritised by health services and governments.

Kimberley Renal Service: A case study

Dr James Stacey is a doctor from the Kimberley Renal Service (KRS) a subsidiary of Kimberley Aboriginal Medical Service. He presented at the 2019 National Indigenous Dialysis & Transplantation Conference explaining how KRS have clearly identified the need for transplantation workup and follow up to be well coordinated and supported (Stacey 2019).

In 2011, the Kimberley region of WA had a surge in transplantation with eight people transplanted, however, most of these people had poor outcomes and logistical difficulties, and this led to community apprehension. Following 2011, transplantation numbers dropped in the Kimberley areas and for a few years no one had transplant.

Renal transplants for Kimberley residents (by year)
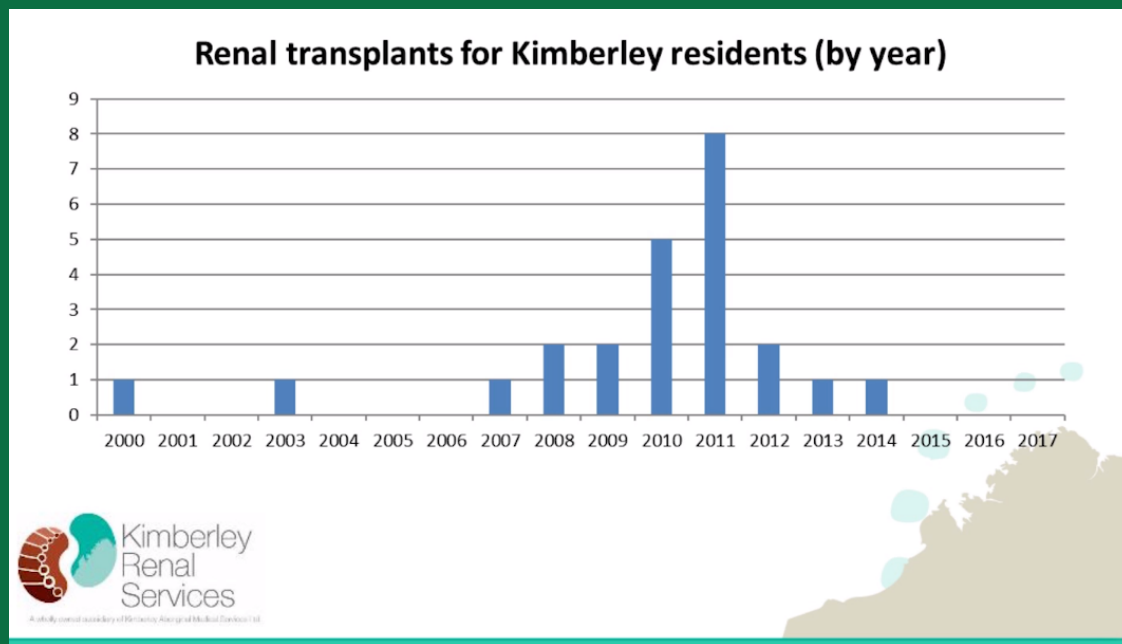
Since that time, KRS has been working on local initiatives to increase the numbers again and to provide better coordination, workup and support within the Kimberley. Their strategies included:

- bringing together doctors, allied health, and specialist services working across a range of services provided by ACCHOs, WA Health, RFDS, GPs, allied health, renal services and communities
- developing shared care models, improving coordination of care, chronic disease management and prevention, outreach, and increasing visiting nephrologist access
- spending time educating patients, communities and staff.

There has also been a move to support patients better while on dialysis and anywhere on their CKD journey. KRS have updated their model of care to be more patient focused; their services are now location based rather than structured around stages of kidney disease. There is a strong emphasis on screening, early diagnosis, balancing the demand for acute and chronic care, including CKD educators in regional trips, focusing on work up and triage, building more effective and shared data systems, and increasing monitoring and advocacy. The KRS have now developed Kimberley protocols in collaboration with local, jurisdictional and national services to ensure a localised response that also meets national guidelines and standards. This has improved their care planning and risk

stratification. There is also a strong focus on workforce, with emphasis on training and employing Indigenous health professionals.

Table 3: Identified systemic biases by transplantation phase (adapted from Garrard & McDonald 2019 TSANZ review Appendix A)

PHASE	SYSTEMIC BIAS IDENTIFIED IN TSANZ REVIEW (APPENDIX A)	MITIGATING STRATEGY IDENTIFIED
BE ELIGIBLE	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. Standardised eligibility criteria can disadvantage Aboriginal and Torres Strait Islander people and can limit their access to the waitlist.	Current eligibility criteria need to be reviewed and further research undertaken on how eligibility criteria disadvantage Aboriginal and Torres Strait Islander patient and how the criteria could change to address this inequity.
STAY WELL	Indigenous renal failure patients are more likely to be overweight or obese compared to non-Indigenous patients and this limits their access to the waitlist. There is little specific weight loss support available for Indigenous patients.	Further evidence is needed to determine the safest body composition for kidney transplant given different fat distributions compared to non-indigenous patients.
COMPLETE WORK-UP	Patients who delay assessment and work-up tests due to family or cultural obligations may be perceived as non-adherent and are less likely to be waitlisted.	Establish pre and post-transplant multidisciplinary teams and outreach services in regional, remote and rural areas. Each renal unit to have a holistic support system in place for Aboriginal and Torres Strait Islander patients including accommodation, transport, interpreters and patient navigators.
BE INFORMED	There are few resources available to engage interpreters or patient navigators to support Indigenous patients.	Increased funding for interpreters and patient navigators.

BE SUPPORTED	Patients may delay assessment and work-up tests due to conflicting family and cultural obligations and often need to travel long distances away from family to attend renal units and transplant centres.	Establish pre and post-transplant multidisciplinary teams and outreach services in regional, remote and rural areas. Each renal unit to have a holistic support system in place for Aboriginal and Torres Strait Islander patients including accommodation, transport, interpreters and patient navigators.
RECEIVE A DONATION	Higher rates of diabetes and CKD in the Indigenous population may mean family members are less likely to be allowed to donate a kidney to a family member. There is currently a lack of evidence about how these decisions are made and variable protocols across the country.	Clear and transparent protocols for family donation which address the specific health profile of the Aboriginal and Torres Strait Islander population need to be developed and disseminated.

Ultimately, the TSANZ review recommended 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 (Garrard & McDonald 2019).

To address the issues identified in the review and disparities in kidney transplantation, the NIKTT is focusing on three objectives each with a corresponding working group:

1. enhance data collection and reporting
2. pilot initiatives to improve patient equity and access, and
3. evaluate cultural bias initiatives.

In 2019, the NIKTT hosted the National Indigenous Dialysis and Transplantation Conference in Alice Springs. Through a multidisciplinary lens, the conference focused on dialysis and transplantation issues that affect Aboriginal and Torres Strait Islander peoples, capturing the kidney failure journey from the commencement of renal replacement therapy through to the management of post-transplant care.

2.3.3. Kidney Transplantation Guidelines

Since 2018, there has been a focus on reviewing transplant guidelines and practices generally and specifically in relation to kidney disease and Aboriginal and Torres Strait Islander people. There is also provision within the National Health and Medical Research Council (NHMRC) ethical guidelines for organ transplantation from deceased donors that states that there must be no unlawful or unreasonable discrimination again potential recipients on the basis of race, cultural and religious beliefs, gender, relationships status, sexual preference, social or other status, disability or age; location of residence (e.g. remote, rural, regional or metropolitan) (NHMRC 2016, p.6) .

In 2018, in response to growing concerns about the disparity of access to kidney transplants for Aboriginal and Torres Strait Islander people, the COAG Health Council agreed that the Australian Government would undertake a review of the Australian organ donation retrieval and transplantation system (EY 2019) and commissioned EY to undertake the review commencing in May 2018. The review considered current systems, practices and processes in the retrieval and transplantation sector including equity of access for all Australians, wait listing criteria, and organ allocation processes.

The review found that the overall health experienced by Aboriginal and Torres Strait Islander people, as well as the health literacy of health services and individuals in relation to organ donation, were barriers to organ donation. Ultimately the review recommended the development of a national strategy for the retrieval and transplantation sector to optimise organ donation and maximise transplant outcomes.

In relation to kidney transplantation for Aboriginal and Torres Strait Islander Australians, the EY review recommended that as part of the development of a national strategy the Australian Government develop a specific strategy and nationally coordinated approach to organ donation for Aboriginal and Torres Strait Islander people (Recommendation 20) — in collaboration with the National Aboriginal Community Controlled Health Organisation, its affiliates and the states and territories and with oversight and input from Aboriginal and Torres Strait Islander stakeholders (Recommendation 21). The strategy would assist to overcome barriers to wait listing and transplantation outcomes and improve overall health outcomes for Aboriginal and Torres Strait Islander Australians.

Additionally, the EY review recommended that:

- All kidney transplantation programs should implement formal outreach arrangements with rural dialysis units as a condition of funding within the state or territory. These rural outreach arrangements must include a clearly defined pathway to kidney transplantation for rural residents, including specifically designed pathways for Aboriginal and Torres Strait Islander people, as well as a commitment to 'work-up' a potential kidney transplantation recipient as close to their place of residence as possible (Recommendation 12).

- All kidney transplantation programs should implement formal arrangements with Aboriginal Community Controlled Health Organisations to increase the understanding of transplantation as a possibility for Aboriginal and Torres Strait Islander patients on dialysis (Recommendation 13).

- The planned review of the kidney matching algorithm to be conducted by the TSANZ should include Aboriginal and Torres Strait Islander health expertise and community representation (Recommendation 28).

- Improvements to data collection and reporting (Recommendation 51).

2.4. Dialysis

This part of the report describes some of the cultural bias initiatives that have been, or are being implemented to assist Aboriginal and Torres Strait Islander people to understand, and have access to, regular dialysis. This section does not intend to provide an exhaustive list of everything happening in Australia, but rather provide some examples that can help inform approaches to address cultural bias in kidney transplantation.

> **Types of dialysis**
>
> Haemodialysis (the machine) involves filtering a person's blood through an artificial kidney, known as a dialyzer attached to a machine. A fistula is created in a person's arm for vascular access, and a needle is inserted for each dialysis session. The majority of people attend a dialysis centre or satellite unit three times a week and undergo dialysis for 3-5 hours per session. Some people had a dialysis machine at home that they use (Kidney Health Australia 2013).
>
> Peritoneal dialysis (the bag) consists of the placement of a catheter into a person's peritoneum and bags of fluid filled with dialysate solution comprising

electrolytes, bicarbonate and glucose. Dialysis is achieved by convection and diffusion of water and solutes across the peritoneum. Treatment can be undertaken via continuous ambulatory peritoneal dialysis (CAPD) involving four manual bag exchanges daily or automated peritoneal dialysis (APD), overnight exchanges by machine (Saxena & West 2006).

Both forms of dialysis require patients to adhere to a strict fluid and dietary regime to ensure a safe balance of fluid and electrolytes are maintained between treatment sessions (Kalantar-Zadeh et al. 2015).

2.4.1. Accessing dialysis in remote and regional areas

Many Aboriginal and Torres Strait Islander people have had to leave their homes, families and communities in rural and remote locations and move to regional and city locations in order to receive life supporting dialysis (Preston-Thomas, Cass & O'Rourkey 2007). This often results in an experience of extreme isolation and grief as a result of this disconnection from family and Country, and being unable to participate in important community and cultural events. A number of research efforts spanning over two decades have shown that patients, their families and communities have a strong desire for them to be able to return home (Hughes et al. 2017; Devitt & MacMasters 1998).

Regional and remote dialysis units

Over the last 20 years there has been an emphasis on providing haemodialysis in remote locations. Australia's first satellite remote dialysis unit became operational on the Tiwi Islands in 1999 (Gorham 2000), the Kimberly Satellite Dialysis Centre in Broome in 2002 (Kimberley Aboriginal Medical Services 2020), and the first Purple House dialysis clinic in Kintore, Western Desert in 2004 (Purple House n.d..). The number of remote clinics across Australia has increased each year, funded — and coordinated — through state and federal health funding, Aboriginal Community Controlled Health Services (ACCHSs), and other agencies such as Purple House. For example, the Satellite Renal Dialysis in Remote NT Communities Project was an Australian Government project that led to the building of 'Renal Ready rooms' in all re-built and renovated remote primary health clinics in the Northern Territory (Gorham et al. 2018; NT Government 2005). Purple House is an ACCHO that established and runs 18 remote dialysis clinics in the Northern Territory and Central Australia (Purple House n.d.). In 2019, Purple House established the first functioning remote dialysis unit the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, SA.

Alongside these fixed structures, renal buses and trucks that visit regional and remote locations have been introduced, enabling Aboriginal patients to return home to Country for short periods of time. In 2010, the NT State Government funded a truck with a mobile dialysis clinic on-board to service remote communities (Gorham et al. 2016). While evaluation of the truck service had positive results, it was ultimately discontinued. Reasons for its discontinuation are not clear, but some barriers to success identified in the evaluation included lack of dedicated funding, part-time staff and the high numbers of nurses needed for each trip (Gorham et al. 2016). In 2012, the Purple House Purple Truck was established to provide patients the chance to return home to remote communities (Purple House 2020). The SA Mobile Dialysis Unit and the Kimberley Renal Services Mobile Dialysis began in 2014 (Conway et al. 2018; Kimberley Aboriginal Medical Services 2020). The SA mobile dialysis unit was identified as a cultural bias initiative that was formally evaluated and published and is discussed in Section 3 of this report (Conway et al. 2018).

MBS item – remote area dialysis care – closer to home

In November 2018, the federal government introduced a new Medicare Benefits Schedule (MBS) item to provide funding for the delivery of dialysis by nurses, Aboriginal and Torres Strait Islander Health Practitioners and Aboriginal Health Workers in a primary care setting in remote areas. Item 13105 pays for the supervision of dialysis in very remote areas of Australia defined as Modified Monash Model 7 (Department of Health 2018):

2.4.2. Supporting people while on dialysis

We need more consultation with the government, about getting more renal dialysis machines over there [in communities], keeping family on Country, and maybe train them up on how to be on the dialysis machine, with local renal nurses to train and teach our mob to do things for ourselves. (Hughes et al. 2017 p.12)

There are a number of initiatives that seek to better understand the challenges and support Aboriginal and Torres Strait Islander people when they first commence dialysis, and on an ongoing basis.

A 2014 PhD study highlighted the perspectives of rural Aboriginal people in NSW who were haemodialysis patients (Rix. et al. 2014). These patients described their experiences and suggested ways to improve haemodialysis that provide better support. Six themes emerged in this study:

1. shock of diagnosis and commencing dialysis
2. the development of positive attitudes to treatment
3. the importance of family for support
4. culturally unsafe hospital care
5. the need for simple language and cultural awareness, and
6. desire to educate younger generations about kidney disease prevention (Rix et al. 2014).

The major finding of this study was that 'family enables Aboriginal people to endure dialysis', and that patients believed that family centred, culturally appropriate healthcare systems are critical to the improvement of services. Additionally, patients expressed a strong need for improved access to screening services to detect kidney disease earlier (Rix et al. 2014).

Programs that aim to provide social and emotional wellbeing support for kidney failure patients include those focusing on peer support. For example, Panuku Patient Preceptors — who themselves have lived experience of kidney disease, dialysis and/or transplantation — describe being able to help clients to recover from the initial shock and reassure them that there is life after a kidney disease diagnosis (Purple House 2019). Patient Preceptors walk alongside their clients when they are struggling and help make sense of the health system (Purple House 2019). Mobile dialysis buses provide a different service, one that supports remote patients' social and emotional wellbeing by enabling them to visit Country and their families and communities (Conway et al. 2018). Patients accessing these services in SA reported being much happier, and nurses who accompanied them on the trip also described major improvements in their patients' emotional wellbeing (Conway et al. 2018).

In Darwin, the Nightcliff renal unit created a space for Aboriginal patients and their families called the 'Strengthening Spirit Room', designed to support kidney patients and their families. This room allowed patients to have space to spend time together and recharge outside of the usual clinical space. Similar initiatives are occurring across Australia.

Although an extremely important component of kidney disease management, culturally supportive strategies to address and support diet and nutrition are conspicuously missing from the literature. This may be due to either a limitation in the search strategy, a lack of literature about this topic, or clinicians and units implementing local strategies that are not widely publicised. Community interest in this topic has been identified in community consultations (Kidney Health Australia 2020). One initiative that was reported during the NIKTT consultations is the grant application by the Nightcliff renal unit to support their patients — some of whom were struggling with malnourishment — with their nutrition (Owen 2020). The renal unit realised that many patients were sending money home to support their families and were unable to afford healthy kidney appropriate meals as a result. The Nightcliff program now provides a hot meal and a takeaway pack to take home (Owen 2020). The lack of available literature on diet and nutrition support indicates that more research needs to be done in this area.

2.4.3. Responsive models of care

Across Australia, there is increasing recognition that in order to improve access to care, changes may need to be made to models of practice and models of care (Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute & Aboriginal and Torres Strait Islander Health Project Working Group 2017). Collaborative, participatory and implementation research projects provide unique opportunities for community members and health services to come together to re-envision and redesign renal care.

The AKction – Aboriginal Kidney Care Together – Improving Outcomes Now project involved forming a multi-disciplinary research team, an AKction Reference Group compirising Aboriginal people with lived experience of kidney failure, dialysis and transplantations, and then co-designing and conducting community consultations (Kelly, Olivia et al. 2019; Kelly, Stevenson et al. 2019) and patient journey mapping. A major stakeholder workshop was held to discuss new approaches to address transport and accommodation issues, particularly for Aboriginal patients from rural and remote areas who have to relocate to receive dialysis treatment in Adelaide. The Central Northern Adelaide Renal & Transplantation Service (CNARTS), conducted an internal review and cost analysis of missed dialysis, emergency department presentations and admissions. As a result, two dialysis chairs were placed at the Kanggawodli Aboriginal hostel unit and made available for those most struggling to attend regular dialysis in hospitals and sattelite dialysis units. The pilot program involves an Aboriginal Health Practitioner and dialysis nurse attending the hostel to deliver dialysis, supported by a visiting nephrologist. This pilot is being evaluated by an independent Indigenous-led evaluation team. Early anecdotal evidence indicates that the service has been very well received by community members, has improved attendance to dialysis and appointments, and has led to a decrease in emergency admissions. Improved kidney health has also enabled two participants in the Kanggawodli program to return home and continue dialysis in their remote community. A successful grant application is enabling this service to expand to meet growing demand, and there are plans to provide more comprehensive care for dialysis patients at Kanggawodli, including dental care. The Indigenous governance and participatory action research approach utilised by the AKction project has enabled community members to be actively involved in identifying gaps and solutions, making key decisions and working in collaboration with research team members and health service staff to prioritise needed changes in renal care.

2.5. Prevention and early detection

As identified in the TSANZ Performance Report (Garrard & McDonald 2019), the pathway to transplantation begins early in the kidney health journey. Early detection of kidney disease, and prevention of complications are crucial to successful outcomes. This early detection often takes place in primary healthcare settings.

Responsive approaches to prevention, health promotion and early detection of kidney disease have been developed in a range of primary healthcare sites across Australia, often led by ACCHOs, as discussed earlier in relation to the Kimberley Renal Services. Effective, targeted and responsive strategies have been developed to improve access and enhance care; there are key learnings and approaches to holistic client centred care that may help inform new models of care within hospital and transplantation services.

The Durri Aboriginal Corporation Medical Service in rural Kempsey, NSW, employed a nurse practitioner in 2012 to systematically screen and treat clients with CKD (Barrett et al. 2015). A high number of patients with CKD were identified and management plans were developed. The comprehensive strategy included chronic disease education, medication review and referral to nephrologist via telehealth clinics. Alongside this was an education and support program for GPs and other clinical staff, and community education.

The Outback Vascular Health Service (OVHS) in far West NSW, delivered a specialty service through a collaboration between Maari Ma Health Aboriginal Corporation, the George Institute and Royal Prince Alfred Hospital. Funded by the Scully Fund and Commonwealth Government Medical Specialist Outreach Assistance Program, the 2009 OVHS clinic brought cardiology, nephrology and endocrinology specialist care to Maari Ma clients, as part of their Chronic Disease Strategy that was prioritised by the community and Board of Directors. This strategy aimed to create systems to support self-care, link community health and hospital services and medical care with public health. The effectiveness of this approach was evaluated by the George Institute through clinical audits and interviews with health professionals and managers (Tchan et al. 2012). They identified a series of enablers as follows:

- Clients were seen in a familiar, culturally safe environment with primary healthcare providers (whom they knew) as part of the team.
- Professional relationships and communication were built between specialists, local health service staff and clients and between services. Visits were conducted in one week blocks.
- The personality and characteristics of individual specialists improved access to specialist services and improved coordination between services.
- Aboriginal Health Workers were actively involved in the consultation, benefiting clients and leading to two-way role modelling, knowledge transfer and up-skilling.
- Care plans and case management were modified to suit individual client needs and situation.
- Institutional links to increase sustainability beyond individual positions and capacity were created.
- The project was locally owned by Maari Ma – the ACCHS.
- Transport assistance was provided.
- Coordination, referral, follow up and monitoring of clients was ongoing (Tchan et al. 2012).

In Darwin, in 2008, the Danila Dilba Aboriginal Health Service appointed a Renal Case Manager and implemented a new service design focussed on prevention progression towards kidney failure. The service focussed on providing services close to home and prioritied people rather than numbers. All PHC staff were supported to provide systematic patient monitoring and best practice care to meet their complex clinical challenges. Clients were given access to expert knowledge at the tertiary level, while still maintaining coordination and support within the ACCHO. An evaluation was conducted of the electronic clinical record system screening records, GP management plans, self-management goals with data points taken over a ten-year period regarding management and disease trajectory of people with CKD pre- and post- the appointment of the Renal Case Manager. Results indicated that patients with diabetes and renal disease were better managed and their progression through the stages of kidney failure slowed (Menzies School of Health Research 2020; Turner 2019).

A paragraph has been removed from this section, pending approval for inclusion by an important project related to reduction of hospital admissions through prevention, detection and early management of CKD.

2.6. Addressing cultural bias across all stages of kidney care

This part of the report identifies cultural bias initiatives that are occurring across all stages of kidney care. The sub-headings are the same as the themes identified in the peer reviewed literature in Section 3. This part reports on activities occurring in kidney care that seek to address cultural bias, but have not yet been evaluated, and/or have not been peer reviewed and published.

2.6.1. Domain 1: Inclusion of Aboriginal and Torres Strait Islander peoples

Inclusion of family in care and decision making

Across Australia, both kidney care patients and community members have discussed the importance of family members being actively involved in healthcare, discussions and decision making (Kidney Health Australia 2020; Owen 2020). They have very clear ideas about how this can happen, and how it might be different in different health services, communities, and for different families. In the Kimberley region, an educator accompanies visiting specialists and GPs, and speaks to a range of family members (Stacey 2019). In Ceduna, SA, community members expressed the need for the whole community to learn more about kidney disease through community education focused family and community events. This would enable them to have more health literacy and be better informed when supporting family members. In Port Augusta, the preference was for education to be based in schools, and information shared through kidney journeys painted on old dialysis machines, the local newspaper and radio. Community members felt they needed to be better informed so that they could be better prepared.

> *"How can we help mum make informed decisions without being included into these important conversations? We were Mum's support system to keep her healthy outside of a dialysis unit. Health mob need to educate us, explain mum's treatment options and effects of ongoing medications with us. We were excluded, left in the dark and only had bits of mum's health information."*
>
> Loveena Kruger

Many patients and family members clearly wish for family to be involved in their care and decision making, but this does not always happen (Anderson et al. 2008).

This was reflected in the community consultations by Kelli Owen, NIKTT National Community Engagement Coordinator. Recently members of the Kruger family in Katherine, NT, shared their experiences. Their mother passed away in January 2017 after being on haemodialysis for a decade and never making the active waiting list for a transplant. The kidney conversation between Kelli and the family focused on the importance for family members to be part of the kidney care education, decisions and going communication from diagnosis onward.

Indigenous governance, community consultations and reference groups

Advocacy efforts and community consultations with patients and community members have been conducted for over the past 25 years (Anderson et al. 2013; Cass et al. 2004; Carney 2000; Devitt & McMasters 1998). This work has continued over the last four years through a series of community consultations aimed at identifying and informing needed changes in kidney care guidelines, policies and practices. The Indigenous Patient Voices Symposium in Darwin enabled Indigenous patient-experts, support people and carers, health and allied health professionals, researchers and policy leaders to meet and discuss kidney care in ways that ensured Indigenous voices were privileged and heard (Hughes. et al. 2017).

There were then three projects which sought Indigenous renal patient-expert, family and community input to inform the writing of the first Aboriginal and Torres Strait Islander specific renal clinical guidelines. The voices of community members living with or supporting chronic kidney disease were sought in all three projects, and the resulting reports and recommendations are informing the guidelines writing process and content.

The first, the **Catching Some AIR: Asserting Aboriginal and Torres Strait Islander Rights in Renal Disease (C-AIR)** project held consultations in Darwin, Thursday Island and Alice Springs and informed both the guidelines and Indigenous data governance (Duff et al. 2018). The second was the **AKction – Aboriginal Kidney Care Together – Improving Outcomes Now** (AKction) project in SA that held consultations with community members, Aboriginal health and renal health staff in urban Adelaide (Kelly, Olivia & Jesudson 2019), regional Port Augusta (Kelly et al. 2019), and remote Ceduna (Stephenson, Kelly & O'Donnell 2019). These were undertaken in collaboration with Kidney Health Australia and NIKTT and informed the guidelines, NIKTT and local dialysis care. The third was led by Kidney Health Australia who continued holding **Yarning kidneys** community consultations around Australia (until COVID) to more fully inform the writing of the new guidelines (Kidney Health Australia 2020). A key recommendation is that Aboriginal and Torres Strait Islander peoples voices need to be included and heard at all levels of health care, policy and funding decision making.

There has also been a strong focus on Indigenous governance, community consultations and community reference groups as part of the NIKTT initiatives. Kelli Owen has met with community members in a number of sites across Australia in her role

of National Community Engagement Coordinator, complementing the work of Yarning Kidneys.

Members from Ballina community echoed what has been said across Australia in the Yarning Sessions:

> *we have the answers to help keep us healthy and provide culturally safe kidney care, we just need them to be applied*. (Kelli Owen)

Five national transplant units are now collaborating with community members and initiating changes in response to feedback. The Royal Adelaide Hospital, Sir Charles Gairdner Hospital, Princess Alexandra Hospital, Westmead Hospital and Prince Alfred Hospital have committed to establishing Indigenous Reference Groups (IRGs) as part of a sustainable and cyclic system to address patient and families concerns and co-design better models of kidney care. The implementation of recommendations collated from IRG members will help address equity issues and ultimately lead to smoother kidney health journeys. Anecdotal evidence suggests a strong commitment from IRG members to effect positive change for their communities. A Broken Hill member contacted Kelli Owen to express excitement about her involvement in the project, her commitment to seek positive change for her people, and her readiness to act (Joy Williams, telephone conversation 18 December 2020). In WA, Geraldton's Leanne Taylor is a member of the Sir Charles Gairdner Hospital IRG and has already held her own community IRG meeting in the town, gathering issues identified by community members, and meeting with local renal professionals to discuss and address the community's concerns. The themes from Geraldton will be fed into the Sir Charles Gairdner Hospital IRG, with issues added to the agenda and collaboratively worked through to find solutions that meet these expressed needs (Owen 2020).

The Northern Territory has led the way in supporting Indigenous renal reference groups. In 2012, the Renal Advocacy Advisory Committee (RAAC) formed in Darwin as a self-formed patient advocacy group for improved services for Aboriginal renal patients (Purple House 2019). Initially supported through Menzies School of Health Research, RAAC is now supported by Purple House.

A year later, the Central Australia Renal Voice (CARV) was established in Alice Springs to provide patients with a forum to advocate for change in the provision of dialysis treatment, accommodation and social support to drive better health outcomes. This group has worked with Menzies School of Health Research, Purple House and Central Australia Health Service (Purple House 2019). RAAC and CARV help inform kidney care and have a strong conduit role between community members and health professionals. The RAAC and CARV model allow for authentic Indigenous governance practices to be implemented during their meetings. Representatives attending face-to-face meetings are given time to telephone back to community and relay and discuss information to be voted on. A specific person back on Country is then nominated to gather community opinions on topics and relay back community perspective.

Purple House — as are other ACCHOs — is governed by a board comprising Aboriginal community members. Key decisions regarding kidney care and support services and structures are determined by that board (Purple House n.d.).

In SA, the AKction ARG was supported by an Aboriginal researcher, this group developed terms of reference, guided the AKction project, co-designed and co-facilitated community consultations, and are actively involved in improvement activities within SA. The terms of reference are now being shared with other ARGs starting up around Australia (Kelly, Oliva & Jesudason 2019).

Patients' perspectives and feedback

One of the key mechanisms of providing culturally safe care is to identify and respond to patient and client's needs and preferences.

In response to feedback from patients, the Nightcliff Renal Unit in the Northern Territory has a new renal complex which operates under a wellness approach. Patient perspectives and feedback are routinely collected and used to inform and provide culturally safe care in a welcoming environment. The facility offers access to a multidisciplinary team, and includes different rooms for families, strengthening spirit, art, and provides hot healthy meals to address nutritional needs, as well as providing local bush tucker (Owen 2020). Clinical Unit Manager, Selina Signal highlights the success of the unit, highlighting that of 1500 haemodialysis treatments offered only 15 were not attended.

One area of patient feedback that requires specific attention in terms of cultural bias is the establishment of safe processes that enable patients to provide constructive feedback regarding gaps and barriers in care without negative impact on their care. Disturbingly, some patients have reported that after lodging a complaint, they have been labelled as a troublemakers and have experienced 'payback' behaviours from some staff (Owen 2020). Reference groups, peer navigators and Indigenous health professionals have therefore become safe channels for patient feedback, without fear of reprisal.

2.6.2. Domain 2: Workforce

Indigenous workforce

Research projects and community consultations have often identified the need for better training and support of the kidney care workforce, and for increasing the number of Indigenous workers in the sector. Aboriginal community members from WA, NSW, QLD, SA and NT have all strongly and clearly expressed their concern about the low number of Aboriginal and Torres Strait Islander staff who are caring, needling, transporting, educating and following up on their kidney journeys (Owen 2020). Numerous initiatives, suggestions and creative ideas are being put forward to increase the number of Indigenous people employed in kidney health positions so that they can help community members access and receive treatment (Owen 2020). Rochelle Pitt, a Aboriginal and Torres Strait Islander Nurse Navigator working in Metro South, Brisbane, has a vision for Indigenous renal health professionals to be able to support community members at each stage of their kidney journey. This would require human resources and executive support, adequate training and other resources (Owen 2020).

Purple House in Darwin have documented their renal patient preceptor's workforce development project in the 'Our work is for our people' project report (Purple House 2019). This includes professional development plans, employment conditions, intercultural communication, accredited training and taking into account the lived experience of people experiencing dialysis and transplantation. These experiences have been unpacked and addressed, leading to increased employment of people with renal disease and better support for the large influx of new patients learning to live with CKD and kidney failure (Owen 2020).

In 2019, a new taskforce of Aboriginal and Torres Strait Islander clinicians was formed to address the needs of an Indigenous-led kidney health workforce across Northern Australia. They identified the need for their voices to be heard, and for their support needs and leadership to be recognised:

> *Together and individually, we have authority to speak as health professionals who are also community members. We are obligated culturally and through family lines to achieve*

health advancement. We hold and value long term relationships with patients and their communities; culture and family are centred in the strength of our work, and this is valued by patients. We are experts in our own history, our own identity, and in renal clinical care. (Hughes et al. 2019 p.1)

Knowledge and skills of all workforce

The need for better cultural training for non-Indigenous staff has been highlighted by Aboriginal and Torres Strait Islander people in community consultations and research projects (Togni et al. 2016). This feedback was put into action by one project in Alice Springs involving a training program for nurses in regional and remote renal clinics co-designed with patient-experts as co-researchers (Togni et al. 2016). Each workshop was evaluated and the model improved over time. The topics included: language; traditional medicine; how to show respect in Aboriginal culture; aspects of Aboriginal culture and ways of living; how to make people feel comfortable at dialysis clinics; personal life stories; and what giving means for Aboriginal people and kinship and family. Aboriginal co-researchers reflected positively on the workshops, and nurse participants reported that they found the workshops useful and that it had improved their understanding of their patients. One participant remarked:

The biggest thing I have learnt is to look at my patients as people not patients. Listening to their stories [in Workshop 3] just changed everything for me. They're more than just patients on dialysis. There is more to them, there is so much more. And I think that I never stopped and thought about that [before]. (Togni et al. 2016)

2.6.3. Domain 3: Service delivery, approach & models of care

Advocacy

Advocacy has been identified as an important aspect of service delivery and approach of both Indigenous and non-Indigenous healthcare providers.

> *"This system allows for our people to approach identified hospital staff and help First Nations patients and families with their needs."*
>
> Brett Mooney

In Queensland, Kidney Health Worker Brett Mooney, from Princess Alexandra Hospital, has implemented his own cultural appropriate way of identifying others as 'cultural champions' within the hospital setting. Brett provides an Aboriginal/Torres Strait Islander flag lapel pin to staff who he trusts and upskills to allow Aboriginal and Torres Strait Islander people to approach them within the hospital. This lapel flag pin system is explained to patients and their families. Brett has a checklist of attributes and skills he expects from non-indigenous representatives before giving them a flag lapel pin.

Panuku Patient Preceptors advocate strongly for their clients:

We work as members of advocacy groups, talking with other Aboriginal people and medical and health professionals concerned with the way our people experience the health system and how they feel. We help form advice, recommendations and resolutions to give back to people in the health system and the government. There are two main advocacy groups for Aboriginal people on the renal journey in the NT, Top End Renal Advocacy Advisory Committee and Central Australian Renal Voice. (Purple House 2019)

The Catching Some AIR: Asserting Aboriginal and Torres Strait Islander Information Rights In Renal Disease project endorsed four points specifically around strategic advocacy at multiple levels, as follows:

- Advocate for the creation of coordinated and economically sustainable strategies across all levels of government to achieve Aboriginal and Torres Strait Islander renal health.

- Advocate for the development and support of Renal Disease Prevention Centres in rural and remote Aboriginal and Torres Strait Islander communities.
- Advocate for and support Aboriginal and Torres Strait Islander cultural leadership in renal health prevention, diagnosis, treatment and clinical management and data management and custodianship.
- Advocate for and support the allocation of existing funding and policy efforts to improve Aboriginal and Torres Strait Islander renal health (Mick-Ramsamy et al. 2019).

Case management, referral and follow up

Accessing and navigating different parts of the healthcare system is often complex, confusing and disjointed for all patients, and is made more difficult for those experiencing language, communication, distance and/or socioeconomic barriers. Often patients are well supported to get into city hospitals but are less well supported to transition back into primary care, and to have adequate follow up (Kelly, Dwyer et al. 2015).

> *"Follow up on our people is needed as we do everything at a hospital level prior to their release but our people need local and personal follow up to stay on top of their health needs. Having a model of care between the hospitals and GP's/ACHOS within community is necessary."*
>
> Darren Quartermaine SCGH

Undertaking work-up for kidney transplantation is a huge undertaking, requiring specific support and case management, referral and follow up. This is highlighted by Kelli reflecting on her own transplantation work-up journey:

> *On my kidney journey I had a CTG case manager who helped me through my complex walk. Linking appointments, staying on top of work-up tests, dental & ongoing appointments. A few tests were able to be done locally in my regional town due to the knowledge of the CTG case managers (nurse knowledge).* Kelli Owen, Transplant recipient

Collaboration with other healthcare providers

Responsive care often requires healthcare providers to collaborate with other healthcare and support services to better meet patient and client's needs and co-create solutions with limited resources and time. Yet, collaborative approaches occur daily across Australia in clinical care. Two end-of-life journeys illustrate this well.

Recently, in one regional area, an Aboriginal woman was nearing the end of her kidney health journey. The dialysis manager worked with another dialysis centre in a smaller regional hospital to get her closer to home, to spend time with family while she still could (Owen 2020). Often renal patients stay at the local Aged Care facility when there are accommodation issues, but due to COVID restrictions, that would mean that she would not be able to have any visitors. The small regional hospital arranged a bed for her within the hospital so that she could still see family members between dialysis sessions (Owen 2020).

End-of-life journeys that enable Aboriginal and/or Torres Strait Islander people from remote communities to return home to be with family, community and County again before they die, are vitally important. They can also be difficult to arrange quickly at short notice if no clear end of life pathway or support services are in place, and the person is rapidly becoming unwell. In Port Augusta, dialysis Nurse Unit Manager (NUM) Kylie Herman used the *Managing Two Worlds Together Patient Journey Mapping Tools* to map the journey of a client in this situation, and how she negotiated and collaborated with a range of services to enable the person to get home in time (Kelly et

al. 2015c). The resulting case study was then used by another staff member to arrange an end of life journey at short notice when Kylie was on leave.

Communication, understanding, trust and transparency

The importance of clear two-way communication, shared understanding and trust in healthcare encounters has been identified repeatedly in a range of kidney care studies. Effective and respectful communication continues to be a major component in determining quality of care and improved outcomes (Devitt et al. 2017; Rix. et al. 2016). Many units and services have practices in place to enhance these aspects of care (Kimberley Aboriginal Medical Services 2020); however, they continue to be raised as unmet needs in studies and community consultations (Hughes. et al. 2017) (Kelly, Oliva & Jesudason 2019; Mick-Ramsamy et al. 2019; Kelly et al. 2019) (Stevenson, Kelly & O Donnell 2019). The Communicate Study Group in the Northern Territory have specifically trialled strategies to improve communication related to language barriers, by employing an interpreter coordinator, training healthcare providers in how to work effectively with interpreters and promoting interpreter use (Communicate Study Group 2020). The study reported an immediate increase in Aboriginal interpreter bookings and a decline in self-discharge numbers. (Note: this study may have met the inclusion criteria for the peer reviewed literature; however it was published after the peer review process for this proect was completed).

When conducting consultations in the Northern Territory, Kelli Owen found the following two examples of initiatives to address and improve communication:

> *Dr Majoni and the Top End Interpreters (Aboriginal interpreters) have been included onto the ward when he conducts his rounds. This approach has strengthened relationships, understanding and trust between patient and doctor by using mother tongue to educate and explain each individual patient's health care options.* (Owen 2020)

> *The Top End Renal Unit has a 10 week educational program being delivered to individual and families. It is a scaffolded weekly program detailing all aspects of a possible kidney journey.* (Owen 2020)

Continuity of care and carer

NIKTT community consultations identified that continuity of care is a crucial aspect of quality care in kidney journeys. Darren Quartermaine from Sir Charles Gairdner Hospital (cited in Owen 2020) discussed how he ensures there is continuity of care for patients released from hospital:

> *The link between hospitals, GP's & ACCHO's need to be strengthen in their delivery to make certain that CKD patients have continuity of care, checking on their health and journey to stay proactive in treatment approaches and making sure there is open communication with medicines, updates, future needs and education.* (Owen 2020)

The increased use of telehealth, videoconferencing and outreach services are central to effective continuity of care for patients from rural and remote areas across Australia (Venuthurupalli et al. 2018).

Cultural safety, responsiveness, and addressing racism and whiteness

There is increasingly an emphasis on improving the cultural safety of healthcare practitioners and services; this is discussed further in this section, under Domain 4: Structures and policies. Enacting cultural safety requires increased responsiveness, and increased flexibility within Western healthcare processes and systems.

The recognition of the need for Aboriginal and Torres Strait Islander patients, families, and healthcare professionals to attend important cultural events, and to return to County is an important aspect of addressing racism and whiteness. There are multiple other aspects, and these will be dependent on the people involved, as cultural needs

are not homogenous. For example, Rochelle Pitt (Nurse Navigator introduced earlier) has been advocating for the inclusion of Cultural leave for family and Country responsibilities for renal patients on dialysis. This cultural inclusion into their care plan is needed to be implemented for patients to return to Country and family (Owen 2020).

The Managing Two Worlds Together project developed a set of patient journey mapping tools that brought together the experiences of Aboriginal and Torres Strait Islander patients and families, the perspectives of health professionals and services, and standards of care (Owen 2020). The team worked with patients and families and renal, dialysis and kidney transplantation nurses and managers to identify gaps in care and co-design responsive strategies. A series of co-authored case studies illustrated the challenges for patients and staff, and creative ways of identifying gaps in care and improving responsiveness (Kelly et al. 2015c). This type of tool helps identify what cultural safety looks like in practice. Further mapping work by the AKction project provided new opportunities and Aboriginal and Torres Strait Islander patient and family involvement to identify what needed to change in dialysis care, including the opportunity to co-create the Kanggawodli dialysis pilot (discussed under Dialysis earlier in this section). This pilot aims to increase cultural safety and responsiveness and address institutional racism and whiteness in dialysis care. The AKction Reference Group envisioned an Aboriginal-specific dialysis service that provides holistic care, accessible information, and wraparound healthcare and support services.

Health promotion and health education

Aboriginal and Torres Strait Islander people need to have access to sufficient information, knowledge and resources to be able to make informed decisions, address risk factors and care for themselves and their family members in relation to kidney disease and other chronic health conditions. This often requires a holistic approach which includes the historical and social context for Aboriginal and Torres Strait Islander people (Calma & Dick 2007). A number of successful programs have been led by, or work in collaboration with, Aboriginal and Torres Strait Islander families, communities, health professionals and services (Morley 2015). For example, a 2012 program developed in NSW involved an ACCHS that employed a nurse practitioner to systematically screen and treat CKD (Barrett et al. 2015). The project identified a high number of patients with CKD who were previously undiagnosed. It initiated improved collaboration with nephrologists through telehealth.

Another example is the Antecedents of Renal Disease in Aboriginal Children and Young People (ARDAC) study, which is a community based, longitudinal study based at the Centre for Kidney Research at the Children's Hospital at Westmead, Western Sydney. This study monitors the heart and kidney health of Aboriginal and non-Indigenous children and young people in NSW and assesses the social determinants for health. If participants return abnormal test results they are referred to a local health centre (Craig et al. 2002):

> *Over the last fourteen years the ARDAC study has been screening young Aboriginal people that may have an increase in risk factors for kidney disease during late adolescence and early adulthood. They work closely with Aboriginal health services to deliver this program, and are based on Aboriginal concepts of health and wellbeing of Communities.* (Owen 2020)

Improving access by responding to holistic health, wellbeing and socioeconomic needs

The most supportive kidney health projects and services are those that recognise and address Aboriginal and Torres Strait Islander people's holistic health, wellbeing and socioeconomic needs, which may be similar, or different, to those of other kidney care patients. Ongoing colonisation, racism and marginalisation is experienced by many

Aboriginal and Torres Strait Islander people in their daily lives, which significantly impacts on their access to resources and determinants of health. Therefore, services may need to enhance or change their models of care to better respond to the additional access needs of these patient groups. Transport and referral are two areas that can cause significant challenges for patients:

> *Leeanne Taylor from Geraldton spoke about the GRAMS (Geraldton Regional Aboriginal Medical Service) approach in relation to transporting Elders to Perth for medical appointments. "Our Elders were travelling by themselves by bus to a big city. They struggled to get on the bus with the size of the big stairs and then were left to fend for themselves with limited support once they arrived in Perth. Now we have health workers transporting our Elders by car, assisting, supporting them throughout their specialist appointments and not being alone throughout the complex trip.* (Owen 2020)

Another area of care, increasingly being highlighted in community consultations is social and emotional support, mental health and wellbeing (Kidney Health Australia 2020). There are very few published studies or programs targeting mental health specifically for Aboriginal and Torres Strait Islander kidney care patients and clients. The Wellbeing Intervention for Chronic Kidney Disease (WICKD) study introduced a wellbeing app to assist Aboriginal and Torres Strait Islander kidney patients to stay mentally strong throughout their illness. The acceptability, utilisation and overall effectiveness of this study are yet to be published (Dingwall et al. 2019).

Peer support

Emerging in the literature is the recognition of the importance of Aboriginal and Torres Strait Islander peer support workers who have lived experience of kidney disease, dialysis or transplantation. Peer support workers are able to provide integral insights for kidney patients and help them walk their difficult road with more ease and ability to see what is up ahead (Purple House 2019). One example of peer support is that of the Patient Preceptors employed by Purple House in the NT. Patient Preceptors provide expert advice and reassurance to patients (Purple House 2019).

Rhanee Tsetsakos (a dialysis patient) in Adelaide has spoken of the urgency for positions to be implemented locally and in regional and remote areas:

> *Many families are unaware of what is expected along the way (kidney journey). Things we talk about range from symptoms being experienced, who to contact, what happens when they meet with the specialist, accommodation available in the metropolitan area and how important it is to have another support with them. I've starting videoing my journey and broadcasting my live feeds to family and wider community to give them an idea of what they may expect.* (cited in Owen 2020)

Hunting Team members (Lachlan, David, Peter & Neil) have been filling this role from the Top End and throughout the Territory's communities (Owen 2020), sharing insights on lived experience, knowing the system, who to talk with, what the machines do, how the medicines affect your body and offering social supports for CKD patients flying into Darwin to receive emergency treatment (Owen 2020).

Quality, safety, evaluation and continuous quality improvement

There may be a range of quality and safety initiatives being utilised in health services across Australia that are not yet available publicly. The National Safety and Quality Health Service Standards include six specific actions related to meeting the needs of Aboriginal and Torres Strait Islander people in healthcare. A user guide was developed by the South Australian Health and Medical Research Institute (SAHMRI) and the Aboriginal and Torres Strait Islander Health Project Working Group. These standards focus on working in partnership, governance, cultural awareness/competency/safety, addressing racism and bias and improved identification of Indigenous patients.

2.6.4. Domain 4: Structures and policies

There are very few cultural bias and racism policies that specifically target kidney care and transplantation. As such, this section provides an overview of broader policies that encompass kidney care and different structures and policies that aim to address cultural bias in Aboriginal and Torres Strait Islander health.

Organisational governance, commitment, leadership and management

At a national level, existing policy frameworks in Aboriginal and Torres Strait Islander health provide a promising and enabling agenda from which to address cultural bias in kidney transplantation. The National Aboriginal and Torres Strait Islander Health Plan outlines a vision for an Australian health system free of racism and inequality, and similar to the new national agreement on Closing the Gap, it emphasises principles of Aboriginal and Torres Strait Islander community control, partnership, accountability, and shared decision making.

Within healthcare more broadly there are also a number of positive policy developments which further support the implementation of initiatives to address cultural bias in kidney care. These include:

- The new National Safety and Quality Health Service (NSQHS) Standards which include six actions to meet the needs of Aboriginal and Torres Strait Islander people. Prior to these standards being released in 2017 there were no specific standards for hospitals about care for Aboriginal and Torres Strait Islander clients.
- The Australian Health Ministers Advisory Council Cultural Respect Framework 2016-2026, with similar supporting strategies also existing in some jurisdictions.
- APHRA's Aboriginal and Torres Strait Islander health and cultural safety strategy 2020-2025 released in February 2020.

APHRA's strategy commits to creating a culturally safe health workforce through nationally consistent standards, codes and guidelines across all practitioner groups with the National Registration Scheme for health practitioners. It defines cultural safety as the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism. To ensure culturally safe and respectful practice, health practitioners must:

- acknowledge colonisation and systemic racism, social, cultural, behavioural and economic factors which impact individual and community health
- acknowledge and address individual racism, their own biases, assumptions, stereotypes and prejudices and provide care that is holistic, free of bias and racism
- recognise the importance of self-determined decision-making, partnership and collaboration in healthcare which is driven by the individual, family and community
- foster a safe working environment through leadership to support the rights and dignity of Aboriginal and Torres Strait Islander people and colleagues.

Work has also been conducted in Queensland in 2014 and more recently in South Australia to report on institutional barriers to health equity for Aboriginal and Torres Strait Islander people. The studies involved the use of a matrix framework to assess the level of institutional racism in health services over time. The purpose of the audits is to act as a conversation opener and show where improvements can be made. In Queensland the work showed that hospitals and healthcare services can reduce institutional racism

against Aboriginal and Torres Strait Islander people and produce better health outcomes by:

- including Aboriginal and Torres Strait Islander people in the governance of the organisation
- implementing Aboriginal and Torres Strait Islander health policy
- publicly reporting on their outcomes for Aboriginal and Torres Strait Islander people
- employing Aboriginal and Torres Strait Islander staff at all levels and occupations
- enabling accountability, and in particular financial accountability, for the policies and outcomes of the organisation for Aboriginal and Torres Strait Islander people.

Equity in a public healthcare system that is free of institutional racism will deliver better healthcare outcomes for Aboriginal and Torres Strait Islander people and make a significant contribution to Closing the Gap in life expectancy between Aboriginal and Torres Strait Islander people and non-Indigenous people (Marrie, Adrian & Bourke 2020).

The Australian Institute of Health and Welfare has recently developed the *Cultural safety in health care for Indigenous Australians: Monitoring framework* to bring together available data on cultural safety in the health system for Indigenous Australians. The framework covers how healthcare services are provided; Aboriginal and Torres Strait Islander patients' experience of healthcare; and access to healthcare. The framework notes that monitoring cultural safety in the health system is limited by a lack of data, especially in relation to policies and practices of hospitals and primary healthcare services and the experiences of Aboriginal and Torres Strait Islander healthcare users – a critical element of cultural safety (AIHW 2019). Broader national frameworks such as the National Strategic Framework for Chronic Conditions (Australian Health Ministers' Advisory Council 2017) are increasingly focusing on addressing the social determinants of health and ensuring equitable access through targeted, culturally safe, appropriate, flexible and responsive services that are adequately resourced and evaluated.

Physical environment

The physical environment where patients receive care plays a significant role in determining whether patients feel welcome and safe.

The structural layout of dialysis units was discussed extensively during community consultations. Many regional hospitals are in scenic locations, and patients and staff have discussed that it would be incredibly beneficial if rebuilds could ensure dialysis patients had a good view given they are often on dialysis five hours a day, three days a week (Kidney Health Australia 2020).

There has also been discussion of single gender areas, or rooms large enough to accommodate family members to visit and be with patients during dialysis and transplantation work up and recovery (Kidney Health Australia 2020).

Policies, guidelines and standards

Currently in Australia, there are no national clinical guidelines regarding renal care specifically for Aboriginal and Torres Strait Islander people (Duff et al. 2018; Schwartzkopff, Kelly & Potter 2020). The Catching Some AIR (Asserting Indigenous Rights) project has conducted consultations with community on how to create effective, safe and 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 et al. 2018; Mick-

Ramsamy 2019) and ensure that Aboriginal and Torres Strait Islander people play a fundamental role in developing the guidelines to improve Aboriginal and Torres Strait Islander kidney patient outcomes (EY 2019). Once developed, these guidelines will need to be funded, implemented and evaluated.

The National Strategic Action Plan for Kidney Disease, developed by Kidney Health Australia in 2019 outlines an action plan for transforming kidney disease in Australia over the next ten years, including the most pressing needs in kidney disease. The plan includes a focus on addressing the disproportionate burden of kidney disease among Aboriginal and Torres Strait Islander people by including actions to implement the Aboriginal and Torres Strait Islander Renal Health Roadmap and support the NIKTT and the recommendations of the TSANZ performance report: *Improving access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander People in Australia* (Garrad & McDonald 2019).

Resources and funding

Recent initiatives and announcements have seen a temporary increase in resources and funding for Aboriginal and Torres Strait Islander kidney transplantation. The most significant of these is $2.3 million to establish the NIKTT and implement the recommendations from the TSANZ performance report (Garrard & McDonald 2019). In 2020, NIKTT announced Equity and Access Sponsorships to provide funding for resources and projects that improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people. Kidney Health Australia also received funding in 2018 from the Federal Government that enabled them to undertake consultations with Aboriginal and Torres Strait Islander community members, health experts, service providers and peak bodies to inform the development of the KHA-CARI clinical guidelines.

More broadly, the federal government has committed $34.8 million to support renal dialysis for Aboriginal and Torres Strait Islander people in remote areas through a new MBS item to support the delivery of dialysis by nurses, Aboriginal and Torres Strait Islander Health Practitioners and Aboriginal Health Workers in primary care settings in remote areas.

Resources and funding are necessary to initiate and sustain cultural bias initiatives. Recent initiatives have only come about as the result of dedicated funding and any future initiatives will need dedicated long-term funding to be successful.

3. Systematic review of peer reviewed literature

Section 3 includes a systematic review of the peer reviewed literature. The review aimed to find evaluated initiatives for Aboriginal and Torres Strait Islander people that addressed cultural bias. Initiatives for all types of care were included, not just for kidney care. Initiatives from other areas of care can provide examples and opportunities to learn from where cultural bias initiatives are more strongly developed.

3.1. Method

3.1.1. Search criteria

The peer reviewed literature search was conducted in four databases (PubMed, EMBASE, CINAHL, and APA PsycNet) using terms related to Aboriginal and Torres Strait Islander peoples, cultural bias, healthcare and initiatives. Publications were included if they reported a specific initiative or program targeting cultural bias for Aboriginal and/or Torres Strait Islander adults in Australia, which was also formally evaluated. Publications were excluded if 1) they did not include Aboriginal and Torres Strait Islander adults, 2) did not include an initiative that was evaluated and 3) did not report an outcome. A description of the search strategy, and inclusion and exclusion criteria is provided below.

3.2. Data selection

The following criteria for selecting relevant peer reviewed literature to inform this scoping review was developed and agreed upon in Zoom meetings with the Cultural Bias Working Group.

Settings, in order of prioritisation:

1. renal, transplantation and tertiary care setting (what is already occurring)
2. other tertiary settings (good examples that could inform renal transplantation)
3. PHC settings (if there are aspects that could be relevant to improve renal tertiary transplantation care).

Sources: Peer reviewed literature in PubMed, EMBASE, CINAHL, APA PsycNet databases.

Cultural bias may include:

- Racism
- Bias – unconscious, implicit
- Discrimination
- Cultural safety, competency
- Privilege
- Assumptions
- Prejudice
- Stereotypes
- Quality and safety

Initiatives may include:

- Intervention
- Initiatives
- Education
- Training
- Practices
- Programs
- Model of care
- Model of practice
- Workforce
- Delivery
- Frameworks
- Policies
- Evaluations
- Patient perspectives
- Cultural safety

Potential outcomes (ways effectiveness is discussed) may include:

- Relationships
- Access
- Quality
- Interactions
- Improvements in care
- Patient outcomes
- Experiences of care

3.2.1. Literature search strategy

A search of the peer reviewed literature was conducted using four databases: PubMed, EMBASE, CINAHL, and APA PsycNet. PubMed and EMBASE were chosen as major biomedical and life science databases. CINAHL was chosen as a database for nursing, allied health and biomedicine. Finally, APA PsycNet is a database that includes articles of psychology and social science and as cultural bias and racism is a social phenomenon this database was chosen.

Table 4: Search terms – peer reviewed literature

Indigenous	Cultural Bias	Health Care	Initiatives
Aborigin* OR Torres Strait Islander OR ATSI OR Indigenous OR First Natio*	Racism OR cultural bias OR cultural competency OR cultural Safety OR racial prejudice OR racial bias OR cultural prejudice	Health care OR health care OR tertiary care OR Primary care OR hospital OR PHC OR general practice OR renal dialysis OR kidney transplantation OR Outpatient OR dialysis	Model of care OR program OR policy OR initiative OR education OR training OR model of practice OR delivery OR practice OR intervention

3.3. Inclusion and exclusion criteria

Table 5: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria

Country: Australia
Population: Aboriginal and/or Torres Strait Islander people aged 18 years and older
Setting: Renal and hospital healthcare (primary healthcare only if particularly relevant) Initiative or program targeting cultural bias
 	
- Randomised controlled trials (RCTs)
- Non RCTs
- Systematic reviews
- Observational studies:
    o Retrospective and prospective cohort studies
    o Case control studies
    o Health service studies
    o Health service evaluations
    o Analytic cross-sectional studies
	- Focus on Culturally and Linguistically Diverse not Indigenous
	- International paper (where it is difficult to extract Australian data)
	- Does not include Aboriginal and/or Torres Strait Islander people
	- Initiative includes children only
	- Setting is not a healthcare setting
	- Does not target cultural bias
	- Does not include an initiative
	- Does not report outcomes
	- University based education
	- Prison, dental, mental health, community-based health promotion.

o Descriptive epidemiological study designs.	

Figure 7: Prisma diagram of included studies
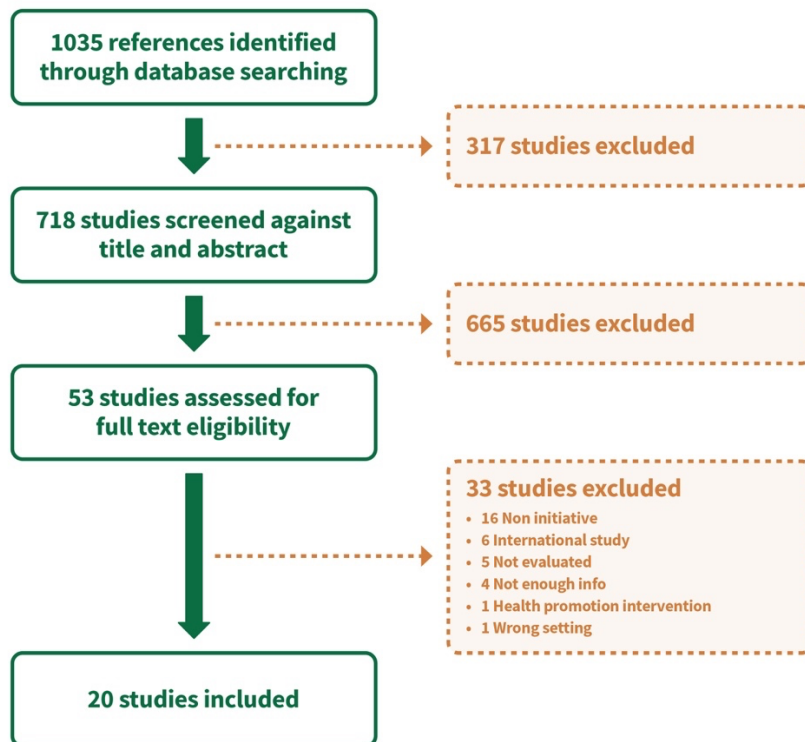
3.4. Analysis

The selected studies were analysed in three different ways.

First they were analysed to identify **efficacy** from a patient, healthcare provider and clinical outcomes perspective.

Second, they were analysed using the **Healthcare action framework** for Aboriginal and Torres Strait Islander people (Bourke et al. 2020). This conceptual framework brings together four domains to guide institutions and health professionals in their work to deliver better healthcare outcomes for Aboriginal and Torres Strait Islander people, including those with kidney disease.

Finally, an analysis of **key enablers** at the individual, health service and systems level (micro, meso, macro)level of healthcare, that identifies how healthcare providers, services, programs, systems addressed the impacts of colonisation, racism, inequities and disadvantage within the initiatives, at an patients-clients-family-community, workforce, service delivery/models of care, and structures and policies level. This analysis is used to discuss the emerging themes in detail.

3.5. Results of peer reviewed literature

3.5.1. Peer reviewed literature results summary

The search of the peer reviewed literature identified 20 articles that met the criteria.

3.5.2. Other areas of care

In our initial search, a very limited amount of published literature was found that both described and evaluated kidney health cultural bias initiatives. A decision was made to

include initiatives that targeted cultural bias in other care areas, the rationale being that findings could be learned from these areas and applied to the kidney care space.

These are summarised in the following three tables and text.

Table 6: The area of care, jurisdiction and location of the peer reviewed studies selected (n=20)

Area of Care	Cancer	5
	Diabetes	1
	Emergency	1
	General- hospital	1
	Maternity	10
	Renal	2
Jurisdiction	NSW	5
	NT	1
	SA	5
	QLD	6
	VIC	1
	WA	2
Location	Metro	6
	Metro & regional	1
	Regional	4
	Regional & remote	1
	Remote	2
	Statewide	5
Healthcare site	ACCHO/PHC	3
	ACCHO/PHC/Hospital	8
	Hospital	6

3.5.3. Area of care, jurisdiction and location

The papers that met our selection criteria come from five main healthcare areas: cancer (x 5), diabetes (x 1), emergency (x 1), maternity (x 10) and renal (x 2), with the remaining paper focusing on the Indigenous health and cultural education of interns across the hospital (x1). Of note, no papers focusing on cardiac care cultural bias initiatives met our specific systematic review inclusion criteria.

The papers report on studies that occurred across all mainland states of Australia and Northern Territory. Six were in metropolitan areas, seven in regional and remote areas, one spanned metropolitan and regional and five were statewide. Eight reported on initiatives that occurred across PHC and hospital sites, three focused on primary healthcare, six on hospital care, and three on telehealth and outreach. Those occurring in primary healthcare sites included ACCHOs. The majority of the studies occurred in the last 10 years, with 13 of the 20 papers published in the last five years.

3.5.4. Initiatives – overview

A diverse range of initiatives to address cultural bias were identified. All 10 maternity studies focused on new or improved models of care. They included Aboriginal and

Torres Strait Islander roles, extended midwifery practice, working collaboratively with other services, advocating for improvement in women's care and meeting holistic health and access needs of Aboriginal women. The five studies in cancer care discussed a range of initiatives, including an extended model of care, a patient education flipchart, a specialist videoconferencing outreach program, a communication and cultural safety workshop, and strategies to improve cross-cultural collaboration and relationship building between staff. The two renal studies focused on regional and remote outreach via a renal bus and tele/video health. The remaining three studies reported on a diabetes patient education resource, a strategy to improve identification and cultural competence within an emergency department and an education program for medical interns about the role of Indigenous Liaison Officers (ILO).

Evaluation approaches varied. Seven studies used qualitative interviews and focus groups as their evaluation method; three of which involved both patients/clients and health professionals (Conway et al. 2018; Ivers et al. 2019; Mooi et al. 2012), and the remaining four involved both Indigenous and non-Indigenous health professionals (Hickey et al. 2019; Stamp et al. 2008; Xu et al. 2018; Zubrzycki, Shipp & Jones 2017). The remaining 13 studies used qualitative and quantitative mixed methods approaches. Four used mixed methods surveys (Bertilone et al. 2017; Bierbaum et al. 2017; Brown et al. 2016; Sinnott & Wittmann 2001), one used both a survey and qualitative interviews , and two combined surveys, qualitative interviews and clinical/hospital/outcomes data (Josif et al. 2014; Kildea et al. 2012). One study used longitudinal data and organisational goals (Murphy & Best 2012). Another workshopped analysis of attendance and outcomes data (Kildea et al. 2018). The remaining mixed methods studies used a range of mixed methods approaches combining interviews with observational data, cost analysis, outcomes data (Gadsden et al. 2019) (Hartz et al. 2019; Middleton et al. 2017; Venuthurupalli et al. 2016; Venuthurupalli et al. 2018).

Table 7: Overview of selected studies (more detail available in Table 13 in Appendix)

	Publication	Jurisdiction	Setting	Participants Indigenous	Initiative type	Evaluation approach
Cancer	Bierbaum 2017 (Bierbaum et al. 2017)	SA	Statewide ACCHOs and PHC	18 Aboriginal and other health professionals (HPs)	Cancer Healing Journey Flipcharts	Survey of Aboriginal health professionals using or aware of flip charts.
	Durey 2017 (Durey et al. 2017)	WA	Metro Tertiary	39 radiation oncology HPs	Communication /cultural safety workshops	Mixed methods. Pre and post-workshop survey of workshop participants.
	Ivers 2019 (Ivers et al. 2019)	NSW	Metro ACCHO	8 clients *4 Aboriginal*, 4 non-Aboriginal HPs	New extended model of care, continuity of care	Semi-structured interviews, grounded theory analysis.
	Mooi 2012 (Mooi et al. 2012)	QLD	Regional and Remote Telehealth	9 patients, 2 family, *1 Aboriginal* 5 non-Aboriginal HPs	Specialist video consultation outreach	Semi-structured interviews.
	Zubrzycki 2017 (Zubrzycki, Shipp & Jones 2017)	NSW	Regional Cancer Service	*20 Aboriginal*, 21 non-Aboriginal HPs	Staff cross-cultural collaboration & relationship building	Participatory action research, interviews, focus groups. Reference Group involvement.
Diabetes	Xu 2018 (Xu et al. 2018	Victoria	Statewide	*6 Aboriginal* and 12 non-Aboriginal HPs	Patient education resource	Semi-structured interviews.
Emergency Department	Gadsden 2019 (Gadsden et al. 2019)	NSW	Metro and regional Tertiary	*6 Aboriginal* and 17 non Aboriginal HPs and managers	ED care, identification, cultural competence collaboration strategy -	Mixed methods – CQI, linked data, case note audit, interviews.

	Publication	Jurisdiction	Setting	Participants Indigenous	Initiative type	Evaluation approach
General	Sinnott 2001 (Sinnott & Wittmann 2001)	QLD	Statewide Tertiary	16 ALOs 64 medical intern HPs	Promoting Indigenous Liaison Officer role to interns	Semi-structured interviews & questionnaire.
Maternity	Bertilone 2017 (Bertilone et al. 2017)	WA	Metro ACCHO, PHC, and Tertiary	*16 clients*, 7 Aboriginal, 8 non Aboriginal HPs, *8 Aboriginal and* 14 non - Aboriginal stakeholders	Expanded Midwifery Group Practice	Organisational Cultural Competence Assessment Tool, surveys.
	Brown 2016 (Brown et al. 2016)	SA	Statewide	313 Aboriginal mothers (344 women in total)	Aboriginal Maternal Infant Care (AMIC) program	Survey – self conducted or via interview.
	Hartz 2019 (Hartz et al. 2019)	NSW	Metro Tertiary	9 women 13 HPs Service data of 505 women	New extended midwifery & holistic care & link service	Mixed methods. Comparative cohort study, interviews.
	Hickey 2019 (Hickey et al. 2019)	QLD	Metro ACCHO & Tertiary	21 Indigenous and non-Indigenous HPs	New extended midwifery care program	Participatory action research, semi-structured interviews, thematic analysis.
	Josif 2014 (Josif et al. 2014)	NT	Remote Maternity clinic	12 women clients, 2 AHWs 1 senior woman 14 midwives 34 health staff 3 other staff	Establishment of regional maternity group practice	Participatory action research, mixed methods design – clinical and costing data, questionnaires, interviews, observations.
	Kildea 2012 (Kildea et al. 2012)	QLD	Metro Maternity Clinical ACCHO/PHC Tertiary	46 service users 157 staff 17 stakeholders	Maternity clinic for Indigenous women and babies	Triangulation mixed methods. Interviews and focus groups, surveys, audit data, hospital databases, outcomes comparison.

	Publication	Jurisdiction	Setting	Participants Indigenous	Initiative type	Evaluation approach
	Kildea 2018 (Kildea et al. 2018)	QLD	Metro ACCHO and tertiary	Consumers, stakeholders, community members policy advisors	Extended midwifery care program	World café workshop, analysis of attendance and outcomes data, gap analysis.
	Middleton 2017 (Middleton et al. 2017)		Statewide ACCHO/PHC	20 AFBP clients 107 health professional *20 AMIC*	Aboriginal Maternal Infant Care program	Interviews with health professionals and clients. Quantitative analysis of birth data.
	Murphy 2012 (Murphy & Best 2012)	NSW	Statewide ACCHO/PHC Hospital	Health service and outcomes data, patient feedback	Continuity of care model	Evaluation by external consultants using longitudinal data. Evaluation against goals.
	Stamp 2008 (Stamp et al. 2008)	SA	Regional ACCHO/PHC Hospital	5 AMIC workers 4 midwives	Aboriginal Maternal Infant Care program	Semi-structured interviews.
Renal	Conway 2013 (Conway et al. 2018)	SA	Remote Outreach	15 patients 10 nurses	Mobile Dialysis Truck to remote communities	In-depth interviews.
	Venuthurupalli 2016 & 2018 Venuthurupalli et al. 2016; Venuthurupalli et al. 2018)	Qld	Regional Telehealth	Clinical attendance and outcomes data	Tele/video health specialist outreach and multidisciplinary care	Mixed methods, interviews, observational data, cost analysis.

Table 8: Efficacy summary table

	Publication	Initiative type	Measure used	Efficacy			Explanatory comments
				Patient perspective	Health perspective	Clinical & administrative data	
Cancer	Bierbaum 2017	Cancer Healing Journey Flipcharts	Survey HPs	-	Mixed (Yes & No)	-	Availability. Some content and structure changes suggested.
	Durey 2017	Communication /cultural safety workshops	Pre/post survey. HP Workshop participants	-	Mixed		Overall positive in relation to critical reflection and communication, but changes need to be studied over time.
	Ivers 2019	New extended model of care, continuity of care	Interviews clients & HPs	Yes	Yes	-	Being based at Aboriginal health service was central to success.
	Mooi 2012	Specialist video consultation outreach	Interviews - patients, family & HPs	Yes	Yes	-	Care closer to home, closer working relationships, two way learning.
	Zubrzycki 2017	Cross-cultural collaboration & relationship building	Interviews and focus groups with HPs	-	Mixed	-	Some improvements, but tension and conflict are also an integral part of collaboration. Relationships and trust built over time.
Diabetes	Xu 2018	'Feltman' patient education resource	Interviews with HPs	-	Mixed	-	Culturally appropriate useful resource, but variable availability. Different format required for 1:1.

	Publication	Initiative type	Measure used	Efficacy			Explanatory comments
				Patient perspective	Health perspective	Clinical & administrative data	
Emergency Departments	Gadsden 2019	ED improvement strategy	Mixed methods – CQI, linked data, case note audit, interviews HPs	-	Mixed	No	Identification accuracy improved variably across sites, however, organisational improvements in data collection, training, referral pathways and response plans were initiated.
General	Sinnott 2001	Promoting ILO role to interns	Interviews with HPs	-	Mixed		Limited education opportunities have limited impact on HP's knowledge.
Maternity	Bertilone 2017	Expanded Midwifery Group Practice	Interviews & surveys with HPs & partner orgs	Yes	Yes	Mixed	New practice approved by women and staff, but institutional barriers meant the same benefits were not seen across all sites.
	Brown 2016	Aboriginal Family Birthing Practice	Survey with women	Yes	-	Yes	Women were more likely to access antenatal care early and regularly with transport and AFBP assistance.
	Hartz 2019	New extended midwifery & holistic care & link service	Interviews, outcomes data	Yes	Yes	Mixed	New practice approved by women and staff, but complex client health, risk & SDOH factors impact on clinical results.
	Hickey 2019	Establishing teams for culturally safe care	PAR & interviews with HPs	-	Mixed	-	Mixed understanding of cultural safety between

	Publication	Initiative type	Measure used	Efficacy			Explanatory comments
				Patient perspective	Health perspective	Clinical & administrative data	
							staff. Organisations are both a barrier and enabler to promoting/supporting cultural safety.
	Josif 2014	Establishment of regional maternity group practice	Interviews with clients and HPs	Yes	Yes	Yes	Model has multiple benefits for clients, MGP and hospital staff and a reduction in early labour presentations.
	Kildea 2012	A maternity and antenatal clinic for Indigenous women and babies	Interviews/FG clients and HPs surveys, audit & outcomes data analysis.	Yes –clinic No-hospital care	Mixed	Yes	Women appreciated care, had better birth outcomes & less babies admitted to NICU. Staff identified operational and physical challenges as well as enablers.
	Kildea 2018	Extended midwifery care program	Clinical outcomes gap analysis/response with community members, health services & policy advisors	Yes	Yes	Yes	Many women and staff preferred this model of care. Improvement across multiple clinical indicators: improved antenatal care attendance, increased breastfeeding, decreased smoking. Improved coordination of care.
	Middleton 2017	Aboriginal Maternal Infant Care program	Interviews with clients and HPs, birth data analysis	Yes	Mixed	Unclear	Women and staff appreciated model of care, but role of AMIC workers poorly

	Publication	Initiative type	Measure used	Efficacy			Explanatory comments
				Patient perspective	Health perspective	Clinical & administrative data	
							understood by other staff. Organisational challenges. Women had complex care needs; no statistically significant improvements.
	Murphy 2012	Continuity of care model	Patient feedback, service & outcomes data analysis	Yes	-	Yes	Women prefer this model. Improved attendance and outcomes data.
	Stamp 2008	Aboriginal Maternal Infant Care program	Interviews with HPs	-	Yes	-	Partnership model working well within program, but noted AMIC role is less understood more widely.
Renal	Conway 2013	Mobile Dialysis Truck to remote communities	Interviews with patients and HPs. Realist evaluation	Yes	Yes	-	The bus provided connection to Country and cultural-clinical two way sharing between patients and staff.
	Venuthurupalli 2016 & 2018	Tele/video health specialist outreach and multidisciplinary care	Clinical attendance and outcomes data analysis	-Yes	-	Yes	High level of acceptance and retention in telehealth clinics. No admission for emergency dialysis since commencement of telehealth clinic.

3.6. Efficacy of initiatives

Three types of efficacy results were reported: patient feedback, healthcare provider feedback, and clinical and administrative data. Many studies reported on more than one type of result. The majority of the studies used qualitative analysis, and highlighted both enablers and barriers of implementation and effectiveness from multiple perspectives.

3.6.1. Renal specific

Both of the studies focusing on kidney care (Conway et al. 2018; Venuthurupalli et al. 2016) were outreach initiatives that aimed to improve access to care for rural and remote patients. Conway et al. (2018) described an initiative where a bus with three dialysis chairs travelled out to rural and remote areas on SA with nurses from metropolitan Adelaide. The initiative allowed patients who had relocated to access care to visit their families, community and Country. The initiative was evaluated using interviews with patients and nurses and received overwhelmingly positive feedback. The initiative described by Venuthurupalli et al. (2018) enabled patients who lived more than 50 km from the tertiary care centre to receive specialist care via videoconferencing. This initiative allowed patients to remain with their support system at home, while also saving the health system money through reduced travel costs that were preciously subsidised for patients (Venuthurupalli et al. 2016). The initiative was not specifically targeted for Aboriginal patients but included a large number due to the population characteristics of the geographical area. The evaluation for this initiative included clinical outcomes, patient's satisfaction, and attendance records. The evaluation was effective from all three measurements. There was lower mortality for the teleconferencing group (4.5 cases per 100 patient years vs. 5.3 per 100 patient years). Patients reported a high level of satisfaction with 98 per cent of patients preferring the teleconferencing method. Finally attendance improved and none of the Aboriginal patients from one area presented at the hospital after the introduction of teleconferencing clinics (Venuthurupalli et al. 2016).

3.6.2. Cancer care

Each of the five initiatives involving cancer care used quite different initiatives, a *Cancer Healing Messages* flip chart (Bierbaum et al. 2017), communication/cultural safety workshops (Durey et al. 2017), extended model of care (Ivers et al. 2019), specialist video consultation outreach (Mooi et al. 2012) and cross-cultural collaboration and relationship building (Zubrzycki, Shipp & Jones 2017). Three studies sought only health professional evaluation (Bierbaum et al. 2017; Durey et al. 2017; Zubrzycki, Shipp & Jones 2017) and were assessed as having mixed efficacy. Staff reflected that the *Cancer Healing Messages* flipchart and associated training was useful, but highlighted that the format, structure and availability did not always meet their needs and was not relevant for later stages of the cancer journey after treatment had commenced, and was too simplified for some clients (Bierbaum et al. 2017). Health professionals in the communication and cultural safety workshops gave mixed evaluation due to overall positive feedback in relation to critical reflection and communication, but recognition that changes need to be studied over time to show real improvement and changes (Durey et al. 2017). Similarly, cross-cultural collaboration and relationship building (Zubrzycki, Shipp & Jones 2017) showed some improvements, but tension and conflict were also found to be an integral part of collaborations and relationships and trust need to be built over time.

Two of the studies sought feedback from both a patient and health professional perspective (Ivers et al. 2019; Mooi et al. 2012) and were found to be effective from both of these perspectives. Reasons cited include being based at an Aboriginal health services and enabling care to be closer to patient's homes and families.

3.6.3. Diabetes, Emergency Department, General Hospital

Another initiative to be evaluated by health professionals alone involved a patient education resource, '*Feltman*' for diabetes education (Xu et al. 2018). This received mixed responses of efficacy due to being very useful for group and interactive education, but too large to use in smaller rooms with patients one on one (Xu et al. 2018) and difficult to transport.

One initiative was a continuous quality improvement program that sought to create culturally safe emergency departments for Aboriginal people (Gadsden et al. 2019). This was evaluated by staff using interviews, and administrative outcomes through analysis of linked data. Although the initiative did not result in a reduction of incomplete emergency department (ED) visits, or lead to a statistically significant increase in accurate identification of Aboriginality in the records in all sites, it did lead to more accurate recording of Aboriginality in two of the eight sites. In addition, organisational changes were achieved across the EDs, including modifications to waiting areas and improved processes for identifying Aboriginal patients and managing incomplete visits. The authors warn that relying on administrative outcomes alone could be misleading; in at least one site the practice of identification of Aboriginality was already high and therefore no statistically significant change or improvement was recorded. In addition, the authors summarise that it is possible that the outcomes across the project were assessed prematurely; the system changes that they sought to achieve can take considerable time to institutionalise (Gadsden et al. 2019).

One hospital wide initiative involved promoting the role of ILOs to interns. This initiative was assessed from a health professional perspective through interviews with ILOs and interns and identified that short education opportunities have limited impact on intern's knowledge and ability to incorporate this knowledge into practice (Sinnott & Wittmann 2001).

3.6.4. Midwifery

All 10 midwifery initiatives focused on new models of care involving Aboriginal Family Birthing Practice, maternal infant care workers, extended midwifery group practice and Aboriginal and Torres Strait Islander maternity services.

Eight of these studies included evaluation from the recipients of care – the Aboriginal and Torres Strait Islander women who attended the services (Bertilone et al. 2017; Hartz et al. 2019; Hickey et al. 2019; Josif et al. 2014; Kildea et al. 2018; Kildea et al. 2012; Middleton et al. 2017; Stamp et al. 2008). All eight studies indicated that the women clearly appreciated the care provided, expressing their preference for continuity of carer, AMIC worker, and in one study, the Grandmother employed within the team (Bertilone et al. 2017). The flexibility, outreach, transport assistance, cultural safe and holistic care and equitable approach enabled women who were/ would have experienced difficulty in accessing care to remain engaged throughout their pregnancies.

Evaluation from health professionals were sought in eight of the maternity studies. Two focused on workforce and the creation of culturally safe teams and respectful two-way clinical-cultural learning between Aboriginal and non-Aboriginal health professionals within Aboriginal and Torres Strait Islander maternity services (Hartz et al. 2019; Stamp et al. 2008). Staff in these studies found that partnerships between midwives and Aboriginal maternity infant care workers worked well within their model of care, but roles of Aboriginal workers were sometimes poorly understood by other practitioners. In the remaining six studies, all studies were evaluated as effective by health professionals, but in three studies, specific issues related to mixed understanding of cultural safety between staff within the program (Hickey et al. 2019) operational and physical challenges as well as

enablers, and the AMIC role poorly understood in some sites (Middleton et al. 2017) led to these studies being assessed as having mixed efficacy form a health provider perspective.

Eight of the studies included administrative and clinical measures; five indicated efficacy linked to improved antenatal attendance (Brown et al. 2016; Josif et al. 2014; Kildea et al. 2018; Kildea et al. 2012; Murphy & Best 2012). The remaining three studies when using administrative and clinical measures show unclear or mixed improvement or benefit when compared to other cohorts of women (Bertilone et al. 2017; Hartz et al. 2019; Middleton et al. 2017). However, these three studies also identify that the women attending their clinic have significant clinical and socio-economic complexities. Middleton 2017 explains:

> *These [Aboriginal women attending AFBP services] have very complex care needs, and might well have had worse outcomes rather than outcomes similar to other patient cohorts. Nearly 70% of the women who attended AFBP services were classified as living in areas with the greatest level of disadvantage. Given the apparent higher level of vulnerability of women attending the AFBP services, the fact that fewer women attending the AFBP experienced adverse birth outcomes (although not reaching statistical significance) suggests that the program is both reaching out to women with the greatest need, and providing care that may be promoting better outcomes for this group of women. Improving the routinely collected data and monitoring over a longer period will be required in order to draw stronger conclusions regarding the impact of the AFBP services on maternal and infant outcomes over time.* (Middleton et al. 2017 p.26)

These studies highlight the challenges, considerations and contextualising required when using administrative and clinical data to measure effectiveness of initiatives.

3.7. Healthcare action framework – addressing racism

The following table analyses the 20 papers in relation to addressing racism to improve healthcare outcomes, using Bourke et. al.'s Healthcare action framework for Aboriginal and Torres Strait Islander people (see table below and figure on next page) (Bourke et al. 2020).

Table 9: Peer reviewed literature: analysis using healthcare action framework for Aboriginal and Torres Strait Islander people

	Initiative	NSQHS					Reducing institutional racism				Race discrimination law				Cultural safety		
		Identification	Monitoring S&Q	Address specific needs	Working in partnership	Welcoming environment	Service delivery	Policy Implementation & comm. ref groups	Financial Accountability	Inclusion in Governance	Policy or practice disadvantage workers	Policy or practice disadvantages patients	Special measures to achieve equality-	Interpersonal racism	Indigenous employment & Workforce	Decolonising practice	Recognising power inequity
Cancer	Bierbaum 2017						X										
	Durey 2017						X										
	Ivers 2019				X		X	X									
	Moori 2012					X	X										
	Zubrzycki, 2017				X		X			X					X		
Diab	Xu 2018						X										
ED	Gadsden 2019	X	X		X		X	X									
Gen	Sinnott 2001						X									X	X
Maternity	Bertilone 2017				X		X	X									X
	Brown 2016				X		X			X					X		
	Hartz 2019				X		X		X		X				X		
	Hickey 2019				X	X	X								X	X	
	Josif 2014	X				X	X										X
	Kildea 2012	X	X			X	X								X		
	Kildea 2018				X		X			X					X	X	X
	Middleton 2017		X		X		X										
	Murphy 2012				X		X			X					X		
	Stamp 2008					X	X			X					X	X	X
Renal	Conway 2013					X	X										
	Venuthurupalli 2016 & 2018						X								X		

Figure 8: Healthcare action framework for Aboriginal and Torres Strait Islander people (Bourke et al. 2020)
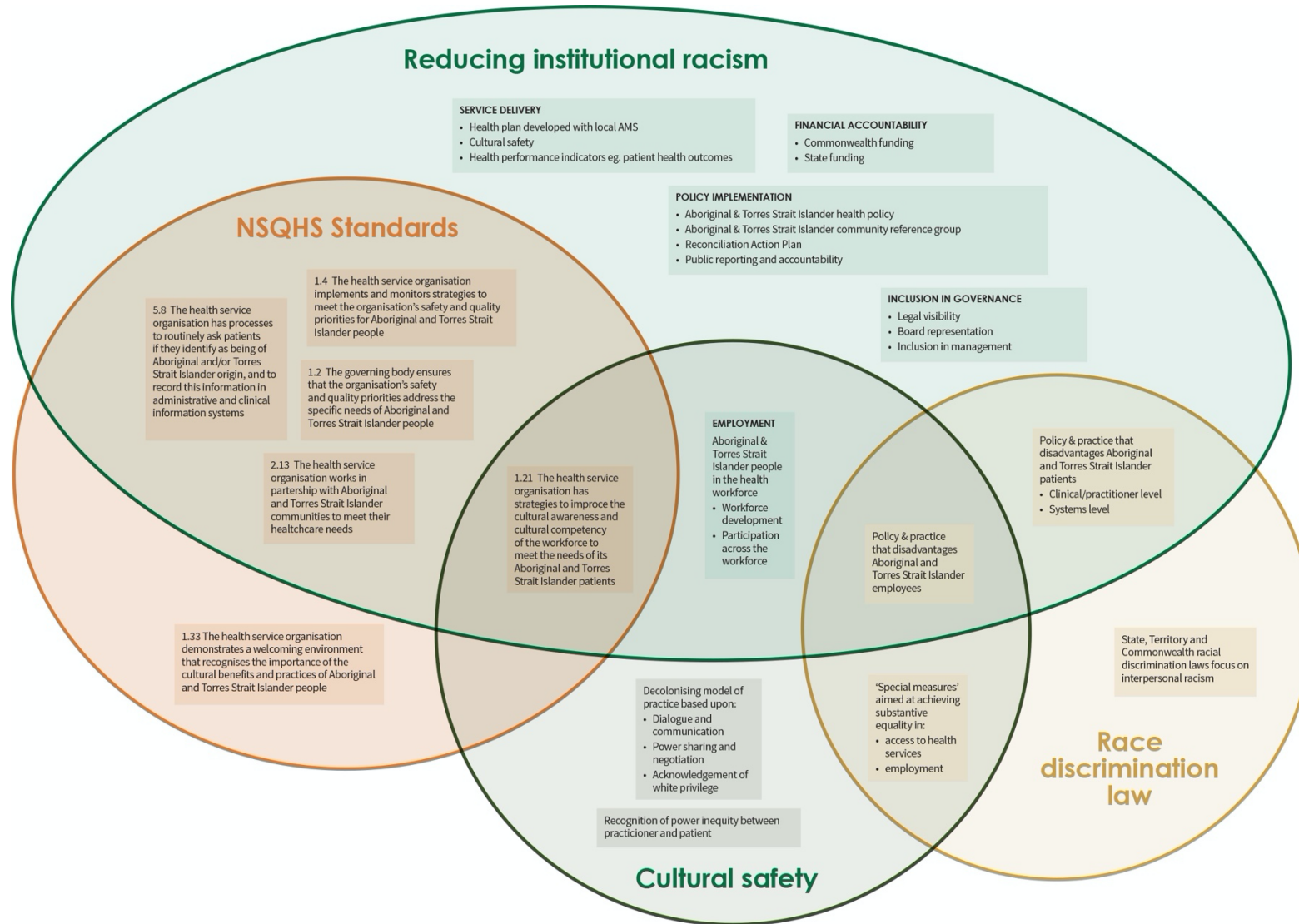
Table 10: Peer Reviewed literature: Key ENABLERS within each study initiative

Category	Initiative	Inclusion of family in care & decision making	Indigenous governance, community consultations reference groups	Patient perspective feedback	Indigenous workforce	Knowledge, skills all workforce	Two-way learning	Advocacy	Case management, referral, follow up	Collaboration with other healthcare providers	Communication, understanding and trust & transparency	Continuity of care and carer	Cultural safety & responsiveness	Flexibility	Health promotion, health education	Improving access by responding to holistic health and wellbeing socioeconomic needs	Peer support	Quality, safety, evaluation, CQI	Organisational governance, commitment, leadership mgt/management and exec & board	Policies, guidelines & standards	Physical environment	Resources & funding
		Inclusion			**Workforce**			**Service delivery, approach & models of care**											**Structures & policies**			
Cancer	Bierbaum 2017				X	X									X	X						X
Cancer	Durey 2017	X				X					X		X			X						X
Cancer	Ivers 2019	X			X			X	X	X	X	X	X	X	X	X	X		X			X
Cancer	Moori 2012	X	X	X	X	X																
Cancer	Zubrzycki 2017								X	X	X	X	X			X					X	X
Diab	Xu 2018				X	X					X	X		X	X						X	X
ED	Gadsden 2019		X		X						X		X					X	X	X	X	X
Gen	Sinnott 2001																					
Maternity	Bertilone 2017	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X
Maternity	Brown 2016		X	X	X							X	X	X	X	X		X	X			
Maternity	Hartz 2019	X	X	X	X	X		X	X	X	X	X	X	X	X	X		X	X			X
Maternity	Hickey 2019	X	X	X	X	X	X				X		X			X		X	X	X	X	
Maternity	Josif 2014				X	X	X	X	X	X	X	X	X			X				X		
Maternity	Kildea 2012				X	X			X	X	X	X	X					X		X	X	
Maternity	Kildea 2018	X	X	X	X	X		X	X	X	X	X	X	X		X		X	X	X	X	X
Maternity	Middleton 2017	X			X	X	X		X	X	X	X	X	X	X	X		X	X	X	X	X
Maternity	Murphy 2012		X	X	X				X	X			X	X	X	X		X	X	X		X
Maternity	Stamp 2018	X	X		X	X	X	X			X		X			X			X		X	X
Renal	Conway 2013	X	X	X		X	X		X	X	X	X	X	X	X	X					X	X
Renal	Venuthurupalli 2016 & 2018	X	X	X	X	X	X		X	X	X	X	X	X		X		X	X	X		X

3.8. Key enablers emerging from each study in the peer reviewed literature

The 20 studies identified key enablers that organisations used to address cultural bias. These are identified in tables 10 and 11 and are discussed in detail in this section under four main headings; Inclusion of Aboriginal and Torres Strait Islander peoples, Workforce, Service Delivery, Approach and Models of Care, and, Structures and Policies, with subheadings under each. These main headings are presented as the four domains of kidney care, with associated sub domains.

Although many of the initiatives included in this review are very different and for different conditions there are common factors across many of the effective initiatives.

Table 11: Summary of enablers to address cultural bias as identified in the peer literature

	Theme	Sub-themes	Number of studies
		Enablers – what works	
Individual	Inclusion of Aboriginal and Torres Strait Islander people	Inclusion of family in care and decision making	11
		Indigenous governance, community consultations and reference groups	11
		Patients' perspective and feedback	10
Individual/ Health Service	Workforce	Indigenous workforce	16
		Knowledge, skills and training of all workforce	14
		two-way learning	7
Health service	Service delivery, approach and models of care	Advocacy	7
		Case management, referral & follow up	11
		Collaboration with other healthcare providers	14
		Communication, understanding, trust and transparency	14
		Continuity of care and carer	13
		Cultural Safety and Responsiveness	12
		Flexibility	12
		Health promotion and health education	11
		Improving access by responding to holistic health wellbeing and socioeconomic needs	15
		Peer support	1
		Quality and safety, evaluation and CQI	10
Health systems	Structures and policies	Organisational governance, commitment, leadership and management	9
		Physical environment	5
		Policies, guidelines and standards	10
		Resources and funding	14

3.8.1. Domain 1: Inclusion of Aboriginal and Torres Strait Islander peoples

3.8.1.1. Inclusion of family in care and decision making

Eleven of the studies included key strategies for including family members in care and decision making, or discussed the importance of family being involved. Hartz et al. (2019) described a new extended midwifery and holistic care and link service and that women attending the service appreciated –

> that midwives 'understand how the family situation works, and provide an additional layer of care beyond the individualised mother's needs. (Hartz et al. 2019 p. 433)

Other maternity studies also identified the importance of being able to support the whole family (Middleton et al. 2017), and to provide women and family centred care (Kildea et al. 2018).

Actively involving family members helped to support cultural connectedness and cultural safety:

> the role of grandmothers etc. It's very good when you see the mother feeding the baby doing it the proper way for the culture…we need to learn about these things to be of assistance and in our work. I'd like more input of the Elders. (Stamp et al. 2008, p.9)

Two of the studies highlighted the importance of family being actively involved in telehealth and videoconferencing. The first provided cancer specialist video conferencing:

> Family members, Indigenous health worker (HW), nurse or local medical officer usually accompany the patient at the remote site during video consultation (VC). (Mooi et al. 2012 p.266)

The second involved renal focused telenephrology, and this study noted that *involvement of a family member or carer during the telenephrology clinic visit improved communication* (Venuthurupalli et al. 2018 p.1341) and that more than 90 per cent of consultations included a family member or carer. Family members were involved in the initial assessment, education, family meetings and decision making regarding renal replacement treatment via telenephrology before the patients attended Toowoomba Hospital for dialysis access creation.

One of the cancer studies described their new extended model of care and continuity of care, and the importance of providing support for carers and family members, and alleviating their fears and worries. This support extended beyond the time the patient was in their care:

> The CCT was able to provide counselling, in particular around the time of death, including supporting partners and children of those who had passed away. (Ivers et al. 2019 p.89)

3.8.1.2. Indigenous governance, community consultations and reference groups

A range of cultural governance models were used and discussed in 11 studies. In some, community members, including Elders, sat on steering groups within health districts, services or organisations (Bertilone et al. 2017). Others identified the importance of strong engagement with Aboriginal communities and Aboriginal Community Controlled Organisations (Gadsden et al. 2019), and of active community involvement in co-designing new models of care (Hickey et al. 2019; Kildea et al. 2018; Murphy & Best 2012; Stamp et al. 2008). Community engagement and inclusion enabled the opinions and priorities of community members for whom English is not their first language, to be included (Stamp et al. 2008).

In the study involving the dialysis bus, Elders were able to return to their communities and be actively involved in teaching the younger generation about both culture and dialysis:

> The dialysis bus enabled Elders to return home and …increased the capacity of patients to be teachers of Indigenous culture for the younger generations as well as to their nurses, nurturing shared understandings and trust. This was of particular importance to community Elders who felt they were unable to pass on valuable cultural information to the younger generations. Patients could also pass on health information to their young ones; in particular, about their dialysis stories. The children in the communities were also given the opportunity to see inside the dialysis bus and form an understanding of what dialysis is. (Conway et al. 2018 p.7)

3.8.1.3. Patients' perspectives and feedback

Many studies sought feedback from patients and clients, but most often this formal feedback occurred during the evaluation of the innovation through interviews, rather than as an integral part of the innovation. One of the maternity studies identified that –

> [t]he interviews with clients of the program and capacity to consider women's views and experiences added a depth to the evaluation that is still rare in the published literature. (Middleton et al. 2017 p.26)

Two of the studies identified that they had not sought patient feedback and that this should be a priority in future studies (Bertilone et al. 2017; Xu et al. 2018).

3.8.2. Domain 2: Workforce

3.8.2.1. Aboriginal and Torres Strait Islander workforce

The benefits of Indigenous workforce

Sixteen of the 20 studies discussed Indigenous workforce, and indicated that the inclusion of Aboriginal and Torres Strait Islander professionals in work teams was a major strength and enabled services to be more responsive, connected, welcoming and culturally safe.

Relationships and networks within communities

Studies identified the unique relationships and networks that Indigenous workers have within their communities and this can help clients/patients know about the service. Indigenous workers can be involved in active outreach in ways other health professionals cannot (Hickey et al. 2019):

> …and they all say "oh yeah my sister's you know, gonna have a baby" and so we will make contact like that and go and see them, and . . . they're okay for us to go and see them at home because they know who I am. (Bertilone et al. 2017 p.124)

> …and they hear a whisper that so and so's pregnant and we [the antenatal clinic] get to know, and we can just say bring them here on this day, and we'll get them booked in. (Bertilone et al. 2017 p.124)

Support roles

Many Indigenous workers provided a support role, such as ALOs in emergency departments:

> … to provide emotional, social and cultural support to Aboriginal patients and their families when in hospital. (Gadsden et al. 2019 p.3)

… a coordination and advocacy role for patients during videoconferencing clinics:

> *A local aboriginal liaison officer was included in the program to organise these clinics, who happens to be a great advocate for patients with renal disease.* (Venuthurupalli et al. 2018 p.1339)

…or Aboriginal Health Workers (AHWs) in maternity care:

> *…the integral role of AHW in supporting mothers' ease of access and sense of safety cannot be underestimated. One woman described this as, "so you've got the Aboriginal Worker and like… they just get it. That's the only way I could put it.* (Hartz et al. 2019 p.432)

This crucial role was recognised by both Indigenous and non-Indigenous staff in some studies:

> *Indigenous and non-Indigenous staff, in management and service delivery, all described the importance of the Indigenous workforce in ensuring cultural safety and the need to increase the Indigenous presence within the program. [The Indigenous clinician] brought tremendous cultural appropriateness of course by virtue that she was from the same group.* (Hickey et al. 2019 p.542)

Health promotion and education

Indigenous health professionals often play a key role in health promotion and education, bringing a unique approach and knowledge:

> *Women appreciated the way AMIC workers explained things, 'breaking it down' and talking 'in a way I can understand as well'.* (Middleton et al. 2017 p.24) p24

> *Health promotion is achieved through Aboriginal Health Workers using community development strategies in partnership with other agencies.* (Murphy & Best 2012 p.69)

> *The employment and adequate training of AHWs to provide culturally appropriate diabetes education is pivotal in reducing health disparities and preventing diabetes among Aboriginal people.* (Xu et al. 2018 p.496)

Role definition and complexity of roles

Many innovations involved the introduction of new Indigenous specific roles and workers. While many studies recognised the importance and benefit of including Indigenous health professionals in teams, there was also recognition of the complexity and multifaceted nature of these roles, and that at times other staff may lack understanding of these roles and where they fit into the work team (Hartz et al. 2019).

This sometimes led to a period of adjustment or difficulty with some staff struggling to incorporate this new role into patient and client care (Hickey et al. 2019; Stamp et al. 2008):

> *However, for the staff currently working within the program, there appeared to be some confusion and some contention of the roles and responsibilities between the midwives and health workers about how they best work together. For midwives who are very used to working in quite a one-to-one relationship with a woman and family. There's now another person in the mix and so working out exactly what [is] the purpose, the role, the value-add (Jenny, non-Indigenous) The midwives didn't sort of see the importance of taking a health worker out. And it was a bit sad actually, [the health worker] was sort of stuck in the office.* (Hickey et al. 2019 p.454)

One approach suggested to improve this situation was through national standardised competencies and training:

> *…the integration of this role in the tertiary setting has been challenging, due, in part, to a lack of standardised national competencies and training, although the partnership is making great improvements in this space.* (Kildea et al. 2018 p.233)

Another study specifically identified a leadership role for Aboriginal workers (Stamp et al. 2008). There was also discussion about the need to support career progression for Indigenous workers (Kildea et al. 2018)

'Responsibility' for cultural safety

Often there has been very strong reliance on sole Aboriginal health professionals to play a key role in creating safe spaces within health services, with some studies calling for increased Indigenous staff.

> *This latter issue was raised by more than half of all of the staff respondents. Sometimes, as one staff member recalled, "it is difficult to meet the cultural needs of women when there is no Aboriginal support person or health professional available to advocate for women at the interagency interface". This perceived difficulty about providing culturally safe care, was more prominent when the only Aboriginal staff member was off duty or on leave.* (Hartz et al. 2019 p.432)

But at times there can be an over reliance or assumption that Indigenous health professionals would ensure care by all staff and services was culturally safe, rather than cultural safety being a responsibility of all staff and services:

> *Non-Indigenous staff had a tendency to frame the accountability of being culturally safe practitioners to Indigenous staff. Hiring Indigenous staff was sometimes assumed to be the panacea for acquiring a culturally safe workforce.* (Hickey et al. 2019 p.454)

Indigenous workers were able to provide health information and education in ways, languages and styles that met patient and clients' needs (Bierbaum et al. 2017). In one study, the employment of Aboriginal Grandmothers into the midwifery team to incorporate long established cultural practices, education and support roles within communities:

> *One or more Aboriginal Grandmothers were employed in the program that operated within each district as part of a common core model that also employed Aboriginal Health Officers and midwives. The Grandmothers working in the AMGPP were respected local Elders whose role was to provide cultural support, pregnancy and parenting advice, advocacy, and transport.* (Bertilone et al. 2017 p.122)

3.8.2.2. Knowledge and skills of all workforce

There were two main aspects of knowledge and skills of workforce discussed: cultural knowledge and clinical knowledge.

A number of studies discussed the importance of all staff undergoing cultural awareness and cultural safety training as part of their professional development (Bertilone et al. 2017; Durey et al. 2017; Gadsden et al. 2019; Hickey et al. 2019; Kildea et al. 2018):

> *The midwives should have had a cultural awareness course… because yes clinically, they were fine. But as far as the cultural side of it, they weren't.* (Wendy, Indigenous, cited in Hickey et al. 2019 p.455)

In some studies there were opportunities to incorporate the knowledge of Indigenous staff, but this was not always utilised:

> *If the Indigenous staff were not comfortable or aware of something, they knew the culturally appropriate process to obtain that information. This skill appeared to be currently underutilised within the program. One suggestion was to design a new role specifically for a 'cultural mentor' within the program.* (Hickey et al. 2019 p.455)

This was despite the fact that:

[…n]on-Indigenous staff reported the 'cultural dimension' of their work providing maternity care to Indigenous families as an additional pressure to their clinical care, unsure of how they should operate and what they should do; in contrast to the Indigenous staff who saw it as inherent to the work and instinctive (Hickey et al. 2019 p.456)

There was also an emphasis on clinical and condition-specific training for Indigenous health professionals to enable them to undertake new roles (Bierbaum et al. 2017; Middleton et al. 2017; Mooi et al. 2012; Murphy & Best 2012; Stamp et al. 2008; Xu et al. 2018). Some of the resources such as the 'Feltman' diabetes education provided training that was:

refined with the introduction of a 'script' to guide health care practitioners when delivering a diabetes education session using Feltman. Additional 'refresher' training sessions were also offered to maintain diabetes knowledge and skills. (Xu et al. 2018 p.500)

3.8.2.3. Two-way learning

Some studies recognised the importance of two-way learning between Indigenous and non-Indigenous staff, and between long established and newer clinical roles (Hickey et al. 2019). This was particularly apparent in some of the maternity programs:

A key component of the model is the exchange of knowledge between AMIC workers and midwives, with equal weight being placed on cultural and community knowledge of the AMIC workers and clinical and medical knowledge of the midwives. (Middleton et al. 2017 p.26)

Program staff discussed the importance of working together in partnership, and the two-way learning process. Aboriginal Health Officer: … That's when [midwife] came in handy, she'd do antenatal checks at home, you know, just listening to the baby . . . and if she thought she needs to get to a doctor while we were engaging with this client, she would be on the phone ringing the surgery up saying "can we just pop in?" … [SM04] Midwife: [Aboriginal Health Officer] was such a fantastic cultural support person, you know I really value that it isn't appropriate to go house visiting as a non-Indigenous person, without having that local Aboriginal person with you. Because you help that family feel safe, culturally, and it gave me assurance that I've got [Aboriginal Health Officer's] wisdom, you know, assisting me … [SM03] (Bertilone et al. 2017 p.124)

In the renal study of the renal dialysis bus, two-way learning occurred between non-Indigenous health professionals and Indigenous patients:

Staff also described how patients were more likely to engage in conversations around their health. Staff also felt that, through shared understandings cultivated during the trips, a deeper appreciation for the dislocation that the patients have suffered meant that staff were more comfortable and understanding when caring for their Indigenous patients in the dialysis centres. (Conway et al. 2018 p.8)

And between different staff:

Not only did the experience of working on the bus improve relationships between staff and patients, but also between rural and metropolitan staff. It also helped forge mentorships between junior and senior staff. Rural and metropolitan staff worked together on trips enabling the exchange of experiences. (Conway et al. 2018 p.8)

Recognising and respecting each other's skills was crucial to good working relationships within many teams:

In relation to working in partnerships with AMIC workers clinical skill sharing and mentoring continued to be important and midwives enjoyed sharing their skills and

knowledge with the AMIC workers in equivalent working relationships. (Stamp et al. 2008 p. 73)

However, this does not happen automatically, and may not come easily to some professional staff at first:

…it goes both ways, so at the end of the day we have to keep reminding ourselves that this is AMIC worker led… and I have learned to listen. (Stamp et al. 2008 p.8)

The willingness of non-Indigenous staff to critical reflect and recognise their whiteness and the limitations of Western health systems of care was variable, with some staff very keen and engaged, and others not interested, or purposefully not engaging:

In these interviews, the power dynamic between midwife and health worker was apparent: the midwives framed midwifery care as taking precedence in this transaction with women, which was supported by institutionalised Western Scientific knowledge and responsibilities in the maternity health system and regulatory bodies and codes of practice. The Indigenous staff stressed the importance of cultural safety or cultural ways of 'doing' for the success of this program, and that community knowledge should be equally valued within the health system and community responsibilities and protocols also recognised. (Hickey et al. 2019 p.456)

Focusing on reciprocal learning without understanding power dynamics has the potential to lead to further inequalities within relationships and marginalisation of Indigenous knowledge's in mainstream healthcare settings (Hickey et al. 2019).

3.8.3. Domain 3: Service delivery, approach and models of care

3.8.3.1. Advocacy

Advocacy was identified as an enabler, described variably across studies. At times it referred to program staff advocating for a change in hospital policy (Bertilone et al. 2017):

Some hospital policies regarding contraception provision prior to discharge postpartum were successfully changed in response to advocacy from program staff. (Bertilone et al. 2017 p.125)

Indigenous staff also advocated for Aboriginal women to have their cultural needs met within health services (Hartz et al. 2019; Middleton et al. 2017):

A crucial part of the role was to advocate for Aboriginal women in a hospital setting. Sometimes a woman might feel shame or be too shy to seek the help she needed with a non-Aboriginal staff member. (Stamp et al. 2008 p.5)

Health professionals such as midwives also advocated for changes in the way the health service or program operated (Josif et al. 2014).

3.8.3.2. Case management, referral and follow up

Case management referred to both managing what was needed for patients and clients within a specialty area, and coordinating care across services and different stages of their healthcare journey:

Dedicated staff member (telehealth coordinator) to ensure efficient operation of teleoncology clinics and coordination between main centre and distant sites. (Mooi et al. 2012 p.269)

Often case management is very complex:

and those with existing or treated cancers. Frequently, these clients were also experiencing mental health problems, unstable chronic disease or were homeless. The

CCT [Cancer Care Team] was able to refer them for more intensive psychological or housing support. (Ivers et al. 2019 p.89)

Case management may become a bigger task than originally anticipated, requiring additional time and resources:

The interagency linking and social and emotional needs of women required more case management than expected, resulting in additional meetings. (Kildea et al. 2018 p.233)

The benefit of good case management for renal patients and clients is both improved outcomes, referral and follow up (Venuthurupalli et al. 2018), and case management also reduces the need for patients to tell their stories repeatedly to different providers (Kildea et al. 2012).

3.8.3.3. Collaboration with other healthcare providers

Working in partnership and collaboration with other health professionals and services, within and across healthcare and support services was another key enabler discussed in 14 of the 20 projects:

The Malabar Community Midwifery Link Service (Malabar Midwifery Service) is an exemplar of an urban model of Aboriginal maternity care that integrates multidisciplinary, holistic, wrap-around services, alongside a continuity of midwifery care model. (Hartz et al. 2019 p.428)

Collaboration is an approach to case management that improves access to available services and responds to the holistic health and wellbeing needs of patients and clients. It also supports patient journeys across health services to be more connected and streamlined:

Partnerships were integral in all districts, with program partners including local community health service providers (such as general practitioners, obstetricians, child health services, imaging services and pathology services), and providers of social services (such as relevant government agencies, and organisations providing financial or housing assistance). (Bertilone et al. 2017 p.122)

Working in collaboration was particularly important for staff and patients in visiting specialist services, as was identified in the dialysis bus initiative:

The dialysis bus always made contact with the local primary care clinic on arrival, this provided another avenue of support if required. (Conway et al. 2018 p.8)

Similarly, health professionals working in collaboration assists patients and clients from rural and remote areas when they transfer to city hospitals for care:

The quality of care provided to women who transfer to the regional centre has improved. The MGP had positively influenced maternity services and how remote dwelling women were cared for in this service. (Josif et al. 2014 p.321)

Working in collaboration enabled some health professionals and teams to encourage other health professionals to address cultural bias and improve cultural safety and responsiveness to Aboriginal and Torres Strait Islander patient needs:

Program staff working with maternity units positively influenced the degree of culturally appropriate care provided by hospital staff, as well as some community health service providers, in at least three districts. (Bertilone et al. 2017 p.125)

Many of the hospital based initiatives identified the importance of working in collaboration with local ACCHSs, particularly thos initiatives focused on emergency department care (Gadsden et al. 2019) and maternity care (Hartz et al. 2019; Kildea

et al. 2018; Kildea et al. 2012; Middleton et al. 2017; Mooi et al. 2012; Murphy & Best 2012; Stamp et al. 2008). For example:

> *Developing a multiagency Aboriginal–mainstream partnership: Successful Aboriginal–mainstream partnerships 'develop genuine, trusting relationships' between strategic organisations to address the 'complex social determinants driving poor Aboriginal health while working towards a more culturally competent model of service delivery'.* (Kildea et al. 2018 p.232)

This approach increased options for clients and staff, and ensured safety and quality of care, regardless and regardful of location and skills of individual practitioners:

> *The promotion of this shared-care model optimally delivered quality care to Indigenous cancer patients 'at their doorstep'….Formal skills training and effective communication between specialist and local HWs are essential to maintain safety of practices.* (Mooi et al. 2012 p.268)

> *We liaised with Cherbourg Hospital as well as Barambah Regional Medical Services (currently known as CRAICCHS) to actively send referrals to renal services…There was an immediate contact with the primary care physician and pharmacy to inform of any changes in care plan and medications. The NP later followed these patients in clinics locally to address any concerns or issues identified during the telenephrology session.* (Venuthurupalli et al. 2018 p.1339)

Coordination

Coordination was an important aspect of successful programs, particularly for the renal bus travelling to regional and remote areas:

> *All staff recognised the need for a dedicated bus coordinator position. This position added continuity for building and maintaining relationships between satellite units and communities, ensuring the bus visited at appropriate times.* (Conway et al. 2018 p.8)

Also for cancer and palliative care services:

> *The CCT coordinated care with palliative care services and supported palliative clients at home, in hospital and in nursing homes. The CCT developed an advanced care plan template and assisted the clients to complete them and also assisted them in making appointments to prepare wills, power of attorney and enduring guardianship.* (Ivers et al. 2019 p.89)

3.8.3.4. Communication, understanding, trust and transparency

Effective communication underpinned all interactions and initiatives. This included clear communication between healthcare providers and patents and clients that explained medical language and unfamiliar terminology and explanations of treatment and treatment options (Durey et al. 2017; Ivers et al. 2019; Kildea et al. 2012; Mooi et al. 2012):

> *Yarning was an effective way of providing health promotion advice.* (Bertilone et al. 2017 p125)

Communication was not just about getting a clinical message across, it was about building relationships and trust:

> *Appropriate verbal and non-verbal communication skills, the ability to build rapport and establish a level of mutual trust, be able to work as a team/ involve the patient's family to provide an effective level of health care.* (Durey et al. 2017 p7)

This was necessary to counter the judgemental and discriminatory attitudes Aboriginal and Torres Strait Islander patients and clients had received, and sometimes continue to receive, from some staff (Kildea et al. 2012).

Some initiatives showed that effective communication and rapport could be established using tele-and video health options involving specialists, and that additional training could assist with this process:

> HWs reported good rapport established between the patient and the specialist despite initial patient 'shyness' at first VC episode…All physicians and health staff participating in VC and the teleoncology service should undergo formal competency training in communication skills, basic operational skills for VC equipment and cultural awareness. (Mooi et al. 2012 p.268–9)

Often Indigenous health professionals were seen as a safe communication option by patients and clients:

> Women appreciated the way AMIC workers explained things, 'breaking it down' and talking 'in a way I can understand as well': 'With the AMIC worker because they were Aboriginal … I could express more to the AMIC worker than to the actual midwife and get her to pass it on.' (AFBP client cited in Middleton et al. 2017 p.24)

Patients and clients were very clear about what they valued in communication. This included having positive interactions (Hartz et al. 2019) and knowing what to expect next in their healthcare journey (Hartz et al. 2019). This helped to relive anxiety and worry for patients (Ivers et al. 2019; Kildea et al. 2012).

For some, it was also about being able to initiate communication with healthcare professionals themselves, both within, and outside of clinic appointments and interactions:

> Mothers spoke of the benefit of having 24/7 phone access to the staff at Malabar, with the sense that they could call with any questions or concerns without hesitation or fear of judgement. (Hartz et al. 2019 p.432)

Interpreters

Only a few of the studies discussed the importance of ensuring access to interpreters (Bierbaum et al. 2017; Mooi et al. 2012; Stamp et al. 2008). In some initiatives, Indigenous health professionals incorporated the role of interpreter because they spoke the same language as the patient or client (Mooi et al. 2012).

3.8.3.5. Continuity of care and carer

Thirteen studies identified the importance of continuity of care and/or carer to improve patient experiences. This enabled services to engage clients long term (Bertilone et al. 2017; Ivers et al. 2019; Middleton et al. 2017), monitor risks (Bertilone et al. 2017; Josif et al. 2014), improve outcomes (Bertilone et al. 2017; Hartz et al. 2019; Kildea et al. 2018; Kildea et al. 2012; Murphy & Best 2012; Stamp et al. 2008) and enhance cultural safety (Hickey et al. 2019).

While for many patients, having access to Indigenous staff was of high importance, for others, particularly those with high risk of complications, continuity of care was more important than cultural background of the health professional:

> Although staff considered Indigeneity to be an important feature of the Murri Clinic, their clients seemed less concerned about the Indigenous status of staff, stipulating that more important was access to the same care provider who was well qualified and experienced, with good listening skills: …
>
> - I'm more concerned about their qualifications and how much experience they've had [.. .]. I'm not really worried about whether they're Indigenous or not. (Participant- antenatal clinic client)
>
> - It's someone that's going to listen to you, then it don't matter what they look like. (Participant antenatal clinic client cited in Kildea et al. 2012 p.7)

Client from remote areas speak about the difficulty of engaging with 'different faces':

> *Lack of continuity of carer for women was described … as seeing 'different faces'. … 'you don't know what it's like for us girls to come in and have our babies and see different face every time we go up to the hospital'.* (Josif et al. 2014 p.320)

This changed drastically with continuity of carer:

> *…first and second babies no one and then I had my third one and I had my midwife.'* (Josif et al. 2014 p.320)

This midwife 'knew' the woman and her family and had an established a trust relationship (Josif et al. 2014; Kildea et al. 2012).

Some studies identified that in reality, establishing and maintaining continuity of care could be hard to achieve, particularly if it involved collaborating and coordinating across multiple agencies:

> *Combining multi-agency resources to increase continuity of carer, including during birth, culturally responsive care, Indigenous employment, capacity building, education and training is desirable, but has rarely been achieved in the area of maternity service provision.* (Kildea et al. 2012 p.1)

There were also reminder to always check patient preferences and options. In one study, patients expressed a desire for confidentiality over continuity of carer:

> *One family member reported dissatisfaction with the care provided by the medical staff at their local site … Two patients reported that it was not important to have a local doctor/nurse sit in with them at their local site during the VC.* (Mooi et al. 2012 p.267)

3.8.3.6. Cultural safety and responsiveness, and addressing racism and whiteness

This quote from the study focusing on improving emergency department care underlines the importance of addressing cultural bias and racism:

> *Providing culturally safe health care can contribute to improved health among Aboriginal people. However, little is known about how to make hospitals culturally safe for Aboriginal people. (*Gadsden et al. 2019 p.1)

> *... An Aboriginal person may choose not to identify as Aboriginal if they feel culturally unsafe in the ED, especially if they think that identifying as Aboriginal will negatively influence the quality of care they receive.* (Gadsden et al. 2019 p.4)

Patients in some studies identified that they felt safer in Aboriginal Community Controlled Health settings (Ivers et al. 2019) or in Aboriginal and Torres Strait Islander specific programs with Indigenous staff (Kildea et al. 2012; Stamp et al. 2008).

There was discussion about different approaches to increase staff knowledge and understanding of cultural safety. In the dialysis bus project, staff reflected that they had learned experientially during the trip to remote areas with patients to remote communities:

> *Many staff felt privy to meaningful cultural experiences. The cultural experience was described as far more valuable than other forms of cultural training.* (Conway et al. 2018 p.8)

This kind of approach was also suggested by Aboriginal health professionals in a study examining how to establish teams to provide cultrally safe maternity care:

> *"I reckon a weekend workshop where we go on Country with Elders and they're actually, believe it or not, sitting around a camp, I know it sounds a strange, but sitting around a campfire and talking. Talking, talking, talking (Bronwyn, Indigenous health professiona]" … This experiential learning, coupled with critical reflective practice was*

seen as more effective than book learning, with greater potential to value Indigenous knowledges as it is often how Indigenous people themselves learn about cultural protocols. (Hickey et al. 2019 p 465)

Critical reflection was identified as an important step for health professionals, to counter the tendency of staff to focus on what patient were or were not doing, rather than on their own assumptions, skills and abilities (Durey et al. 2017; Mooi et al. 2012):

Rather than participants reflecting on their own assumptions or on the impact of the organisational structure on patients' responses, [staff] participants' difficulties relating to Aboriginal patients focused more on poor communication and patient 'non-compliance' with treatment and attendance. (Durey et al. 2017 p.8)

The need for systems change to reduce racism and address healthcare disparities, rather than focusing on health providers cultural competence alone was also raised (Durey et al. 2017).

3.8.3.7. Flexibility

Twelve of the studies stressed the importance of flexible programs, services and health professionals. Built in flexibility enabled patients to access care more often in ways that meet their needs and life situation (Kildea et al. 2018; Kildea et al. 2012):

The findings show that compared with women attending mainstream regional services for pregnancy care, women attending regional Aboriginal Family Birthing Program services were twice as likely to attend their first pregnancy check up in the first trimester after adjusting for potential confounders. (Brown et al. 2016 p.138)

Sometimes flexibility extended to changing guidelines to better reflect how illnesses such as renal disease impacted and progressed for Aboriginal patients:

The [renal] program was modified to suit the specific needs of the Aboriginal population from the Cherbourg area. Referral guidelines were changed to accept them in renal clinics at earlier stages of CKD. (Venuthurupalli et al. 2018 p.1339)

The two renal studies involved outreach and flexibility of location, enabling patients from rural and remote areas could receive care closer to home, and stay or be reconnected with family, community and Country:

Patients could begin their dialysis locally (Kingaroy unit) or transferred back to the local unit quickly. (Venuthurupalli et al. 2018 p.1341)

A major benefit identified by patients was that they could safely dialyse on their homelands and avoid urgent evacuation to hospital. It gave them an alternative to returning to their communities without dialysis support. (Conway et al. 2018 p.7)

This was dependent on the flexibility of timing of trips :

The need for flexibility was identified for success of the program, both in the ability to be fluid with concepts of time and meeting points during trips, as well as flexibility in the bus's visit timetable and scheduling of trips. Examples of this flexibility includes changing scheduling to enable patients to attend funerals, or adapting to accommodation issues (e.g. one staff member had to sleep on a couch on one trip). If patients were not able to attend dialysis promptly, the timing of dialysis had to be altered - staff had to relinquish the rigidity of urban practice regimes in this setting. (Conway et al. 2018 p.9)

Working flexibly at times took considerable adjustment:

For many of the MGP midwives the 'on call' component was a potential negative …'it took a bit to get used to being on call and that feeling that the phone is going to ring at any minute … the stress of that … but I am switched off to it now'. Others found

working in MGP 'very tiring, very draining and invades your space a bit'. (Josif et al. 2014 p.321)

3.8.3.8. Health promotion and health education

Health promotion, education and prevention messages were made more effective in many of the studies through the unique approaches of Indigenous staff (Middleton et al. 2017; Murphy & Best 2012; Stamp et al. 2008). Yarning – a culturally appropriate conversations to share stories and information was often used (Bertilone et al. 2017).

In one of the renal studies, Aboriginal patient-experts and Elders took on a key role in health education about renal care, dialysis and prevention, supported by the bus and dialysis team:

> *Patients could also pass on health information to their young ones; in particular, about their dialysis stories. The children in the communities were also given the opportunity to see inside the dialysis bus and form an understanding of what dialysis is.* (Conway et al. 2018 p.7)

Two of the studies focused on new resources that had been developed to help Aboriginal health professionals provide health education of diabetes (Xu et al. 2018) and cancer care (Bierbaum et al. 2017). These were accompanied by specific training which helped Aboriginal health professionals gain skills and confidence in sharing key messages effectively.

There was also an emphasis on all staff providing clear information for patients and clients (Hartz et al. 2019; Ivers et al. 2019).

3.8.4. Improving access by responding to holistic health and wellbeing and socioeconomic needs

Many studies recognised that a key component of increasing access is responding to the holistic health, wellbeing and socioeconomic situation and needs of Aboriginal and Torres Strait Islander patients and clients.

The most common access issues were transport (Bertilone et al. 2017; Bierbaum et al. 2017; Ivers et al. 2019; Kildea et al. 2018; Kildea et al. 2012; Middleton et al. 2017; Murphy & Best 2012; Stamp et al. 2008) and accommodation (Bertilone et al. 2017; Bierbaum et al. 2017; Stamp et al. 2008).

This was particularly well understood in maternity initiatives:

> *Addressing the social determinants of health, through care coordination and referrals to partner organisations, was an essential first step for some clients before health risk factors could be addressed.* (Bertilone et al. 2017 p.127)

> *Data provided by the POU provide a sobering view of the clustering of Aboriginal women in the most socially disadvantaged areas of South Australia; nearly 70% of the women who attended AFBP services were classified as living in areas with the greatest level of disadvantage. What this means in practice for services is that it is essential to address social determinants of health.* (Middleton et al. 2017 p.25)

The difference that access to transport made was clear:

> *Women who had their own car … were also more likely to have received care in the first trimester.* (Brown et al. 2016 p.137)

Patients from rural and remote areas had specific access issues related to distance (Bierbaum et al. 2017).

Some studies included strategies of having Aboriginal health professionals accompany patients to appointments in other services as well:

> *The services offered by the CCT included assisting clients with bookings, arranging transport and accompanying clients to specialist appointments. They ensured payments for specialists via the Supplementary Services Program and the provision of subsidised or free medication under the Close the Gap program. They were able to accompany clients to initial chemotherapy and radiotherapy sessions.* (Ivers et al. 2019 p.89)

3.8.4.1. Peer support

Interestingly, peer support was only mentioned in one study. This was the cancer team approach that included a monthly yarning support group that:

> *…allowed for peer interactions between clients. The group was hosted by CCT workers to talk and to do craft, such as beading and painting, and to participate in public cancer fundraising campaigns. The program also incorporated traditional healing activities.* (Ivers et al. 2019 p.88)

3.8.4.2. Quality, safety, evaluation and continuous quality improvement

Half of the studies embedded evaluation, quality improvement and/or feedback from patients within their innovation.

This was in the form of a pre and post evaluation- of an education programs with (Durey et al. 2017) or resource and training (Xu et al. 2018).

One study outlines a continuous quality improvement program in an emergency department (Gadsden et al. 2019) that sought to improve service quality through ongoing cycles of reflection and refinement. They examined existing organisational processes and developed and tested modifications:

> *Each participating ED implemented a CQI project with a focus on working with Aboriginal people to improve the cultural safety of ED services for Aboriginal patients. Each ED employed a project officer and established a working group to lead and guide project implementation. Working group membership typically included key hospital staff, staff of Aboriginal Community Controlled Organisations and local Aboriginal community members.* (Gadsden et al. 2019 p.9)

Several of the maternity services had built in evaluation and continuous improvement strategies focused on for example clinical outcomes (Hartz et al. 2019; Kildea et al. 2012; Middleton et al. 2017) and cultural safety (Hickey et al. 2019) including through patient and staff feedback (Middleton et al. 2017).

These evaluations were used to inform immediate practice within projects, and also to measure against national and jurisdictional policies and legislation (Murphy & Best 2012). The renal video conferencing outreach project used the CKD QLD Registry to record and analyse data (Venuthurupalli et al. 2018). However, one study noted that:

> *Improving the routinely collected data and monitoring over a longer period will be required in order to draw stronger conclusions regarding the impact of the AFBP services on maternal and infant outcomes over time.* (Middleton et al. 2017 p.26)

3.8.5. Domain 4: Structures and policies

3.8.5.1. Organisational governance, commitment, leadership and management

Nine of the studies discussed the importance of organisational commitment and support and leadership form management, executives and or boards. This was often one of the factors determining whether a program was able to be successfully

implement cultural bias/safety/respect strategies or not (Bertilone et al. 2017; Gadsden et al. 2019; Middleton et al. 2017):

> *A culturally safe health system can only prevail when there is institutional and operational support to do this and a broad understanding of how to do it.* (Hickey et al. 2019 p.456)

This became clearly obvious where initiatives were implemented across a range of specific sites with varying levels of management or organisational support:

> *Staff reported supportive hospital management in three districts. These same three districts had the most evidence for improvements in cultural appropriateness of care of maternity unit staff and community health service providers in their district.* (Bertilone et al. 2017 p.125)

It could also be difficult to maintain support over time:

> *Health service managers were challenged by the need to design, implement and maintain new organisational systems to support the AFBP. 'The face-to-face meetings just aren't happening. It was all happening when we were implementing the program. It was very active, good, and now 12 months down the track, it … feels like it is not as strong … Staff [now] … have to come in their own time.'* (Health service manager cited in Middleton et al. 2017 p.25)

3.8.5.2. Physical environment

At times the physical environment became a key enabler or barrier for cultural bias strategies. A common example in maternity care was the size of rooms and waiting areas big enough to accommodation Aboriginal families, and/or enable privacy (Bertilone et al. 2017; Kildea et al. 2012; Stamp et al. 2008):

> *Male partners in particular were reported as being loathe to spend time in the waiting room, opting instead to use mainstream facilities: Yeah they (male partners) wait outside [.. .] (they) don't feel comfortable Male partners in particular were reported as being loathe to spend time in the waiting room, opting instead to use mainstream facilities: Yeah they (male partners) wait outside [.. .] (they) don't feel comfortable.* (Kildea et al. 2012 p.8)

3.8.5.3. Policies, guidelines and standards

A range of studies discussed how they used existing policies and plans to frame or support their new project and approach (Gadsden et al. 2019; Hickey et al. 2019; Mooi et al. 2012; Murphy & Best 2012):

> *Several policies and procedures are in place to improve Aboriginal peoples' experiences of emergency care in NSW, including mandatory Aboriginal cultural competency training for all hospital staff, mandatory recording of the Aboriginal status of hospital patients in information systems and a strategy for increasing and building the capacity of the Aboriginal health workforce in public hospitals, including EDs.* (Gadsden et al. 2019 p.3)

At times it was necessary to challenge, change or 'scale up' existing policies (Bertilone et al. 2017; Hickey et al. 2019; Middleton et al. 2017; Venuthurupalli et al. 2018):

> *A Reconciliation Action Plan was developed and implemented throughout the SMHS, as part of program implementation… Some hospital policies regarding contraception provision prior to discharge postpartum were successfully changed in response to advocacy from program staff.* (Bertilone et al. 2017 p.125)

> *Referral guidelines were changed to accept them in renal clinics at earlier stages of CKD.* (Venuthurupalli et al. 2018 p.1339)

3.8.5.4. Resources and funding

Resources and funding determined scope and extent of practice (Hartz et al. 2019; Ivers et al. 2019; Middleton et al. 2017; Murphy & Best 2012; Stamp et al. 2008), responsiveness of services (Bertilone et al. 2017; Kildea et al. 2018), functionality (Mooi et al. 2012; Venuthurupalli et al. 2018; Xu et al. 2018) and how frequently services such as the renal bus could operate (Conway et al. 2018):

> *The sense that the resources were being tightened as reflected by fewer trips in the most recent year was demoralising for patients who wanted more opportunities to visit their communities.. "It's really disheartening how the trips have gone from nine weeks [of the year] to only two. We just have to sit here on the machine, getting disheartened."* (Conway et al. 2018 p.6)

Conversely, there was also recognition of the benefit of the resources that were available:

> *The fact that there were three chairs on the bus was also identified by patients as a facilitator, meaning up to 12 patients could attend any one trip.* (Conway et al. 2018 p.7)

Funding was also used to support and enhance professional development opportunities (Durey et al. 2017). Two of the studies discussed specific physical health promotion resources that had been designed. These are discussed under health promotion and education above.

4. Discussion

This scoping review aims to inform the design of future initiatives to address cultural bias in health services and improve service delivery for Aboriginal and Torres Strait Islander Australians with kidney disease. It set out to answer three key questions:

1. What health service cultural bias initiatives currently exist and have been evaluated in healthcare settings in Australia for Aboriginal and Torres Strait Islander peoples?

2. What is the potential effectiveness of these initiatives in relation to outcomes such as (but not limited to) wait listing for kidney transplantation?

3. What do patient, carer/support person and provider experiences and outcomes of these initiatives reveal about the acceptability and effectiveness of existing interventions, as well as barriers and facilitators of implementation?

Enablers of successful initiatives across the grey and peer reviewed literature have been arranged under four main domains throughout this report:

- inclusion of Aboriginal and Torres Strait Islander peoples
- workforce
- service delivery, approach and models of care; and
- structures and policies.

Under each of these are sub-domains. These sub-domains are closely linked to each other, but are also important in their own right, and address specific considerations necessary for planning, implementing and evaluating effective cultural bias innovations.

4.1. Limitations

Before looking to the findings and recommendations of this scoping review, it is important to acknowledge a number of limitations. Scoping reviews, by their very nature, are exploratory and dynamic. This review contains both a well-defined systematic peer reviewed component, and a more fluid search of the grey literature, informed by healthcare experts and community consultations. This has enabled a broader understanding of cultural bias in kidney care and other healthcare settings but is also limited by the resources and time available to complete the review. We identify the following limitations:

- Cultural bias is an emerging and less clearly defined term in the Australian context. This ambiguity and fluidity was challenging for the reviewers when setting search terms, and as a result some relevant terms and concepts may have been missed. The reviewers attempted to mitigate this by using Medical Subject Headings (MeSH) headings or equivalent, and to define the term 'cultural bias' in collaboration with the working group, but it is now known that some of the potentially relevant articles did not appear in the search. For example, during the final review of this report an expert forwarded a relevant Australian cluster randomised controlled trial that did not appear in the search (Liaw et al. 2019). Upon investigation it was found that this study was not included in the original search due to the use of the term 'cultural respect' which was not one of our search terms used. It was also not identified using MeSH headings. Future studies should aim to have broader search terms to allow for the ambiguity of cultural bias as a concept.

- The final definition of cultural bias and what it entails described in this report is quite broad, as a result of extensive discussion, analysis and consideration. However, at the beginning of the study, when the search terms were being devised, a narrower definition of cultural bias was utilised. Future reviews could include a broader definition of cultural bias that includes, for example, improved access.

- The KHA-CARI and AKction community consultations included in this review are not fully representative of each jurisdiction across Australia. Although KHA-CARI intended to include Victoria and Tasmania in the consultation process, COVID-19 prevented this from occurring. We recognise that further consultations that include the needs and perspectives of Tasmanian and Victorian patients and their families and communities are needed.

- Both reviewers and the working group identified a number of cardiac care initiatives that were potentially relevant to this topic, such as the Lighthouse Project. However, these initiatives did not appear in our search. After repeated and targeted searches, it was discovered that there were no publicly available documents that identified a cardiac focused cultural bias initiative that were evaluated, peer reviewed and published. Cardiac initiatives were not included in the scope of grey literature, only renal initiatives. These search limitations and inclusion criteria remain a challenge for scoping reviews. We recognise that busy clinicians and healthcare services may indeed be carrying out cultural bias initiatives but do not have the time or resources to produce publicly available reports or write articles. There is also a time lag in publication of initiatives. We therefore recognise that innovative initiatives may be occurring but do not appear in this review.

- This is a rapidly expanding area of interest, and a number of relevant documents have been published following our literature searches. This includes the Communicate Study Group article discussing improved communication through improved hospital interpreter use and coordination (Communicate Study Group 2020). Again, this is an issue common to all literature reviews.

- A limited number of governance and organisational policy documents have been included in this review. This may be due to there being very few documents specifically targeting kidney care for Aboriginal and Torres Strait Islander people, gaps in the grey literature search strategy, or difficulty accessing organisational policy documents. We attempted to mitigate this by using the Australian Indigenous Health*Info*Net as an additional search strategy, but future reviews may seek additional methods to search organisational websites.

- In initial discussions with the working group it was decided that the peer reviewed literature should only include initiatives that had an element of tertiary care to increase the relevance to kidney transplantation. A number of potentially relevant primary care initiatives may have been missed as a result.

- There are a further seven NIKTT initiatives currently underway that aim to address inequities in transplant access and outcomes. These projects will add significantly to the evidence.

- Internationally, there is a broader body of evidence regarding cultural bias concepts, including more than 20 systematic reviews on cultural competence in healthcare since 2011 (Truong 2019). The majority of these reviews are from the United States and focus on culturally and linguistically diverse groups. Very

few refer specifically to Indigenous peoples and so were not included in this review. It is however, worth noting the overall findings of these reviews, are generally consistent with our findings, and show that:

- o health practitioners hold both implicit and explicit bias. These generally include positive attitudes towards European and white people and negative attitudes towards people of colour
- o there are limitations on the quality of the studies as most rely on self-assessment measures rather than objective measures of change
- o there is a moderate level of evidence on the effectiveness of interventions to improve health practitioners' knowledge, awareness and attitudes
- o there is weak or limited evidence on the impact of practitioner or system-level interventions to address cultural bias on patient outcomes.

When summarising this evidence at the 2019 National Indigenous Dialysis and Transplantation Conference, Truong (2019) highlighted that these findings demonstrate the importance of different and more novel methods to address the effect of bias in healthcare. These include reflective learning models for health practitioners such as cultural safety which focuses on examining health practitioners' own culture, values and bias rather than learning about the culture of 'others'; community-based participatory approaches which centre the voices of patients and communities; greater acknowledgment and focus on the organisational and systemic culture of medicine and the health system and the role of racism and privilege within it; and the need for well-designed multi-level studies to evaluate initiatives and monitor change.

4.2. A framework for planning, implementing and evaluating cultural bias initiatives

The enablers identified in the grey and peer reviewed literature in Part 2 and Part 3 of this review have been used to create a framework for planning, implementing and evaluating cultural bias initiatives. These enablers combine key elements from 1) the 20 peer reviewed studies across a range of healthcare areas, 2) renal specific examples of transplantation, dialysis and prevention/detection care, projects and priorities from across Australia and 3) the principles within the Health care action framework for Aboriginal and Torres Strait Islander people (Bourke et al 2020). This cultural bias framework is informed by an evaluation of effectiveness from a recipient of care, or health professionals or administrative and clinical data perspective, and identification of key facilitators and barriers at an individual, service and systems level.

Figure 3: The framework for planning, implementing and evaluating cultural bias initiatives
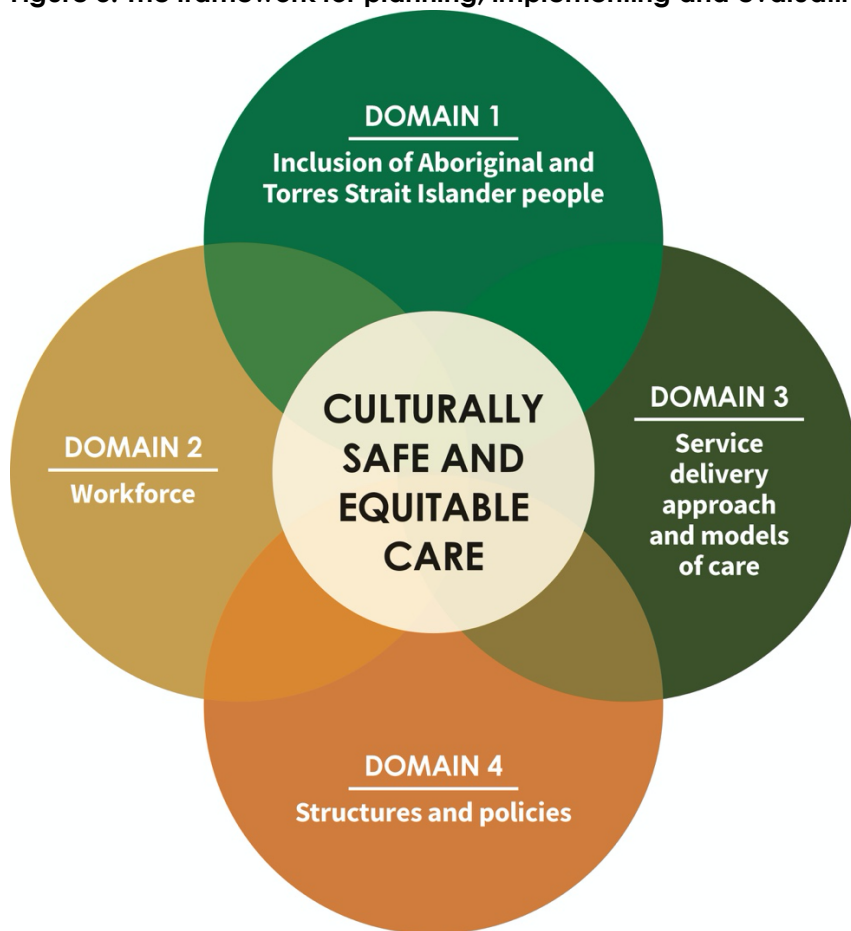

Figure 4: Framework domains and subdomains

DOMAIN 1 Aboriginal and Torres Strait Islander peoples	DOMAIN 2 Workforce	DOMAIN 3 Service delivery, approach & models of care	DOMAIN 4 Structures and policies
• Inclusion of family in care and decision making • Indigenous governance, community consultations reference groups • Patient perspectives and feedback	• Indigenous workforce • Knowledge and skills of all workforce • 2 way learning	• Advocacy • Case management, referral and follow up • Collaboration • Communication, understanding, trust and transparency • Continuity of care and carer • Cultural safety and responsiveness • Flexibility • Health promotion, education, prevention • Responding to holistic health, wellbeing and socioeconomic needs • Peer support • Quality, safety, evaluation and CQI	• Organisational governance, commitment, leadership and management • Policies, guidelines and standards • Physical environment • Resources and funding

Each of these domains and sub-domains are now synthesised and summarised, explaining why each of these aspects are important and need to be included in cultural bias initiative designs.

Domain 1: Inclusion of Aboriginal and Torres Strait Islander peoples

The inclusion of Aboriginal and Torres Strait Islander people at all levels of the health system and healthcare is central to improving outcomes and providing culturally safe and responsive care. Although cultural awareness and cultural safety training are important, alone they are not sufficient to negate institutional and interpersonal racism in healthcare services. Rather it must be recognised that Aboriginal and Torres Strait Islander people are experts in their experiences and to provide quality services they must be included in all aspects including design, implementation and care. Inclusion of Aboriginal people in the health system must operate at different levels:

1. Indigenous governance, community consultations, and reference groups
2. Patient perspective and feedback;
3. Inclusion of family in care and decision making.

It is recognised by accreditation standards and research guidelines that working in partnership with Aboriginal and Torres Strait Islander people is needed to meet their healthcare needs (NHMRC 2018; The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute 2017; Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute & Aboriginal and Torres Strait Islander Health Project Working Group 2017). This is achieved through Indigenous governance, community consultation and reference groups. Indigenous governance is important in flipping the power imbalance that exists between Indigenous and non-Indigenous groups. Indigenous governance helps to rebalance a system that has traditionally given far greater weight to the importance of colonial culture rather than Indigenous cultures. In addition, community consultations are important in understanding community needs. Co-design of services is another way of addressing power imbalance and is a step further to achieving a health system that is culturally safe.

As with Indigenous governance, patient perspectives and feedback are a central aspect of providing culturally safe and responsive care. Regular, ongoing and safe processes that enable patients to provide feedback, without fear of reprisal, and while programs and services are still underway, are critical. This may include robust and private complaint systems as well as culturally appropriate patient experience measures.

Finally, the inclusion of family members in care and decision making has been a repeated theme in community consultations and patient feedback. The Australian health system is built upon individualist Western paradigms and does not necessarily account for collective cultures and values. There are multiple benefits for patients, family members and health professionals when family members are actively involved and included in healthcare conversations, care planning and decision making (as long as this is the preference of the patient involved). Inclusion in discussions enables families to better support patients between healthcare visits, share the burden of making difficult or informed decisions, and strengthens cultural and community connectedness. It also assists health professionals to become more aware of and responsive to patient and family member's needs and priorities. Patients have reported that they often rely on family members to engage in discussions with health professionals and 'hold onto' the health information provided until they themselves are able to absorb it.

Recommendations

1. Establish Indigenous Reference Groups in every transplantation unit to help co-design culturally appropriate pathways and models of care that are tailored to the needs of Aboriginal and Torres Strait Islander transplant recipients and candidates.

2. Increase Indigenous representation on relevant kidney health advisory boards and steering groups, especially within boards and management of transplant units.

Domain 2: Workforce

Workforce changes are a key enabler to improving cultural bias in the healthcare system. This can be achieved through the employment and support of Aboriginal and Torres Strait Islander people. There is an abundance of research that has demonstrated the desire of Aboriginal and Torres Strait Islander patients to have a bigger, better supported Aboriginal and Torres Strait Islander health workforce (Hughes et al. 2017; Rix et al. 2015). There are multiple benefits of increasing the Indigenous workforce in healthcare and programs. These include strengthening relationships and networks with communities, and better incorporating and supporting clinical and cultural health needs of patients and family members. Aboriginal and Torres Strait Islander health professionals bring a depth of understanding, relationships and connectedness that enable health promotion and education to be contextualised and explained in new and more effective ways. It is important that there is both clear role definition within programs and services, as well as flexibility to grow and meet patient/client needs. There is often deep complexity within these roles; Indigenous health professionals juggle the expectations and perceptions of patients, family and community members, staff within their team, staff outside of their team, managers, and funders.

There is often a fine balance between Aboriginal and Torres Strait Islander health professionals encouraged to provide a support and advocate role for patients, and an expectation and over reliance on them to ensure cultural safety because of their Indigeneity. It is important that cultural safety and addressing racism is seen as a whole of staff and organisation responsibility.

Peer support is a growing area in kidney care, strongly advocated for and sought by Aboriginal and Torres Strait Islander reference groups and community members. The benefits of having patient navigators and other models of peer support have been discussed across Australia in community consultations. Cultural bias initiatives need to consider how peer support programs can be co-designed, initiated, resourced and supported. Similar to other Indigenous workforce roles, there needs to be a balance between clear role definition and flexibility to respond to individual patient and client needs.

The inclusion of Aboriginal and Torres Strait Islander health professionals in work teams was identified in this review as a critical factor and enabled services to be more responsive, connected, welcoming and culturally safe. Many of the evaluated cultural bias initiatives involved the introduction of new Indigenous-specific roles and workers. Concerns have been raised about the low numbers of Aboriginal and Torres Strait Islander renal health professionals across Australia. The development of

regional Aboriginal Kidney Care Coordinator positions could allow for Aboriginal and Torres Strait Islander health professionals to care for patients across their kidney journey including transplantation.

Additionally, non-Indigenous staff must be better trained and supported to work with Aboriginal and Torres Strait Islander people in a culturally safe way. This includes cultural safety training in addition to a system that supports cultural safety. The emphasis on cultural safety and competency and skill level of staff is central to improving healthcare experiences for Aboriginal and Torres Strait Islander people, but varies between programs and workplaces. There is often a tendency to focus on increasing the clinical skills of Indigenous health professionals or on the cultural awareness skills of non-Indigenous staff, rather than a focus on enhancing the cultural safety of the system and critical reflection skills of non-Indigenous staff. Cultural safety is a fundamentally different approach to cultural awareness, which involves learning about the culture of 'others'. Cultural safety on the other hand involves a critical and ongoing reflection of one's own culture, bias's and privilege and is about how care is provided. Cultural safety centres the perspective of the recipient and care and is determined and measured by the experiences of Aboriginal and Torres Strait Islander peoples. The AIHW Cultural Safety Monitoring Framework represents the beginning of measuring cultural safety across the health system however there is currently little to no data or methods available to measure cultural safety from a patient perspective, although emerging work is occurring to fill this gap (Elvidge et al. 2020).

The strongest collaborations and partnerships in cultural bias innovations involve two-way learning. There are unique two-way clinical and cultural learning opportunities within teams that can lead to strong working partnerships that are recognised and appreciated by Aboriginal and Torres Strait Islander patients and clients. Learning occurs between long established and newer clinical roles, and between experienced clinicians and experienced community members/patient-experts. It is important to recognise and address the inherent power dynamics in Western hospital settings, because focusing on reciprocal learning without understanding these power dynamics has the potential to lead to further inequalities within relationships and marginalisation of Indigenous knowledges (Hickey et al. 2019).

Recommendations

3. Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, including the development of specialised clinical roles such as Aboriginal Regional Transplant Care Coordinators, Case Managers and Health Practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).

4. Establish and fund sustainable kidney patient navigator/peer support roles in transplant units and kidney health services. These roles involve peer support from an Aboriginal and Torres Strait Islander person with lived experience of kidney disease and require long term funding.

5. Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.

Domain 3: Service delivery, approach and models of care

The rigid Australian healthcare system takes a one size fits all approach, allowing for systemic, indirect racism, often leaving Aboriginal and Torres Strait Islander people behind. To respond to the effects of systemic racism in the health system, initiatives require flexibility and holistic models of care. The current Australian healthcare system is often siloed between disciplines. Chronic conditions like kidney disease impact all aspects of a person's life and cause logistical challenges that need to be addressed beyond single medical disciplines Initiatives that do not account for thewide ranging impacts of kidney disease on a persons life are unlikely to fully address people's needs and therefore make little progress towards improving care outcomes.

Flexibility was identified as an enabler of health initiatives in this review. Flexibility of programs, services and health professionals increases responsiveness and access. Built-in flexibility enables patients to access care more often in ways that meet their needs and life situation (Kildea et al. 2012). When a health service is flexible in the type of services it provides, it can help to address the barriers that usually stop people from receiving care even if they fall outside the traditional health services. For example, two of the most common access issues are transport and accommodation. These are long standing issues that have been funded variably over time, and by different organisations and levels of government. Patients from rural and remote areas face specific access issues related to distance (Bierbaum et al. 2017). These may be addressed through additional support and alternative care models such as telehealth, video conferencing and outreach services.

Cultural safety can be addressed in two ways in a service: indirectly and directly. Addressing cultural safety indirectly includes accounting for cultural differences and making changes to the service that improve access and quality of care for Aboriginal and Torres Strait Islander people but are not specifically aimed at racism. Direct cultural safety initiatives are those that aim to specifically address racism through training that makes healthcare providers aware of the social and historical background that they operate in and a greater understanding of their own culture, so they are able to see how that impacts their practice. Cultural awareness training is not yet mandatory in all health services, cultural competency is rarely assessed, and understanding of the differences between equality and equity is variable. In contemporary Australia, whiteness and racism are still theoretical concepts that many staff in hospitals struggle to relate to, understand and incorporate into their thinking and practice. Effective cultural bias initiatives need to incorporate ways of transforming these concepts into practice at a health professional, service and systems level.

Based on self-reported efficacy measures such as patient feedback, there are a number of effective cultural bias initiatives occurring across a range of health services and health professionals. ACCHOs and Aboriginal and Torres Strait Islander programs have developed specific approaches and responses that can be adapted and adopted by Western mainstream and more bio-medically focused healthcare services. There needs to be a change in thinking and focus so that addressing cultural safety is seen as important as addressing clinical safety.

Mainstream health services are not always safe physically or emotionally for Aboriginal and Torres Strait Islander people. The non-Indigenous workforce are not always able to identify their own biases and understand the complexities that Aboriginal and Torres Strait Islander people experience in order to receive dialysis. Patient-experts around the country have described experiencing family challenges

that have made them late for dialysis but when arriving they are treated poorly for not adhering to the time constraints of the rigid health services. This rigidity is an example of cultural bias that may not occur to non-Indigenous people. Even without the additional complexities that may cause people to be delayed for their appointment, it has been argued that the concept of Western time itself is a colonial construct, built on capitalism, and is not in accordance with Indigenous cultures. This exemplifies the depth of cultural bias in the healthcare system. Indigenous cultures often value taking time to do things the right way. Aboriginal patient feedback continually brings up the issue of healthcare workers not taking proper time to care for them. Even for healthcare workers who are aware that time must be taken to build trust and rapport, they are operating in a system that does not always allow for this. In fact, if healthcare workers do adjust their methods and take more time the system may penalise them for not meeting necessary KPIs. This is demonstrative of the need for systemic rather than individual change when addressing these issues. While individual change is important, if individuals are operating in a system that is not accommodating of differences, there is no way that parity in quality of care will be achieved.

Patient-experts have continually identified that Aboriginal and Torres Strait Islander spaces are key in allowing Aboriginal and Torres Strait Islander people to feel safe in care. It is important to start to change mainstream health services but retrofitting an inherently biased system will have limited efficacy. In contrast, Aboriginal and Torres Strait Islander spaces can operate differently to mainstream services and from conception are built on an understanding of Indigenous cultures. Although in early days of operation, the Kanggawodli Hostel dialysis chairs are representative of what community have been asking for in South Australia: Aboriginal dialysis units. Aboriginal dialysis units have the potential to improve attendance of patients who have not felt safe or understood in the mainstream setting. Staff will not have to operate in a system that asks them to achieve KPIs that are not possible, and flexibility can be built into the model of care.

Improving cultural safety means understanding that the health system often does not feel safe for Aboriginal and Torres Strait Islander people. This is why it is critcial to build relationships and trust. Continuity of care and carer can help build relationships and trust as it allows patients to get to know the people who are caring for them over time. Relationships are developed through communication and trust and this must underpin all healthcare interactions and initiatives. Effective communication is not just about extracting information or getting a clinical message across; it is about building rapport and mutual trust. Respectful and effective communication is needed to counter experiences of judgemental and discriminatory attitudes and for patients and family members to feel safe, welcomed and informed. Patients place great value in transparency in healthcare communication, in unpacking confusing terms and requirements. This is particularly relevant to kidney care and transplantation work-up. Aboriginal and Torres Strait Islander health professionals and interpreters may be required to ensure patients have access to the right information, fully understand the options available   to make informed decisions. Moreover, health promotion initiatives must be communicated to patients in a way that they understand. Health promotion, education and prevention messages may become more effective through unique approaches, resources and clearer messaging that relates to patient's world views, priorities and contexts. Patients may need health messages explained more often than health professionals realise, particularly when patients are acutely unwell or away from their family and community supports. Indigenous health professionals may have greater success in working with

Indigenous patients and clients due to language, relationship and contextual factors.

One finding that emerged in the literature was the lack of kidney specific initiatives that have been evaluated with only two studies meeting our criteria. Programs that have built in quality and safety measures and incorporate effective continuous quality improvement, rather than a one-off evaluation at a particular point in time, or at the end of the program, are more likely to be effective. As with all measures for Aboriginal and Torres Strait Islander health in the mainstream health system, careful consideration of which evaluation methods are most appropriate, and from whose perspective, is required. Ideally, evaluations would be co-designed and actively involve community members and recipients of care. Clinical outcomes and administrative data may not improve rapidly as it takes time for system changes to be incorporated into practice and then be reflected in evaluation. Changes in attitudes, practice and behaviour may be difficult to measure, but are important signifiers of improvement. The lack of this published information may show a need for greater resourcing to ensure that reporting of important work being done around the country is available for more people to access.

Recommendations

6. Fund, design, implement and evaluate tailored models of care for Aboriginal and Torres Strait Islander kidney transplant recipients and candidates that:

   i.   are client and family centred, and include continuity of care;
   ii.   are based on the feedback and perspectives of patients and consistently involve family in healthcare discussions, decision making and health education;
   iii. are responsive to holistic health and wellbeing and the socioeconomic needs of Aboriginal and Torres Strait Islander peoples, including specific needs around transport, accommodation, social and emotional wellbeing and involvement of traditional healers;
   iv.   are based on partnerships and collaboration between services, especially with Aboriginal Community Controlled Health Organisations
   v.   recognise and include the role of the Aboriginal and Torres Strait Islander workforce, including establishing new roles such as Aboriginal Transplant Coordinators and Patient/Peer navigators
   vi.   include multidisciplinary pre and post-transplant teams in urban areas and outreach services in regional, rural and remote areas

   These models of care should be co-developed to address the needs of local communities and may vary across the country. They should be a means of addressing inequities in access to and outcomes from kidney transplantation and will require long term funding.

7. Expand and embed the use of telehealth and videoconferencing services for kidney transplant recipients and candidates and ensure the inclusion of Aboriginal and Torres Strait Islander health workers/practitioners (and interpreters when required) in these consultations.

8. Support and fund the further use of interpreters.

9. Co-develop specific health promotion and health education resources and approaches on kidney transplantation with Aboriginal and Torres Strait Islander people.

Domain 4: Structures and policies

Structures and policies can be either an enabler or barrier to addressing cultural bias in healthcare. At a national level, existing policy frameworks in Aboriginal and Torres Strait Islander health provide a promising and enabling agenda from which to address cultural bias in kidney transplantation. The *National Aboriginal and Torres Strait Islander Health Plan* (Australian Government Department of Health and Ageing 2013) outlines a vision for an Australian health system free of racism and inequality, and similar to the new national agreement on Closing the Gap (Coalition of Aboriginal and Torres Strait Islander Peak Organisations and all Australian Governments 2020), it emphasises principles of Aboriginal and Torres Strait Islander community control, partnership, accountability, and shared decision making.

There are also a range of other national or jurisdictional policy frameworks which further create an enabling environment for action. In many cases these frameworks have not been utilised to their full effect—for example, the AHMAC cultural respect framework released in 2017 is yet to be widely embraced—or others are very new and yet to be implemented in practice. This is the case for the new strategy for embedding cultural safety into the education and registration standards for the Australian health workforce released by AHPRA in February 2020 and the new National Safety and Quality Health Service Standards for hospitals which came into full effect in January 2019 and include six new actions specific to the care of Aboriginal and Torres Strait Islander peoples (The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute 2017). While these policies exist there is a delay to them being incorporated into practice. For example, while the new AHPRA standards exist, feedback from patients about practices such as health professional pay back indicate that there is some way to go before these standards are reliably reflected in practice.

At a national level within Aboriginal and Torres Strait Islander health, the right policy settings exist to implement new and novel approaches to address racism and cultural bias. These settings can be used to drive further action within the context of kidney care and transplantation.

Within kidney care, there are also promising initiatives that can be further built upon, particularly in the form of polices, standards and guidelines. The new national clinical guidelines for Aboriginal and Torres Strait Islander people are significantly and inherently informed by community members through community consultations (C-AIR, AKction, KHA-CARI). This is a new and welcome approach to clinical guideline development and an example of the decolonising approaches required to effect change. Reviewing and developing specific care policies and guidelines, such as these, embed long term system change and lessen dependence on individuals acting in isolation to enact change.

Despite these promising national policies frameworks and specific initiatives, policies, protocols and guidelines at varying levels across the kidney care journey can also pose known or unknown barriers for addressing cultural bias. Institutional racism audits, like those conducted in Queensland and more recently in South Australia are a potential tool for assessing existing policies and governance structures within transplantation units and kidney health services.

Through the review of the literature, organisational governance, commitment and leadership were identified as critical factors for successful implementation of cultural bias initiatives. New models of care and service delivery approaches require a high level of support and resourcing from multiple levels—within units and organisations,

across services and from funders—as well as individual champions to envision, develop and implement new initiatives. Organisational leaders need to understand the impacts of colonisation on health equality and equity and reflect on the culture of their organisations and the health system to understand the role of racism and privilege. Based on this understanding leaders and managers need to take active steps to share decision making, increase the role and representation of Aboriginal and Torres Strait Islander people in governance structures and, advocate for patients based on their needs. It takes real leadership to move people through the anxiety of racism to a place of self and organisational reflection and action.

The physical environment where patients receive care plays a significant role in determining whether patients feel welcome and safe. The physical environment needs to be functional and meet the needs of health professionals, with good levels of clinical safety and workflow, but it also needs to provide a welcoming and culturally appropriate space for Aboriginal and Torres Strait Islander patients. For example, community consultations have bought about suggestions that any hospital rebuilds could consider the needs of dialysis patients to capitalise on the views, be near to car parking (Mick-Ramsamy et al. 2019), provide single gender spaces, and provide both communal spaces and privacy.

Resources and funding ultimately determine the scope and extent of practice, responsiveness of services, functionality and if new models of care can be implemented and evaluated. Throughout the literature, long term funding was identified as critical to rolling out and sustaining any cultural bias initiatives. Recent announcements from the federal government for funding to establish the NIKTT and for Kidney Health Australia to undertake consultations with Aboriginal and Torres Strait Islander community members, health experts, service providers and peak bodies to inform the development of the KHA-CARI clinical guidelines are encouraging but need to be followed by long-term, specific and embedded healthcare funding for Aboriginal and Torres Strait Islander kidney care.

Recommendations

10. Review existing CQI processes, policies, protocols and guidelines in transplant units and kidney health services to ensure equity of access for Aboriginal and Torres Strait Islander people and safe feedback channels for Aboriginal and Torres Strait Islander people.
11. Assess institutional racism within transplant units and kidney health services using an institutional racism audit tool.
12. Develop and implement specific clinical guidelines for Aboriginal and Torres Strait Islander kidney care and evaluate their effectiveness in increasing equity of access to kidney transplantation.
13. That the Australian Government Department of Health allocate a dedicated funding stream to implement the recommendations in this report across multiple jurisdictions to increase equity of access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander Australians.
14. That the NIKTT undertake further work to assess the baseline status of these recommendations within transplant units and further develop an evaluation framework and supporting data development to monitor the implementation of the recommendations and provide public reporting.

Within the literature we analysed there were a large number of evaluated cultural bias initiatives in maternity care which arguably reflects earlier investment in this area. This highlights the time and investment which is required to effectively implement initiatives and have them evaluated.

Cultural bias and racism are deep rooted in our healthcare system. Without systemic, holistic change, inequitable and unjust outcomes will continue, regardless of individual efforts. The domains listed are all equally important to addressing cultural bias and should not be approached separately—rather, they interact and work to strengthen one another to achieve better outcomes. This should be kept in mind when designing initiatives or funding policy to address this issue. These domains aim to cover two of the three levels of racism: systemic and interpersonal. Racism can be intended or unintended, and elements such as unconscious bias and entrenched health system structures may cause services and health professionals to perpetrate racism without intent. Whether intended or unintended, the experience and impact of racism is still distressing and causes people to feel unsafe in healthcare.

Future research

Multiple studies conducted over the last 20 years have clearly identified gaps in care for Aboriginal and Torres Strait Islander peoples in kidney care and/or kidney transplantation. Many of these propose specific strategies for improvement. In order to effect change and improve kidney transplantation rates and kidney health outcomes, future research needs to focus on implementation and evaluation of effectiveness from the perspective of patients, families and communities, and on healthcare services and systems' models of care, quality improvement, guidelines and standards. Co-designed and co-created participative approaches to research, implementation and evaluation offer the greatest opportunities for the development of new models of transplantation care that meet the complex clinical and cultural care needs of Aboriginal and Torres Strait Islander people living with kidney disease.

Increasingly, research that addresses disparities and meets the needs of Aboriginal and Torres Strait Islander people is being led, informed, undertaken and evaluated by First Nations people. If this approach were supported and funded adequately within kidney care and transplantation across Australia, significant and targeted improvements in addressing cultural bias could be achieved.

4.3. Summary of recommendations

4.3.1. Recommendation MAPPING (who is responsible?)

	For transplant units and kidney health services:	Recommendations 1, 2, 3, 4, 5, 6, 7, 8, 10, 11
	National peak bodies and organisations (NIKTT):	Recommendations 2, 6, 9, 12, 14
	For governments and funders:	Recommendations 3, 4, 6, 7, 8, 13

Table 12: Summary of recommendations

No.	Recommendation
1.	Establish Indigenous Reference Groups in every transplantation unit to help co-design culturally appropriate pathways and models of care that are tailored to the needs of Aboriginal and Torres Strait Islander transplant recipients and candidates.
2.	Increase Indigenous representation on relevant kidney health advisory boards and steering groups, especially within boards and management of transplant units.
3.	Support and increase the Aboriginal and Torres Strait Islander kidney health workforce, including the development of specialised clinical roles such as Aboriginal Regional Transplant Care Coordinators, Case Managers and Health Practitioners (with ongoing recognition and support of these unique roles as a core member of the healthcare team).
4.	Establish and fund sustainable kidney patient navigator/peer support roles in transplant units and kidney health services. These roles involve peer support from an Aboriginal and Torres Strait Islander person with lived experience of kidney disease and require long term funding.
5.	Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.

6.	Fund, design, implement and evaluate tailored models of care for Aboriginal and Torres Strait Islander kidney transplant recipients and candidates that:
	
	   i. are client and family centred, and include continuity of care;
	   ii. are based on the feedback and perspectives of patients and consistently involve family in healthcare discussions, decision making and health education;
	   iii. are responsive to holistic health and wellbeing and the socioeconomic needs of Aboriginal and Torres Strait Islander peoples, including specific needs around transport, accommodation, social and emotional wellbeing and involvement of traditional healers;
	   iv. are based on partnerships and collaboration between services, especially with Aboriginal Community Controlled Health Organisations;
	   v. recognise and include the role of the Aboriginal and Torres Strait Islander workforce, including establishing new roles such as Aboriginal Transplant Coordinators and Patient/Peer navigators;
	   vi. include multidisciplinary pre and post-transplant teams in urban areas and outreach services in regional, rural and remote areas.
	
	These models of care should be co-developed to address the needs of local communities and may vary across the country. They should be a means of addressing inequities in access to and outcomes from kidney transplantation and will require long term funding.

7.	Expand and embed the use of telehealth and videoconferencing services for kidney transplant recipients and candidates and ensure the inclusion of

	Aboriginal and Torres Strait Islander health workers/practitioners (and interpreters when required) in these consultations.
8.	Support and fund the further use of interpreters.
9.	Co-develop specific health promotion and health education resources and approaches on kidney transplantation with Aboriginal and Torres Strait Islander people.
10.	Review existing CQI processes, policies, protocols and guidelines in transplant units and kidney health services to ensure equity of access for Aboriginal and Torres Strait Islander people and safe feedback channels for Aboriginal and Torres Strait Islander people.
11.	Assess institutional racism within transplant units and kidney health services using an institutional racism audit tool.
12.	Develop and implement specific clinical guidelines for Aboriginal and Torres Strait Islander kidney care and evaluate their effectiveness in increasing equity of access to kidney transplantation.
13.	That the Australian Government Department of Health allocate a dedicated funding stream to implement the recommendations in this report across multiple jurisdictions to increase equity of access to, and outcomes from, kidney transplantation for Aboriginal and Torres Strait Islander Australians.
14.	That the NIKTT undertake further work to assess the baseline status of these recommendations within transplant units and further develop an evaluation framework and supporting data development to monitor the implementation of the recommendations and provide public reporting.

5. Appendix

Table 13 includes those articles that mention patient efficacy measures and can be seen to be either effective or unclear impact. They may or may not have been included in the main report – but for now inform our writing and consideration.

Table 13: Details of cultural bias initiatives, evaluation, acceptability, effectiveness, barriers and suggestions for improvement

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
Cancer	Bierbaum, 2017 (Bierbaum et al. 2017) SA ACCHOs and PHC Statewide n =18 HPs	Cancer Healing Journey Flipcharts developed discussing diagnosis, treatment, self-care, support, accommodation, access to appointments and hospital, preparation, going home, staying healthy.	Formative evaluation - a survey of Aboriginal Health Workers using or aware of the resources.	Most of the 18 participants agreed the flip chart was valuable, culturally appropriate, explained the Aboriginal cancer patient journey, prepares patients and explains about cancer. The resources were considered useful, valuable and culturally appropriate by most participants. They reflect best practice and were available in one Indigenous language.	**Barriers:** Discrepancy between intentions to use the resources and actual uptake, which was low. Not appropriate for some patients, not available in all sites. **Suggested strategies:** Develop a long term strategy, clear implementation plan involving education, training and promotion of materials. Ongoing evaluation of effectiveness, usage and uptake.
	Durey, 2017 (Durey et al. 2017) WA Metro Tertiary n=39 HPs	Conducted workshops aimed at improving the confidence of radiation oncology health professionals in their knowledge, communication and ability to offer culturally safe healthcare to Aboriginal Australians with cancer. Facilitated by an Aboriginal and non-Aboriginal researcher.	Pre and post-workshop survey, immediately post-training workshop and two months later. Survey adapted using existing mixed methods tool for undergraduate students. 14 questions related to culturally safe practice, participant confidence, demographics, with open-ended questions.	The workshop raised awareness about barriers and enablers to delivering respectful services, led to a willingness by staff to critically reflect on their beliefs, assumptions and practice, and in some cases resulted in improved care, and a more holistic approach. Reported increased staff confidence in communication and working in partnership.	**Barriers:** Clinicians still wanted a list of dos and don'ts, highlighting the challenge of promoting cultural safety approaches instead of cultural awareness. Some staff disconnected. One-off rather than ongoing. **Suggested strategies:** Sustaining improvements may require ongoing professional development and longer term evaluation to measure sustained professional and practice change.
	Ivers 2019 (Ivers et al. 2019) NSW Metro	A multipronged approach across all stages of the disease to improve continuity of care and support between home, ACCHS/PHC and tertiary hospital	Semi-structured interviews with current clients of the cancer care team, and stakeholders (AHWs, RNs, GP care coordinator). Grounded theory	This approach led to improved access to services and increased support for families. Prevention and health promotion programs, increased resources enabled	**Barriers:** Part-time positions of staff for this pilot program. **Suggested strategies:** Trial over a longer time period with full-time or increased position. Mixed

Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
ACCHO n = 16 8 clients 8 HPs (4 Aboriginal)	settings. This included: transport, accompanying clients to investigations, appointments, diagnosis, treatment, monthly yarning support group.	analysis with emerging themes.	more time to be spent explaining processes and information and supporting clients to develop an advanced care plan, case management, increased referral to psychological and housing support and counselling.	method evaluation including using yarning methodology or Dadirri deep listening. Consideration of funding and evaluation in other locations across Australia.
Mooi 2012 (Mooi et al. 2012) QLD Regional and Remote Telehealth 9 patients 2 family members 6 HPs	Regional Cancer Centre providing specialist video consultation (VC) services to patients in rural/remote regions.	Semi-structured interviews with patients, their nominated family member/s and health workers who had accompanied them during VCs.	High levels of satisfaction from patients, families and health professionals. Telehealth reduced waiting time, cost, travel and distance from local support networks. Enhanced partnerships between local health workers and specialist teams.	**Barriers:** Health professionals needed to be adaptive to individual patient and community needs. Not all patients wanted to be accompanied by a local health provider due to privacy concerns. **Suggested strategies:** Mandatory informed consent procedures for telehealth, the presence of third parties, and recording the session; formalised cultural, and telehealth competency training for staff; clear clinical documentation and communication between sites.; promotion of telehealth as an option to overcome physician barriers.
Zubrzycki 2017 (Zubrzycki, Shipp & Jones 2017) NSW Regional Cancer Service 20 Aboriginal and 21 non-Aboriginal HPs	The Working Together project involved the development of cross-cultural working relationships to increase accessibility and utilisation of cancer services by Aboriginal people within the region. This study identified how Aboriginal and non-Aboriginal workers understand and experience cross-cultural collaboration in cancer care.	Participatory action research involving face-to-face or telephone interviews and focus groups. Analysis over four stages. 1 reference group thematically analysed interview data; 2 grounded theory-informed analysis by researchers; 3 comparing, contrasting, and merging the results 1&2 to ensure that the research findings reflected both Aboriginal and non-Aboriginal perspectives. The final stage of data analysis (Stage 4) presenting back to reference	General agreement that working well cross culturally is important. Clear emphasis by Aboriginal participants regarding the difference between consultation and collaboration, and the importance of including knowing, being and doing. Emphasis on the importance of taking time to build trust relationships, non-verbal as well as verbal communication, recognising colonisation impacts and why each worker	**Barriers:** Knowledge and actions are situated, contextualised and understood and experienced differently by Aboriginal and non-Aboriginal people. This can lead to conflict and misunderstanding. **Suggested strategies:** Building and utilising trust relationships, acknowledging location and characteristics of knowing and legitimacy of Aboriginal knowledge, support of team leaders and managers,

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
			group and participants.	approaches relationship building, care and support in the way that they do.	organisational commitment. Greater understanding of the impact of colonisation and social determinants of health. Effective and respectful strategies to work through disagreements and differing understandings.
Diabetes	Xu 2018 (Xu et al. 2018) Victoria Statewide ACCHO & PHC 18 HPs 6 *Aboriginal* and 12 non-Aboriginal	The Feltman resource kit was developed to educate patients on the disease process of diabetes that is used with individuals and groups in Aboriginal communities in Victoria.	Semi-structured interviews with health professionals who had attended the Feltman training or were using the resource in Victoria between 2010 and 2016. Content analysis resulting in three categories focusing on utilisation, tool effectiveness and barriers and challenges to use.	The 18 health professionals agreed this was a useful resource, visual and hands on that could be used to explain pathophysiology, diabetes management and complications with clients. Useful for discussing diabetes with groups, the visual and tactile nature contributes to acceptability and health literacy. It was also used as a professional development tool. The Feltman training increased staff confidence.	***Barriers:*** Large size is difficult for one-to-one and small spaces, storage challenges, one per busy organisation may not be enough, staff confidence levels, diabetes education being out of scope for their job role. ***Suggested strategies:*** A smaller more portable version, more than one kit per organisation. Develop a pregnancy focused version. Seek client feedback on effectiveness.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
Emergency Departments	Gadsden, 2019 (Gadsden et al. 2019) NSW Metro and regional Tertiary 23 HPs	Tailored strategies were developed, implemented and refined to meet the following objectives: Improving care in ED departments for Aboriginal and Torres Strait Islander people. Identification, improved cultural competence of ED and other hospital staff; Improve collaboration between the ED and Aboriginal Community Controlled Organisations; and reduce incomplete ED visits.	Mixed methods. Quantitative, multiple baseline design and secondary analysis of linked administrative health data, continuous quality improvement program assessing accuracy of recording Aboriginal status in ED information systems; incomplete ED visits; as indirect indicators of the cultural safety of ED service provision. Qualitative interviews with staff, thematic analysis.	The program did not have an overall effect on accuracy of recording identification of Aboriginality. However, organisational changes were achieved across EDs that may lead to a more welcoming and culturally safe experience. These include mandatory cultural competency training, improved referral to Aboriginal health services, the establishment of a critical incident response procedure and a performance indicator dashboard, modifications to waiting areas and processes for identifying Aboriginal patients and managing incomplete visits were improved.	***Barriers:*** Feeling culturally unsafe is the main reason Aboriginal people leave ED. ***Suggested strategies:*** Supportive hospital executive staff and high level of engagement with local Aboriginal Community Controlled Health Services and Aboriginal Liaison Officers in project design and implementation. Interventions that combine organisational change strategies with efforts to develop individual competency are more likely to be effective than stand-alone low intensity interventions.
General tertiary	Sinnott, 2001 (Sinnott & Wittmann 2001) QLD Statewide Tertiary 80 HPs 16 ALOs 64 medical interns	Promoting awareness of the role of Indigenous hospital liaison officers among new doctors, for patient support and as a source of information and resources related to Indigenous health and cultural issues for medical staff.	Semi-structured telephone interviews with Indigenous hospital liaison officers and/or medical education officers following intern orientation. Feedback via questionnaire from those attending training. Interns at the two hospitals that did not implement tier one training were surveyed and used as a comparison.	All those interviewed agreed that orientation programs involved information about Aboriginal Liaison Officers' role. Most interns self-reported their knowledge of Indigenous health and culture as less than 'fairly good'.	***Barriers:*** Few interns reported an awareness of cultural influences in clinical situations or an ability to adapt to such clinical situations. ***Suggested strategies:*** Increased training of medical practitioners in university and clinical settings to improve their responsiveness and communication skills.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
Maternity	Bertilone, 2017 (Bertilone et al. 2017) WA Metro ACCHO, PHC, and Tertiary N=53 31 Indigenous 15 staff 16 clients 22 individuals from 14 partner organisations	An expanded Aboriginal Maternity Group Practice that included Aboriginal Grandmothers, Aboriginal Health Officers and midwives working together to provide comprehensive care. Grandmothers provided cultural support, pregnancy and parenting advice, advocacy, and transport. AHOs worked with the midwife to perform home visits, organise appointments, health promotion advice and referrals. Program staff assisted clients with accommodation, financial, administrative issues through care coordination and referral to partner organisations.	The Organisational Cultural Competence Assessment Tool was used to analyse data from client surveys, staff interviews and program partner surveys.	All 16 clients surveyed stated they would recommend the program to a family member or friend. Quantitative data indicated high uptake of the program by pregnant Aboriginal women. The partnership model impacted positively on the level of culturally appropriate care provided by other health service staff, particularly hospitals. Two-way learning was increased. Improved access to care, and improved attendance throughout pregnancy, particularly for younger women. Having respected Grandmothers in the team helped support young women to make lifestyle changes. Program staff valued being able to work in partnership to provide improved continuity of care.	***Barriers:*** Institutional barriers. The same benefits were not seen across all sites. ***Suggested strategies:*** Leadership advocating change, culturally inclusive policies and practices at a hospital land health service provider level. Existing structures may not support needed changes, such as clinic rooms too small to accommodate large families. Embedding programs as standard practice (and funded) by health services.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Brown 2016 (Brown et al. 2016) SA Regional hospital 344 women 91% Aboriginal (313)	New Aboriginal Maternal Infant Care-AMIC worker position with a leadership role within maternity services; partnerships and skill exchange between AMIC workers and midwives working in the program; on-the-job training, a new formal education pathway for AMIC workers; mechanisms for community consultation and ongoing community engagement in establishment and development of local programs; a commitment to continuity of caregiver. An Aboriginal Advisory group guided the development and conduct of the study.	Structured interview or questionnaire with clients, by an Aboriginal researcher. Univariable logistic regression, multivariable logistic regression.	Women attending regional Aboriginal family Birthing program were twice as likely to have had their first visit in the first trimester, utilised the transport arranged by services to attend appointments, and had more home visits.	*Barriers:* Women who smoked, were younger, had lower health literacy were less likely to attend antenatal care. These are also the women more likely to have adverse pregnancy outcomes. *Suggested strategies:* Ensuring that services recognise the 'window of opportunity' to provide care for potentially disengaged clients and support them well. Improving equitable access by addressing system-level barriers such as transport provision and improving appointment structures, decreasing social distance between health professionals and clients, and supporting and engaging with Aboriginal families.

Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
Hartz 2019 (Hartz et al. 2019) NSW Metro Tertiary Interviews 9 women 13 HPs Service data of 505 women	The urban-based Malabar Community Midwifery Link Service integrated multidisciplinary wrap-around services alongside continuity of midwifery care for Aboriginal and Torres Strait Islander mothers and babies. Midwives provide continuity of care for women throughout their pregnancy, birth and 6 weeks postnatal. The midwives work in collaboration with an Aboriginal Health Worker and a multidisciplinary team that includes: an Aboriginal maternal and infant health worker; an obstetrician; a social worker; a child and family health nurse; and a community paediatrician. Women self-referred or referred, sometimes in parallel to specialist care.	Mixed methods. A comparative cohort study to determine differences in clinical outcomes. Primary outcome measures include the proportion of babies with: a low birth weight; women smoking after 20 weeks; preterm birth; and breastfeeding at discharge from the hospital. Qualitative analysis of: the stories (interviews) of the women who have had care with the service; and interviews with staff who had experienced working in or with the Malabar Midwifery Service over the designated time period.	Women experienced greater psychosocial complexity but were well supported. Often women were younger and had complex care needs. Mothers described the service as reassuring and informative, with good resources and knowledgeable, receptive staff who were available 24/7 via phone. Consistency of support, non-judgemental staff and continuity of care. The AHW played an integral role in helping women feel culturally safe. Staff valued being able to provide continuity of care and culturally appropriate care.	**Barriers:** Staff identified it was more difficult to provide culturally supportive care when Aboriginal staff were not on duty. It was also difficult to meet the administrative workload and reporting expectations that do not always reflect the holistic, trauma-informed work performed by the service, **Suggested strategies:** an increase in the number of Aboriginal Health Workers and a broader understanding of their role within the team, with other health services and with family and c community members. More flexible administration and reporting that reflects the model of care being provided.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Hickey, 2019 (Hickey et al. 2019) QLD Metro ACCHO & Tertiary 21 Indigenous and non-Indigenous HPs.	Women accessing new service received 24/7 case load midwifery care during pregnancy to six weeks postnatal, with Indigenous health workers and Indigenous Liaison Officers providing social-emotional, cultural and practical support during weekday business hours. Midwives and staff involved in frontline service delivery attended orientation at each of the partner organisation and an initial two-day orientation at one of the ACCHOs including a component of the social, historical and structural factors that impact the health of Aboriginal and/or Torres Strait Islander peoples. Joint clinical and cultural supervision to guide critical reflective practice initiated by an ACCHO for midwives.	Participatory action research. Semi-structured interviews with staff, thematic analysis. Findings were fed back to participants and Steering Committee and changes made to staff orientation, clinical and cultural supervision and off-site workshops.	The Indigenous health worker played an important role in ensuring the cultural safety of the service, but interviewees made it clear that cultural safety was also the responsibility of all staff. It was acknowledged that non-Indigenous staff needed to be self-reflective, understand their privilege influenced their clinical practices as well as being receptive to learning from their Indigenous colleagues.	*Barriers:* Differences were found between Indigenous and non-Indigenous staff experiences and power dynamics. Some non-Indigenous struggled with the added layer of providing culturally responsive care. Organisations were seen as both an enabler and barrier for promoting cultural safety. *Suggested strategies:* Investment in the workforce at the initial stages of team development that privilege Indigenous ways of knowing, being and doing. Four key learnings were identified as important when forming new teams aiming to be culturally safe: (a) having a shared understanding of what characterises culturally safety in the local program context; (b) understanding and valuing different roles and knowledges people bring to the team; (c) acknowledging the influence of race and culture on staff behaviour; and (d) acting on individual and organisational responsibilities for continuous improvement towards cultural safety.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Josif, 2014 (Josif et al. 2014) NT Remote Maternity clinic 14 midwives 2 AHWs 1 senior woman 34 health staff 3 other staff 12 women	Establishment of a regional maternity group practice maternity service for Aboriginal women living in Top End remote communities, involving MGP midwives, Aboriginal Health Workers, social worker, GP, specialists. Aimed to deliver a woman-centred, quality, sustainable, and culturally responsive model of care for women of all risk status. Routine pregnancy care in community, birthing in hospital, follow up in community.	A pragmatic participatory action research with mixed method design comprised of quantitative (clinical and costing data and questionnaires) and qualitative (interviews and observations thematically analysed). A more comprehensive interpretation of complex research questions by combining these.	Women reported more positive experiences and felt more welcome and safe. Continuity of carer is possible in this regional area for the first time. MGP midwives influenced the culture, and cultural responsiveness of the wider maternity services and staff. The transfer of information between the regional service and remote community health services, and the quality of care has improved. There is increased responsiveness to women's cultural needs.	*Barriers:* There was initial resistance to the new model of care by mainstream services. *Suggested strategies:* Careful attention to the dynamics between different healthcare providers and services when introducing new models of care. Purposeful strategies to build relationship, prevent or work through an 'us and them' mentality, and ensure the safety of clients/patients throughout.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Kildea 2012 (Kildea et al. 2012) QLD Metro Maternity Clinical ACCHO/PHC Tertiary 46 service users 157 HPs 17 stakeholders	A maternity and antenatal clinic for Aboriginal and Torres Strait Islander women or women have Indigenous babies. Referral to the Murri Clinic via GP, mainstream clinic or self-referral. Clinical care by a hospital-employed Indigenous midwife and a non-Indigenous obstetrician; additional support from Indigenous Liaison Officers (ILOs) who welcomed women and their families and helped them to feel comfortable, and provided support for women transferred in from rural and remote areas. The ILOs followed up women who 'failed to attend' their scheduled appointments; accompanied women to appointments, referred to support services, and performed an important 'cultural brokerage' and advocacy role, particularly for the most vulnerable women.	A triangulation mixed method was used to generate qualitative and quantitative data from a range of sources (individual and focus group interviews; surveys; mother and infant audit data; and routinely collected data (from hospital databases) gathered con-currently over a 12-month period. A retrospective analysis compared clinical outcomes of women who attended the Murri Clinic (n=367) with Indigenous women attending standard care (n=414) provided by the same hospital over the same period. Both services see women of all risk status.	The majority of women attending the Murri Clinic reported high levels of satisfaction, specifically with continuity of carer antenatally Multivariate analysis found higher normal birth (spontaneous onset of labour, no epidural, non-instrumental vaginal birth without episiotomy) rates amongst women attending the Murri Clinic. The employment of an Indigenous midwife and ILOs was well received by women and other care providers, particularly hospital staff.	*Barriers:* Some women felt abandoned and uncared for and were disappointed with the lack of continuity during labour/birth and postnatally. *Suggested strategies:* Ongoing cultural competency training for all hospital staff, reducing duplication of services, improving coordination and communication between community and tertiary services, and working in partnership with community-based providers. Combining multi-agency resources to increase continuity of carer, culturally responsive care, and capacity building, including creating opportunities for Indigenous employment, education, and training is desirable, but challenging. Empirical evidence can be used to leverage multi-agency agreements to progress goals.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Kildea, 2018 (Kildea et al. 2018) QLD Metro ACCHO and tertiary Consumers, stakeholders and community members Policy advisors	The Birthing in Our Community program provides 24/7 midwifery care in pregnancy to six weeks postnatal by a named midwife, supported by Indigenous health workers and a team coordinator. The initiative included the development of a strong partnership between maternity services and the ACCHS; oversight from a steering committee, including Indigenous governance; clinical and cultural supervision; monthly cultural education days; and support for Indigenous student midwives through cadetships and placement within the partnership.	World café workshop involving community Elders, service users, service providers and policy advisors to review services to date, suggest new strategies, models of care and staff training, and to develop partnerships. Analysis of pregnancy visit attendance and infant and maternity outcomes data compared to national trends (preterm birth, caesarean section, neonatal intensive care admissions etc.). Gap analysis to identify the role and support provided by Indigenous health workers.	Birthing on Country principles can be successfully applied to the urban context. Three years in, the partnership program is proving successful with clients, as well as showing early signs of improved maternal and infant health outcomes.	*Barriers:* Transport times, case load, successful partnerships require significant investment of time, *Suggested strategies:* Collaborative partnerships, flexibility, sharing of resources, seek further funding to develop and evaluate a new service model, streamlining processes, community involvement.

Cultural Bias Indigenous Kidney Care and Kidney Transplantation Report

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Middleton, 2017 (Middleton et al. 2017) SA Statewide ACCHO/PHC Hospital Interviews 107 HPs (20 AMIC) 20 AFBP clients	The AMIC program has been implemented in a different way in different sites. Most of the regional programs employ two part-time Aboriginal and Maternal Infant Care (AMIC) workers/trainees and one or two part-time midwives, each aiming to provide care to around 20-30 Aboriginal women per year. The three major city programs generally care for larger numbers of Aboriginal families each year. Key roles of the AMIC workers include: community engagement and promoting the program to women in the local community; health promotion and health education; advocacy on behalf of women and families; supporting women to access support for social health issues; clinical care under supervision of midwives and/or medical practitioners; supporting women in labour and birth; and supporting women with infant care and feeding in the first 6-8 weeks after birth.	Quantitative analysis of births to Aboriginal women in SA 2010-2012; interviews with health professionals and AFBP clients.	Even with greater social disadvantage and higher clinical complexity, pregnancy outcomes were similar for AFBP and other Aboriginal women. Despite challenges, the AFBP reaches out to women with the greatest need, providing culturally appropriate, effective care through partnerships.	*Barriers:* There are differing levels of commitment to the model, with some lack of clarity about AMIC workers and midwives roles. At several sites it has been difficult for program staff to establish and maintain systems to facilitate communication between health professionals responsible for antenatal care. Several sites had struggled to find a regular time for AMIC workers and midwives to meet to discuss clients. Lack of access to a common medical record. Health service managers were challenged by the need to design, implement and maintain new organisational systems to support the AFBP. *Suggested strategies:* The exchange of knowledge between AMIC workers and midwives, with equal weight being placed on cultural and community knowledge of the AMIC workers and clinical and medical knowledge of the midwives. Improved communication and collaboration between staff, teams and services, with access to shared clinical records. Increased focus on the organisational systems required to support new models of care.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Murphy, 2012 (Murphy & Best 2012) NSW Statewide ACCHO/PHC Hospital External consultants health service and outcomes data .	A continuity of care model was developed in which midwives and Aboriginal Health Workers work together to provide a high-quality maternity service. AMIHS midwives and Aboriginal Health Workers provide antenatal and postnatal care, from as early as possible after conception up to 8 weeks postpartum. The care is provided in the community but is linked into mainstream maternity services to ensure that risk management and education are available to AMIHS teams. AMIHS takes a holistic approach to Aboriginal women's health. Local programs encourage innovative community development projects to engage and empower Aboriginal women and their communities. Health promotion is achieved through Aboriginal Health Workers using community development strategies in partnership with other agencies.	Evaluation of the service by external consultants using longitudinal data collected at four time periods over 3 years. Evaluation against its goals and identification of strengths.	Aboriginal women trust and support the service provided, and rate home visiting, inclusion of an Aboriginal Health Worker, appointment reminders and transport assistance very highly. All programs are designed in consultation and in line with local context and needs, community relationships and community and health sector expectations. Flexible service delivery and transport provision. S holistic approach to Aboriginal women's health. AMIHS takes a holistic approach to Aboriginal women's health. Local programs encourage innovative community development projects to engage and empower Aboriginal women and their communities. Health promotion is achieved through Aboriginal Health Workers using community development strategies in partnership with other agencies.	*Barriers:* Additional focus on child health needs and smoking cessation needed. *Suggested strategies:* Effective collaboration between different programs with early intervention, smooth transition of care, training and support, adequate funding, service delivery model, workforce and recruitment strategy, working with other programs and national strategies. Indigenous staff are employed, trained supported and provided opportunities for further study, including midwifery.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Stamp 2008 (Stamp et al. 2008) SA Regional ACCHO/PHC Hospital 9 HPs 5 AMIC workers 4 midwives	The Anangu Bibi Family Birthing Program aims to provide culturally focused perinatal care for Aboriginal mothers and families at two sites in regional South Australia. A birthing program was introduced in the regional towns of Whyalla and Port Augusta. The key principles, components and design of the program were: ¨ expert cultural guidance from an Aboriginal Women's Advocacy group that included Elders from language groups in and around the Spencer Gulf area ¨ Aboriginal Maternal and Infant Care (AMIC) workers in a leadership role ¨ inter-cultural partnerships and skill exchange with midwives with GP back up ¨ education and training for AMIC workers in antenatal, birthing and postnatal care, as appropriate ¨ commitment to continuity of care and primary healthcare principles.	A qualitative research methodology using semi-structured interviews with open-ended questions was used to address the research aim. The questions were developed by two Aboriginal researchers and a midwife. The AMIC workers and midwives were asked about their work role; their experience of working in inter-cultural partnerships with each other; benefits of working in this way; and their perceptions of the value of the program for mothers and babies.	The AMIC role is complex and meets a range of holistic, clinical and cultural client needs. Strong partnerships and sharing of knowledge between AMIC workers and midwives, with women increasingly trusting non-Indigenous midwives over time. Clinical and cultural safety benefits.	*Barriers:* Development of the partnership took commitment and time. There were issues initially with resistance from hospital staff and infrastructure challenges. *Suggested strategies::* Future programs should factor in the time required to build and sustain partnership relationships. Skill sharing and two-way learning engendered mutual respect. Infrastructure such as phones, desk space, appropriate clinical spaces

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
Renal	Conway 2013 (Conway et al. 2018) SA Remote Outreach 15 patients 10 nurses	The South Australian Mobile Dialysis Truck is a service which visits remote communities for one to two week periods; allowing patients to have dialysis on 'Country', reuniting them with their friends and family, and providing a chance to take part in cultural activities.	In-depth interviews were used to investigate the perspectives of staff and patients on the dialysis bus. Interviews with patients were conducted in a story-telling or 'yarning' manner. Interview questions to guide the yarn were subject to ongoing review throughout data collection.	Benefits of the service included the ability to fulfil cultural commitments, minimisation of medical retrievals from patients missing dialysis to return to remote areas, improved trust and relationships between patients and staff, and improved patient quality of life. The bus also provided a valuable cultural learning opportunity for staff. The Mobile Dialysis Truck was found to improve the social and emotional wellbeing of Indigenous patients who have had to relocate for dialysis, and build positive relationships and trust between metropolitan nurses and remote patients. The trust fostered improved engagement with associated health services.	*Barriers* to trip attendance included lower trip frequencies, ineffective trip advertisement, lack of appropriate or unavailable accommodation for staff and patients, inclement weather, staffing issues and poor patient health. Staff also relayed difficulties with additional expectations and working longer hours while feeling culturally and geographically isolated. *Suggested strategies:* Facilitators for successful trips include having adequate support and support for staff, clinical back-up and a coordinator role. This format of health service may improve cultural competencies with nursing staff who provide regular care for Indigenous patients.

	Publication details	Initiative What they did	Evaluation method	Acceptability and effectiveness	Barriers and suggestions to improve initiatives
	Venuthurupall 2016 & 2018 Qld Regional Telehealth Clinic and observational data.	Use of tele-nephrology clinics for the management of patients with chronic kidney disease in rural, regional and remote areas. Program was modified to suit the needs of the Aboriginal population of the Cherbourg area - dietitian, a diabetes educator, and a podiatrist onsite was encouraged to provide a multidisciplinary approach to patient care. An ALO was included in the program to organise clinics.	Observational registry-based study. Baseline characteristics, comorbid profiles, attendance rates, cost and distance calculations, patient preference/acceptability, family involvement, continued involvement in initiative, clinical outcomes.	An innovative approach using telehealth, NP clinics and opportunistic co-habitation by allied health workers captured a vulnerable population, with improved clinic attendance, multi-disciplinary care and review at earlier stages of CKD. This allowed provision of education and preparation of RRT with planned access creation.	***Barriers*** to many Aboriginal people are reluctant to attend specialist clinics, due to remoteness, cultural issues, perceived racism and transport concerns leading to delayed presentation and poor clinical outcomes. ***Suggested strategies:*** Change in guidelines to accept patients with earlier stages of CKD. O CKD nurse practitioner as direct contact person and coordinator, onsite multi-disciplinary care, specialist review via telehealth. Local Aboriginal Health Workers to provide support and advocacy.

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