RECOMMENDATIONS FOR CULTURALLY SAFE AND CLINICAL KIDNEY CARE FOR FIRST NATIONS AUSTRALIANS

CARI GUIDELINES
CARING FOR AUSTRALIANS & NEW ZEALANDERS WITH KIDNEY IMPAIRMENT

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Digital version of the guideline available online

Developed in partnership with:

Kidney Health Australia

FLOW & THRIVE

Flow & Thrive represents the **landscape of living with a kidney condition.**

The design represents the **different stages** of the health journey. At times the **waters are murky and turbulent**, which is represented by the **tsunami** on the **top right** of the design, and the **mangroves** to the **top left**. The mangroves represent the **challenges** of patients moving through their varying journeys, which traverse through the rivers and into calmer seas. From the **right bottom hand corner** of the design, a **sunrise emerges**, symbolising the **strength and resilience** of those living with kidney conditions.

This design reinforces the idea that those on this journey are never alone. The boats within the river represent the **family, friends, community and support networks** that surround the patients on their wellness journey. To the **far left** of the design is a series of **lines**, which represent the **various medical practitioners** and **clinical support personnel** who **guide and support** the patient with their **ongoing expertise and care**.

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SUGGESTED CITATION

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HISTORICAL CONTEXT FOR THESE GUIDELINES

CARI Guidelines recognises the unceded land of Aboriginal and Torres Strait Islander Peoples on which this work was undertaken and developed. During the development of these guidelines, the Transplantation Society of Australia and New Zealand (TSANZ) produced a comprehensive review examining the cultural bias in transplantation in Australia and providing recommendations for improving care. The National Indigenous Kidney Transplantation Taskforce (NIKKT) was established to implement and evaluate these recommendations. Further information can be found at https://tsanz.com.au/committees/nikkt.htm. More broadly, The Uluru Statement from the Heart has been developed and considered for constitutional change in Australia. The Statement is a proposal for substantive recognition of First Nations Peoples in Australian history. Further information can be about the Uluru Statement from the Heart can be found at https://ulurustatement.org/

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Cultural safe and responsive kidney health care

Inequity and institutional racism in healthcare

a. **We recommend that health services evaluate, monitor, and act upon the institutional racism within their system by addressing all domains identified in the "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services" *(Strong recommendation).***
b. **We recommend that First Nations Reference Groups should advise kidney health services within Australia *(Strong recommendation).***
c. **We recommend removing Indigenous status as a risk factor for chronic kidney disease because the increased risk is explained by adverse social determinants of health, leading to a greater burden and progression of chronic kidney disease *(Strong recommendation).***

Ungraded statements

- Social determinants of health associated with lower kidney function among First Nations Australians include:
    - Low socioeconomic status
    - Living in a remote area
    - Housing insecurity
    - Unemployment
    - Surviving on welfare
    - Poor food security
- Institutional racism could be addressed by actively decolonising services by starting with:
    - Exercising critical reflexivity (1)
    - Enabling reciprocity
    - Transformative practice
    - Recognising and addressing power imbalances,
    - Fostering two-way communication and understanding between clinicians and patients/their families,
    - Increasing access to culturally shaped care and;
    - Increasing self-determination and empowerment of patients, families, and communities required to engage with mainstream kidney health services.
- A confidential, culturally appropriate complaints process should be established to enable patients, families, and community members to provide feedback on their experiences regarding all kidney health services in Australia.

Cultural safety

d. **We recommend that healthcare staff receive effective and responsive cultural safety training, and continuous quality improvement strategies are undertaken to address institutional racism, using tools such as the "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services" (recommendation a) *(Strong recommendation).***
e. **We recommend that First Nations Australians are a part of the design and delivery of cultural safety training for healthcare staff, which includes using Indigenous ways of knowing, being and doing, for example, informal Yarning style communication *(Strong recommendation).***

Ungraded statements

General

- First Nations Australians with chronic kidney disease and their family members should be recognised as experts in their own lives, healthcare needs and priorities.
- First Nations Australians' connection to culture and community should be actively supported, as it contributes to, and is protective for their health and wellbeing.
- Cultural, family and community commitments and priorities should be assigned equal importance to clinical care considerations for First Nations Australians.
- Culturally safe care is determined by the recipient of care.

Cultural safety training

- Providing culturally safe care is a lifelong shared commitment that involves ongoing critical self-reflection for healthcare professionals and a supportive work environment.
- Health services are responsible for mandating and delivering effective, targeted, and sustainable cultural safety training that actively addresses unconscious bias, interpersonal and systemic racism, delivered in a non-threatening and supportive workplace.
- All cultural safety training should be evaluated for effectiveness, and opportunities actively identified to improve its delivery and implementation.

Family and community centred engagement and involvement in managing chronic kidney disease

f. **We recommend that the family and community of First Nations Australians with chronic kidney disease are actively involved in all clinical appointments, according to individual preferences *(Strong recommendation).***

Ungraded statements

- Health systems should facilitate appropriate mechanisms to support family members to accompany First Nations Australians who are forced to relocate for the management of chronic kidney disease.
- Psychological and social support should be made available for family members supporting First Nations Australians with chronic kidney disease.
- Family and community should be included to support patient decision-making regarding dialysis and transplantation, in line with First Nations kinship systems and patients' preferences.

Transport and accommodation services for First Nations Australians

g. We recommend that health services develop clear pathways for ensuring transport and accommodation needs are prioritised, and options made available to patients and their family members for all healthcare interactions *(Strong recommendation).*

First Nations kidney health workforce

h. We recommend that health services aim to develop professional support for First Nations Australians with chronic kidney disease according to their needs *(Strong recommendation):*
- **First Nations nurses, allied health professionals and doctors**
- **Aboriginal Health Practitioner and/or Aboriginal Health Liaison**
- **Patient preceptors/navigators**
- **Interpreters**

Ungraded statements
- First Nations Health Practitioners should receive formal education and training in chronic kidney disease, treatment options and management.
- Further financial investment and strategic commitment to implement, evaluate and upscale a multidisciplinary, community-based First Nations health workforce is required.

Screening, and referral of chronic kidney disease

Identification of factors associated with chronic kidney disease in First Nations Australians

Ungraded statements

- An individual's susceptibility of chronic kidney disease (Figure 1):
  - Is increased by the following the factors:
    - Family history of chronic kidney disease
    - Diabetes mellitus
    - Hypertension

- Obesity
- Established cardiovascular disease
- History of acute kidney injury
- Cigarette smoking

- Additional considerations for First Nations Australians:
  - History of low birthweight
  - History of recurrent childhood infections
  - Remoteness
  - Low socioeconomic status
  - Housing insecurity and overcrowding
  - Education levels
  - Other impacts of colonisation

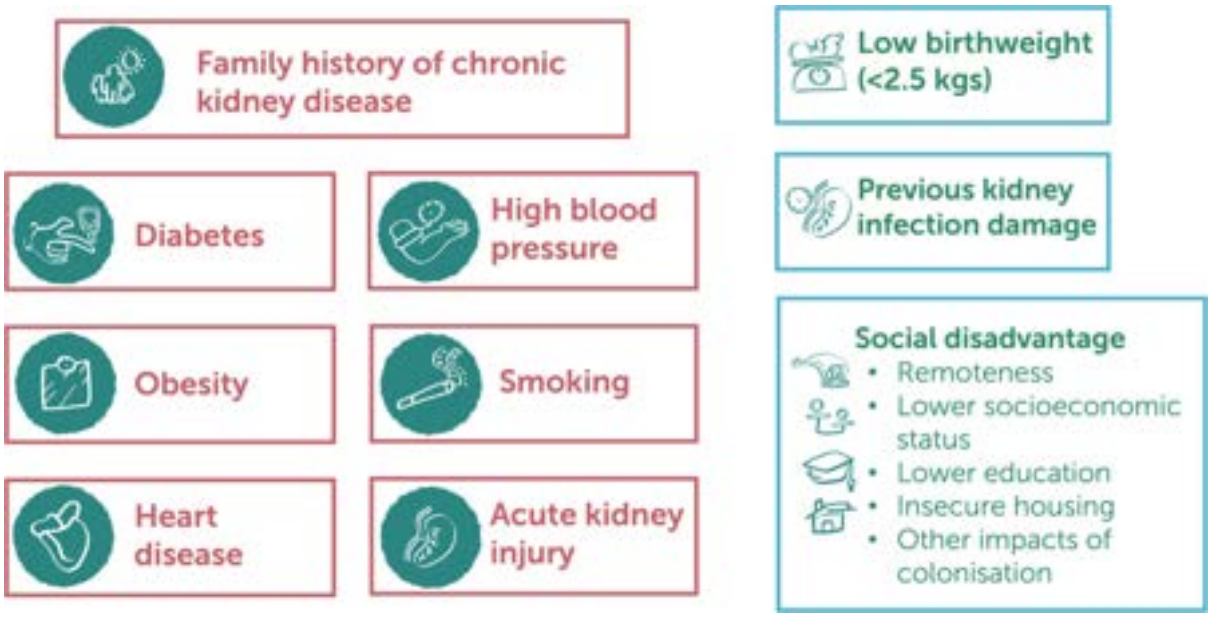

Figure 1. Factors associated with CKD among First Nations Australians

Screening and early detection programmes for chronic kidney disease among First Nations Australians

i. **We suggest that chronic kidney disease screening programmes for First Nations Australians are community-controlled, co-designed with the community, and utilise an integrated multidisciplinary approach.** ***(Conditional recommendation)***

j. **We recommend that First Nations Australians receive age-appropriate health assessments to screen for chronic kidney disease, at least annually. Including utilising the specific Medicare item number for Aboriginal and Torres Strait Islander Peoples Health Assessment (Figure 2)** ***(Strong recommendation).***

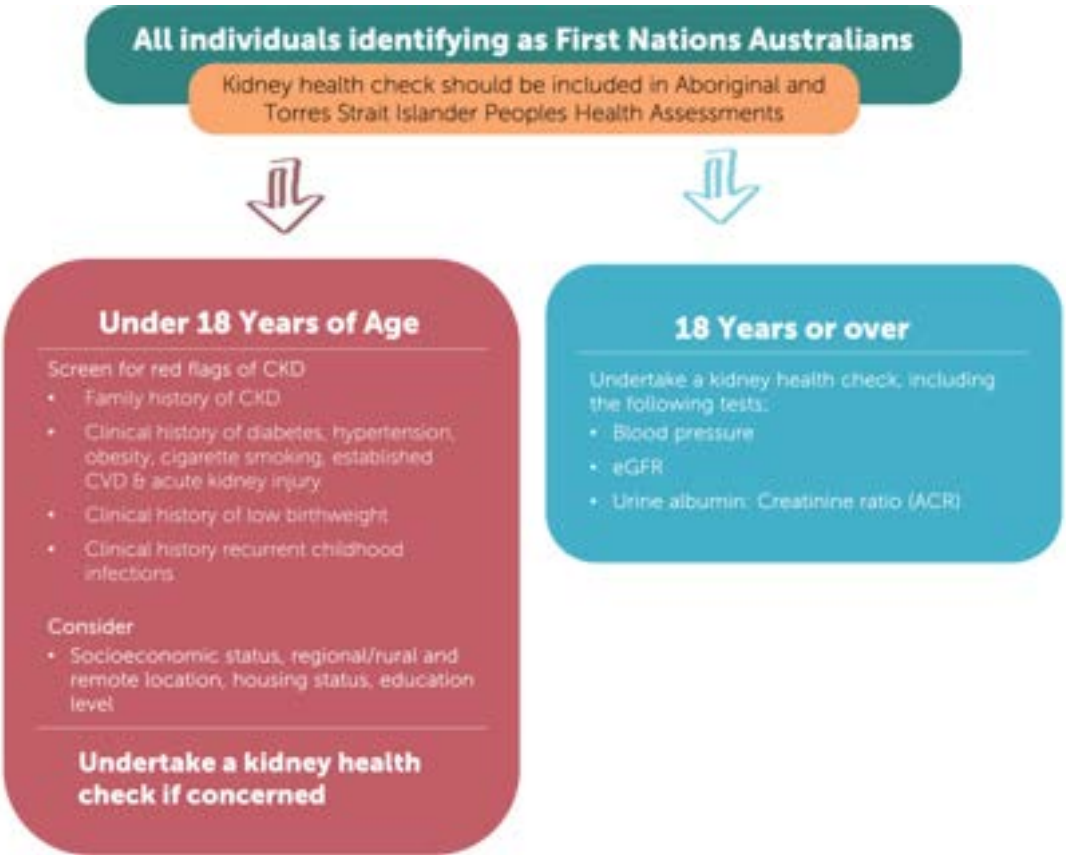

Figure 2. CKD screening matrix for First Nations Australians

Ungraded statements

- Screening for chronic kidney disease among First Nations Australians should occur at least annually.
- The measurement of a urine albumin: creatinine ratio (UACR) in a first void specimen is preferred, but a random "spot" urine specimen may be adequate when conducting opportunistic testing.
- The diagnosis of persistently elevated albuminuria by urine albumin: creatine ratio (UACR) requires at least two measurements over three months.

Referral practices for First Nations Australians with chronic kidney disease

k. We suggest referrals of First Nations Australians with chronic kidney disease to nephrologists (or specialist-supported kidney health teams) using one or more of the following criteria (Figure 3) *(Conditional recommendation):*

- **eGFR ≤45 mL/min/1.73m^2**
- **Persistent significant albuminuria >30 mg/mmol**
- **A sustained decrease in eGFR >10 mL/min/1.73m^2/ year**

- **Elevated blood pressure that is not within the target range despite at least three antihypertensive agents.**

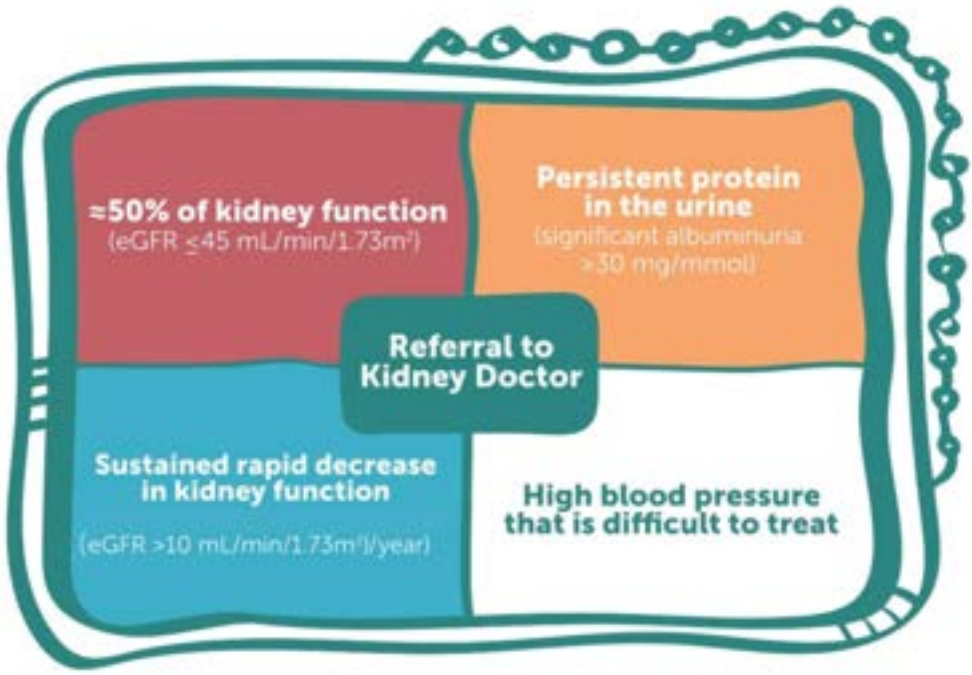

Figure 3. Referral matrix for First Nations Australians

Public awareness, education, and self-management

Public awareness – to enable First Nations Australians to access information about chronic kidney disease prior to screening and diagnosis

l. **We recommend that all health promotion and public awareness campaigns be co-designed with the community and include First Nations Australians with lived experience of chronic kidney disease *(Strong recommendation)*.**

m. **We suggest that health services co-create public health promotion tools with First Nations Australians to increase awareness of chronic kidney disease using Indigenous methods and a range of resources, including the sharing of stories in community settings *(Conditional recommendation).***

Education to support engagement and treatment

n. **We recommend that educational initiatives that facilitate engagement and self-efficacy in the management of chronic kidney disease are community-led and co-designed *(Strong recommendation).***

Ungraded statements

- Education resources and programmes should be translated and interpreted to local languages to actively address language barriers.
- Education resources and programmes should be included as part of a multifactorial approach to managing chronic kidney disease in First Nations Australians.
- Education should encompass a range of techniques and programmes, and include elements such as:
    - Yarning circles and storytelling
    - Involvement of Elders and First Nations Australians with lived experience of chronic kidney disease and family/community members supporting those with chronic kidney disease
    - Interactive lectures and videos
    - Cooking classes, shopping classes, community gardens
    - Art and music

Self-management programmes and initiatives

o. **We recommend self-management support (interventions and programmes) should be *(Strong recommendation):***
    - **Available to patients across all stages of chronic kidney disease (not exclusive to dialysis patients) and initiated upon initial engagement with healthcare services.**
    - **Ongoing and collaborative, utilise a whole-person approach, and acknowledge the roles and responsibilities of both patients and healthcare providers and the reciprocal interactions between the intra-, inter-personal and institutional domains.**
    - **Facilitate access to multidisciplinary input (including exercise physiology, psychology, dietetics, audiology, podiatry, physiotherapy, optometry, and oral health/dental services) according to the individual's needs.**

p. **We recommend that adequate, sustainable, and long-term funding models be developed and implemented to support the co-design, development, implementation and continuation of self-management and behaviour change programmes *(Strong recommendation)*.**

Ungraded statements

- Culturally appropriate self-management support is necessary for an individual's social, cultural, and emotional wellbeing. Self-management support and strategies should:
    - Be culturally safe, personalised, contextual, and holistic (social, physical, psychological, and spiritual).

- Focus on social and emotional wellbeing, including connection to Country, community, and family.
- Ensure that time and effort is taken to understand the individual and their social context, and to develop a trusting clinician-patient relationship. This relationship building should employ active listening strategies and utilise a non-stigmatising approach.
- Ensure that individual independence and autonomy are maintained.
- Include establishing peer story-sharing programmes and resources to support self-management and behaviour change across all stages of chronic kidney disease.

- Self-management programmes need to be consistent, particularly regarding the information and advice about diet and nutrition for chronic kidney disease (see CARI commentary on the KDOQI Nutrition Guidelines), and occur within a framework of First Nations food knowledge and customs. The broader elements influencing eating behaviours and food security, such as availability, accessibility, affordability, and facilities for storage and preparation, should also be acknowledged and addressed.

Models of care

Models of care in chronic kidney disease (pre-dialysis)

q. We recommend the development of dedicated programmes specific for First Nations Australians, to identify those at risk, and diagnose and manage chronic kidney disease *(Strong recommendation).*

r. We recommend that these programmes *(Strong recommendation):*

- **Are co-designed and governed by First Nations communities and embedded into existing chronic disease programmes.**
- **Are adapted to ensure they are culturally safe, tailored to the community and flexible to the changing needs of the community.**
- **Explicitly identify and address barriers to care, including (but not limited to) institutional racism, cultural, social and/or geographical barriers, transportation and/or other related healthcare costs for patients and families.**

s. We suggest maintaining clinical and medical information systems (technology, programming, documentation) according to appropriate data sovereignty principles, alongside ongoing quality improvement tools to support programme delivery, audit, and evaluation *(Conditional recommendation).*

t. We suggest programmes of care *(Conditional recommendation):*

- **Be conducted within community-controlled health services.**
- **Use a multidisciplinary approach, with program-specific healthcare workers dedicated to facilitating these programmes.**
- **Promote a culturally safe workplace culture, with built-in support for the multidisciplinary team, including (but not limited to) the provision of**

continuing education programmes, case management workshops, clinic guidelines/protocols, and online education materials.

- **Incorporate patient education and training within the programme, to increase patient and community empowerment.**
- **Use an integrated care approach when specialised nephrology services are required as part of a patient's management, including the use of telehealth services where appropriate.**

Models of care in chronic kidney disease (kidney failure)

u. **We recommend health services work in partnership with Aboriginal community-controlled health organisations (ACCHOs) to establish community-controlled models of care that address local needs and conditions, allowing First Nations Australians to have nurse-supported and Aboriginal Health Practitioner-supported dialysis on Country, particularly in remote areas *(Strong recommendation).***

v. **We recommend kidney health services incorporate dialysis services (for example, mobile dialysis) to facilitate patients to have dialysis in locations where it is not otherwise available. This service should include adequate transport, accommodation, and workforce support to ensure equity. *(Strong recommendation).***

w. **We recommend the availability of First Nations Australians specific and co-designed programmes to address the social and emotional wellbeing of people undergoing kidney replacement therapy *(Strong recommendation).***

x. **We recommend that First Nations Australians have access to dedicated multidisciplinary teams for the management of kidney replacement therapy, including, where available, First Nations doctors and nurses, Aboriginal Liaison Officers, Aboriginal Health Practitioners and/or First Nations peer navigators *(Strong recommendation).***

y. **We suggest supported home dialysis models, such as community-based home dialysis, to allow First Nations Australians to access the benefits of home dialysis *(Conditional recommendation).***

z. **We recommend kidney health services utilise telehealth/video link models to augment face-to-face care for those living and receiving dialysis in regional and remote areas *(Strong recommendation).***

Ungraded statements

- There is insufficient evidence to recommend a standard approach for vascular access choice or management. A patient-centred approach based on local practices should be adopted and undertaken.

Models of care for transplantation

Ungraded statements

- Kidney transplantation should be considered and discussed as a treatment option for all First Nations Australians with chronic kidney disease requiring kidney replacement therapy.
- There are ongoing studies regarding the most appropriate and effective models of care for transplantation that will inform the future development of guideline recommendations.

GLOSSARY

First Nations Australians: Refers to the Aboriginal and Torres Strait Islander Peoples who were the original peoples and custodians of the lands of Australia.

Community Voice *(in the context of these guidelines)*: Refers to the voices of First Nations Australians in community settings and contexts, sharing their perspectives, priorities, and preferences for how, where and why services should be provided for themselves, their families and community members with chronic kidney disease. To inform these Guidelines, community voices were gathered across a number of Indigenous Nations, States and Territories, as part of the national consultation process: Kidney Health Australia 'Yarning Kidneys' (2) and 'Catching Some Air' (3).

Country: The term often used by First Nations Peoples to describe the lands, waterways, and seas to which they are connected. The term contains complex ideas about law, place, custom, language, spiritual belief, cultural practice, material sustenance, family, and identity. On Country may refer to rural, remote, or urban settings (4).

Critical Self Reflection: Consideration of how oneself is situated within broader social and institutional contexts, and identifying assumptions that one may not have been aware of, challenging questions and issues rather than taking them at face value. Adapted from (4).

Cultural Determinants of Health: Cultural determinants originate from and promote a strength-based perspective, acknowledging that stronger connections to culture and Country build stronger individual and collective identities, a sense of self-esteem, resilience. As well as improved outcomes across the other determinants of health including, education, economic stability and community safety (5).

Cultural Safety: What is important to First Nations Australians as defined by the recipient of care. Responsive and patient centred care.
Practising cultural safety ensures that care provided is responsive and patient-centred, and acknowledges what is important to a First Nations Australian individual is defined by the recipient of care.
"Cultural safety requires healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided. In doing so, cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity. Cultural safety requires healthcare professionals and their associated healthcare organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment" (6).

Decolonisation: *"A process that begins with an understanding that one is colonised (at whatever level that may be). [Decolonisation] is creating and consciously using strategies to liberate oneself*

from [oppression]. It is the restoration of cultural practices, thinking, beliefs and values that were taken away or abandoned but are still relevant or necessary for survival…it is the birth and use of new ideas, thinking, technologies and lifestyles that contribute to the advancement and empowerment of [all people]" (7).

Family: The notion of family in First Nations Peoples culture is closely tied to themes of connectedness and kinship. It includes the various arrangements people make to ensure the young are nurtured, Elders respected, and people looked after. In this setting, family structures are pivotal to identity formation, understanding one's own spiritual and cultural belonging, and assists in establishing strong links with the community. Family and kinship are a cohesive force that binds First Nations Peoples together. With over 500 Indigenous Nations across Australia, a vast array of First Nations communities exist. These Nations are often made up of clan groups, and within these clan groups are family groups that often share a kinship system and common language (based on either patrilineal or matrilineal lines of descent). Traditionally, First Nations families were made up of a collaboration of clan groups. However, in today's terms, this is known as 'extended family' (8).

Institutional Racism: Institutional racism refers to societal systems or patterns that have the net effect of imposing oppressive or otherwise negative conditions against identifiable groups based on race or ethnicity. It may be covert or overt and resides in the policies, procedures, operations and culture of public or private institutions. It reinforces individual prejudices and is reinforced by individuals in turn (9, 10).
Institutional racism is the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping, which disadvantage minority ethnic people (11, 12).

Social Determinants of Health: The social determinants of health are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems. Social determinants of health include but are not limited to: history; racism; policy processes; poverty and social class; education; employment; social capital; food insecurity, access to health care and appropriate housing (13, 14).

Yarning: Yarning is used across Australia by many First Nations Peoples. Sometimes it refers to a comfortable conversation with a family member or friend. At other times Yarning involves a more formal conversation with a stranger, service provider or researcher, where time is taken to talk and be listened to. Lin, Green & Bessarab describe three kinds of yarns used in a health care setting to enhance communication – Social Yarn, Diagnostic Yarn, and Management Yarn. Yarning requires deep listening and being heard without interruption (15, 16).

BACKGROUND

First Nations Australians have inhabited Australia for at least 65,000 years. The colonisation of Australia has resulted in fragmentation of communities, loss of culture, violence, disease, and death. The impacts have been devastating and are still evident; colonisation is still occurring today, leading to social injustices that influence the underlying determinants (including environmental, social, and political) that result in inequitable health for First Nations Australians (17), including a disproportionate burden of chronic kidney disease. Despite the past history and ongoing f colonisation of Australia, First Nations Peoples are resilient, and their culture has continued and connects people to one another and the environment.

The circumstances in which First Nations Peoples, grow, live, work, and age impacts their health (18). Compared to non-Indigenous Australians, First Nations Australians experience lower incomes, education attainment, rates of home ownership, and higher rates of unemployment and imprisonment (19). Recent studies have reported that socioeconomic disadvantage leads to worse kidney function (20) and increased the prevalence of chronic kidney disease (CKD) among First Nations Australians (21). The burden of CKD among First Nations Australians reflects this social gradient. Those at the greatest disadvantage experience the highest incidence, prevalence, and impacts of disease (22, 23); evident in the two times higher prevalence of CKD (24) and rates up to 30 times higher in remote regions (25) and eight to nine times higher age-adjusted rates of kidney replacement therapy (26). These disparities exist despite the current absence of evidence regarding a strong genetic association (27), and thus demonstrate the impacts of ongoing social disadvantage.

The World Health Organisation recognised the importance of disadvantage with the landmark report 'Closing the gap in a generation: Health equity through action on social determinants of health' (18). The Australian Government's 'Closing the Gap' strategy aimed to address socioeconomic disadvantages and life expectancies of First Nations Australians, through equitable policy and access to primary health care. However, the Closing the Gap initiative has been widely recognised to have not met its targets, as the programmes have failed to address the social determinants that impact the health and wellbeing of individuals (28), and there has been little attention to health equity in First Nations Peoples in public policy (29). Furthermore, the 2020 Closing the Gap Report highlighted the need for a true partnership with First Nations communities, to ensure a community voice is present, in order to co-design policies and programmes that are relevant and targeted to improving health and wellbeing (30).

The impacts of historical and present-day injustices experienced by First Nations Australians affect health inequities (17). It is the role of all individuals, health care providers, researchers, consumers, and the health system to recognise the impacts of colonisation on health, and re-evaluate their assumptions and beliefs to improve care for First Nations Peoples (31).

OBJECTIVE

Scope of the guidelines

These clinical practice guidelines were developed to address the issues and inequities facing First Nations Australians identified through a targeted community consultation (2, 3, 32). The guidelines are predominantly focused on the delivery of health care, as well as the screening for and referral of chronic kidney disease (CKD) among First Nations Australians. The management of CKD among First Nations Australians is an ongoing priority for CARI Guidelines. When appropriate, future guideline development will focus on specific recommendations for First Nations Australians. For example, a targeted recommendations for First Nations People in Australia and New Zealand were developed for the Management of cholesterol-lowering therapy in people with chronic kidney disease CARI Guidelines (33).

Aim

To develop clinical practice guidelines that are targeted towards improving the clinical care for First Nations Australians with chronic kidney disease. Through the development of recommendations that enhance the equity of the health systems and improve clinicians' understanding of culturally safe kidney care provision.

COMMUNITY CONSULTATION

"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" (Pat Turner CEO, National Aboriginal Community Controlled Health Organizations, National Indigenous Dialysis & Transplantation Conference (NIDTC), Alice Springs 2019)

The guidelines have been developed in consultation with First Nations communities. The Kidney Health Australia (KHA) Yarning Kidneys (2) and Catching Some Air (3) provided an extensive purposive community consultation. The KHA Yarning Kidneys partnered with Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) to undertake consultations in South Australia (Adelaide, Ceduna, and Port Augusta) (34, 35). Consultations were conducted across metropolitan, regional, and remote areas in Australia. The process was developed using a partnership approach with First Nations Australians with three engagement strategies as detailed in Duff et al. 2018 (36) and summarised below:

1. Engaging a panel of First Nations health clinicians
2. Targeted site engagements with formal evaluation, with locally based First Nations consumers and services; and
3. Consultation and feedback from the Australian national peak organisations in First Nations Australians health

The consultations aimed to discuss what is important to First Nations Australians and their kidney health, to inform First Nations information rights and data sovereignty for the Australian clinical quality registry in kidney disease (for example, ANZDATA) (3) and identify the priorities of the First Nations Peoples with lived experience of CKD. The priorities identified in the consultations have been used to inform the scope of the clinical practice guidelines.

Planned ongoing engagement and consultation with all First Nations Australians communities throughout guideline development were interrupted by the COVID-19 pandemic. Yarning sessions occurred during 2022 with local reference groups or with local champions. The guidelines were circulated to peak national organisations and experts in kidney health in First Nations Peoples for expert peer review. All feedback was considered and discussed among the Working Group, and the guidelines were updated accordingly.

IMPLEMENTATION AND AUDIT

The KHA Yarning Kidneys Expert Clinician Panel Consultation (37) identified significant barriers to implementing guidelines. The Working Group determined that the guidelines must be delivered in culturally appropriate ways and proposed the production of resources and education tailored for First Nations Peoples and communities. The academic document will form the basis for this work. Further funding will be required to implement the guidelines and will be led by an expert group including First Nations Health Researchers, Nephrologists, Renal Nurses, and Implementation Scientists. The Working Group acknowledges that many guideline recommendations are statements relevant to the entirety of the health system, not just kidney health. People with lived experience of CKD or those caring for First Nations Australians with CKD have provided feedback on the guidelines and their perspectives on relevant content and dissemination strategies. Planned dissemination of the main guidelines messages includes presentations at annual scientific meetings and clinical unit meetings and production of video content featuring people with lived experience of CKD.

SEARCH STRATEGY AND EVIDENCE REVIEW METHODS

Clinical practice guidelines methods have traditionally been developed with a Western biomedical view of health. They have not incorporated the holistic view of health held by First Nations Australians, nor did they integrate Indigenous health research methods, such as Yarnings. These guidelines have been developed after extensive consultation with First Nations communities, ensuring that Indigenous knowledge systems are incorporated along with the general Western view of guideline development.

Targeted community consultation has informed the scope and the underpinning rationale of these guidelines. Priorities and topics identified by the community in the Catching Some Air (3) and KHA Yarning Kidneys (2) consultations were transformed into research questions, using relevant population, intervention/exposure, comparator/control, outcome, and methods (PICOM/PECOM format) by the CARI Guidelines Office (DJT & AY). The Guideline Working Group reviewed PICOM/PECOM questions and provided feedback. All PICOM/PECOM questions are listed in Table A1 in Appendix A.

The CARI Guidelines Office (DJT & AY) undertook a systematic review of the literature using medical literature databases (MEDLINE and Embase). The search was conducted from 31st March to 20th August 2021 and updated in May 2022 using Medical and Subject Headings (MeSH) terms and text words relevant for each PICOM/PECOM question. Additionally, the Australian Indigenous HealthInfoNet was searched to identify supplementary reports and literature not identified in the medical literature database search. Details of the search and screening process can be found in Figure 1 in Appendix A. A systematic review was planned and undertaken by members of the

guideline Working Group (SB, OP, MH, SJ), examining models of care for kidney failure for First Nations Peoples (PROSPERO Number (CRD42020207425)). The preliminary findings from this review have informed the development of recommendations on models of care for kidney failure (recommendation u - z). Table 2 and 3 in Appendix A provides the guideline recommendations nomenclature and implications.

Please see Appendix B for the complete search strategy underpinning the evidence review for this guideline. Included studies were identified, abstracted, and appraised by a member of the CARI Guidelines Office (DJT or AY) and then reviewed by the Guideline Working Group. All studies were summarised descriptively in Appendix C, and findings across studies were synthesised using a mixed-method synthesis approach (38). The certainty of the evidence was assessed using a combination of the conventional GRADE approach for interventions and exposures (39) and GRADE CERQual for qualitative findings (40). The Summary of Findings for the evidence review is available in Appendix D.

The evidence review findings were presented and discussed by the Guideline Working Group. The Working Group has relevant expertise in clinical nephrology, nursing, First Nations Health, lived experience of CKD, health economics, and cultural safety. Guideline recommendations were developed using an amended GRADE Evidence to Decision Framework (41). The adaptation focused on inclusion and emphasised the importance of the First Nations voice identified in the community consultation. The framework developed has been named the 'Four C's' and includes Community Voice, Clinical Evidence, Cultural Safety Considerations, and Cost, Capacity, Equity and other considerations. Further detail on the Four C's Criteria is available in Appendix A.

The final draft of the guidelines underwent targeted peer review by individual experts and peak organisations in First Nations Australians kidney health. Feedback from the First Nations communities involved in the initial community consultations (2, 3) has also been incorporated prior to guideline publication. For further details on the guideline development methods, please see Appendix A.

RATIONALE

Cultural safety and responsive kidney health care

Inequity and institutional racism in healthcare

a. We recommend that health services evaluate, monitor, and act upon the institutional racism within their system by addressing all domains identified in the "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services" *(Strong recommendation).*

Institutional racism, embedded in an organisation's processes, values, attitudes and behaviours is a cause of disparity in health outcomes even when other social and cultural determinants of health are considered (42). There has been limited scientific evidence evaluating the impact of institutional racism in CKD care among First Nations Australians (43, 44). However, the experience of institutional racism was ubiquitously expressed in the community consultation (2, 3), and the Working Group determined that a guideline recommendation to examine, monitor and act upon identified institutional racism in the health system was needed. We recommend the implementation of the "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services" (45) should be undertaken by organisations and people experienced in its use and implementation, and First Nations Peoples.

Community voice

The targeted community consultations for these guidelines found that institutional racism was evident and experienced by First Nations Australians with CKD. Catching Some Air identified First Nations Peoples with CKD in The Northern Territory, and Thursday Island experienced pervasive and persistent experiences of bias and racism in healthcare delivery in Australia (3).

The Catching Some Air targeted policy brief recognised racism as a challenge for closing the gap in kidney health (32). Providing safe, accessible, and effective health services will ensure First Nations Peoples are treated with respect and have the right to live with optimal kidney health. The KHA Yarning Kidneys reported that First Nations Australians with CKD experienced bias and racism in their healthcare.

> *"Services have to understand cultural reasons for non-compliance are not because [a] patient doesn't want to go"* (First Nations Australians participant, Perth, 2019)

In addition, engagement with community throughout the guideline development identified that First Nations Health workers experienced racism in their professional capacity during work. They felt funding and governance models of healthcare systems do not incorporate appropriate First Nations voice. A lack of First Nations healthcare workers leads to a lack of awareness of cultural protocols that may lead to unconscious bias, racism, and not culturally safe healthcare delivery.

Clinical evidence

The evidence review identified four relevant studies that have examined institutional racism in the management of CKD among First Nations peoples (Summary of Findings Table D1). Two studies reported experiences of the Stolen Generation (the removal of children from their families) as

contributing factors to a level of mistrust that impacted engagement with health services (43, 44). Another report noted that healthcare in Australia was not culturally safe, with healthcare workers inadequately trained in treating First Nations Peoples with CKD (44). Similar experiences were detailed in qualitative studies from Aotearoa New Zealand, where Māori People with CKD described feeling alienated and disempowered when a healthcare system does not incorporate Māori values, culture and protocols (46, 47). The rigidity in the design of the healthcare system magnified the impacts these issues have on First Nations Peoples with CKD (44) .

Additional studies identified by the Working Group have evaluated institutional racism in Australian health systems. Bourke et al. 2018 (12) applied an external matrix of institutional racism (Table 1) (45) to the Cairns and Hinterland Health Service, in which First Nations Australians account for one-third of hospital admissions. The evaluation revealed that despite Federal and State Government policies, extremely high levels of institutional racism were apparent. There was an absence of First Nations representation in the governance structure, a lack of a community consultative mechanism, a declining First Nations workforce, no public reporting or evaluation of First Nations health expenditure and poor annual reporting on progress in Closing the Gap. In response, the Cairns and Hinterland Health Service have undertaken changes in their health systems. First Nations Peoples have been appointed to the governance structure, Executive Committee, and a Community Consultation Committee has been established. A First Nations Traineeship program has been established, which is reporting data on cases of 'discharges against medical advice' and potentially preventable hospitalisations. These changes have improved their rating of institutional racism by 25 points in four years, moving down from a rating of extreme to very high institutional racism. The "very high" status remains due to ongoing items in the matrix not being addressed, such as the health service still lacked financial accountability to First Nations Peoples.
The "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services" (45) has also been applied to the South Australian Health Service (48). Institutional racism was evident across the ten local health networks in South Australia, evidenced by the low engagement of local health networks with First Nations communities. There was limited annual reporting relevant to First Nations health, and few local health networks had adequately completed cultural safety training for the workforce and had an Aboriginal Health Plan.

Certainty of the evidence
The overall certainty of the evidence of the recommendation was rated as low. As the identified studies exhibited methodological limitations, and some findings were only evident in one study, concerns about precision were evident. All included studies were conducted before or around the publication of the Aboriginal and Torres Strait Islander quality appraisal tool (49) and the CONSIDER statement (50). All studies exhibited strong engagement, prioritisation, and ownership from the communities.

Cultural safety considerations
The included studies and community voice have identified that First Nations Australians with CKD have experienced institutional racism in their healthcare. Furthermore, the intergenerational and intragenerational trauma of colonisation, including the role of healthcare professionals in removing children from their parents due to the implementation of bad policy, is recognised to impact First Nations Peoples' trust and access to mainstream health services in Australia (51). Additionally, First Nations Peoples have a deep connection to their Country and community, and the frequent experience of needing to move off Country to access appropriate care for CKD is not culturally

grounded practice. Australian health services have not been structurally designed to address the cultural needs of First Nations Australians with CKD (44).

Cost, capacity, equity, and resource considerations

There has been little to no examination of the cost of institutional racism in the Australian Health system. However, the disparities in health outcomes seen in First Nations Australians with CKD also cost the health system. Applying the "Matrix for Identifying, Measuring, and Monitoring Institutional Racism across Public Hospitals and Health Services" may incur a financial cost. However, improving the delivery of health services to vulnerable people with CKD may be cost saving, with improved outcomes and a reduction of expensive dialysis services. Health service providers may have limited capacity to evaluate their department, public hospital, or health system. Implementing the scoring matrix would be suited towards a whole health systems approach, as issues of Institutional racism are likely to impact First Nations Australians with other non-kidney-related diseases. Health services leadership should formally evaluate in partnership with appropriate consultancy firms. Implementation and evaluation of the guideline recommendation is vital to improving care and ensuring accountability for health systems.

Table 1. Matrix for identifying, measuring and monitoring institutional racism within public hospitals and health services. Please see Marrie et al. 2014 (45) for implementation

Domain	Key Indicators and Criteria
1. Participation in organisation leadership/governance	• Legal visibility in relevant health service legislation
	• Aboriginal and Torres Strait Islander representation at health service board level
	• Representation at Executive Management level
2. Policy implementation	• Closing the Gap in Aboriginal and Torres Strait Islander health outcomes
	• Community engagement
	• Public Reporting and Accountability in annual reports
3. Service delivery	• Aboriginal and Torres Strait Islander Health Service Plan
	• Cultural competence
	• Selected Health Service Performance Indicators
4. Recruitment and employment	• Aboriginal and Torres Strait Islander Health workforce development
	• Aboriginal and Torres Strait Islander participation in health workforce
5. Financial Accountability and Reporting: Closing the Gap Funding	• Commonwealth contribution
	• State/Territory contribution

b. We recommend that First Nations Reference Groups should advise kidney health services within Australia *(Strong recommendation).*

Community voice

Consultations with the community reported the importance of First Nations kidney health Reference Groups for CKD (2). The consultation with the First Nations Dubbo community and Mt Isa identified that a kidney health Reference Group would provide vital information on raising awareness and health literacy on CKD to improve the health of their community.

Clinical evidence

The systematic review conducted for the guidelines failed to find any relevant studies evaluating Reference Groups as an intervention for addressing institutional racism. However, the Matrix for identifying, measuring, and monitoring institutional racism within public hospitals and health

services recognises that Reference Groups are an effective mechanism for community consultation (item 17) (47).

Certainty of the evidence
The certainty of the evidence was rated as very low, as no studies were identified.

Cultural safety considerations
Effective engagement with First Nations Australian communities results in a sustained relationship between groups of people who are working towards shared goals. Closing the Gap has found that lower levels of engagement, such as one-off consultations, are less effective than high levels of participation and collaboration, especially where there are complex problems (52). The disparity in CKD evident in First Nations Australians compared to non-Indigenous peoples (27, 53) and the ongoing colonisation of First Nations Peoples in Australia (17, 31) warrant continuing engagement and not one-off consultations. An example of ongoing collaboration is the establishment of kidney health Reference Groups within Australia, such as the National Indigenous Kidney Transplantation Taskforce (NIKTT) by the Transplantation Society of Australia and New Zealand (TSANZ) (54) and the Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) Reference Group established throughout South Australia, supported by funding from the National Health and Medical Research Council (55). Further establishment and engagement of Reference Groups to work together to improve access and kidney health care for First Nations Australians is needed.

Costs, capacity, equity and resources
There have been limited cost-evaluations of First Nations kidney health References Groups. There are costs associated with the administration of Reference Groups and expenses related to the training of appropriate staff to organise, maintain, and build relationships between Reference Groups and communities. The Reference Groups identify issues, develop strategies, and assist in devising means to help address the problems of CKD facing the First Nations Australians and hence address issues of inequity within the Australian community. Ensuring the First Nations' voice informs health systems, policy, access, and kidney health services may be cost-effective as local solutions to local problems will reduce waste in healthcare expenditure. The implementation of First Nations Australians kidney health reference groups will be dependent on the size and capacity of the health services. Reference groups may be national, state-wide, regional or hospital-based, depending on the needs of the local community and health service.

c. We recommend removing Indigenous status as a risk factor for chronic kidney disease because the increased risk is explained by adverse social determinants of health, leading to a greater burden and progression of chronic kidney disease *(Strong recommendation).*

First Nations Australians experience higher rates of CKD (56), with rates of kidney failure recorded 8-fold higher than non-Indigenous Australians (26). Despite these increased rates of CKD, studies to date have found few associations of genetic alleles with CKD diagnosis and progression in First Nations Australians (57). The inequalities seen in CKD largely result from social disadvantage and the marginal position of First Nations Peoples in mainstream society (58). First Nations Australians are disproportionately negatively impacted by social determinants of health, leading to an increased burden of ill health compared to non-Indigenous Australians. The Working Group recognised the need for a recommendation conveying the importance of removing Indigenous status as a risk factor

for CKD due to its potential for the unconscious and conscious bias (prejudice) in the care that First Nations Peoples may receive for their CKD.

Community voice

Participants in the targeted community consultation for these guidelines (KHA Yarning Kidneys and Catching Some Air) recognised that First Nations Australians had higher rates of CKD than non-Indigenous Australians. The Yarnings identified a need to improve understanding and educate First Nations Peoples about factors that increase the susceptibility for CKD (2, 3).

Clinical evidence

The systematic review conducted for this guideline chapter focused on initiatives to address institutional racism. However, the Working Group felt commentary on social determinants of health and their relationship to CKD was warranted. Studies with First Nations Peoples have documented the relationship between socioeconomic determinants and health (59, 60). First Nations Australians, compared to non-Indigenous Australians on average, have lower income, education attainment, home ownership, higher unemployment rates, imprisonment and illness from chronic and infectious diseases (19). An increase in incidence and burden of CKD among First Nations Peoples is associated with indicators of social disadvantage (23, 61, 62).

The relationship between individual markers of socioeconomic factors and kidney function among First Nations Australians has not been described until recently (20). An observational study explored the relationship between socioeconomic status and CKD in 20 First Nations communities from the Top End, Central Australia, Far North Queensland, and remote Western Australia. Ritte et al. 2020 found that low-socioeconomic status, remote living, renting, unemployment, and receiving welfare were all associated with eGFR < 60 mL/min/1.73m^2, while a higher socioeconomic status was associated with an eGFR ≥ 60 mL/min/1.73m^2 (20).

Certainty of the evidence

The certainty of the evidence has been rated as low. The certainty of the evidence was downgraded due to the observational nature of the data and study imprecision with a limited number of studies describing the impacts of individual social determinants of health on CKD. The included studies exhibited strong First Nations ownership, prioritisation, and involvement in the conduct of the research.

Cultural safety considerations

Currently, clinical practice guidelines on the medical management of CKD (63, 64) list Aboriginal and Torres Strait Islander status as a risk factor for CKD. However, race is a social construct (65) and labelling people according to ethnicity in medical management may lead to discrimination and racism such as that commonly experienced by First Nations Peoples with CKD (2, 3). Internationally, there is a move towards removing race being taught as a risk factor in medical school (66). The Working Group advocates for removing Aboriginal and Torres Strait Islander identity/nationality as a risk factor for CKD in clinical practice guidelines and medical school education. The recommended removal of First Nations Australian status has the potential to address the public misunderstanding about cultural identity and CKD, and may potentially combat bias, and empower First Nations Australians to self-manage and improve outcomes.

Costs, capacity, equity and resources

According to the Working Group, there are little to no costs associated with the recommendation. However, the recommendation may help address unconscious bias developed throughout clinical training and improve equitable care delivery.

Ungraded statements

- **Social determinants of health associated with lower kidney function among First Nations Australians include (but not limited to):**
    - **Low socioeconomic status**
    - **Living in a remote area**
    - **Housing insecurity**
    - **Unemployment**
    - **Surviving on welfare**
    - **Poor food security**

The recent eGFR study undertaken in regions in Australia with high incidence of kidney failure (Top End, Central Australia, Far North Queensland, remote areas of Western Australia) found that the listed socioeconomic factors after adjusting for age and gender were associated with a lower kidney function (<60 mL/min/1.73m^2) (20).

- **Institutional racism could be addressed by actively through decolonising services by starting with:**
    - **Exercising critical reflexivity (1)**
    - **Enabling reciprocity**
    - **Transformative practice**
    - **Recognising and addressing power imbalances,**
    - **Fostering two-way communication and understanding between clinicians and patients/their families,**
    - **Increasing access to culturally-shaped care and;**
    - **Increasing self-determination and empowerment of patients, families, and communities required to engage with mainstream kidney health services.**

Decolonising practice is a well-established approach that has been developed by First Nations academics and leaders (1). A prominent First Nations Australian scholar, Yin Paradies expressed that the reduction of racism can only be achieved through the 'community awareness of racial prejudice, improving cultural competency among health workers and health services and the redesign of health services to facilitate optimal access' (67). All administrators and healthcare professionals are on individual journeys to learn what true partnership with First Nations Australians means (68). CARI Guidelines Working Group has indicated some approaches that are fundamental for health services and individuals to improve the kidney care for First Nations Australians. These include critical reflection to see how their own perspective and assumptions are socially constructed (exercising critical reflexivity) (1). To ensure that clinicians and administrators think independently and undertake transformative thinking to dispose of knowledge acquired through life experiences (69). The inclusion of First Nations Australians in the design and delivery of health services will ensure the taking into account divergent cultures and communities, ensuring that Indigenous knowledge can inform the nuanced decision-making process involved in kidney health care for First Nations Australians (70).

- **A confidential, culturally appropriate complaints process should be established to enable patients, families, and community members to provide feedback on their experiences regarding all kidney health services in Australia.**

First Nations Australians often feel unsafe when providing critical feedback or highlighting gaps in care. Experience of lodging a complaint can lead to negative care responses by staff which counters effective and safe mechanisms (71).

Cultural safety

d. We recommend that healthcare staff receive effective and responsive cultural safety training, and continuous quality improvement strategies to address institutional racism, using tools such as the "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services" (recommendation a.) *(Strong recommendation).*

Cultural safety training is provided to healthcare staff in Australia. The training varies from a short online tick box exercise to a more in-depth exploration of cultural safety, power, racism, and ongoing colonisation impacts. Improving cultural safety training would be enhanced by linking it to the systematic evaluation of institutional racism in health services. While there is limited evidence of the effectiveness of cultural safety initiatives on health outcomes, the community strongly voiced the impacts that bias has on them and their engagement with kidney health services.

Community voice

The Kidney Health Australia (KHA) Expert Clinician Panel Consultation highlighted the need for improved cultural safety training, as staff involved in managing CKD may lack culturally appropriate communication skills and cultural awareness. Cultural safety training is necessary for all health services, including staff not experienced in the management of First Nations Peoples with CKD and those who may only rarely provide care for First Nations Australians with CKD (37). The KHA Yarning Kidneys consulted with First Nations communities across Australia, and experiences of bias among healthcare staff, either conscious or unconscious, were evident. First Nations participants in the KHA Yarning Kidneys identified that improved cultural understanding and learning were required by all healthcare staff (2).

"New doctors, new training – All new healthcare staff should all be trained" (First Nations participant, Brisbane)

"There should be cultural awareness training in hospitals – not once, but constant training at the workplace, on an ongoing basis" (First Nations participant, Kalgoorlie)

Catching Some Air highlighted that cultural safety was required to ensure a culturally appropriate and communicative workforce. Messaging about CKD to First Nations Australians was highlighted as lacking by First Nations participants. A need for health services to evaluate messaging about detection, prevention and management of CKD to First Nations Peoples in Australia was identified as a solution to improving cultural safety in the Catching Some Air (3).

Clinical evidence

Very few studies have examined the impact of cultural awareness training on the provision of healthcare for First Nations Peoples (Summary of Findings Table D2). No studies have examined the usefulness of cultural safety to address the issues and concerns identified by the "Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services". A systematic review found that cultural safety training improved confidence in understanding cultural protocols, and may increase knowledge in First Nations culture (72). Furthermore, observational studies have demonstrated that cultural safety training improved one's understanding and knowledge (73, 74).

In a cultural safety training workshop for general practice (GP) supervisors and medical educators, where an example video consultation between a GP registrar and a First Nations Australian patient was shown, Abbott et al. 2014 found that all participants (n=64) identified that general communication and consultation skills required improvement. However, despite the majority (72%) of participants identifying the need for the clinician to improve their consideration of the patient's culture, the study reported participants' overall lack of awareness and understanding of the specific cultural factors that impacted the quality and effectiveness of the simulated consultation. These included cross cultural communication, identification of and terminology around 'Aboriginality', significance of involving one's community and Elders, cultural appropriateness of the lifestyle advice provided. Further, few participants (8%; n=5) recognised that access to government-funded support services was required for the patient. Additionally, when asked to identify educational resources and initiatives to support ongoing cultural safety learning and professional development, only 20% (n=13) identified the need for cultural awareness learning resources; with 16% (n=10) recognising the need to access cultural advice and First Nations mentorship (73).

Further, qualitative studies from Aotearoa New Zealand, Australia and Canada have highlighted that cultural safety training in healthcare is currently inadequate. Clinical staff often feel ill-prepared to offer culturally safe care to patients. The studies found that participants relied on their previous professional experiences to provide culturally safe care, instead of receiving proper cultural safety learning and training support (44, 75-78). Additionally, there is a lack of resourcing for cultural safety professional development, resulting in lower quality training initiatives. As a result, the appropriate application of cultural safety in clinical care is hampered, and the quality of care provided to patients is compromised (44, 75-78).

Certainty of the evidence

The certainty of the evidence was rated as low. Findings from the included studies were rated as low to moderate, with downgrading occurring due to methodological limitations or a lack of precision with limited data available. The studies exhibited no concerns regarding the involvement, prioritisation, governance, and ownership of First Nations Peoples

Cultural safety considerations

Improved cultural safety of healthcare staff and services would help enhance kidney health services' trustworthiness for First Nations Australians. Actively improving health services by improving cultural safety training will allow First Nations Peoples to receive care that is careful, appropriate and respectful of culture in all ways.

Cost, capacity, equity and resource implications

Cultural safety training is undertaken by most healthcare staff within Australia. Enhancing the delivery of cultural safety training and tailoring toward improving deficiencies and outcomes identified in a systematic evaluation of institutional racism will substantially benefit the experience of kidney health services for First Nations Peoples.

e. **We recommend that First Nations Australians are a part of the design and delivery of cultural safety training for healthcare staff, which includes using Indigenous ways of knowing, being and doing, for example, informal Yarning style communication *(Strong recommendation).***

Improving the delivery of cultural safety training through better inclusion of the community was considered necessary by the guideline Working Group due to the racism experienced by participants in the community consultation. The community recognised pervasive bias and racism in their experiences of kidney care in Australia. They identified a need for greater understanding by healthcare staff of how to work respectfully and responsively with people of differing First Nations cultures. They also determined that this would likely result in increased trust and engagement with health services, including units, clinics, and programmes targeted at kidney health.

Community voice

The Catching Some Air and KHA Yarning Kidneys community consultations that informed these guidelines found that First Nations Australians with CKD want further involvement of their family and community in their clinical care (2, 3). Participants recognised that the First Nations perspectives on health would be informative for training.

"They don't understand how we think about health." (First Nations participant, Dubbo)

The community consultations also identified various culturally safe approaches that should be incorporated into the education of healthcare staff, including yarning communication (2).

Clinical evidence

The systematic review undertaken for this guideline topic did not identify any studies examining the involvement of First Nations Peoples in the co-design or delivery of cultural safety training in healthcare services.

Certainty of the evidence

As no studies were identified, the certainty of the evidence was rated as very low.

Cultural safety considerations

The involvement of First Nations Australians in further embedding Indigenous ways of doing and learning in cultural safety may improve the understanding of healthcare staff, promoting trust and engagement between the community and mainstream healthcare services.

Cost, capacity, equity, and resource implications

As all mainstream health services in Australia offer some cultural safety training to healthcare staff, the incorporation of First Nations Australians using appropriate approaches is unlikely to be high costs relevant to the total costs of delivery of healthcare services. However, healthcare services need to provide proper resourcing for implementation. It will, however, likely improve the relevance, delivery, and impact of cultural safety training.

Ungraded statements

General

- **First Nations Australians with chronic kidney disease and their family members should be recognised as experts in their own lives, healthcare needs and priorities.**

The community consultations informing these guidelines identified overt racism and unconscious bias towards First Nations Australians when receiving care for CKD (2, 3). All patients have the right to be educated and contribute to clinical decision-making, including the right and refusal of treatment. Principles of self-management advocate that patients are vital in the collective decision-making process regarding their health, and should be recognised as experts in their own needs and management of their health (79, 80).

- **First Nations Australians' connection to culture and community should be actively supported, as it contributes to, and is protective for their health and wellbeing.**
- **Cultural, family and community commitments and priorities should be assigned equal importance to clinical care considerations for First Nations Australians.**
- **Culturally safe care is determined by the recipient of care.**

"Cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity" (6). The experiences of First Nations Australians in receiving their care for CKD are important, valid, and valuable to the kidney health community in Australia. Culturally safety requires health professionals to critically self-reflect on their own practices and examine their biases and prejudices. Cultural safety can be measured by the progress in health equity (6).

Cultural safety training

- **Providing culturally safe care is a lifelong shared commitment that involves ongoing critical self-reflection for healthcare professionals and a supportive work environment.**
- **Health services are responsible for mandating and delivering effective, targeted, and sustainable cultural safety training that actively addresses unconscious bias, interpersonal and systemic racism, delivered in a non-threatening and supportive workplace.**
- **All cultural safety training should be evaluated for effectiveness, and opportunities actively identified to improve its delivery and implementation.**

A summary infographic on these guideline recommendations and ungraded statements is provided in Figure 4 below.

Figure 4. Cultural safety for healthcare among First Nations Australians

Family and community centred engagement and involvement in managing chronic kidney disease

f. We recommend that the family and community of First Nations Australians with chronic kidney disease are actively involved in all clinical appointments according to individual preferences *(Strong recommendation).*

Community consultation revealed a strong community voice for the further involvement of family and community in the care of First Nations Australians with CKD (2, 3). However, family and community dynamics will differ, and the implementation of this recommendation will depend on the patient's preferences and the context of their kinship system. Relevant studies have found that family participation can improve clinical decision-making, resulting in enhanced community understanding regarding dialysis and transplantation (81), with the potential to combat the stigma experienced by First Nations Peoples with CKD. The potential benefits are improved engagement with the health system, greater community awareness and understanding, and improved decision-making regarding kidney replacement therapy.

Community voice

The Catching Some Air and KHA Yarning Kidneys community consultations found that First Nations Australians with CKD wanted increased involvement of their family and community in their clinical care (2, 3).

"*Bring in training for family and carers, teach [the] family how to do dialysis.*" (First Nations participant, Mt Isa)

Catching Some Air identified family as essential support for First Nations Peoples with CKD (3). In the KHA Yarning Kidneys community consultations, family was described as critical for First Nations Peoples receiving dialysis (2), providing practical and emotional support throughout treatment. First Nations Peoples are regularly disconnected from their families to manage CKD (3) due to relocation away from Country, resulting in disconnection between culture and community. Accommodation to support relocation was described as inadequate to support family involvement in the relocation (2, 3).

"A dialysis patient being away from home and families, is no good." (First Nations participant, Darwin)

However, it is essential to note that all families and community contexts and dynamics differ. The patient's autonomy should be referred to in this situation, and their preference for the inclusion of their family and community in their care should inform the implementation of their care planning.

Clinical evidence

CARI Guidelines conducted a systematic review but did not find any intervention studies evaluating the impact of family and community involvement in the clinical care of First Nations Peoples with CKD. However, three qualitative studies from Australia and Aotearoa New Zealand gathered perspectives and experiences of First Nations Peoples receiving kidney replacement therapy (43, 81, 82) (Summary of Findings Table D3). The participants conveyed the desire for their family's involvement in their clinical care, resulting in an improved connection between participants to their community and minimising misunderstanding about treatment and the potential burden of the

stigma of CKD. The studies also found that family involvement in clinical care facilitated improved decision-making, with increased community understanding and support, particularly regarding decisions about dialysis and transplantation.

An overview of published systematic reviews in the general First Nations population on family and community involvement in clinical care found two relevant reviews (83, 84). The reviews focused on the overall aspects and enablers of family and community involvement in clinical care and its impacts on health outcomes. Due to the heterogeneity of the reviews' findings, they could not be meta-analysed or synthesised. The scoping review found that family-centred initiatives for primary health services for First Nations Peoples resulted in improved family behaviours and self-care, increased maternal knowledge, linkage with the clinic, promotion of cultural/community connectedness, and advocacy for social determinants of health (83). A systematic review on non-clinical support for eye healthcare found that the involvement of family members or other community liaison workers/and First Nations health workers resulted in improved social and emotional support, increased attendance to specialist care appointments, and understanding of disease medical care pathways (84).

Certainty of the evidence

The overall certainty of the evidence was moderate. The finding from the three qualitative studies exhibited high certainty of the evidence. The included studies were well-conducted with little to no methodological concerns and conducted in a relevant population with rich data and no concerns of coherency. The finding from the general First Nations population reviews was graded as moderate certainty of the evidence due to methodological limitations with concerns regarding the analysis. All the included studies were conducted before guidance on First Nations Peoples involvement were published (49, 50). The qualitative studies identified no concerns, but the systematic reviews exhibited limited reporting of First Nations methodologies, prioritisation, involvement, and governance.

Cultural safety considerations

First Nations Australians are deeply connected to their culture and support networks (85). The loss of family and community members from CKD, either through relocation or death, has lasting effects on the communities' perspectives on CKD. Greater and improved involvement of family and community in the care of First Nations Australians with CKD may help combat the experiences of stigma that are often described by First Nations Peoples (43) through improved awareness and education of CKD.

Cost, capacity, equity, and resource considerations

There has been little examination of the costs of adequately involving family and community in the clinical care of First Nations Peoples with CKD. Increased time in consultations and expenses due to travel and out-of-pocket costs for patients would be expected. However, the impacts that a more holistic approach through the involvement of family and community would have on attendance to specialist appointments and effects on health outcomes may be improved.

Ungraded statements

- **Health systems should facilitate appropriate mechanisms to support family members to accompany First Nations Australians who are forced to relocate for the management of chronic kidney disease.**

The relocation of First Nations Australians away from their family and community was described as causing distress and disconnection in the Catching Some Air consultations. The consultations also identified that current services to support family involvement in the relocation were inadequate (3). As a result, individuals are not supported to make these important arrangements, and the health system should take responsibility for organising accommodation, transport, and other social support services. However, the Working Group recognises that some of these experiences are not unique to CKD, and health services support should be available for other people with other conditions as well.

- **Psychological and social support should be made available for family members supporting First Nations Australians with chronic kidney disease.**

The community consultations identified that there was a strong desire for psychological support for the family members who care for those with CKD. Many peoples with lived experience of caring for those with CKD described the psychological burden of responsibility and associated trauma (2, 3).

- **Family and community should be included to support patient decision-making regarding dialysis and transplantation, in line with First Nations kinship systems and patients' preferences.**

One study identified that family and community involvement in care improved understanding, acceptance and choice regarding dialysis and kidney transplantation (81).

Transport and accommodation services for First Nations Australians

g. We recommend that health services develop clear pathways for ensuring transport and accommodation needs are prioritised, and options made available to patients and their family members for all healthcare interactions *(Strong recommendation).*

The community consultations and systematic review of the evidence both identified that access to transport and accommodation is vital to ensuring First Nations Peoples receive adequate care for their CKD. Whilst various support subsidies and services exist, the experience of First Nations Peoples showed that access remains problematic. As a result, the CARI Guidelines Working Group were compelled to provide a strong recommendation with the onus on the health service(s) to provide adequate, safe, and suitable transportation and accommodation for their patients, particularly those in rural and remote locations. The supporting data from the community consultations and scientific studies focused mainly on support pathways surrounding dialysis and transplantation. The Working Group identified that appropriate transport and accommodation pathways for all clinical interactions would be required to support First Nations Australians throughout the whole CKD management journey; from diagnosis to transplantation.

Community voice

The Catching Some Air consultations identified the lack of essential support services, including accommodation, to support the management of people with CKD.

"It is very expensive to live here, very expensive, and it is hard to find accommodation – you have to wait for months and months or years" (First Nations participant, Darwin)

Many First Nations Australians with CKD who were forced to relocate for their treatment found that safe, suitable housing close to their treatment centre was inadequate. Accommodation support services were limited, and the available housing was expensive. It was also inappropriate due to overcrowding, and at times unsafe for First Nations Peoples who were forced to live away from their families (3). In certain regions, waitlists for public housing were variable, some up to five years. There was a desire and need for purpose-built facilities and culturally safe accommodation services for people with CKD (2, 3).

Furthermore, transportation was a barrier to accessing care. The lack of transportation options, alongside high out-of-pocket transport costs, resulted in missed clinical appointments.

"Transport should be available to all patients, and not only to Aboriginal patients – all of us need it." (First Nations participant, Adelaide)

Participants also wanted improved access to mobile dialysis services, to allow them to receive treatment, but to still be able to participate in cultural and community events and remain connected to their families and community (2).

"Get a truck for us in our own place – a dialysis truck" (First Nations participant, Kalgoorlie)

Although there are subsidies and services for transport and accommodation available for First Nations Australians with CKD (Table 2), the community consultations highlighted that access to these resources was difficult, due to structural issues. Closing the Gap funding, which once supported access to travel and accommodation, is no longer available. The participants highlighted that travel subsidies are only available for travel greater than 100/150 kilometres (depending on the

jurisdiction), which does not meet the needs for those who have relocated for care (i.e., those within 100/150 kilometres of their home) but still require transport. Additionally, the subsidies are not always available, and the administrative processes required to access the programs can be difficult and may not be culturally appropriate, especially due to potential literacy and language barriers (2, 3).

Clinical evidence

There has been limited evaluation of the impact of improving access to transport and housing on the outcomes of First Nations Peoples with CKD (Summary of Findings Table D4). Majoni et al. 2021 (86) retrospectively examined the patients referred for transplantation from the nephrology department of the Royal Darwin Hospital in the Top End of Northern Australia from 2010 to 2017. The study found that the lack of transport and housing were barriers to waitlisting work-up for transplantation. Qualitative studies conducted in rural and remote Australia and Aotearoa New Zealand also reported that lack of transportation was a barrier to transplantation (46, 47, 87, 88). Similarly, a systematic review on transport and accommodation services for First Nations children with chronic diseases found that the lack of transport was a barrier, with increased financial costs to access healthcare for families (89). An abstract-only publication presented at the 2018 ANZSN Annual Scientific Meeting outlined data linkage undertaken using ANZDATA and the Northern Territory Housing Datasets (90). It analysed 222 participants, 77% from remote or very remote communities, and 94% of those people were First Nations Peoples. The study found that the number of individuals requiring less than 11 haemodialysis sessions within 30 days decreased for those who had accessed Northern Territory urban social housing, compared to those who had not accessed social housing (OR 0.55, 95%CI 0.51, 0.59). However, access to social housing had little to no impact on cases requiring overnight hospitalisations (OR 0.97, 95%CI 0.91, 1.04).

Numerous services to support First Nations Peoples requiring dialysis close to their communities have been developed, but there has been limited evaluation of these services. An abstract presented at the 2018 ANZSN Annual Scientific Meeting detailed the impact of a mobile dialysis unit for First Nations Australians requiring haemodialysis in the Northern Territory (91). These services allowed First Nations Peoples to attend important community events and connect with their families while receiving their required clinical care. Walker et al. 2019 examined the perspectives and experiences of Māori and Pacific Islander people in Aotearoa New Zealand receiving haemodialysis in a community setting (92). The study found that community-based dialysis allowed participants to receive high-quality care, and remain close to their support networks, whilst avoiding the burden that home-based or peritoneal dialysis places on their family and friends.

Certainty of the evidence

Overall, the certainty of the evidence was graded as low. All studies exhibited methodological limitations, and many findings were based on one study only, or were conducted in populations that included people with CKD or First Nations Peoples by chance. All included studies exhibited concerns regarding the prioritisation, agency, ownership, and involvement of First Nations communities within the research, noting that the studies were published before the development of the Aboriginal Quality Appraisal Tool (49) and the CONSIDER Statement (50). Hence, the reporting may be limited and not accurately represent the true nature of the partnership between the community and the researchers in undertaking the research.

Cultural safety considerations

The proportion of First Nations Peoples of the total population increases with remoteness (93). The lack of access to safe and suitable housing compounds the social exclusion and disadvantage experienced by First Nations Peoples (94). First Nations Peoples in Australia have a deep connection to Country, including those living in urban settings. Relocation away from their community (particularly those in rural and remote locations) to receive care for their CKD may disconnect them from their culture and support networks (85). Providing support services, such as safe and accessible transport to attend appointments and receive the required care, would enable First Nations Australians to remain in their communities, and allow them to maintain and foster their connections to their community and culture.

Cost, capacity, equity, and resource considerations

There has been limited evaluation of the cost-effectiveness of transport and accommodation services to support the management of people living with CKD. The financial impact of transport and accommodation to access healthcare is greatest for people from lower socioeconomic status, including rural and remote communities in Australia, which have higher proportions of First Nations Peoples (87). However, transport and accommodation issues also impact those living in urban centres (95, 96), where there may be high out-of-pocket costs, such as for vehicle maintenance, fuel, parking, and public transport. Although various subsidies are available for travel and accommodation, these however do not support all First Nations Peoples with CKD, due to the strict qualifying criteria, including those who fall within the proximity/distance requirements close to treating centres. Please see Table 2 for some examples of National and State-based supports.

Additionally, patients with private health insurance may be able to access benefits, and various non-government organisations may offer assistance. The community consultation recognised these subsidies do not cover all costs for patients and families. Improving overall appropriate and equitable support will likely result in increased expenses. The guideline recommendation will likely increase access to these multiple subsidies. The Working Group felt this was important due to the disparity in CKD prevalence and outcomes between non-Indigenous Australians and First Nations Australians with CKD and the dislocation of patients from their communities and culture.

Other reports and publications

The recognition that the issues of transport and housing increase the financial strain and limit the access to kidney care has been highlighted by The National Indigenous Kidney Transplantation Taskforce (NIKTT), convened by the Transplantation Society of Australia and New Zealand (TSANZ) (97). NIKTT has highlighted that bringing outreach services to communities ensures that most patients receive the care they need. However, providing appropriate transport and housing allowances to achieve equity for First Nations Peoples from remote areas is required. Essential health services such as Purple House (https://www.purplehouse.org.au), an Aboriginal community-controlled organisation, actively provide dialysis in remote communities and transport services for patients to attend festivals, funerals, and other cultural events. State Health jurisdictions provide similar mobile dialysis services, such as the South Australian Mobile Dialysis Unit. Improving patients access to care and connection to their community is also evident in ongoing programs such as the Bringing Renal Dialysis and Services Closer to Home Program by The Western Australian Government.

Table 2. List of some travel and accommodation programs and schemes available in Australia for patients with CKD (Available in November 2022)

Program	Organisation	Comment
Aboriginal Hostels Limited	Australian Federal Government	• Provides accommodation and support services across a national network in hostels. • Patients with CKD requiring care including dialysis and transplantation are eligible • More information here
ACT Interstate Patient Travel Assistance Scheme	Australian Capital Territory Government	• Travel and accommodation costs to receive specialist medical treatment not available in the ACT • More information here
Isolated Patients Assistance Scheme (IPTAAS)	New South Wales Health	• Subsidy programme for travel and accommodation costs for people and eligible escorts who need access to specialist treatment not available locally • More information here
Patient Assistance Travel Scheme	Northern Territory Government	• Travel and accommodation subsidy program • More information here
The Patient Travel Subsidy Scheme (PTTS)	Queensland Health	• Financial assistance for travel and accommodation • Dialysis included in active clinical management • More information here
South Australian Transport Subsidy Scheme (SATSS)	Government of South Australia	• Travel, accommodation, and escort subsidy for travel over 100 kms to receive specialist care • More information here
Patient Travel Assistance Scheme (PTAS)	Tasmanian Government Department of Health	• Travel and accommodation subsidy for Tasmanian permanent residents, including patients referred to dialysis treatment centre more than 50 kms • More information here
Victorian Patient Transport Assistance Scheme (VPTAS)	Victorian Department of Health	• Travel and accommodation subsidy incurred by rural Victorians that must travel >100 kms one way for specialist medical treatment • More information here
Patient Assisted Travel Scheme (PATS)	Western Australia Health	• Subsidy scheme for permanent resident of WA Country Health Service region and potentially eligibility for residents from Peel

Program	Organisation	Comment
		• Includes travel for ≥70 kms from renal treatment centre • More information here

First Nations kidney health workforce

h. We recommend that health services aim to develop professional support for First Nations Australians with chronic kidney disease according to their needs *(Strong recommendation)*:

- First Nations nurses, allied health professionals and doctors
- Aboriginal Health Practitioner and/or Aboriginal Health Liaison
- Patient preceptors/navigators
- Interpreters

The community has voiced a need for further involvement of healthcare staff such as Aboriginal Health Practitioners, patient preceptors/navigators, and interpreters in the management of people living with CKD. The limited scientific evidence indicates that the involvement of First Nations healthcare staff improves communication between the patient and healthcare provider, knowledge, and adherence, as well as the consideration of important social and cultural determinants of health. The Working Group recognised that while the cost-effectiveness of these roles in caring for First Nations Peoples with CKD is unknown, the community's voice and potential benefits outweigh any cost to the health system. Whilst the availability of First Nations health professionals currently may be limited, these are essential roles and professional support pathways to increase numbers and access are required.

Community voice

Throughout the community consultations, participants expressed the desire for access to health workers focused on improving communication and understanding between the patient and the clinical staff. The inclusion of interpreters and the provision of information in traditional First Nations language was identified as a need by both people with lived experience of CKD and healthcare staff to minimise the language barrier and improve understanding and adherence with treatment (2). Additionally, people with CKD wanted First Nations health practitioners involved in their care and for these practitioners to be embedded in kidney health (renal) units. The community described First Nations health practitioners as critical, whilst recognising they were under-resourced and time-poor to provide culturally safe care for all First Nations Peoples with CKD. First Nations health workers also provided an important education role, with culturally safe knowledge on CKD to their community (2, 3).

"…health workers [are needed] as role models, educating young children about kidney disease, have more community consultations." (First Nations participant, Cairns and Yarrabah)

Across the community consultations, the role of a preceptor/navigator with lived experience of CKD was wanted to provide emotional support to First Nations Peoples undergoing the challenges of diagnosis and managing their CKD.

"The hospital should employ an [Aboriginal experienced kidney patient] to explain to Aboriginal people about dialysis and what is a kidney transplant, and what are the consequences of these treatments" (First Nations participant, Adelaide)

Navigators may also provide practical support, such as organising appropriate accommodation for care or helping to identify and complete appropriate forms for financial support (2). The Catching Some Air participants recognised that employing expert patient navigators was one solution to ensure more equitable and culturally safe engagement with healthcare to help address the disproportionate impacts of CKD among First Nations Peoples (3).

Clinical evidence

The systematic review undertaken by CARI Guidelines identified no relevant intervention studies examining the role of person-focused healthcare staff, such as First Nations health workers, patient navigators, and interpreters in the management of CKD among First Nations Peoples (Summary of Findings Table D5). A qualitative study was identified in the systematic review. The study examined the communication between Yolngu People (north-east Arnhem land) and healthcare staff at a satellite dialysis unit in Suburban Darwin, Australia (98). The study found a lack of control for participants limited the opportunity to request interpreters in clinical consultations. Participants described that the lack of interpreters resulted in "gratuitous concurrence" – responding with answers the healthcare worker wanted to hear. Furthermore, due to the limited involvement of interpreters in clinical care, there was little consideration of the important social factors and traditional ways of caring for and managing CKD.

Our overview of reviews on healthcare staff focused on care beyond clinical management of CKD found six relevant studies (99-103). These reviews varied from examining First Nations health workers' involvement in managing First Nations Peoples with asthma to patient navigators for First Nations Peoples with cancer. The reviews found that the involvement of First Nations health workers improves trust and communication between the patient and healthcare staff, resulting in an enhanced understanding of First Nations culture and its incorporation in clinical care (99-102). Additionally, patient navigators' involvement in cancer care for First Nations Peoples (102), and First Nations health workers (101, 103) in various chronic diseases resulted in improved knowledge and adherence to care and identification of First Nations status.

Certainty of the evidence

Overall, the certainty of the evidence was low due to some methodological limitations and the limited adequacy of evidence with clinical outcomes available. The certainty of the evidence for the identified qualitative study on the role of interpreters in the management of CKD among Yolngu People was moderate due to methodological bias, whilst the findings from the non-CKD focused, systematic reviews ranged from moderate to low due to issues around methods and adequacy of the data. All studies were published prior to the CONSIDER statement (50) or the Aboriginal Quality Appraisal Tool (49). However, the primary qualitative study was conducted with appropriate prioritisation, ownership, and engagement with the First Nations community. The systematic reviews did not assess First Nations Peoples involvement in their included primary studies or incorporate First Nations knowledge in conducting their systematic review.

Cultural safety considerations

The community consultations recognised the need for culturally safe information and care for First Nations Australians with CKD.

Cost, capacity, equity, and resource considerations

The guideline recommendation will likely increase the demand for First Nations health workers, patient preceptors/navigators, and interpreters in managing kidney disease, which will require further investment from health services to support these roles. There have been limited cost evaluations of these healthcare roles in the management of chronic kidney disease among First Nations Peoples. However, in other areas, such as cancer, patient navigators have been found to have yielded financial benefits with increased screening, improved diagnosis, and outcomes (104). Purple House has developed and delivered a patient preceptor programme to support First Nations Australians receiving dialysis (105). Further evaluation of the program, in terms of clinical outcomes, the cultural impact and community connectiveness, and economic outcomes, will be fundamental to informing health systems approach to further the involvement of patient navigators in the care of First Nations Peoples with CKD.

The recommendation recognises the importance of First Nations Peoples in managing CKD and will increase the need for First Nations health workers, interpreters, and patient preceptors/navigators. The increased demand will need to be met with increased capacity for these important roles by health services providing appropriate staffing numbers and professional development opportunities. The Indigenous Doctor's Association Blueprint for Action (106) provided recommendations about improving pathways into the health workforce that relevant regulatory bodies and governments should consider and address in full. People from communities of high disadvantage, i.e., those with lower socioeconomic status, from remote or very remote areas, and those with lower health literacy, may likely benefit from more health care staff focused on providing culturally safe information and care. As there will be improved communication between First Nations Peoples with CKD and clinical care staff, resulting in greater consideration of culture and the social determinants of health.

Ungraded statements

- **First Nations Health Practitioners should receive formal education and training in chronic kidney disease, treatment options and management.**

The community recognised Aboriginal and Torres Strait Islander Health Practitioners as having an essential role in managing CKD. However, the Working Group recognised that not all health workers receive the appropriate training in kidney health. Training programs should be developed to support the professional development of First Nations Health Practitioners to facilitate and coordinate, as well as provide care to First Nations Australians with chronic kidney disease under the supervision of an appropriate registered nurse or doctors.

- **Further financial investment and strategic commitment to implement, evaluate and upscale a multi-disciplinary, community-based First Nations health workforce is required.**

The feedback on these guidelines from participants involved in the community consultation informing these guidelines highlighted a need to improve entry for First Nations Peoples into the health workforce. The community identified challenges in people entering training roles due to changes in offerings at educational institutions, leading to substantial travel and relocation and acting as a deterrent for young people to enter careers in First Nations healthcare in Australia. The

Australian Indigenous Doctor's Association 2008 Blueprint for Action recommended further flexible entry pathways for First Nations Australians to enter the health workforce (106). The Working Group identified that this statement is relevant to kidney health and other chronic diseases impacting First Nations Australians.

Screening and referral of chronic kidney disease

Identification of factors associated with chronic kidney disease progression in First Nations Australians

Ungraded statements

- An individual's susceptibility of chronic kidney disease (Figure 1):
    - Is increased by the following the factors:
        - Family history of chronic kidney disease
        - Diabetes mellitus
        - Hypertension
        - Obesity
        - Established cardiovascular disease
        - History of acute kidney injury
        - Cigarette smoking
    - Additional considerations for First Nations Australians:
        - History of low birthweight
        - History of recurrent childhood infections
        - Remoteness
        - Low socioeconomic status
        - Housing insecurity and overcrowding
        - Education levels
        - Other impacts of colonisation

The CARI Guidelines systematic review (Summary of Findings Table D6) identified numerous observational studies assessing the association of various factors associated with the progression of CKD in First Nations Australians, including diabetes, high blood pressure, albuminuria, haematuria, and older age (107-117). Although the literature did not examine other traditional risk factors such as cigarette smoking, established cardiovascular disease, or acute kidney injury, the Working Group agreed that these were relevant. Other factors, such as low birth weight (< 2.5 kgs) (118-120) and post-streptococcal glomerulonephritis (119-121), are associated with CKD progression. Post-streptococcal glomerulonephritis amplified the effect of low birth weight on CKD disease progression (120). A recent systematic review found that 26% of the included studies identified that racism and colonisation are determinants of CKD and its progression (122). Racism and ongoing colonisation lead to socioeconomic disadvantages, such as remoteness of an First Nations community (20, 123, 124), lower socioeconomic status, renting, and lower education, which have all been associated with the burden and progression of CKD (23, 61, 62).

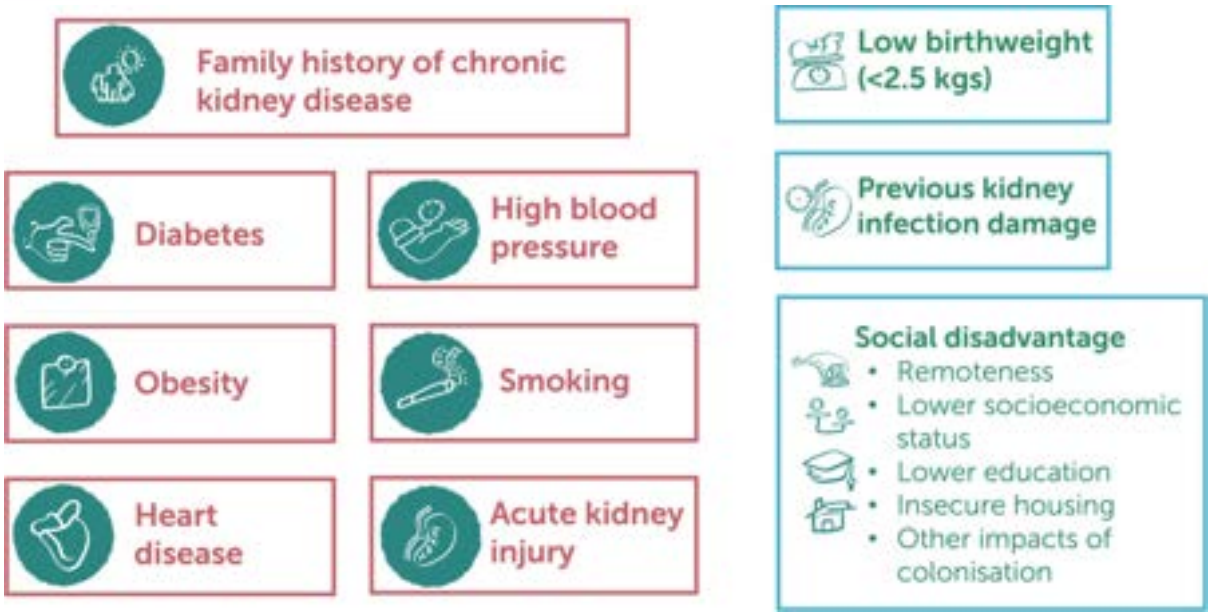

Figure 1. Factors associated with CKD among First Nations Australians

Screening and early detection programs for CKD among First Nations Australians

i. We suggest that chronic kidney disease screening programmes for First Nations Australians are community-controlled, co-designed with the community, and utilise an integrated multidisciplinary approach *(Conditional recommendation).*

Community involvement in all aspects of care for First Nations Australians with CKD, including screening, was identified in community consultation (2, 3). There is limited evidence assessing the impacts of community involvement in screening programs. Studies have found that the frequency and coverage of CKD screening in First Nations Peoples are inadequate (124-128), and the involvement of community-controlled health organisations improved rates of CKD screening (124-127, 129, 130). There are no known harms, but there may be increased costs to incorporating screening programs in decentralised community-controlled health services. Although no cost evaluations have been performed, the benefits of early detection of CKD in First Nations Australians may outweigh the costs. The strength of the recommendation was rated as conditional as community-controlled health services may not be available to all communities within Australia.

Community voice

Catching Some Air (3) and KHA Yarning Kidneys (2) identified the need for culturally sensitive preventative health care that includes local First Nations leadership. Co-designing screening programmes will improve the lack of access and information about appropriate services within the community. There was evident frustration when important community-designed and owned programmes stopped operating.

"*Good programs were discontinued due to the loss of funding."* (First Nations Community Leader, Kalgoorlie)

The current models of care, including screening, are biomedically focused and not holistic and, as a result, may not incorporate domains of health important to First Nations Peoples (2, 3). Participants described a need for improved messaging and communication with First Nations Australians, with many concerned about the blame they may receive, despite inadequate systems and resources to support appropriate CKD.

"Patients need to be empowered, not scolded when something goes wrong. Why would they want to engage with the health service if they are just going to get in trouble." (First Nations participant, Ceduna)

Clinical evidence

The systematic review undertaken by CARI Guidelines identified observational studies that examined screening for CKD in First Nations communities across Australia, Canada, and the United States of America (124-130) (Summary of Findings Table D7). Studies have demonstrated that the frequency and coverage of screening for CKD do not meet appropriate guideline recommendations (128). Integrating screening programs into First Nations community-controlled health services improved screening rates of CKD (124-127, 130). These programmes utilised a multidisciplinary team approach to implement routine CKD-specific screening measures alongside assigning dedicated healthcare staff (124-127, 129-131).

Certainty of the evidence

The certainty of the evidence for these studies was very low, as they exhibited methodological limitations and concerns about imprecision, as the studies were primarily descriptive with no comparisons undertaken. Studies were conducted in relevant First Nations populations, but the incorporation of Indigenous knowledge, prioritisation, and ownership in these studies were not well reported by the authors. Although, most of these studies were published before the Aboriginal Quality Appraisal Tool (49) and CONSIDER Statement (50) were available.

Cultural safety considerations

Health and screening programs need to be led and owned by First Nations communities. Community Controlled Health Organisations are vital to improving the health and outcomes of First Nations Peoples with CKD and the trust between mainstream health services and First Nations Australians. The policies derived in past and ongoing colonisation, including health services' role in the removal of children from their parents, have led to a common mistrust of mainstream health systems by First Nations Peoples in Australia (51).

Cost, capacity, equity, and resource implications

There has been little to no examination of the cost-effectiveness of screening programs incorporated into community-controlled health services. However, a cost-effectiveness analysis of one-of screening and risk-based assessment of CKD in the FINISHED study in Manitoba, Canada (rural and remote communities) found that screening compared to usual care had an incremental cost-effectiveness ratio of $23,700 per quality-adjusted life year (QALY) (132). Reilly et al. 2016 identified that early management programs, including early detection and screening, were cost-effective (133). Improved early identification of CKD may result in reduced crisis initiatives required for kidney disease and hence reduced costs to the health systems. Screening programs run through and controlled by the community will have resource implications for community-controlled health services. Appropriate funding and staffing will be required to ensure the successful implementation of holistic screening programs run by the community for the community. People from remote or very remote communities face the least access to appropriate screening and would benefit from programs that are decentralised and provided within their communities.

j. We recommend that First Nations Australians receive age-appropriate health assessments to screen for chronic kidney disease, at least annually. Including utilising the specific Medicare item number for Aboriginal and Torres Strait Islander Peoples Health Assessment (Figure 2) *(Strong recommendation).*

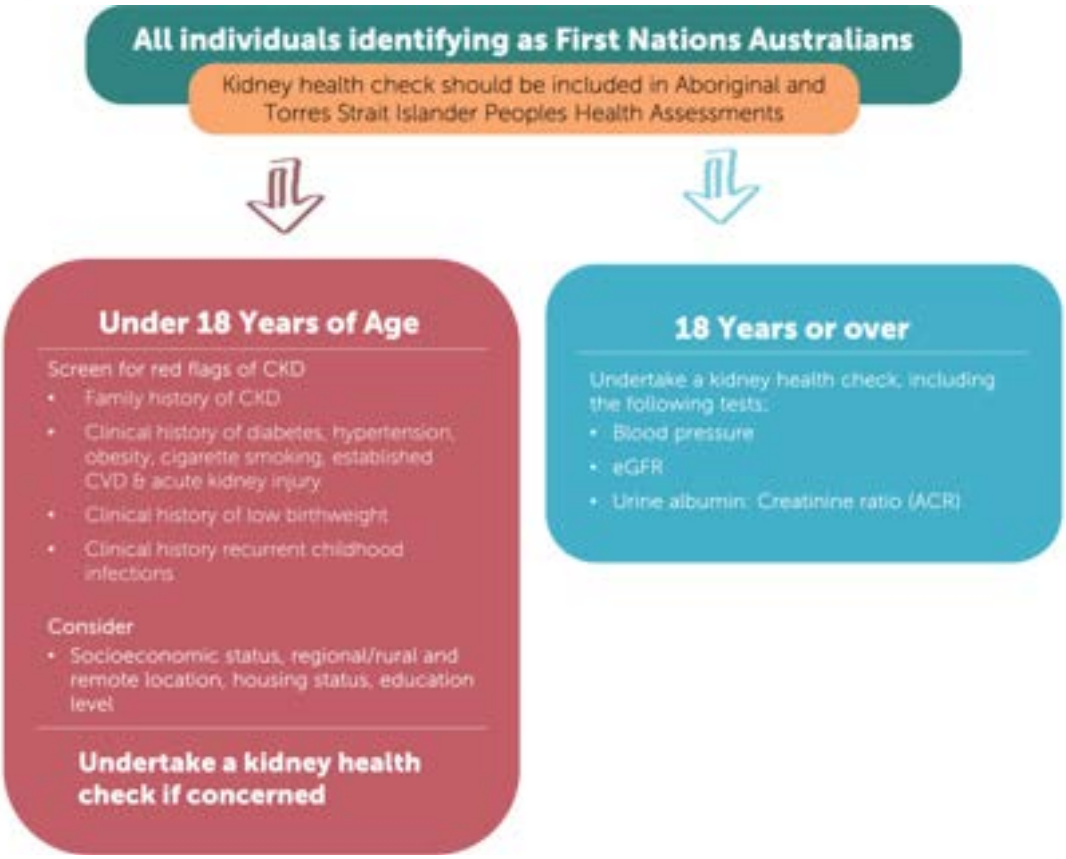

Figure 2. CKD screening matrix for First Nations Australians

The community has identified a desire for improved early detection of CKD among First Nations Australians (2). Examining factors associated with increased CKD among First Nations Peoples in Australia should occur at an earlier age. As the community consultations identified a need for earlier detection of CKD and the high prevalence of CKD in this population (107-117), including those 18 years and older. Family history should be examined in all First Nations Australians, including those under 18. The guidance of Kidney Health Checks in the general population (63, 134) should apply to First Nations Peoples, however, at an earlier age due to the increased prevalence of CKD. Ensuring all components of the publicly subsided Kidney Health Check are undertaken at least annually, including urine albumin: creatinine ratio (ACR) test among First Nations Peoples at risk of CKD, may increase early identification of CKD. Screening for chronic kidney disease can and should occur outside of a Medicare's Aboriginal and Torres Strait Islanders Peoples Health Assessment according to the need of First Nations Australians.

Community voice

Throughout the community consultations, the need for early identification of CKD was emphasised, with ideas about local engagement suggested. The KHA Yarning Kidneys project demonstrated that the community wanted periodic health checks for early detection, and family members were encouraged to be screened (2). They emphasised that young First Nations Australians can move between families and may not regularly engage with health services, which is compounded by the health workforce shortages in regional and remote Australia. As a result, young First Nations Peoples' predisposition to CKD, including family history may not be known. Participants were

concerned about their children and the next generation: they wanted early detection and education to prevent children from experiencing CKD.

Clinical evidence

There have been limited studies that have examined the sensitivity and specificity of components of the kidney health check (blood pressure, eGFR, urine ACR) to identify CKD in First Nations Peoples (Summary of Findings Table D7). One study reported the precision of urine albumin: creatinine ratio (ACR) point of care testing in a First Nations community screening and management programme (135). A study in Canada identified that one-off screening conducted in remote Canadian Indigenous communities was cost-effective ($23,700 per QALY) (132), but the generalisability of the finding to the Australian setting is unclear. The recommendation is based on relevant guidance for screening in the general population with CKD (63, 134). The Australian Bureau of Statistics Australian Aboriginal and Torres Strait Islander Health Survey indicates that for First Nations People 18-29 years of age, the prevalence of a CKD risk factor is 77% (95%CI 69.2%, 84.8%) (data unpublished). Thus, providing evidence for undertaking screening for risk factors and CKD at 18 years and above.

Certainty of the evidence

Given the lack of studies relevant to this topic, the certainty of the evidence is very low. The included studies were conducted before the guidance on the reporting of incorporating Indigenous methodology, knowledge, and the prioritisation and governance in scientific studies (50), and critical appraisal of the involvement of First Nations Australians (49).

Cultural safety considerations

Important cultural safety considerations have been identified in the community consultations and the Working Group had no further additions.

Cost, capacity, equity, and resource implications

There has been no examination of the cost of screening tests for First Nations Peoples. However, Reilly et al. 2016 identified that early management programs, including early detection and screening, are cost-effective (133). Various MBS item numbers (item 715 as of July 2022) are available to undertake Aboriginal and Torres Strait Islander Health Assessments. The Kidney Health Check should be included in these examinations annually.

Ungraded statements

- **Screening for chronic kidney disease among First Nations Australians should occur at least annually.**
- **The measurement of a urine albumin: creatinine ratio (UACR) in a first void specimen is preferred, but a random "spot" urine specimen may be adequate when conducting opportunistic testing.**

The Umoona Kidney Project pioneered the use of point-of-care testing of albuminuria in partnership with an Aboriginal community-controlled health service Umoona Tjutagku Health Service. The study found spot urine albumin: creatinine ratio testing had imprecision targets of 7.4% and 3% (ratios of 4.0 mg/mmol and 6.7 mg/mmol) that are within acceptable imprecision targets (135).

- **The diagnosis of persistently elevated albuminuria by urine albumin: creatine ratio (UACR) requires at least two measurements over three months.**

Referral practices for First Nations Australians with chronic kidney disease

k. We suggest referrals of First Nations Australians with chronic kidney disease to nephrologists (or specialist-supported kidney health teams) using one or more of the following criteria (Figure 3) *(Conditional recommendation):*

- **eGFR ≤45 mL/min/1.73m^2**
- **Persistent significant albuminuria >30 mg/mmol**
- **A sustained decrease in eGFR >10 mL/min/1.73m^2/ year**
- **Elevated blood pressure that is not within the target range despite at least three antihypertensive agents.**

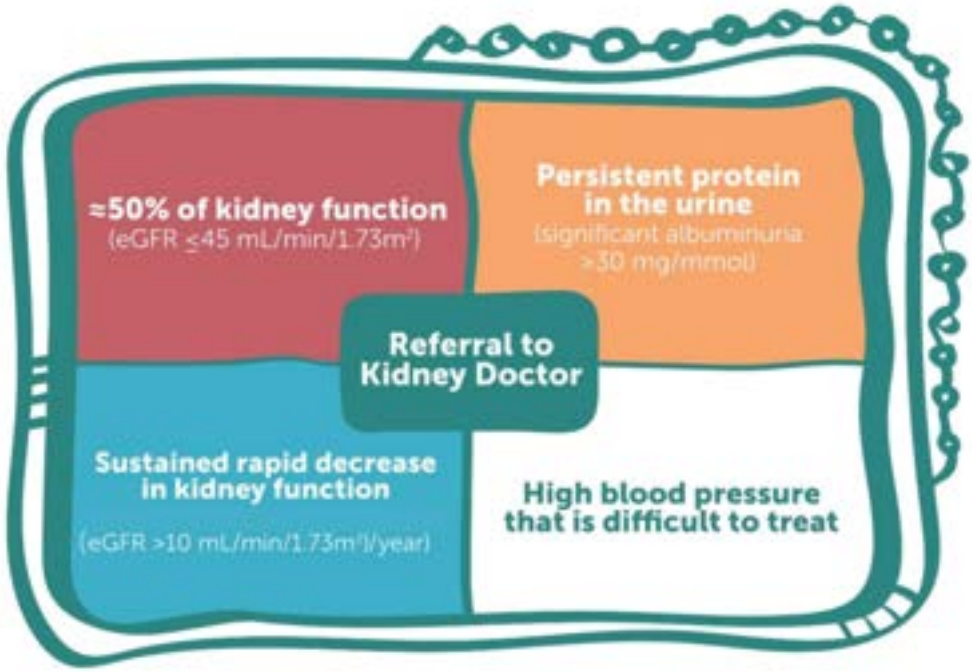

Figure 3. Referral matrix for First Nations Australians

Late referral (<3 months between referral to kidney replacement therapy start) of people with CKD to nephrology services over the last two decades have improved from as high as 25% in 2005 to around 18% in 2018 to 2020 among First Nations Australians (136). The concerted implementation of strategies including the laboratory reporting of automatic eGFR, Kidney Health Australia's promotion of kidney health checks, and their implementation of the primary health care chronic kidney disease education programmes have likely resulted improve the earlier detection of disease (137). However, the excess burden of the disease led the Working Group to alter the referral criteria for First Nations Australians to include a higher eGFR threshold of ≤45 mL/min/1.73m^2 and a sustained eGFR decrease of >10 mL/min/1.73m^2 / year. Despite the lack of published scientific evidence on specific criteria for referral to nephrology, the community actively advocated for earlier identification and management of CKD. The change in the criteria was decided due to an increased incidence of kidney failure and worse clinical outcomes among First Nations Australians. Although The recommendation will likely result in increased demand for nephrology services in Australia, the Working Group agreed that it would be appropriate given the disproportionate impacts CKD has on

First Nations Peoples. A matrix for referral to kidney doctors for First Nations Australians is available in Figure 3.

Community voice

The community consultations did identify the need for early identification and management of CKD among First Nations Australians (2, 3). Many participants described experiences of being shocked at their diagnoses and need for dialysis. The consultations did not specify criteria or pathways for referral of CKD.

"I didn't know I had kidney problems' cause I was pretty active, fishing, hunting, golfing… until one day I felt a bit crook there… so they rushed me to hospital and when I woke up, I was in the intensive care ward… and they said 'Oh you have to go down to dialysis and get blood into you. Your kidneys have had it." (First Nations participant, Lismore, Ballina and the Northern Rivers)

Clinical evidence

Few studies have evaluated referral pathways in CKD among First Nations Australians. The systematic review undertaken by CARI Guidelines identified two studies that found that integrating nurse-led CKD clinics within the community improved the identification and appropriate management of CKD (101, 102) (Summary of Findings Table D8). However, these studies did not evaluate clinical outcomes and provided no data on the impacts of late referral. No published studies have yet examined the effects of the proposed criteria for referral to nephrology services. However, studies have investigated the effectiveness of clinical decision support systems in the Northern Territory in integrating kidney care through primary care and remote health services. These studies are ongoing and will be published soon (personal communication).

Certainty of the evidence

Given the lack of relevant studies to the guideline recommendation, the certainty of the evidence is rated as very low. The included studies were well conducted in partnership with the Indigenous community and incorporated Indigenous knowledge in their design and conduct.

Cultural safety considerations

The guideline recommendation will result in increased referral to specialist services and engagement of First Nations Australians with mainstream health services. Engagement with specialists' health services requires careful and culturally safe practice with substantial involvement of Indigenous Liaison or Health Practitioners in the multidisciplinary team managing the care of First Nations Australians with CKD.

Cost, capacity, equity and resource implications

The criteria for referral to nephrology identified in the recommendation differ from those for the general population (134). The recommendation of increased referral with a ≤45 mL/min/1.73m^2 threshold and lower sustained GFR decrease of 10 mL/min/1.73m^2 per year will have resource implications on nephrology services in Australia. However, given the disproportionate impacts of kidney failure among First Nations Australians, increased engagement with appropriate specialist services may help improve outcomes.

Public awareness, education, and self-management

Public awareness – to enable First Nations Australians to access information about chronic kidney disease prior to screening and diagnosis

I. We recommend that all health promotion and public awareness campaigns be co-designed with the community and include First Nations Australians with lived experience of chronic kidney disease *(Strong recommendation).*

The community voice and the limited scientific evidence indicate that community involvement in the design and development of public awareness and health promotion campaigns on kidney health is needed. The participation of community leaders will ensure that the delivery of these campaigns will be tailored to local needs and may help to overcome the lack of trust in many mainstream services among First Nation Australians.

Community voice

The Catching Some Air and KHA Yarning Kidneys projects identified a vital need for improved awareness regarding kidney health among First Nations Australians (2, 3). Yarning Kidneys consultations in Broome, Cairns and Yarrabah, Brisbane and Kalgoorlie recognised that the campaigns needed to be localised and community-based, involving community leaders and role models, and an extension of already existing programs (Western Desert Kidney Health Project and initiatives and events such as NAIDOC week) (2).

"Kidney Health Australia can set up a health message for kidney health awareness like the diabetes radio skit funded by Diabetes Queensland. It's very effective on the Murri Radio Station. A lot of community people listen to that station and have TV advertising on SBS or NITV that can run all year." (First Nations Australians, Cairns and Yarrabah)

Clinical evidence

The systematic review undertaken by CARI Guidelines identified a qualitative study and a report examining the community's involvement in kidney health public awareness campaigns (138, 139) (Summary of Findings Table D9). The qualitative study examined the perspectives of First Nations Peoples who participated in the Western Desert Kidney Health Project and found that incorporating local First Nations Health Practitioners and the entire community, including children, improved the acceptability and trust of the service (138). The report detailed a social media campaign addressing living kidney donations in three USA Native American communities (Pima, Maricopa, Tohono O'odham) that was community-led and designed. The community initiatives that included people with lived experience and storytelling approaches resulted in improved engagement. A qualitative study following the living kidney donation campaign found that participants engaged more in conversations with family about donation and some offers for kidney donation, a desire to improve health, and increased self-efficacy talking about living donation (140).

Published systematic reviews of health promotion campaigns on all chronic diseases among First Nations Peoples from Australia, New Zealand, and North America identified six relevant systematic reviews. The reviews ranged from examining social media and mobile technologies on health promotion, mental health public awareness, attitudes towards anti-tobacco campaigns, and prenatal and infant-toddler health promotion evaluation among Indigenous peoples in Australia, Aotearoa New Zealand, and Canada (141-145). An overall theme drawn from these systematic reviews was that cultural adaptation of health promotion messaging, including the involvement of community members in various campaigns, improved acceptance and health outcomes (142, 144, 145). For

example, the adaptation of text messaging for quitting smoking campaigns resulted in increased quit smoking rates among Māori (144).

Certainty of the evidence
The overall certainty of the evidence was low. The included primary studies exhibited methodological limitations because of inadequate reporting or concerns regarding residual confounding. Furthermore, the data available was limited, and hence the certainty of the evidence was downgraded due to inadequacy. The systematic reviews were also limited due to a lack of consistency in their findings. The primary studies included strong Indigenous involvement and engagement, indicating appropriate prioritisation, ownership, and leadership in their design and conduct. Hence there are no concerns regarding Indigenous participation in the included studies.

Cultural safety considerations
Mainstream messaging, institutions and usual approaches may not be practical or viewed as trustworthy by First Nations communities due to past and ongoing colonisation, exclusion, and experience of racism. Approaches may need to be inverted and delivered by recognised, familiar and trusted role models – institutions are not always viewed as trustworthy sources of information, whereas lived experiences of known and trusted community members often are.

Cost, capacity, equity and resource implications
There have been limited cost evaluations of community-controlled health promotion campaigns in CKD. It is unclear if community-led campaigns and programmes will ensure that those at the most significant disadvantage will experience improved benefits in understanding and engagement with health services (140). However, tailoring health promotion and public awareness on kidney health to local community needs may help improve trust and First Nations Australians with CKD knowledge and engagement with appropriate health services.

m. We suggest that health services co-create public health promotion tools with First Nations Australians to increase awareness of chronic kidney disease using Indigenous methods and a range of resources, including the sharing of stories in community settings *(Conditional recommendation).*

Community voice
Targeted community consultation has identified that First Nations Australians want improved awareness of CKD among their communities. Catching Some Air highlight the current low appreciation of the impact and burden that poor kidney health can have. As a result, many expressed concerns regarding the significance of CKD on future generations of First Nations Australians (3). KHA Yarning Kidneys similarly found a strong desire for increased knowledge about CKD. Primarily with a focus on the prevention of CKD, the early detection of CKD in young people, and education about CKD to improve self-management and self-efficacy (2).

The community involved in the consultation also identified appropriate methods to deliver public awareness through social media and Indigenous broadcasting, such as Koori Radio and National Indigenous Television (NITV). Essential programs, such as “Tackling Indigenous Smoking” and the Western Desert Kidney Health Project, were raised as models to follow for health promotion in Indigenous communities (2).

Clinical evidence

The systematic review undertaken by CARI Guidelines identified four relevant primary studies evaluating and describing CKD health promotion and public awareness campaigns among First Nations Peoples (Summary of Findings Table D9). Increasing awareness of the causes of CKD can be improved with concerted public health messaging. In Manitoba, Canada, First Nation Peoples comprise 15% of the 1.2 million population and over 30% of the haemodialysis population. Using multimedia, a targeted public health campaign featuring "Kidney Disease — know the risks" increased awareness of CKD from 7% to 25% across all demographics, except for those with low educational attainment and income (146). The Western Desert Kidney Health Project utilised storytelling, art classes and health promotion of CKD and kidney screening achieved high rates of community acceptability and participation in screening (138), and the community wanted the programme to be reinstated and receive ongoing funding (2).

Certainty of the evidence

The overall certainty of the evidence was low. The included primary studies exhibited methodological limitations because of inadequate reporting or concerns regarding residual confounding. Furthermore, the data available was limited, and hence the certainty of the evidence was downgraded due to concerns about adequacy. The primary studies included strong Indigenous involvement and engagement, indicating appropriate prioritisation, ownership, and leadership in their design and conduct. Hence there are no concerns regarding Indigenous participation in the included studies.

Cultural safety considerations

Providing effective and trusted information accessible to all First Nations Australians, families, and communities requires a tailored approach. Ensuring the content is culturally specific for the target audience, using local language and art, will result in more meaningful cultural engagement and aid uptake.

Cost, capacity, equity and resource implications

There is a lack of awareness of CKD in general internationally (147) although awareness does increase with the advancing stage (147). The lack of knowledge about CKD has also s been reported in a survey of people first presenting to nephrology outpatient clinics in Australia, where 2% of the population identified as First Nations Australians (148). There has been little to no-cost evaluation of tailored kidney health promotion programmes among First Nations Peoples. However, focused and effective kidney health awareness campaigns involving diverse community settings, including schools, sporting and art groups, Aboriginal and Torres Strait Islander Community Controlled Health Organisations and primary care settings, may help to improve the early detection of CKD and potentially reduce costs to the health system due to the improved management and outcomes for First Nations Australians with CKD.

Education to support engagement and treatment

n. We recommend that educational initiatives that facilitate engagement and self-efficacy in the management of chronic kidney disease are community-led and co-designed *(Strong recommendation).*

Education initiatives are provided with limited information and access and are not always delivered with appropriate cultural safety principles. Catching Some Air and KHA Yarning Kidneys demonstrated that the community need to be involved in the development as well as the dissemination of educational programmes and initiatives. The evidence review identified that co-design improves trust, engagement, and access to education programmes and resources among First Nations Australians. The Working Group recognised that multiple health services and departmental units developed resources, protocols, and education programmes to suit local needs. Without a national framework and limited evidence of effectiveness, education programmes and resources should continue to be developed locally and in strong partnership with local community-controlled health organisations.

Community voice

The community consultation identified that education was crucial for improving engagement with prevention programmes and strategies to mitigate the progression of CKD among First Nations Australians. The Catching Some Air project identified a need for information about CKD to be provided in an accessible and appropriate manner to prevent harm and offence to patients and their families (3). Additionally, KHA Yarning Kidneys found that while the community wanted information and education, it was unclear where they could access it and whether existing resources were culturally safe or available in First Nation languages (2).

"There are materials in Italian, Greek and other languages, but there is nothing in our languages – yet we are the Traditional owners of the land" (First Nations participant, Adelaide).

The community consultations identified various approaches to education that should be incorporated in delivering CKD information. For example, health services should include:

- Yarning circles
- Cooking classes to facilitate nutritional education
- A community garden to promote nutritional education and community connection
- Incorporation of First Nations Peoples with lived experience of CKD.
- Involvement of Elders and respected community members to enable storytelling for education initiatives.

The KHA Expert Clinician Panel Consultation that was undertaken for the Yarning Kidneys project (2) identified that there was currently a lack of information specifically tailored for First Nations Australians about CKD. They suggested that resources be developed using appropriate educational frameworks and actively address language barriers (37).

Clinical evidence

The systematic review on educational initiatives for CKD among First Nations Australians identified 11 relevant studies (Summary of Findings Table D10). The qualitative studies found a lack of education about CKD, making First Nations Peoples anxious and unprepared for kidney replacement therapy. The studies highlighted the lack of information about transplantation and home-based

dialysis, and the currently available education programmes and training were not tailored for First Nations Peoples (149-151). Incorporating various cultural practices, such as storytelling, was necessary to improve education around CKD for First Nations Peoples (150-154).

Various reviews, reports and qualitative studies have detailed the importance of education initiatives co-designed with First Nations Australians with CKD (150-154) and other chronic diseases (155, 156). Co-design improved the utility and effectiveness, as well as the cultural safety, of education programmes and helped challenge pre-conceived ideas regarding CKD and organ transplantation that some First Nations communities may have (151, 152, 154).

Certainty of the evidence

The certainty of the evidence of the included studies was graded as moderate. The qualitative studies identified had limited concerns regarding their conduct, although some included studies were abstract-only publications. The data was rich, from multiple sources, and conducted in the relevant First Nations populations. The scoping and systematic review identified in the evidence review for the guideline did exhibit some methodological limitations. Most of the included studies were conducted before the development of the Aboriginal Quality Appraisal Tool (49) and CONSIDER Statement (50) and hence have not addressed all domains of these tools. However, the qualitative studies were reported in full, not abstract-only publications, and described strong community involvement, prioritisation, and ownership. There are little to no concerns regarding the involvement of Indigenous people in the included studies.

Cultural safety considerations

First Nation Australians may mistrust mainstream health services due to past involvement in racist policy and the bias they have experienced (51). However, co-designing education programmes and resources will improve community trust and engagement with health services (157). Additionally, co-design is becoming more prevalent, and health professionals are becoming more aware of its benefits. However, resentment and fatigue toward quality improvement projects among healthcare staff are potential barriers to implementation (158).

Cost, capacity, equity, and resource implications

As identified in our evidence review and the KHA Expert Clinician consultation (37), various units and services within Australia undertake education programmes and develop educational resources on CKD targeted toward First Nations Peoples. The community's involvement in co-designing these resources, if not already undertaken, may incur additional costs and increase capacity. However, the Working Group agreed that developing culturally safe programs and resources that overcome cultural and language barriers between health providers and First Nations Australians may improve care and outcomes. The recommendation will depend on the context, with rural and remote settings, and urban communities may want different initiatives and implementation. The Working Group identified no concerns about the impact of this guideline recommendation and agreed it would help enhance equity.

Ungraded statements

- **Education resources and programmes should be translated and interpreted to local languages to actively address language barriers.**

The KHA Expert Clinician Panel Consultation report identified communication and language barriers between clinical staff and First Nation Australians (37). The involvement of trained interpreters and

local community co-design may help to break down communication and language barriers and produce educational content that is culturally safe, relevant, and acceptable.

- **Education resources and programmes should be included as part of a multifactorial approach to managing chronic kidney disease in First Nations Australians.**

One study assessed the impact of a multifactorial initiative in managing CKD among First Nations Australians (159). The initiative included an educational component along with treatment for hypertension, dyslipidemia and diabetes if required. The study found that the multifaceted approach compared to the standard of care resulted in a decrease in death and dialysis after a mean of 2.2 years of therapy (adjusted RR 0.47, 95%CI 0.25, 0.86) (159). Although it is impossible to determine the educational component's effect on the participants, there is no evidence to indicate it should not be included in care. The education provided needs to be delivered in a culturally safe manner with strong community engagement and ownership.

- **Education should encompass a range of techniques and programmes, and include elements such as:**
  - **Yarning circles and storytelling**
  - **Involvement of Elders and First Nations Australians with lived experience of chronic kidney disease and family/community members supporting those with chronic kidney disease**
  - **Interactive lectures and videos**
  - **Cooking classes, shopping classes, community gardens**
  - **Art and music**

The community consultations identified strategies, formats and tools that could be used to deliver information to educate the community about CKD (2). Qualitative studies identified in the evidence review for these guidelines also reported similar findings, requiring educational content to be tailored toward First Nations Peoples (150, 151, 154). A scoping review, Jansen et al. 2020 (152) described elements of education programmes that are effective according to local community needs and listed above. Community consultation highlighted the desire to educate their communities about CKD. Suggestions included using mobile dialysis services attending schools and having local First Nations Peoples with lived experience of CKD provide educational talks to young people in community settings.

Various jurisdictions are developing or have developed appropriate educational content on kidney health, including videos and content aimed at First Nations Australians. For example, NSW Health Agency of Clinical Innovation Aboriginal CKD videos – available here

Self-management programmes and initiatives

**Note: as Self-management principles and strategies are fundamental to achieving best-possible, person-centred care for patients across numerous domains of CKD care, they are thus also explored within the 'Models of Care', and 'Education' sections of these Guidelines.*

"Self-management" refers to the tasks patients undertake each day to control or reduce chronic disease impact of chronic disease/s on their health whilst maintaining and optimising their quality of life. It can also be viewed as "at-home" management, namely tasks occurring outside of clinical or healthcare settings, but rather within any setting encountered in one's daily life (work, community) (79). A primary goal of self-management is to slow the progression of kidney failure and traditionally encompasses four key components: management of diet and fluid, smoking cessation, exercise, and medication management (63, 160). As an individual progresses towards kidney failure and is dependent on their medical management and if kidney replacement therapy is undertaken, the complexity of self-management increases, with additional self-monitoring of clinical signs and symptoms (160).

Effective self-management is achieved when there is mutual, shared responsibility between the patient and healthcare provider/s, with tasks and strategies collaboratively developed and refined on an ongoing basis to achieve person-centred quality care (79, 80). Self-management is empowered through knowledge (understanding and awareness of CKD) and the provision of education that is individualised. However, for its activation and implementation to occur, access to appropriate, meaningful, relevant information that is well-timed and at the right volume is paramount (161). Thus, adequate, culturally appropriate, and ongoing communication between patients, communities and healthcare providers is a crucial facilitator.

Goal setting, problem-solving, symptom management, and shared decision-making (160) are key strategies in supporting patients to develop self-empowerment, self-agency, and health literacy skills. This is especially critical in achieving, maintaining, and sustaining self-management behaviours, due to the long-term progressive nature of CKD and increasing management demands, further compounded if an individual has other diagnosed comorbidities (80). It also argues that self-management support should occur within a holistic, integrated 'Chronic Disease Care Model' (162). Lifestyle and dietary management strategies should be consistent across the range of chronic diseases, and an individuals' management is tailored to their specific health situation. Thus, effective, and ongoing multidisciplinary communication and collaboration between clinical specialties and allied health professions is essential. Such integration leads to improvements in healthcare practice and health outcomes for individuals living with chronic disease, as well as in one's self-management and self-efficacy capabilities (162, 163). A summary of the guideline recommendations and ungraded statements are detailed in Figure 5.

- **We recommend self-management support (initiatives and programmes) should be *(Strong recommendation):***
  - **Available to patients across all stages of chronic kidney disease (not exclusive to dialysis patients) and initiated upon initial engagement with healthcare services.**
  - **Ongoing and collaborative, utilise a whole-person approach, and acknowledge the roles and responsibilities of both patients and healthcare providers and the**

reciprocal interactions between the intra-, inter-personal and institutional domains.

- **Facilitate access to multidisciplinary input (including exercise physiology, psychology, dietetics, audiology, podiatry, physiotherapy, optometry, and oral health/dental services) according to the individual's needs.**

Community voice

The KHA Yarning Kidneys (2) and Catching Some Air community consultation projects (3) identified that education regarding and support for developing and implementing self-management strategies was critically needed in contributing toward the prevention and delaying progression of CKD among First Nations Australians. These consultations also specifically identified the need for culturally-safe education and support regarding signs and symptoms of fluid overload, as well as the provision of consistent, evidence-based dietary management strategies. Patients with lived experience wanted ongoing, easily accessible, all-hours support when on home haemodialysis or peritoneal dialysis, mainly when problems arose. They reported that the available support was only accessible through the medical device company and within metropolitan areas creating a significant access barrier for those living in regional and remote locations.

Further, the KHA Expert Clinician Panel Consultation Report (37) identified important considerations to facilitate health professional use of and engagement with guidelines relevant to self-management. The report highlighted the guidelines needed to assist practitioners with decision-making and provided room for care based on the individual and community contexts, circumstances, and clinical skills.

Clinical evidence

Informed by the priorities identified by communities pertaining to the topic of self-management during the community consultations process, CARI Guidelines conducted systematic reviews investigating self-management initiatives *(education, counselling, technology-based interventions)* that supported dietary and fluid management to improve the care and health outcomes *(clinical outcomes, patient knowledge, satisfaction, quality of life, adherence, etc.)* of First Nations Peoples. However, no relevant studies were identified (Summary of Findings Table D12).

As a result, and upon ongoing consultation and discussions with the guideline Working Group, the focus of this guideline topic shifted to the broader principles of self-management in chronic disease care. Without consideration of the principles and structures fundamental to effective self-management, the specific fluid and dietary self-management concerns identified during the community consultations would fail to be successfully implemented and sustained. Moreover, these patient-identified priorities are self-management behaviours that fall under the 'individual' or 'interpersonal' domains whilst simultaneously acknowledging the shared responsibilities and collaborative developmental process between the patient and healthcare providers to achieve quality care (80).

As no relevant studies were identified in the initial systematic review, CARI Guidelines conducted a second search to identify published systematic reviews within the general CKD population, which resulted in eight relevant publications being identified. Most studies included in these systematic reviews were randomised controlled trials (RCTs), comparing different self-management initiatives. Self-management initiatives included psychosocial components, such as cognitive behavioural therapy (CBT), counselling, self-efficacy and empowerment training. Five systematic reviews (164-168) found that when compared to the standard of care, self-management initiatives improved

patients' knowledge about CKD, self-management and self-efficacy. Three systematic reviews (165, 167, 168), which broadly combined a diverse range of programmes, found consistently that self-management aimed at enhancing patients' capabilities. improved peoples indicators of health and wellbeing such as systolic and diastolic blood pressure, HbA1c, C-reactive protein, and quality of life. However, the evidence regarding their effect on kidney function outcomes, including eGFR and urinary protein excretion, was mixed. Two systematic reviews (165, 167) found limited evidence regarding improvements in healthcare utilisation and hard clinical endpoints (death and kidney failure) (Summary of Findings Table D12).

Noting that most self-management initiatives and education programmes incorporate dietary/nutrition-related strategies, there was no clear evidence of their impact on dietary adherence. Mixed effects on interdialytic weight gain in haemodialysis patients were reported, with three systematic reviews reporting an improvement (166, 169, 170), whilst one review found no effect (168). Similarly, effects on other dietary and drug adherence markers, such as serum phosphate and potassium levels, were also mixed. Further, one scoping review identified as part of this secondary systematic review (164) found that only one percent of the self-management initiatives targeted at adults with CKD were co-designed with patients, with only twenty percent based on a theoretical framework.

A review identified by the Working Group investigated self-management initiatives across Stages 1 to 4 of CKD to identify knowledge gaps and future research (163). The review was guided by three key questions; investigating components of self-management, methods used when testing these initiatives, and their efficacy in improving CKD patients' outcomes. Whilst 'knowledge development' was the most frequent component of initiatives, the review reported that none of these incorporated all key CKD self-management behaviours. In contrast, a systematic review found that no self-management initiatives in randomised control studies incorporated all seven domains of patient empowerment (patient education, sense of self-management, constructive coping, peer sharing, enablement, self-efficacy, and quality of life) (171). The review identified the daily performance of seven key behaviours to slow disease progression, which included adherence to medications (angiotensin-converting enzyme inhibitors or angiotensin receptor blockers), dietary modifications/nutrition education, glycaemic control, regular physical activity, systolic blood pressure control, tobacco avoidance, and avoidance of non-steroidal anti-inflammatory drugs. Additional educational content featured in initiatives covered various topics, such as hypertension, diabetes and nephropathy, kidney replacement therapies, foot care, and stress/emotional management. The most common self-management skills included in initiatives were action planning, problem-solving, and enhancing patient-provider relationships. However, decision-making, resource utilisation, and self-tailoring skills were not evident. Some of the included studies also incorporated efforts to improve patients' self-efficacy capabilities; however, these were limited in scope and underdeveloped strategies. This review also supports the finding of Donald et al. 2018 (164), advocating the need for future initiatives to be developed utilising a theoretical self-management framework.

Certainty of the evidence

Overall, the certainty of the evidence was rated as low. The certainty of the evidence of the findings from the included systematic reviews was very low to moderate. Overall, there were no concerns regarding the coherence or consistency of the results, except for the findings regarding interdialytic weight gain and dietary adherence; studies contributing to those relevant systematic reviews

reported mixed benefits. As the target population within these systematic reviews was the general adult CKD population and not focused on First Nations populations, there are major concerns regarding the directness and relevance of these findings. The reviews did not incorporate Indigenous Peoples in their prioritisation, governance, and conduct, as the included studies were systematic reviews focused on the general CKD population.

Cultural safety considerations

Beyond the need for self-management initiatives to utilise a whole-person approach and be a collaborative and iterative partnership between patients and healthcare providers, an interpretative review by Urquhart et al. 2021 (172) proposes that the development of programs should be underpinned by a "First Nations Peoples' lifeworld perspective". 'Lifeworld perspectives', although complex, diverse, and unique to First Nations communities, fundamentally celebrate traditional ways of knowing, being, and doing, and may include ways of sharing knowledge and language, connection to Country, and intergenerational relationships. Urquhart et al. explains that the success of programs has conventionally been measured using a Westernised, system-focused lens (i.e. biomedical outcomes, access, service utilisation, models of care), however shifting from these dominant power structures and expanding evaluations to include a culturally considered, 'lifeworld perspective' provides a means of working towards the decolonisation of First Nations Peoples' health and well-being.

Following a series of investigative 'yarnings', three interdependent communicative relationships ("critical success factors"), alongside a framework of corresponding reflection questions, were identified, which bridge the explicit (system structures) and implicit (lifeworld concepts). The need for continuous and respectful communication is fundamental to the interplay of these 'worlds'. The first notion outlined the need to develop respectful relationships before any programme planning or decision-making. Linked to the 'lifeworld' concept of "being open", the development of these relationships was crucial to understanding what was valued on individual and community levels, creating a culture of open communication, critical awareness and inclusiveness, journeying toward mutual understanding and programme success.

Second, the 'lifeworld' concept of "knowing how" is tied to the two-way process of enabling shared capability. Individuals such as Elders, First Nations health workers and community members are seen as invested key stakeholders and advocates of a program, as they have "one foot" in "each world" and can navigate between the 'lifeworld' and 'system'. Besides their ability to create internal momentum within their community and support peers towards mutual action, they can support health professionals and researchers in navigating this relationship-building process. Enhancing confidence, capacity, and ability also revitalises First Nations Peoples' cultural knowledge. Such knowledge, which is intrinsically connected to one's identity and self-worth, can, in turn, have protective effects on health and well-being.

Thirdly, First Nations governance is critical to affirming accountability to the community and linked to the 'lifeworld' concept of "staying strong". A community governance structure and team allows a journey of ownership to occur, where a programme can be embedded into a community's fabric; it comes from within the community, stems from community voices and benefits community members. Community members ongoing involvement in a program's development can ensure that the entire process (from initial design and implementation to evaluation and dissemination of results) remains true to the 'lifeworld' perspective. Further, embedding First Nations governance within a programme can contribute to longevity. A programme valued, trusted, and supported by

the community can be sustained beyond a brief research intervention and transcend temperamental system pressures, including short-term research grants or contracts and political agendas.

Cost, capacity, equity, and resource considerations
The implementation of self-management support may have associated costs to the health system. Provision of the initiatives and tools accessible at the point of access to First Nations Australians with CKD will improve equity and potential health outcomes. Many of the available self-management supports and expertise are of limited availability.

p. We recommend that adequate, sustainable, and long-term funding models be developed and implemented to support the co-design, development, implementation and continuation of self-management and behaviour change programmes *(Strong recommendation).*

Despite the lack of evidence on funding of self-management programmes, the Working Group agreed on the need for a strong recommendation due to the importance of self-management programmes and the need for ongoing sustainable funding to improve outcomes for First Nations Australians with CKD. Similar needs are evident in other chronic diseases, and a whole health systems approach may be appropriate.

Community voice
The community expressed the need for funding to be sustainable and ongoing. Participants in the Catching Some Air (3) and KHA Yarning Kidneys (2) projects described frustration at important projects being discontinued due to lack of funding (i.e. Closing the Gap funding).

Clinical evidence
No evidence review was undertaken for the topic of funding self-management programmes.

Certainty of the evidence
The certainty of the evidence was rated very low.

Cultural safety considerations
Ongoing commitment to providing adequate, long-term funding for self-management programmes is critical in supporting community ownership and co-design. Supporting First Nations communities in a culturally safe way to develop the necessary capabilities and agency to help those with CKD will also contribute to the establishment of trust and mutually-respectful partnerships between First Nations communities and mainstream health services. There should be the continuous acknowledgement from key stakeholders that a "tension of responsibility" exists between the need to secure system funding via large grant proposals (a Western system approach) and the importance of developing collaborative, First Nations-led governance within the community ('lifeworld' approach), which is crucial to programme success and longevity (169).

Cost, capacity, equity, and resource considerations
As identified in the evidence review and KHA Expert Clinician Panel Consultation Report, currently, there is a lack of published self-management initiatives grounded in theoretical frameworks and co-designed with patients and no interventions tailored to First Nations Peoples. The importance and efficacy of co-designed interventions are widely reported in the literature for the CKD population and other chronic diseases (79, 80).

It is recognised that the development of such programs and initiatives, with the involvement of the community, will require additional resources, including financial and workforce support. The Working Group suggests establishing adequate long-term funding models to co-design, develop, implement, and sustain self-management programs and support strong patient-provider relationships. There is consensus amongst the Working Group that such initiatives and programmes may result in improved care and outcomes for First Nations Peoples across the spectrum of CKD disease stages and care. There are no concerns regarding the impact of this guideline recommendation on equity considerations; co-designed, culturally-appropriate self-management programs may support improved equity outcomes for First Nations Peoples with CKD.

Ungraded statements

- **Culturally appropriate self-management support is necessary for an individual's social, cultural, and emotional wellbeing. Self-management support and strategies should:**
  - **Be culturally safe, personalised, contextual, and holistic (social, physical, psychological, and spiritual).**
  - **Focus on social and emotional wellbeing, including connection to Country, community, and family.**
  - **Ensure that time and effort is taken to understand the individual and their social context, and to develop a trusting clinician-patient relationship. This relationship building should employ active listening strategies and utilise a non-stigmatising approach.**
  - **Ensure that individual independence and autonomy are maintained.**
  - **Include establishing peer story-sharing programmes and resources to support self-management and behaviour change across all stages of chronic kidney disease.**
- **Self-management programmes need to be consistent, particularly regarding the information and advice about diet and nutrition for chronic kidney disease (see CARI commentary on the KDOQI Nutrition Guidelines), and occur within a framework of First Nations food knowledge and customs. The broader elements influencing eating behaviours and food security, such as availability, accessibility, affordability, and facilities for storage and preparation, should also be acknowledged and addressed.**

Throughout the community consultations, patients shared experiences of confusion and frustration arising due to a lack of consistent information provided by different clinicians and specialities and across appointments. They reported that the advice on food and diet provided by a doctor and dietitian often conflicted. Patients on haemodialysis wanted to be trained on how to self-manage instances of excess fluid intake and safe nutrition and hydration strategies pre- and post-dialysis. Patients undergoing long hours of dialysis finishing late into the evening wanted to know what foods were allowed to be eaten late at night or if they became hungry overnight. The evaluation of First Nations dialysis patients' priorities and preferences for developing nutrition education resources found that patients preferred a collaborative resource development process, contributing to an "existing story" rather than novel content development (173).
Current clinical practice guidelines (174, 175) surrounding dietary management across all CKD stages, alongside clinical judgement, should be applied to the dietetic care of First Nations Australians with CKD. If any healthcare or medical professional receives nutrition/diet-related enquires from a patient/caregiver or is required to provide such advice, consultation with or referral

to a dietitian (or nurse practitioner) is advised and strongly encouraged. It would help to ensure consistent, safe, and up-to-date nutrition advice is given to the patient.

In addition to the dietetic management principles available for the general adult population with CKD, nutrition advice should also consider First Nations food knowledge, customs, beliefs, traditional foods ('bush tucker'), and other comorbidities. Nutrition management plans should acknowledge and be tailored to the individuals' food preferences and habits. Comprehensive information on the dietary composition of Indigenous foods has been compiled in the Bush Tucker in Kidney Failure and Diabetes (176) and Tables of Composition of Australian Aboriginal Foods (177), with evidence suggesting that traditional foods form a fundamental part of one's identity and are strongly tied to the psychosocial and spiritual domains of health beyond just the physical act of nourishment (178). Considering that relocation from Country is required for First Nations Australians needing chronic maintenance haemodialysis, it is also reported that such dislocation also negatively impacts on younger generations due to the loss of opportunities to disseminate this traditional knowledge (178).

Figure 5. Self-management of chronic kidney disease among First Nations Australians

Models of care

Models of care in chronic kidney disease (pre-dialysis)

q. We recommend the development of dedicated programmes specific for First Nations Australians, to identify those at risk, and diagnose and manage chronic kidney disease *(Strong recommendation).*

Community voice

The community consultations identified the need for healthcare reform in kidney health services throughout Australia (2, 3). Catching Some Air reported that Alice Springs, Darwin, and Thursday Island communities identified the need for safe, accessible, and effective health services to combat the pervasive and persisting bias evident in participants' experiences. Many First Nations Australians commonly move between families and community groups are therefore unlikely to engage regularly with a healthcare provider who knows their family history and underlying risk factors. Renal Prevention Centres in rural and remote locations with the engagement of local First Nations leadership were recognised as a potential solution by the community (3). KHA Yarning Kidneys also highlighted the need for health care programmes to be community-controlled to drive change. Participants recognised the importance of primary health care.

"Primary health services should be doing a lot more home visits and being aggressive in slow(ing) kidney failure progression down and doing more kidney health early prevention programs to all patients as Indigenous peoples are at risk" (Cairns Yarrabah participant).

Frustration was conveyed about important community CKD detection and management programmes being discontinued due to a lack of funding. Emphasis was placed on ensuring that CKD management models of care are engaging and culturally safe environments and incorporated First Nations Health Practitioners, navigators/preceptors and interpreters (2).

Clinical evidence

The evidence review undertaken by CARI Guidelines identified a well-conducted systematic review on models of care in CKD (133). Riley et al. 2016 included ten relevant studies that examined the effectiveness and cost-effectiveness of CKD management programmes. The review found that all dedicated CKD management programmes improved surrogate markers of disease, including blood pressure, uACR, and HbA1c. There were no data on hard clinical outcomes, such as death and kidney failure and limited data on quality of life and other patient-reported outcomes However, an RCT conducted in the Zuni Native American community in New Mexico, USA, found that the use of home-based kidney care dedicated to the First Nations communities improved patient empowerment (179). A descriptive study examining dedicated kidney care programmes in Native American populations reported improved management according to relevant clinical practice guidelines and decreased incidence of kidney failure. However, the study did not have a comparison arm, and no adjustment was undertaken (131, 180). An abstract-only publication also demonstrated that having nursing staff dedicated to community-controlled health services in the Northern Territory, Australia, compared to usual care, improved care according to National Aboriginal Key Performance Indicators including appropriate testing and achieving appropriate clinical targets such as HbA1c and blood pressure (181) (Summary of Findings Table D13).

Certainty of the evidence
The included studies exhibited moderate certainty of the evidence. The studies had some limitations regarding their methods, with some studies being uncontrolled or being abstract-only publications and hence missing important details in their reporting. There were no concerns regarding the consistency, adequacy, or relevance of the data. The studies were all published prior to the CONSIDER and Aboriginal Quality Appraisal Tool but reported strong community prioritisation, inclusion, and ownership (49, 50).

Cultural safety considerations
Delivering dedicated First Nations programmes for CKD screening, detection and management co-created and co-designed by First Nations Peoples, and the First Nations health workforce will make inroads to decolonising health services. Decolonising health services is critical to improving Indigenous health (31). Rix et al. conducted a qualitative study in New South Wales among First Nations Australians with CKD and their health care providers and identified that designing services according to First Nations culture actively addressed issues of colonisation in mainstream kidney health services (43).

Cost, capacity, equity and resource implications
Dedicated programmes for the screening, diagnosis and management of CKD among First Nations Australians will require increased resources from health services. However, a systematic review on CKD management programmes for First Nations Peoples in Australia, Aotearoa New Zealand, and Canada found that CKD management programmes were cost-effective (133). The models of care, when utilising existing local community resources and integrated within local healthcare systems, improved health outcomes and reduced costs for health systems, including the number of First Nations Peoples starting dialysis. Paramount to the success of these dedicated programmes, appropriate staffing and upskilling of the First Nations health workforce will be required, as has already been recommended by these guidelines.

r. **We recommend that these programmes *(Strong recommendation):***
   - **Are co-designed and governed by First Nations communities and embedded into existing chronic disease programmes.**
   - **Are adapted to ensure they are culturally safe, tailored to the community and flexible to the changing needs of the community.**
   - **Explicitly identify and address barriers to care, including (but not limited to) institutional racism, cultural, social and/or geographical barriers, transportation and/or other related healthcare costs for patients and families.**

Community voice
As illustrated in Recommendation q., the community wanted involvement and self-determination in managing their CKD. Barriers to accessing current service models included a lack of flexibility that conflict with cultural and family commitments, geography, hostile environments, and racism (2). Almost all community consultations highlighted a lack of safe and accessible transportation. Catching Some Air also recognised that the current models are biomedical and lack patient-centred care and proposed community-initiated care (3).

Clinical evidence

The evidence reviews undertaken for these guidelines identified enablers of the implementation of CKD programmes of care. Co-designed programmes with established governance structures with First Nations Australians improved the identification and management of CKD (131, 133, 181, 182). The involvement of multiple disciplines, including the First Nations health workforce (131, 133, 179, 181-183), and culturally safe, tailored, and flexible services facilitated greater impact (131, 133, 179, 182, 183). A well-conducted systematic review (133) and observational study (183) found that not addressing issues such as cost, lack of transportation, and other potential social issues may act as barriers to effective programmes for managing CKD (Summary of Findings Table D13).

Certainty of the evidence
The overall certainty of the evidence for the recommendation was rated as moderate. The included studies exhibited concerns regarding the methodology or adequacy of the data and were downgraded accordingly. All studies were published prior to the CONSIDER statement (50) and the Aboriginal Quality Appraisal Tool (49). The studies varied in their involvement of First Nations Peoples, from little to no reporting (181, 183) and some reported a strong First Nations prioritisation, ownership and inclusion (131, 179, 182).

Cultural safety considerations
The recommendation aimed to improve the design and conduct of health programmes for the screening, diagnosis, and management of CKD for First Nations Australians and to ensure that First Nations voices are incorporated and used to shape health services in Australia. For example, the delivery of co-designed health care with First Nations governance (involvement at executive and board levels in health services, inclusion of reference groups etc.), cultural safety, and addressing barriers to care, including social determinants of health. The incorporation of First Nations Australians in kidney health service delivery will ensuring First Nations Peoples in Australia receive care that responds to the view that health is beyond the western biomedical approach (14).

Cost, capacity, equity, and resource implications
Community-controlled models of care for CKD management have been demonstrated to be cost-effective. Reilly et al. 2016 review (133) found barriers in remote locations such as acute workload, limited health literacy, understaffing, high staff turnover, and the gap between the total funding and actual expenditure for best-practice care. However, the review highlighted those two programmes that utilised existing local community resources integrated within existing local healthcare programmes and/or initiatives improved health outcomes and reduced costs to the health system. The integration of community resources into local healthcare programmes reduced the number of First Nations Australians starting dialysis.

s. We suggest maintaining clinical and medical information systems (technology, programming, documentation) according to appropriate data sovereignty principles, alongside ongoing quality improvement tools to support programme delivery, audit, and evaluation *(Conditional recommendation).*

Community voice
Catching Some Air highlighted the importance of appropriate First Nations ownership and governance of clinical and medical data. The lack of access to clinical data was identified as a barrier to improving the understanding and delivery of health services for detecting, monitoring and managing CKD (3). All collected clinical and medical data should adhere to appropriate standards for

data sovereignty (autonomy for data related to First Nations Peoples) that the Catching Some Air and ANZDATA Aboriginal and Torres Strait Islander Health Working Group have developed (184).

Clinical evidence

Reilly et al. 2016 found benefits associated with dedicated CKD management programmes on various kidney, diabetes and blood pressure outcomes among First Nations Australians (133). A common component of the models of care evaluated in this review was a clinical and medical information system supported programme delivery alongside quality improvement tools. Other studies found that using clinical and medical information tools such as the 'red flag' system integrated into electronic health records (182) improved management according to appropriate clinical practice guidelines and communication between local primary care and nephrology services. A study examined the impact of a public health initiative known as the Kidney Disease Program on a Native American population. The initiative included embedding quality improvement into medical information systems, with routine reporting of eGFR programmed into the system alerts and specific CKD templates available, such as referral to nephrology and kidney health (renal) nutrition forms. The study found increased achievement of appropriate clinical goals and a decrease in the incidence of kidney failure among the Native American population (131) (Summary of Findings Table D14).

Certainty of the evidence

The certainty of the evidence was rated as moderate. Reilly et al. 2016 (133) was a well-conducted review, but the other included studies (131, 182) did not have a comparison arm and have been downgraded due to methodological limitations. There were no concerns regarding First Nations prioritisation, ownership, and inclusion. The studies were published before formal guidance on the reporting First Nations Peoples involvement and quality assessment.

Cultural safety considerations

First Nations Australians emphasised the importance of the sovereignty of their data throughout the community consultations (2, 3). The Working Group identified no further cultural safety considerations.

Cost, capacity, equity, and resource implications

There has been no examination of the costs of appropriate clinical and medical information delivery systems for health services for First Nations Australians.

t. **We suggest programmes of care *(Conditional recommendation):***
   - **Be conducted within community-controlled health services.**
   - **Use a multidisciplinary approach, with program-specific healthcare workers dedicated to facilitating these programmes.**
   - **Promote a culturally safe workplace culture, with built-in support for the multidisciplinary team, including (but not limited to) the provision of continuing education programmes, case management workshops, clinic guidelines/protocols, and online education materials.**
   - **Incorporate patient education and training within the programme, to increase patient and community empowerment.**

- **Use an integrated care approach when specialised nephrology services are required as part of a patient's management, including the use of telehealth services where appropriate.**

Community voice

The community consultations identified current deficiencies in kidney health services in Australia (2, 3). Participants wanted First Nations ownership and governance of health services, with care coordinated by community-controlled health services. Community-controlled health organisations were recognised as the driver for change and improvement in health delivery by the community consultation participants. The Catching Some Air findings proposed increased partnership of community-controlled health services with primary care as a potential solution to address the disparity in kidney health outcomes (3).

An emergent theme throughout the consultations was the deficit of culturally safe care in managing CKD (2, 3). Establishing Renal Prevention Centres within rural and remote First Nations communities with a close link to regional nephrology departments was proposed as a possible solution. While not raised in this discussion, integrated care telehealth/video link technology may improve access to kidney health services for First Nations Australians.

Clinical evidence

The underpinning evidence for the recommendation was evident in multiple studies (131, 179, 181-183) (Summary of Findings Table D13). Observational data and descriptive studies have demonstrated models of care for CKD being integrated within community-controlled health services and engaging a multidisciplinary approach will result in improved identification and management of CKD (131, 181, 182). However, an RCT conducted in the Zuni Native American community in New Mexico, USA, found that community-controlled kidney care within an ongoing patient education improved empowerment and activation in clinical care (179). Additionally, health services that promoted and supported healthcare staff through the provision and delivery of ongoing education, professional development and access to appropriate clinical practice guidelines and protocols demonstrated benefit in the implementation of appropriate care and improvement in clinical outcomes for Native American people with CKD (131).

One observational registry-based study examined the use of telehealth as an outreach service in rural Queensland, Australia (183). The study included non-Indigenous Australians but had a high proportion of First Nations Australians. Care was tailored to the local needs, including the involvement of First Nations Health Practitioners. The study found that telehealth was acceptable, and the majority (98%) preferred telehealth for ongoing management. Attendance to clinical appointments increased in the telehealth arm (>80%) compared to the standard of care (50%) in the First Nations populations. There was a decrease in rates of kidney replacement therapy (telehealth 2 per 100 patient-years versus standard of care 3.5 per 100 patient-years; p-value <0.05) and lower mortality (telehealth 11.1% versus standard of care 18.2%; p = 0.02).

Certainty of the evidence

The overall certainty of the evidence was rated as low. Numerous Summary of Findings were described from the included studies for the guideline recommendation, with most demonstrating low certainty of the evidence due to a reliance on observational data. The Reilly et al. 2016 review (133) was rated moderate certainty of the evidence. However, these findings were supported by

observational studies and descriptive studies that demonstrated various methodological limitations, and as such, the results have been downgraded to low.

Cultural safety considerations

As detailed in the recommendations above, ensuring health services are designed, delivered, and tailored to the needs of First Nations Australians may address colonisation's impacts on health. The effects of a western biomedical view of health and its service delivery often diminish the First Nations' perspective that health is beyond the absence of disease (31). Delivering health services designed and controlled by the community will ensure the First Nations voice is incorporated and may address the disparities in kidney health outcomes between non-Indigenous Australians and First Nations Peoples.

Cost, capacity, equity and resource implications

The delivery of care programmes for First Nations Australians around the principles of community-controlled, multidisciplinary, cultural safety, and education will incur costs to the health systems. However, the appropriate design of models of care will reduce costs. Telehealth nephrology consultations are cost-effective with a total of 100,000 km less travel and hence a reduction of the expenses of the Patient Travel Subsidy Scheme (183). The delivery of programmes of care based on these principles will reduce inequity and improve the health of First Nations Peoples with CKD.

Figure 6 provides a visual summary of the guideline recommendations and ungraded statements for models of care in CKD (pre-dialysis).

Figure 6. Components of models of care for pre-dialysis

Models of care in kidney failure

u. We recommend health services work in partnership with Aboriginal community-controlled health organisations (ACCHOs) to establish community-controlled models of care that address local needs and conditions, allowing First Nations Australians to have nurse-supported and Aboriginal Health Practitioner-supported dialysis on Country, particularly in remote areas *(Strong recommendation).*

Community voice

The need for health services to be delivered on Country, particularly in rural and remote locations, has been a strong and consistent message from the Australian First Nations community for decades (185). The First Nations view of health and wellbeing is dependent upon the 'social, emotional and cultural wellbeing of the whole community' (185), and this relies upon the 'profound bonding of people to one another, to their Country and the species of animals and plants inhabiting it' (186). The Improving Access to Kidney Transplantation (IMPAKT) project (187), established the severe and debilitating effects that the dislocation from Country and community has on First Nations Australians requiring dialysis and their communities (188). The need for people to have their dialysis treatment on Country and the benefits this would bring to patients and their communities were ubiquitously voiced in the Catching Some Air (3) and KHA Yarning Kidneys (2) consultations. Having dialysis services available on Country empowers communities, keeps culture strong and allows education, including health education, to be passed down to younger generations, improving the community's health as a whole (2, 3, 189).

"Family is important to us, and homesickness is a big issue" (First Nations participant, Adelaide).

"The worst thing is the separation – there is no one for you. Biggest threat when a family member passes away, you need to attend the funeral" (First Nations, Broome).

"[I'm] homesick, Cairns not home, miss family members, miss traditional lands, way of life in community, miss activities like fishing, hunting, family gathering" (First Nations, Cairns)

Nurse-supported, home or community dialysis is the preferred form of care for many First Nations Australians, an approach reiterated by participants in the more recent community consultations (2, 3).

Clinical evidence

A systematic review of models of care for First Nations Peoples requiring dialysis identified one study that assessed the safety of remote area, nurse-supported, community-controlled dialysis services (190). The retrospective registry cohort study, performed in 2010, established that there was no increase in the adjusted mortality rate for First Nations Peoples of Kimberly origin receiving dialysis in the Kimberly (n=110) when compared to non-Indigenous Australians receiving dialysis from across the Australia (n=13,274) (AMR 0.80, 95%CI 0.51-1.23) (Summary of Findings Table D14).

Certainty of the evidence

The study was a non-randomised registry cohort study using ANZDATA and had a moderate risk of bias. It was well-conducted research through a First-Nations lens with no concerns identified on retrospective application of the Aboriginal Quality Appraisal Tool (49).

Cultural safety considerations

The need for 'service provision shaped by culture' to reduce the burden of CKD was identified by First Nations Peoples with CKD and their health care providers in a 2014 study by Rix et al. (44). This study highlighted the need for health service redesign to be First Nations led to address institutional racism and other effects of ongoing colonisation faced by First Nations Australians accessing health services. Rigid mainstream health services contribute to the disparity in health outcomes for First Nations Peoples on dialysis . Empowering First Nations communities to incorporate dialysis services within community-controlled health services aligns with the Wellbeing model for First Nations Australians living with chronic diseases that 'Wellbeing is supported by best-practice care that addresses the particular needs of a community' (191). These messages align with the voice of First Nations communities throughout the consultations (2, 3).

Cost, equity, and resource considerations

The costs of community-controlled, staffed, remote area dialysis services (Purple House model) (189) have been established through the Dialysis Models of Care Study (192, 193). An increase in the comparative cost of dialysis service provision in remote areas compared to urban centres (193) is offset by lower health service utilisation in emergency department presentations and all-cause hospital admissions. The result is overall lower total health care utilisation costs when compared with In Centre dialysis ($130,846 (SD 5280) versus ($148,510 (SD 19774) per person per year). The calculated incremental cost increase of dialysis in an urban centre for a person who has relocated from a remote or very remote area is $10,785 and $15,118 per year, respectively (192).

v. We recommend kidney health services incorporate dialysis services (for example, mobile dialysis) to facilitate patients to have dialysis where it is not otherwise available. This service should include adequate transport, accommodation, and workforce support to ensure equity *(Strong recommendation).*

Community voice

Within the context of the known need for dialysis services on Country in remote locations (see above), mobile services were acknowledged by the community as valuable services where permanent facilities were unavailable (2, 3, 189). However, patients express the desire for more frequent services of longer duration. Visiting their communities allows people to connect with family, see their land and fulfil cultural commitments (194). The importance of respite dialysis services, when coordinated with significant cultural events, particularly funerals, celebrations and meetings such as land council meetings, was paramount as it allowed people who would otherwise have missed out on these due to their health needs to participate (194).

"Get a truck for us in our own place – a dialysis truck" (First Nations participant, Kalgoorlie).

"It's difficult to keep our spirits up without spending time on country and with our family and loved ones" (First Nations participant, Ceduna)

Clinical evidence

One qualitative analysis (194) and one case series (abstract form only) (91) of mobile dialysis units in South Australia and the Northern Territory have been published. The data identified that patients forced to relocate for their dialysis suffered a significant burden of grief, loss, shame and dispossession due to the dislocation and the need to have dialysis on the 'wrong Country' (194). Being able to access respite dialysis on Country (in remote locations) through mobile dialysis services was reported by patients to improve happiness and quality of life and enhance relationships with dialysis staff. Improvements in patient engagement with and autonomy over care and significant improvements in social and emotional wellbeing were described by staff (194). Across the Northern Territory, 96 dialysis treatments across 12 remote communities were conducted without needing emergent medical evacuation (91). Across the Northern Territory, 96 dialysis treatments across 12 remote communities were conducted without needing emergent medical evacuation (194) (Summary of Findings Table D14). There has been limited evaluation of other respite dialysis services.

Certainty of the evidence
The certainty of the evidence was downgraded to low. The studies exhibited methodological limitations, and there were concerns about the precision due to the limited data available. The studies were published prior to the CONSIDER Statement (50) or the Aboriginal Quality Appraisal Tool (49). There were some concerns about the historical application of the involvement of First Nations Australians in the research processes of both studies.

Cultural safety considerations
Dialysis services facilitating First Nations Peoples to travel home benefits First Nations communities. It allows patients, some of whom are Elders of their communities, to remain connected by attending funerals and cultural events, allowing knowledge to be passed on and strengthening communities. There is the opportunity for health messages to be concurrently passed down to the younger generation, and community members, particularly the younger generation, benefit from having their family and community members come home. Mobile services have a role in health promotion and can educate the communities on what dialysis is and what it involves (194).

This service provided a privileged cultural experience for staff, increasing cultural safety beyond what was experienced in other forms of cultural awareness training, with lasting effects (194). In this setting, patients were the teachers of culture, empowering patients, and their communities to level the power imbalance otherwise present in mainstream health services. Deeper levels of understanding among staff of the dislocation experienced by patients resulted in improved communication, increased trust and enhanced engagement with First Nations Peoples (194).

Cost, equity, and resource considerations
Barriers to a successful service included a lack of coordination and use of local knowledge, including the timing, frequency, and duration of trips. Inadequate staff supports, including appropriate accommodation, workforce planning, orientation, and clinical and technical support, were barriers to sustainable service. A lack of provision of patient transport and accommodation and poor communication of the timing of trips impacts equitable access to the service. Some patients missed out on trips as they did not have the financial capacity to organise transport. They had no family left in their communities, or their families were anxious to have them stay due to their illness and therefore had no accommodation (194).

w. We recommend the availability of First Nations Australians specific and co-designed programmes to address the social and emotional wellbeing of people undergoing kidney replacement therapy *(Strong recommendation).*

Community voice

There is a large body of evidence of the psychological impact that kidney failure and kidney replacement therapies have on First Nations Peoples (151, 188, 191, 194, 195). First Nations Peoples have resilience and tenacity when dealing with an overwhelming burden of illness within their communities and when accessing and navigating a health system that is racist and discriminatory. As described by First Nations Peoples living with kidney failure, the impact is profound isolation and psychological distress (195). First Nations Australians, dislocated from their Country and communities for their dialysis, describe commencing dialysis as 'the biggest shock of your life' and negative feelings such as deep sadness, loneliness, and homesickness (188). The consultation process highlighted the psychological and emotional distress associated with kidney failure and kidney replacement therapies, particularly dialysis, and the need for these to be addressed through programs developed by and for First Nations Peoples as part of routine, holistic care (2).

"I always feel drained, and its hard explaining to family and getting them to understand why. They think just because I'm on dialysis, I'm alright." (First Nations participant, Brisbane)

"I hate this place. All it is for me is misery" (First Nations participant, Dubbo)

"People alone don't have enough support. Some can't feel their own signs. It's dangerous when no one available to help." (First Nations participant, Dubbo)

"Breaks the whole family down, breaks you down. Everything is impacted." (First Nations participant, Lismore)

Participants in the community consultations recommended simple measures such as an improved physical environment and atmosphere to make the dialysis centre more welcoming. For example, including First Nations artwork in dialysis centres and allowing people receiving dialysis to select music.

Clinical evidence

A systematic review of models of care for First Nations Peoples living with kidney failure found one RCT (196) assessing the efficacy of the Stay Strong Wellbeing digital Application (SSA), which was adapted and co-developed with First Nations communities. The 'app' aims to improve the mental health and well-being of First Nations Peoples on dialysis. This study found that for those with moderate to severe symptoms of distress or depression, there was a significant decrease in psychological distress scores (K-10) for both the SSA (mean difference −6.8 points (− 10.2, −3.5) and a control app followed by a delayed application of the SSA (mean difference − 8.2 points (− 11.3, −5.1) at six months. Similarly, there was a reduction in depression scores (PHQ-9) at both 3 and 6 months for the SSA (3 month mean difference −4.1 points (− 6.4, − 1.8) / 6 month mean difference −4.7 points (− 7.0, − 2.4)) and the control / delayed SSA (3 months mean difference −3.5 points (− 5.6, − 1.5) / 6 month mean difference −3.2 points (− 2.2, − 1.2)). No significant differences were observed in quality-of-life scores or dialysis attendance (Summary of Findings Table D14).

Certainty of the evidence
There were methodological concerns around reporting selected results for this RCT which had a high risk of bias. Assessment through a First Nations lens found it performed well using the Aboriginal Quality Appraisal Tool (49), with no concerns. The certainty of this evidence remains low. However, given its strong and consistent coherence with the community voice and with little harm associated with its use, we strongly recommend implementing programs co-created by First Nations communities to improve mental health and wellbeing.

Cultural safety considerations
To First Nations Australians, health is broader than the absence of disease (197). Addressing the emotional and social health of First Nations Peoples receiving kidney replacement therapy will ensure health is provided according to the First Nations perspective. Considering all physical, emotional, social, and spiritual components may help improve First Nations Peoples receiving dialysis care and quality of life.

Cost, capacity, equity, and resource considerations
No studies have evaluated the cost-effectiveness of models of care designed to address the social and emotional well-being of First Nations Peoples requiring kidney replacement therapy. The Working Group recognises that this recommendation will place an increased demand on the health workforce. The guidelines also recommend (recommendation h) expanding the capacity of the First Nations health workforce, who will likely be involved in delivery programmes of care that are culturally safe for First Nations Peoples receiving kidney replacement therapy.

x. **We recommend that First Nations Australians have access to dedicated multidisciplinary teams for the management of kidney replacement therapy. Development of multidisciplinary teams including, First Nations doctors and/or nurses, Aboriginal Liaison Officers, Aboriginal Health Practitioners and/or First Nations peer navigators should be a priority to health services *(Strong recommendation).***

Community voice
The community reported the time of work-up for and commencement of dialysis as a critical time in the CKD journey. During this time, while patients are suffering a significant burden of illness, they require multiple interactions with health care systems, including multiple appointments, dialysis education sessions, surgeries and initiatives for creating and monitoring dialysis access, and finally, the commencement of dialysis. There is a significant need for culturally safe support in navigating the health system during this time (2, 3). The use of a multidisciplinary team (MDT), which includes First Nations Peoples, to streamline and manage the creation and monitoring of dialysis access, including combining and coordinating appointments, is essential. Increasing the availability of First Nations Health Practitioners and First Nations Liaison Officers and ensuring they are considered an integrated and critical part of the multidisciplinary team within mainstream health services is a community priority (2, 3). The inclusion of First Nations Health Workers is fundamental to improving the cultural safety of health care systems and will work towards decreasing institutional racism (98, 101, 103). There is a ubiquitous community voice of the importance and value of the lived experience of CKD. The value of roles such as peer navigators, where First Nations patient experts

are employed to guide and support other First Nations patients through the journey, was put forward at every consultation.

"*having expert patients being involved in pre-dialysis education"* (First Nations participant, Cairns)

"Tried my best (to understand the Doctors), but the Indigenous health workers were the ones that really supported me." (First Nations participant, Brisbane)

"Would be better with an AHW or home visit to have a cuppa and a yarn." (First Nations participant, Lismore)

"It took me a while to understand why I was in Perth for six months. I cried at night away from my kids and grandkids. That was very hard for me. After associating with other patients in Perth, made me feel a lot better about my situation because I found other people that have been through the same and helped me understand things better" (First Nations participant, Broome).

"The hospital should employ an [Aboriginal experienced kidney patient] to explain [to] Aboriginal people about dialysis and what is a kidney transplant, and what are the consequences of these treatments" (First Nations participant, Adelaide).

Clinical evidence

A systematic review of models of care for First Nations Peoples living with kidney failure found three observational studies involving dialysis access with an MDT approach. Two studies analysed vascular access, one using an MDT approach (198) and one (abstract only) with a vascular access coordinator within an MDT (199). These studies found the MDT approach significantly increased arteriovenous fistulas patency at 12 months (log-rank statistic 8.18; p=0.0042) (198) and the number of arteriovenous fistulas (slope 0.6/month; p<0.05) (199). A third study (200) analysed peritoneal dialysis access creation using a nephrologist inserted catheter and an MDT approach, which involved a First Nations health worker. This study reported 12-month catheter survival rates similar to that seen in the literature but was at critical risk of bias due to the absence of a comparator group (Summary of Findings Table D14).

Certainty of the evidence

Both studies were interrupted time series and therefore non-randomised with a moderate risk of bias. Appraisal through a First Nations lens showed that while both studies were published before the Aboriginal Quality Appraisal tool (49), there were major concerns due to a lack of First Nations governance, participation, and capacity building.

Cultural safety considerations

Including First Nations Peoples within MDTs benefits mainstream health services and the First Nations community. These roles must be fully understood and valued by mainstream health services to be successful. Integration of First Nations team members increases the cultural safety of a multidisciplinary team and the broader health system (98, 101, 103). It is capacity building for First Nations Peoples and their communities.

Cost, capacity, equity, and resource considerations

There is no evidence of the cost benefits of an MDT explicitly designed to support First Nations people, and MDTs are now a standard of care across most kidney health (renal) units. An integral part of this recommendation is the inclusion of First Nations Peoples within these teams to provide more equitable and culturally safe care for First Nations people. However, access to this expertise is currently limited, and further strengthening capacity in the First Nations workforce in kidney health is required for the recommendation to be graded as strong.

y. We suggest supported home dialysis models, such as community-based home dialysis, to allow First Nations Australians to access the benefits of home dialysis *(Conditional recommendation).*

Community voice

Mainstream health care services can be hostile and discriminatory places for many First Nations People. Dialysis, a high-intensity treatment requiring a long time spent within the health care system, is a particularly high-risk environment, with many describing anguish and discomfort associated with large dialysis units (151). Interactions with clinical staff are often negative due to poor communication and discrimination, which leave people feeling ignored and disrespected (151). Home dialysis was seen to have many potential benefits and was the preference for many First Nations Peoples. However, there was a need for additional support to make this a realistic option. Many people, for example, described fear around the responsibility of dialysing independently and the additional burden placed on their family (151).

"*We need 24-hour support when on home haemodialysis and peritoneal dialysis. When a problem occurs, a nurse needs to be on the ground in our communities to assist…"* (First Nations participant, Broome).

"*You cannot expect a lot of Aboriginal people to take on the dialysis responsibilities in their own homes. We need more support ... People have gotten used to being institutionalised. But if they had some encouragement, they could do it ... Because what we're doing wrong is taking our people out of country and breaking their cultural spirit, and this is wrong"* (First Nations participant, Lismore)

"Looking into the bag option or home dialysis so I can be with my family, spend more quality time with them." (First Nations participant, location not specified).

Alternative home dialysis models, such as community-based home haemodialysis, are not common in Australia but have, in First Nations populations of Aotearoa New Zealand, been considered more culturally safe than the mainstream model of care (92).

Clinical evidence

A systematic review of models of care for First Nations Peoples living with kidney failure found one cohort study (201), one case series (abstract form only) (202), and one qualitative study (92) evaluating the benefits of urban community-based home haemodialysis. Two of the three studies (92, 201) considered the New Zealand model, where-by an urban community house is owned and maintained by a non-government patient support society in collaboration with community users. The house is equipped with home haemodialysis equipment for independent use. This model was found to have no difference in crude or adjusted mortality ratios (MR) compared to conventional home haemodialysis (adjusted MR 1.48, 95%CI 0.64-3.40). Patients reported the model reduced the

burden of dialysis on themselves and their families and felt it offered them more freedom, flexibility, and control over their health. The benefits of creating an atmosphere of community support among house users were also reported (92). This model was felt to overcome some of the socio-economic barriers to care, support extended-hours dialysis and be more culturally acceptable for First Nations Peoples (92). Similar findings were reported in an Australian case series but with not as robust data (202) (Summary of Findings Table D14).

Certainty of the evidence
The certainty of the evidence of this recommendation is affected by the generalisability to First Nations communities in Australia. Each study had 35% (186), and 40% (201) First Nations participants. Both studies exhibited a moderate risk of bias. Through a First Nations lens, while published prior to the CONSIDER statement (50), there were concerns over an absence of First Nations governance, participation, and capacity-building reporting in the manuscript. The qualitative analysis (92) had minimal methodological concerns through a First Nations lens and had concerns with the degree of First Nations participation as was reported in the manuscript.

Cultural safety considerations
Facilitating home dialysis in supported environments is decolonising in nature. As described by the community during the KHA Yarnings and Catching Some Air consultations (2, 3), people want to be able to have treatment in their communities. Community-based dialysis addresses many social determinants of health that may act as barriers to accessing home dialysis modalities, such as housing, overcrowding, and stable and reliable water and power provision. Further, the peer support that community dialysis models may facilitate creates opportunities for patients and families to connect and may increase cultural and community activities.

Cost, capacity, equity, and resource considerations
An Australian cost analysis of community-based home haemodialysis conducted in 2010 (abstract form only) found that the model of care had a lower total operation expenditure (cost per/treatment per/year per/patient) than urban dialysis (202). Providing a community house as part of the model of care acts to directly address some of the socio-economic barriers, including home ownership, energy, and water supply, that contribute to the inequitable uptake of home haemodialysis in First Nations communities.

z. We recommend kidney health services utilise telehealth/video link models to augment face-to-face care for those living and receiving dialysis in regional and remote areas *(Strong recommendation).*

Community voice
The burden of travel, time spent away from family, difficulties and cost of transport and accommodation were highlighted in the community consultations as additional and often insurmountable barriers to care (2, 3). These factors contributed to non-adherence and failure to attend appointments and treatment. Coordinating appointments, including kidney care as part of chronic disease management, and ensuring care was provided within engaging, welcoming, and culturally safe environments were all recommendations from the consultation process. Minimising the need for travel and time spent away from home to receive care was seen as a priority (2).

Clinical evidence

A systematic review of models of care for First Nations Peoples living with kidney failure found one interrupted time series cohort study evaluating the safety of tele-haemodialysis models for the care of remote First Nations Peoples of Canada (203). This study of 19 adult Cree residents across two sites over 18 months found that a primary care supported tele-haemodialysis model made no significant impact on the quality of care received (as evidenced by mortality, blood pressure, haemoglobin, albumin, glycosylated haemoglobin, phosphate, parathyroid hormone, and fractional urea clearance (Kt/V)) when compared to standard of care. There was a suggestion of improved care utilisation, evidenced by a decrease in mean medication changes (2.2 [site 1] and 8.1 [site 2] (pre) v 1.8 [site 1] and 3.1 [site 2] (post) p=0.01). There was no change in dialysis attendance or hospital transfer (Summary of Findings Table D14).

Certainty of the evidence
The study was non-randomised and had a moderate risk of bias. Through a First Nations lens, while this study was published prior to the CONSIDER statement (50), there were concerns regarding an absence of First Nations governance over the research, prioritization methodologies or involvement reported in the study manuscript.

Cultural safety considerations
As outlined through the community voice, minimising time spent away from family and community is an important cultural consideration for First Nations Australians. A telehealth/video link model may minimise interruptions to cultural ways of being and living and improve attendance. It would allow patients to participate in important events without sacrificing their health care. Avoiding frequent travel allows people to continue employment and caregiving roles, which benefits both the individual and the broader community.

Cost, capacity, equity, and resource considerations
There has been little examination of the costs of telehealth/video links to augment face-to-face care for First Nations Australians receiving dialysis in regional and remote areas. However, out-of-pocket costs for patients will likely be reduced. Resourcing for primary care will need to be appropriate and provided to ensure the implementation of this recommendation.

Ungraded statements

- **There is insufficient evidence to recommend a standard approach for vascular access choice or management. A patient-centred approach based on local practices should be adopted and undertaken.**

Models of care for transplantation

Ungraded statements

- **Kidney transplantation should be considered and discussed as a treatment option for all First Nations Australians with chronic kidney disease requiring kidney replacement therapy.**

All First Nations Australians should be included in the shared decision-making process and be made aware of their suitability for transplantation.

- **There are ongoing studies regarding the most appropriate and effective models of care for transplantation that will inform the future development of guideline recommendations.**

First Nations communities in Australia have a great interest in kidney transplantation (81, 204). It is seen as the path most likely to allow them to return home and resume 'normal' family life. Due to ongoing practices of colonisation, First Nations Peoples living with CKD feel poorly informed and disempowered in pursuing transplantation as a treatment option (81). The workup process is complex and involves multiple interactions with mainstream health systems, which become barriers to successful transplantation for First Nations Peoples (205). These messages and the need for more education and better access to transplantation were heard across all of the community consultations (2, 3).

"I want to go home with a transplant, rather than going home in a coffin." (First Nations participant, Adelaide)

"It needs to go further than education – advocacy from the people caring for us is so important. Not just from the visiting nephrologists but local GPs right through to Aboriginal Liaison Officers and Social Workers. These people who we know and trust need to encourage and support us – we need those people to fight for us to get on the [transplant] waitlist." (First Nations Participant, Broome).

A systematic review of models of care for First Nations Peoples living with kidney failure PROSPERO Number (CRD42020207425) found very few studies considering models designed to improve access to or outcomes of transplantation for First Nations communities. An education and health promotion campaign designed to increase living kidney donor transplantation among Native American Peoples in the United States of America was identified in two studies (139, 140). The details of this programme, including its impact, are discussed in the Public awareness, education, and self-management sub-section of this guideline.

In New Zealand, The IMProvEmentTs in Live Organ Donations (IMPETRO) project (206) is a multi-faceted health service delivery improvement project aiming to educate, encourage and facilitate live donation for Māori and Pasifika people. The study is still underway, and while an abstract presentation of results has been promising, with increased rates of living kidney donation, there is not yet any formal published analysis. In Australia, the National Indigenous Kidney Transplantation Taskforce (NIKKT) is a government-funded initiative currently underway which is working to; a) establish the National Indigenous Kidney Transplantation Taskforce (NIKTT); b) enhance data collection and reporting; c) pilot initiatives to improve patient equity and access; and

d) evaluate cultural bias initiatives (207). In 2022, NIKKT published a report on cultural bias in kidney transplantation (71) and an associated policy brief. The report details relevant recommendations to the CARI Guidelines (Box 1). The NIKKT recommendations in the report detail considerable overlap to the CARI Guidelines recommendations. Further comparison and is detailed in Table 3.

Box 1. NIKKT Recommendation on models of care for transplantation

Recommendation 6. Fund, design and 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.

Table 3. Comparison between NIKKT recommendations (71) and the CARI Guidelines recommendations

NIKKT recommendation	CARI Guideline recommendation
1. Establish Indigenous Reference Groups in every transplantation unit to help codesign culturally appropriate pathways and models of care that are tailored to the needs of Aboriginal and Torres Strait Islander transplant recipients and candidates.	Recommendation b.
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).	Recommendation h.
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.	Recommendation h.
5. Implement and evaluate comprehensive and ongoing cultural safety training programs for all staff in transplant units and kidney health services.	Recommendation d.
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.	Recommendation z. CARI Guideline recommendation is focused on dialysis services.
8. Support and fund the further use of interpreters	Recommendation h.
9. Co-develop specific health promotion and health education resources and approaches on kidney transplantation with Aboriginal and Torres Strait Islander people.	Recommendation n.
10. Assess institutional racism within transplant units and kidney health services using an institutional racism audit tool.	Recommendation a.

Given the considerable work currently underway in the space, recommendations for models of care around kidney transplantation for First Nations Peoples in Australia will be published in a separate guideline later based on the outcomes. Including the programme of research Return to Country led by the Menzies School of Health Research.

WHAT DO THE OTHER GUIDELINES SAY?

The third edition of the National guide to preventative health assessment for Aboriginal and Torres Strait Islander People, developed by the Royal Australian College of General Practitioners and the National Aboriginal Community Controlled Health Organisation, provides recommendations on the prevention and management of CKD (208) (available here). Recommendations on screening, lifestyle initiatives, education, and management of blood pressure and blood pressure control are included, and these guidelines are in alignment and support and identify them where appropriate.

CARI Guidelines is also developing clinical practice guidelines on the management of CKD for Māori in Aotearoa New Zealand. Similar recommendations emphasise the need for health systems to address equity in care, provide appropriate cultural safety, and inclusion of family to support whānau goals are provided. CARI Guidelines now include equity in their evidence to decision frameworks for all clinical practice guidelines. Where relevant, CARI Guidelines will provide tailored recommendations for the management of CKD for Aboriginal and Torres Strait Islander Peoples, and Māori Peoples. For example, recently produced living guidelines on the management of lipid-lowering therapy in CKD has provided a separate recommendation for statin with or without ezetimibe therapy in First Nations Peoples (33).

SUGGESTIONS FOR FUTURE RESEARCH

Throughout the systematic review process, CARI Guidelines and the Working Group identified the lack of intervention studies to improve outcomes for First Nations Peoples. Additionally, most studies have had limited reporting of the engagement, governance structures, and prioritisation work undertaken for effective research with First Nations Peoples. Researchers need to conduct future studies according to standards in the Aboriginal and Torres Strait Islander Quality Appraisal Tool (49) and reported to the standards of the CONSIDER Statement (50). Collaborative approaches must be undertaken to ensure research must be conducted correctly, in partnership with First Nations Australian communities, particularly by non-Indigenous people. Including appropriate governance, prioritisation structures, relationships, and incorporation of First Nations knowledge will ensure that research will be respectful, culturally safe, and impactful.

Some suggestions for important research topics identified by the Working Group are listed below.

- Further cost-effectiveness analysis of transport and accommodation services provided for First Nations Australians with CKD is required.
- Future evaluation of patient preceptor/navigator programs are required.
- Further studies examining genetic associations with CKD in First Nations Australians
- Evaluation of Aboriginal and Torres Strait Islander Health Practitioners training programmes in kidney health should be undertaken to examine:
    - Aboriginal Health Practitioners knowledge and confidence
    - Impact on outcomes, including clinical endpoints and patient self-efficacy, and life participation
- Community-based and culturally appropriate education initiatives for preventative health measures should be reviewed to identify successful strategies that could be applied to CKD care. There should be a particular focus on evidence on improving diet quality, addressing obesity, and smoking cessation.
- Further examination of the clinical outcomes and cost-effectiveness of community-based nurse-supported dialysis on Country models of care are required.
- Evaluations of initiatives to improve access to kidney transplantation and transplant outcomes among First Nations Australians. These studies are currently ongoing with the NIKKT and Return to Country projects.

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CONFLICT OF INTEREST

- DJ Tunnicliffe, S Bateman, M Arnold-Chamney, M Howell, S Jesudason, J Kelly, K Lambert, K Owen, L Rix, O Pearson, I Roberts, R Stirling-Kelly, A Yip, declare no relevant conflicts of interest.
- KM Dwyer is the current Clinical Director of KHA and Chair of the Clinical Advisory Board.
- G Wittert has received funding from Australian Health Practitioner Regulation Agency for Medico-legal reports. Honorarium for Journal Editor and International Advisory Board for Elsevier, as well as Bayer for an Advisory Board. Received research funding from Bayer and Lilly. None of these declarations were deemed relevant for the guidelines.
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