

Expert Clinician Panel Consultation Report

Consultation to inform the development of the Inaugural
KHA-CARI Guidelines for Management of Chronic Kidney
Disease for Aboriginal and Torres Strait Islander Peoples

Cover: 'My Kidney Journey' by Inawinytji Williamson



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Acknowledgements

In 2018, the Minister for Indigenous Health, the Hon. Ken Wyatt AM, MP, commissioned Kidney Health Australia to undertake consultations with Aboriginal and Torres Strait Islander community members around Australia, as well as health experts, service providers and peak bodies to inform the development of the inaugural Kidney Health Australia Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines for the Management of Chronic Kidney Disease among Aboriginal and Torres Strait Islander Peoples.

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The members of the Panel of Expert Clinicians provided expert input and recommendations via video and teleconferences, and written commentary. Kidney Health Australia thank the valuable contribution of the health professionals who donated their time to contribute to this report.

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Abbreviations

CARPA	Central Australia Rural Practitioners Association
CKD	Chronic kidney disease
ESKD	End-stage kidney disease
KHA-CARI	Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group
NACCHO	National Aboriginal Community Controlled Health Organisation
PEAK	Primary Care Education Advisory Committee for Kidney Health Australia
RACGP	Royal Australian College of General Practitioners
RSA	Renal Society of Australasia

Executive Summary and Key Recommendations

1. Comments on Existing Chronic Kidney Disease Management Guidelines

- 1.1. Guidelines are important supports for delivering best-practice clinical care
- 1.2. Clinicians commonly use local adaptations of national guidelines, particularly the KHA-CARI evidence-base
- 1.3. Existing Guidelines contain varying levels of Aboriginal and Torres Strait Islander-specific content and are of variable relevance to indigenous patients
- 1.4. Implementation of chronic kidney disease guidelines are limited by multiple patient, health professional and guideline-related factors that stem from inadequate communication (particularly language and cultural barriers), education and awareness of CKD care

2. Recommendations to Improve Guideline Usefulness and Implementation

- 2.1. Address the cultural, spiritual and psychological health dimensions of kidney disease for Aboriginal and Torres Strait Islander peoples through direct consultation with communities and patients
- 2.2. Support the Guidelines with innovative, culturally safe and appropriate education resources that address language and literacy barriers and are developed in partnership with local patients and community
- 2.3. Ensure compact, accessible, easy to use format with simple algorithms for integrated chronic disease care useable by all health professionals
- 2.4. Develop Guidelines that are adaptable to local needs and variations, and facilitate individualised patient care
- 2.5. Develop and support local Chronic kidney disease champions through culturally appropriate education and training of health professionals and patient leaders
- 2.6. Utilise Technology platforms where possible to promote and support Guideline use but remain aware of infrastructure limitations in some indigenous communities

3. Gaps in Existing Knowledge where the Evidence-base must be Strengthened

- 3.1. Workforce education and support needs and strategies for retention of staff
- 3.2. Geographical Variation in Chronic kidney disease risk and models of care
- 3.3. Culturally appropriate Patient and Community Education Strategies
- 3.4. Strategies for Prevention of Chronic diseases in Aboriginal and Torres Strait Islander peoples
- 3.5. Managing CKD Stages 1-5 in Aboriginal and Torres Strait Islander peoples – developing models of care

4. Suggested Scope and Content of Guidelines

Guidelines to underpin all aspects of CKD Management for Aboriginal and Torres Strait Islander Cohorts:

- 4.1. Strategies for culturally appropriate CKD education and support
- 4.2. Psycho-social and spiritual support for Aboriginal and Torres Strait Islander peoples living with CKD
- 4.3. Strategies for Health Professional Education and Support of Workforce
- 4.4. Models of care across all CKD stages

Guidelines for Specific Aspects of CKD Management

- 4.5. Chronic Disease Prevention in Aboriginal and Torres Strait Islander Populations
- 4.6. Screening for CKD – recommendations in the Aboriginal and Torres Strait Islander cohort
- 4.7. Child and maternal health including the first 1000 days of life – reducing the impact on future CKD risk
- 4.8. Management of Acute Kidney Injury in Aboriginal and Torres Strait Islander peoples
- 4.9. Management of Pre-dialysis CKD stages
- 4.10. Management of Transition to End-stage CKD care in Aboriginal and Torres Strait Islander peoples
- 4.11. Management of ESKD – Dialysis Care and Transplantation
- 4.12. Management of end-of-life care in patients with ESKD

A. Background

Since 1999, Kidney Health Australia and the Australian New Zealand Society of Nephrology (ANZSN) have partnered to fund The Kidney Health Australia-Caring for Australasians with Renal Impairment guidelines group (known as “KHA-CARI”) to produce evidence based clinical practice guidelines for the management of chronic kidney disease in Australia and New Zealand. More recently, additional funding has been provided via the BEAT-CKD NHRMC project grant.

In 2016, the KHA-CARI Steering Committee prioritised an Indigenous specific guideline in response to a persistent and disproportionate burden of chronic kidney disease (CKD) among Aboriginal and Torres Strait Islander and Maori peoples. KHA-CARI aims to generate a best practice guideline to improve processes and outcomes of care for those Aboriginal and Torres Strait Islander peoples living with kidney disease. In doing so, KHA-CARI identified the importance of partnering with patients and their carers to ensure that any guideline is relevant and meaningful for both patients and clinicians. The engagement of consumers and communities as part of the KHA-CARI clinical guideline development is a new component to the existing methodology. Engagement, consultation and participation of Aboriginal and Torres Strait Islander peoples and communities is very important to ensure the appropriateness, effectiveness, integration and impact on quality of health outcomes.

In 2017, Kidney Health Australia, as the peak consumer organisation, committed to obtain funding for and subsequently undertake a consultation process in Australia to inform the development of new clinical guidelines for the “*Management of chronic kidney disease (CKD) among Aboriginal and Torres Strait Islander Peoples*” (“The Guidelines”). Complementing the consultation to be conducted by Kidney Health Australia, the “Catching Some Air” project team led by the Lowitja Institute committed to undertake these consultations in the Northern Territory, and a separate consultation process is being undertaken in Aotearoa New Zealand with respect to Maori and Pacific Islander peoples.

In 2018, the Hon Ken Wyatt MP, Federal Minister for Indigenous Health, awarded a grant to Kidney Health Australia to undertake consultations with Aboriginal and Torres Strait Islander community members around Australia (except Northern Territory sites covered by Catching Some Air project), as well as health experts, service providers and peak bodies to ensure the new guideline is aligned with community preferences.



Goals for the Consultations

- Seek feedback and advice on the focus and content of new clinical guidelines and the priorities for clinical care.
- Seek feedback and advice on how best to translate the new clinical guidelines into culturally safe consumer information, tools and educational materials that will support implementation into efficient clinical practice.

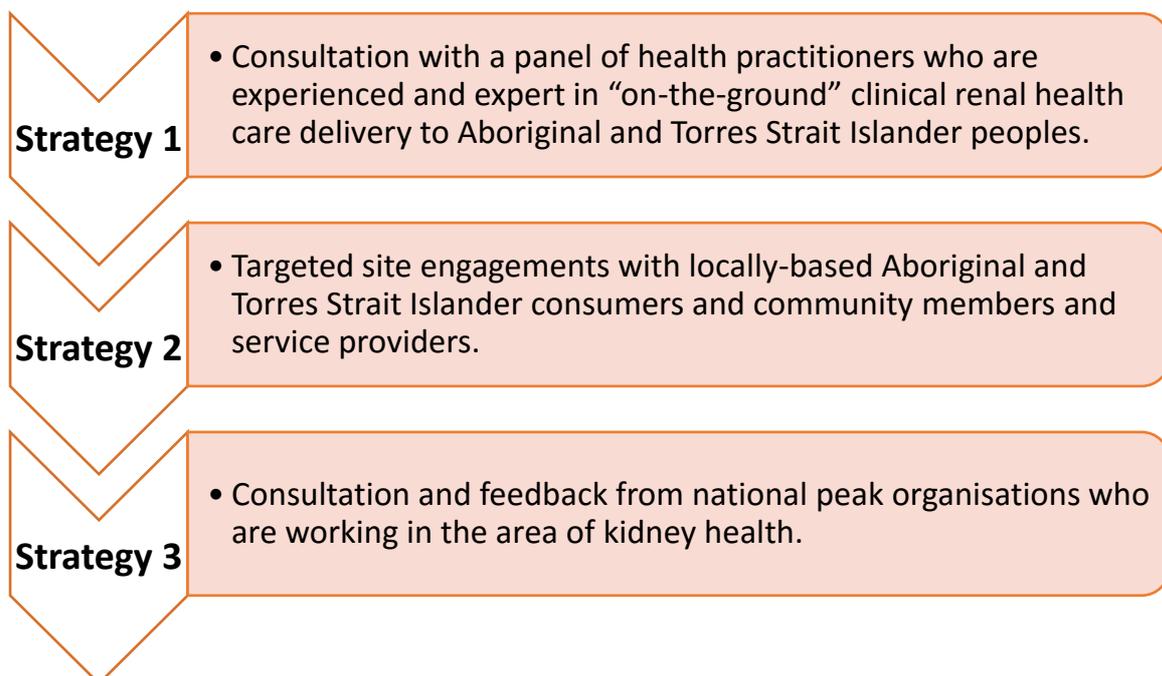
B. Kidney Health Australia Community Consultation Methodology

The consultation is designed to be wide and encompassing to facilitate maximum input from the people who are most likely to use and be affected by the use of the planned Guidelines. The consultation is intended to focus on what is relevant to the planned Guidelines.

The consultation is designed to complement and recognise the decades of activities by many others across Australia in the area of Indigenous Kidney Health research and community engagement.

Over-arching principles for consultation are outlined in detail in Appendix A (*D Duff, S Jesudason, M Howell and JT Hughes. A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease. Renal Society of Australasia (RSA) journal 2018; 14 (3): 84-88*). As outlined in this joint statement on methodology, the consultation findings will complement the Catching Some Air project and align with the KHA-CARI Guidelines development principles.

The consultation involves the following strategies:



The details of these consultations are outlined in appendix A.

This report outlines the outcomes from consultations for **Strategy 1**.

C. Methodology for the Expert Clinician Consultation

WHY: The purpose of this consultation was to have broad, multi-disciplinary input, feedback and engagement from health practitioners “*at the coal face*” of primary, secondary and tertiary renal care.

The health professionals who are utilising existing mainstream or Aboriginal and Torres Strait Islander guidelines in actual practice are best placed to advise the KHA-CARI Guidelines Writing Group on *practical and tangible recommendations* guidelines development for Aboriginal and Torres Strait Islander peoples.

This expert clinician consultation will complement the community consultation with indigenous people and peak bodies (strategies 2 and 3).

WHO: Kidney Health Australia identified expert, community-based health practitioners from metropolitan, rural and remote regions, who were actively involved in clinical care delivery for kidney disease. Also, primary health care professionals in all states and territories were invited to participate. The panel members were encouraged to identify other professionals in their jurisdictions or elsewhere in Australia who they felt should be engaged in this activity. All additional health professionals suggested by panel members were invited to participate. Some invited health professionals were unable to personally participate and therefore nominated a proxy or alternate delegate. Additional health professionals provided input into the draft report, which was distributed widely for consultation. In the writing of this report Kidney Health Australia has reported the stated views of the panel contributors, which may not be the views of all contributors or clinicians. A broad range of views have been represented. All participants in the consultation process for this report are listed in Appendix B.

HOW: The consultation process occurred between June–December 2018. The framework of questions for this consultation (Appendix C) was developed by A/Prof Shilpa Jesudason (KHA), Dr Martin Howell (KHA-CARI) and Dr Jaquelyn Hughes (KHA-CARI Writing Group Co-Chair). Panel members volunteered their time for tele/video conferences (co-chaired by Associate Professor Shilpa Jesudason, Kidney Health Australia, and Dr Martin Howell, KHA-CARI) or direct discussions with A/Professor Shilpa Jesudason and Ms Dora Oliva or via written commentary on the draft report. Tele/video conferences were recorded and transcribed by Kidney Health Australia Staff, Ms Karen Barfoot and Ms Joanna Stoic, and key concepts and recommendations were collated for this report.

Contribution of the Members of the Expert Panel of Clinicians



Advise on the use of existing mainstream and/or Aboriginal and Torres Strait Islander clinical guidelines, barriers/facilitators of use and gaps in care.



Advise on the scope, content and structure of the proposed guidelines.



Advise on best practice for implementation of clinical guidelines and translation into practice.



Feedback on a draft of this report.



Assist in identifying sites, local leads or contacts for Strategies 2 and 3 of this consultation.

D. Chronic Kidney Disease Management Guidelines Used in Current Practice

The panel identified several resources that were utilised regularly in clinical care of Indigenous patients with CKD across Australia.

The main focus of existing guidelines was early detection of CKD and management of early stage CKD for primary care services, with minimal content on pre-dialysis and end-stage kidney disease management.

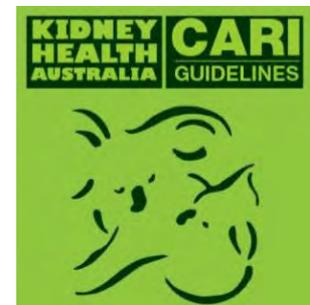
NB: This describe resources highlighted specifically by the expert panel and is not a summary of every resource used in Australia.

1. KHA-CARI Guidelines

www.cari.org.au

The KHA-CARI Guidelines are not indigenous-specific and cover topics related to:

- Chronic Kidney Disease
- Dialysis
- Transplantation



The KHA-CARI Guidelines background and Guidelines Writing process is described in detail on their website. Access to the Guidelines is free. The website has over 1000 unique visitors per month (KHA-CARI Annual Report 2017).

Awareness: Awareness of the KHA-CARI Guidelines was high among nephrologists, but other health professionals felt there was less awareness of these guidelines by non-nephrologists. The KHA-CARI guidelines provide a valuable base for practice but are less known in the primary care community caring for indigenous patients. The lack of indigenous-specific content was felt to reduce awareness among health professionals engaged in care of Aboriginal and Torres Strait Islander patients. In 2009, KHA-CARI produced guidelines for Diagnosis, Prevention and Management of Chronic Kidney Disease in Type 2 Diabetes in conjunction with the Diabetes Australia Guideline Development Consortium, however Aboriginal and Torres Strait Islander cohorts were not specifically addressed.

Barriers to Awareness and Use: The panel acknowledged that these evidence-based guidelines were very important and should underpin recommendations for care of Aboriginal and Torres Strait Islander patients. However, it was noted that often evidence-based guidelines published in journals or on websites are not necessarily referred to by all healthcare professionals. Guidelines that are in hardcopy format in clinics were more likely to be utilised.

Those that were aware of the KHA-CARI guidelines considered them very academic and perceive them to be information for specialist clinicians and “not routinely used in the field”. It was acknowledged that a more “useable” format is desired by health professionals.

The lack of consumer versions of the guidelines enabling patients to understand the management of their disease was raised. The recent production of consumer versions of guidelines by KHA-CARI was welcomed as an important initiative.

2. Kidney Health Australia Chronic Kidney Disease Management in General Practice handbook (the ‘Handbook’)

<https://kidney.org.au/health-professionals/prevent/chronic-kidney-disease-management-handbook>

Chronic Kidney Disease (CKD) Management in General Practice

Guidance and clinical tips to help identify, manage and refer patients with CKD in your practice



3rd Edition 2016 | www.kicat.org.au

Prevent, Detect, Support.



The Chronic Kidney Disease (CKD) Management in General Practice handbook is in its 3rd edition and a 4th edition will be released in 2019. Content of the Handbook is determined by the multidisciplinary Primary Care Education Advisory Committee for Kidney Health Australia (PEAK). The content is derived from the evidence-based recommendations from the KHA-CARI Guideline on “Early chronic kidney disease: Detection, Prevention and Management” (Johnson DW, 2013), as well as current literature and expert opinion. The Handbook provides summarised advice on detection and management of early CKD (to stage 3a/b). Kidney Health Australia has surveyed users of the Handbook who indicated the resource is well utilised within general practice including nurses. It is the highest downloaded resource from the Kidney Health Australia website. The App version of the Handbook (the CKD-Go App) is one of the most utilised medical Apps in Australia.

Awareness: The Handbook was noted by the panel to be a widely used resource in Indigenous Primary care. It was considered to be a practical and accessible document, used widely “out in the field” due to its easy-to-use style and hard copy format. Key information is quick to locate. The CKD staging poster and colour-coded action plans (based on the Handbook) are considered a very useful quick reference guide by general practitioners, especially regarding when to refer to a nephrologist. Apunipima Cape York Health Council promotes the Kidney Health Australia Handbook to general practitioners including locums in North Queensland and remote areas. The Handbook was utilised by medical, nursing and allied health staff, as it was simple to read and use.

Barriers to Awareness and Use: Overall, an expansion of indigenous-specific content was strongly recommended. The panel had varied comments on Indigenous-specific content within the handbook, ranging from “lacking” to “good”. The Handbook lacked of recognition

of cultural, spiritual and psychological health dimensions of kidney disease, which is particularly relevant to indigenous patients (but also to all patients).

To address this gap, organisations in some regions of Australia have drawn on KHA-CARI guidelines and the Handbook to develop local protocols and/or manuals that fit with local conditions and practice (see below).

3. RACGP / NACCHO National Guide to a Preventative Health Assessment for Aboriginal and Torres Strait Islander peoples

<https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/national-guide>

The Royal Australian College of General Practitioners (RACGP) together with the National Aboriginal Community Controlled Health Organisation (NACCHO) have developed the National Guide to a preventive health assessment for Aboriginal and Torres Strait Islander peoples, now in its third edition. This broad-ranging, practical resource for primary care management includes a brief, evidence-based chapter on key recommendations for CKD management, aligned with the RACGP Red Book (*Guidelines for preventive activities in general practice*), Kidney Health Australia Handbook and KHA-CARI Guidelines. The RACGP and NACCHO promote these guidelines, and in 2018-19 have undertaken a review of implementation strategies to facilitate integration into clinical practice and better care.

Awareness and Use: Some health service representatives were unaware of this national guide, while others knew of it but indicated it was not used locally. In some areas, the national guideline is adapted to suit local settings and requirements, with many working locally on how to best deliver care. The kidney-specific chapter is very brief and key recommendations are contained within other guidelines and resources including the Kidney Health Australia Handbook.

4. CARPA Standard Treatment Manual – 7th Edition

<https://www.crh.org.au/the-manuals/carpa-standard-treatment-manual-7th-edition>

This manual of protocols on a very wide range of acute and chronic conditions was developed by the Central Australia Rural Practitioners Association (CARPA) and Centre for Remote Health, Flinders University. It was described by the panel as driven by GPs, informed by specialists, and is very specific to the Northern Territory (NT) catchment area and remote clinicians who may lack specific relevant training. The manual's section on CKD utilises information from the Kidney Health Australia Handbook and KHA-CARI Guidelines.

Awareness and Use: The CARPA manual is widely known and used in the NT, and some areas of WA and SA, and particularly in remote areas. Outside of the NT it remains well known in many jurisdictions along with other Remote Primary Health Care Manuals. Some panel members reported that due to the number of health conditions within the book, requests to increase CKD content to include specific kidney health issues have been declined. However, the eGFR study on the rate of progression is included. Expanding the Indigenous content within the handbook to include specific issues related to Indigenous health or developing a separate handbook would be advantageous.

The main resource used in the NT and many other remote regions are CARPA and related manuals. Importantly, their use is enshrined in legislation, in that nurses and Aboriginal Health Practitioners can only supply medications according to CARPA guidelines – any deviation from these guidelines requires medical input.

While the material on renal diseases is limited, general practitioners are expected to go beyond CARPA and remote Primary Health Care manuals when making decisions. This is where the KHA-CARI Guidelines would be most useful - not in replacing CARPA but going beyond CARPA to advise on complex management issues in renal disease.

5. The HealthPathways Community Care Plans

www.healthpathwayscommunity.org

HealthPathways is an initiative led by Primary Health Networks (PHN) in conjunction with Local Health District (LHD) and Local Health Networks (LHN) across Australia and in other countries. Via an online portal, HealthPathways is providing general practitioners and other health professionals with easy access to comprehensive, evidence-based assessment, management and localised referral resources, for approximately 500 specific health conditions. Adaptation of HealthPathways content for specific jurisdictions occurs through collaboration of primary and specialist services, to develop models of care suited to the local context.

Awareness and Use: The Web-based nature of HealthPathways enables these to be easily maintained, updated and accessed, although access requires pre-registration and is not open. Online-only access is not always useful in some remote areas. There is substantial variation between jurisdictions with respect to the development of CKD-specific pathways, and they are not comprehensive. Overtime, the importance of these guidelines is likely to increase in guiding clinical practice at a local level, addressing resources, availabilities and needs.

6. Local Protocols for CKD care:

Several panel members reported that their local jurisdictions had developed their own protocols or guidelines for care of Aboriginal and Torres Strait Islander patients with CKD. Awareness and use of these resources are largely limited to those jurisdictions. Local/regional adaptations were considered more useful than the KHA-CARI guidelines or other resources

because they are a better fit with local practices and conditions, and therefore more used by the primary care health workforce (GPs, nurses, healthcare workers).

For example, The Kimberley Aboriginal Medical Services (KAMS) and WA Country Health Service (WACHS) have developed multiple protocols including one for CKD, which is used like their 'bible' and follows the Kidney Health Australia Handbook and KDIGO Guidelines closely, but adapted for Kimberley populations. These adaptations incorporate local epidemiology (screening) and referral pathways affected by limited visiting services, time, and distances.

The Apunipima Cape York Health Council's Chronic Conditions Manual: Prevention and Management of Chronic Conditions in Australia in conjunction with the Royal Flying Doctor Service Qld has published the Chronic Conditions Manual: Prevention and Management of Chronic Conditions in Australia <https://publications.qld.gov.au/dataset/chronic-conditions-manual>

This has a large section on CKD management drawn from the KHA-CARI Guidelines and Kidney Health Australia Handbook with minimal adaptation for Aboriginal and Torres Strait Islander patients.

Box 1: Summary of Existing Guidelines for CKD Management:

There is substantial variation across Australia with respect to CKD guideline use although the Kidney Health Australia CKD Management Handbook appears to be widely used in indigenous primary care. A pyramid effect is noted, with evidence-based national guidelines (KHA-CARI content) as the base although they have minimal indigenous-specific content. While these are directly used infrequently, they are interpreted and adapted for use in other national resources (Kidney Health Australia Handbook, RACGP Guidelines, HealthPathways) and as regional/local resources (CARPA manual, KAMS CKD protocol and Apunipima chronic conditions manual).

E. Barriers to the use of guidelines for managing CKD in Aboriginal and Torres Strait Islander patients

The panel highlighted a range of issues that, in their experience, had influenced the ability to implement guidelines in Indigenous chronic disease care. The panel reflected that many of these concepts had been raised over many years by multiple groups, however tangible action had been slow in many areas.

1. Patient-related factors

Awareness of Early Stage CKD:

- The panel agreed that getting the concept of ‘early stage kidney disease’ across to Aboriginal and Torres Strait Islander patients is vital in managing the progression of kidney disease as promoted in CKD guidelines.
- Achieving early diagnosis of CKD (at stage 1-2) is a significant issue within the Indigenous community. Often patients only become aware of their kidneys or seek help when they reach CKD stage 3 or beyond.
- Awareness about primary and secondary prevention of kidney disease is low within the primary health care workforce and among kidney patients. Efforts to raise awareness of earlier stage CKD in Aboriginal Medical Services can be frustrated by healthcare workers’ perception that “they don’t die of Stages 1 or 2 [of CKD] so why discuss it”.
- In addition, competing health priorities may lead to early stage CKD being de-prioritised, even when other priorities are co-morbidities such as diabetes, which can lead to CKD.

Fear of Kidney Disease:

- At present there is little understanding among the broader health professional community regarding the psycho-social and spiritual support needs of Aboriginal and Torres Strait Islander peoples living with CKD. This should be a Guidelines priority.
- Health professionals may minimise early stages of chronic kidney disease.
- Guideline usefulness is hampered by the difficulties faced by health professionals when trying to educate patients to understand the importance of looking after their kidneys, without causing fear.
- Health professionals may minimise the severity of kidney disease in order to engage patients e.g. “you just got a little bit of kidney trouble” or “Your kidneys aren’t quite 100%”.

- The word ‘Disease’ always implies end-stage kidney disease even when used to describe early CKD stages. A diagnosis of kidney disease leads to a pessimism among patients, irrespective of CKD stage. This is a major barrier to strategies targeted at earlier stage CKD.
- Dialysis is almost always the main treatment that patients mentally associate with kidney disease at any stage, and this impedes focus on earlier preventative measures.
- Important messages can be lost or distorted when the patient feels the doctor is not taking a holistic approach or when the patient is “blindsided” by a health assessment which reveals a multitude of health issues.
- Patients may be overwhelmed when they attend health consultations for a specific problems or issue, but the subsequent comprehensive health assessment reveals many more problems.

Inadequate Communication of Guideline Recommendations to Patients:

- The western approach is to develop guidelines based on evidence and apply these consistently to all persons. This approach is not culturally aware or respectful, and may cause harm to patients or disengage patients from their health care.
- The terminology used within the guidelines is often not suitable for translation to Aboriginal and Torres Strait Islander peoples. For example, routine eGFR reporting has assisted in providing a language framework to use when explaining kidney disease but this is not useful in all patients due to language and understanding barriers.
- The benefits of chronic disease treatment are not always explained or are explained in broad terms that have little tangible meaning. This is particularly relevant for asymptomatic disease states.
- Inadequate communication is a central root cause of perceived patient non-adherence, and perpetuate unfair judgement of Indigenous patients by health care providers.
- Aboriginal people respond better to intergenerational learning. Their knowledge is obtained through first-hand (family/personal) experiences. Addressing the care needs of indigenous patients without inclusion of family and support persons can limit the success of the interaction, and may lead to lack of understanding about why certain treatments or interventions are recommended. Decision-making often requires further family and community involvement.

Biological Variations:

- The panel did not strongly feel there were significant biological variations between Indigenous and non-indigenous patients that would preclude the utility of general CKD

guidelines. A lack of research with Indigenous groups to explore biological variability was noted.

- Transplantation (especially tissue typing and organ matching) was one area where biological variation is likely to exist and this should be addressed in any Guidelines related to transplantation care.
- The treatment pathways for early stage kidney disease were thought to be the same for all patients.
- There was some consideration that disease progress may be more aggressive in Aboriginal and Torres Strait Islander peoples especially for diabetic kidney disease.
- There is no clear evidence on variation in drug metabolism for Indigenous patients, but it was noted that research is occurring especially with immunosuppressive agents.

Demographic and Logistical Issues:

- Substantial logistic issues were identified that might impede best-practice clinical care and these should be considered when planning guidelines implementation.
- Geographical disparity and travel burden were considered major issues limiting access to care. New initiatives to support dialysis care in geographically remote areas were welcomed as potential facilitators of better early-stage CKD care, but the model is yet to be fully tested and does not address regions that are less than very remote, which is where the bulk of the population resides.
- Health professionals noted there is a real “battle” between an individual’s desire to seek health care and desire to remain within community. Patients are constantly forced into making this choice to the detriment of their health.
- There are also important socioeconomic burdens for Aboriginal people, and it was noted these have been outlined in the Renal Road Map developed by Minister for Indigenous Health, the Hon. Ken Wyatt AM, MP. Renal care should be approached in a holistic manner but it was acknowledged these Guidelines cannot address all relevant social and demographic issues that impact on kidney care.

2. Health Professional-related Factors

Health Professional Communication:

- Inadequate training regarding culturally appropriate communication with Aboriginal and Torres Strait Islander patients can lead to difficulty in implementing guideline recommendations due to patient disengagement and frustration on both sides.

- Health professionals may not have time or capacity to undertake extensive patient education. This is particularly important for asymptomatic conditions that require drug therapy (for example hypertension, proteinuria).
- Language barriers are also a source of frustration for health professionals. Health professionals may not have the ability to access interpreters or utilise them appropriately or repeatedly.
- It is particularly worrisome that specialists often describe Primary Health Care in negative terms. It is an issue as it contributes to the view that the Primary Health Care sector, and in particular the Aboriginal Community Controlled Health Service sector, is failing. This needs to be addressed in these guidelines and in ongoing work.

Applying Guidelines to Individual Patients:

- Guidelines should facilitate the contextualisation of evidence-based medicine but are often too prescriptive.
- While guidelines may outline best-practice care, the limitations of guidelines application should be acknowledged – particularly for the indigenous cohort and setting.
- Clinicians want and expect to exercise their clinical judgment when treating the patient “in front of them”, and therefore guidelines that are rigid were unhelpful and less likely to be followed.
- A disconnect between guideline recommendations and what actually occurs in practice was noted.

Competing Pressures on Health Professionals for Chronic Disease Care:

- The panel emphasised that health professionals have many competing diseases to address, time-pressures and lack of resources compared with demand which are all major barriers within the primary and secondary care space.
- Health professionals may be overwhelmed by the range of chronic diseases to address, therefore streamlining guideline recommendations was recommended.
- Kidney health should be part of a holistic management consultation for diabetes, cardiovascular disease and other chronic disease (see below).
- Even though the “competing” chronic diseases are linked with kidney disease, the panel noted some health professionals do not see prevention of kidney disease as a top priority, as patients “do not die of stages 1-2 CKD”.
- Best-practice recommendations around disease prevention, or slowing progression (for example, blood pressure targets), were considered harder to implement than

recommendations for acute management of active disease (for example referral to tertiary services for end-stage CKD care).

3. Guideline factors

Integration of Chronic Disease Guidelines:

- Cohesive guidelines that incorporate other conditions that share risk factors and treatments, particularly diabetes, hypertension and cardiovascular disease, was strongly encouraged by the panel.
- Guidelines that exist in disease “silos” or “divide the body” were less useful.
- The usefulness of diabetes / hypertension / cardiovascular disease / infection guidelines would be enhanced by consistent inclusion of information about the identification and treatment of kidney disease within those disease states.
- Mainstream services find it challenging to read multiple disease-specific guidelines and keep up to date with new developments. Over time, overarching standards and guidelines should be developed on chronic diseases that share risk factors, which can be adapted locally and be referred to in disease-specific guidelines.

Format of Guidelines:

- Complexity, academic language, and difficulty of access were considered barriers to guidelines use.
- Rigorous synthesis of the evidence base in the format of the KHA-CARI guidelines was considered essential and unavoidable, however translation of this into easy-to-follow recommendations did not always occur.
- PDF documents and large folders were less useful than smaller handbooks that could be carried easily by health professionals in daily practice or located quickly.

Awareness of guidelines among health professionals – promotion and training:

- Guidelines were not always actively promoted to key health professionals “on the ground” – this was particularly noted for national guidelines.
- Health professionals involved in care of Aboriginal and Torres Strait Islander patients may not always receive education regarding how best to use guidelines in daily practice. Therefore, guidelines are developed and distributed, but in the absence of strategies and training for implementation, they are not followed.
- Guidelines were not always promoted to all levels of staff within health services, and could be considered something only doctors or experts used. Educating non-medical health practitioners about guidelines can improve uptake and embedding into practice.

Consumer Engagement in Guidelines Development:

- Guidelines are often developed without input from the patients and consumers most affected. The enhanced consumer involvement at KHA-CARI was welcomed.
- In the absence of appropriate and meaningful consumer engagement and consultation the Guidelines are likely to be poorly utilised.

F. Recommendations to Improve Usefulness and Implementation of Guidelines

The panel discussed a range of aspects to consider for developing useful CKD guidelines, including the format and delivery, accessibility, consumer engagement, healthcare professional engagement and technology. The panel was asked to consider approaches that had been successful and unsuccessful in their experience.

1. Format and Delivery

- The format and delivery will likely determine the success of the CKD guidelines.
- A compact, easy to use version of the guidelines to improve accessibility (without compromising the evidence base) will allow for greater utilisation “in the field”.
- Guidelines should be more economical in length, and offer health practitioners simplified treatment algorithms for CKD care integrated with other chronic disease conditions. This will create a more functional guideline for better utilisation and success.
- A unified document for chronic disease care will avoid confusion for health practitioners about where to find information and how to apply guideline recommendations for common risk factors for CKD, cardiovascular disease and diabetes.

2. Patient Resources, Education and Engagement of Aboriginal and Torres Strait Islander Patients and Communities

- It was considered essential to translate the guidelines into culturally and linguistically appropriate information for patients to help them navigate the CKD care process, understand the healthcare professional’s message, and communicate their wishes and decisions to the doctor.
- Supporting patient empowerment through provision of kidney health knowledge and facilitating appropriate questions regarding their treatment should be underpinned by resources to assist patients, their families and communities to become more informed and engaged in their CKD care.

Educational Frameworks and Resources:

- Consumers (patients, carers and community) should be involved to address language, cultural and educational issues and ensure the guideline recommendations are implemented in the ‘real-world’.

- Strengthening and evaluating the evidence-base regarding translation of guidelines content to consumers was highlighted as a key priority. Educational resources must have an evidence base demonstrating evaluation and successful use in Aboriginal and Torres Strait Islander cohorts.
- Aboriginal Educational Philosophy should be considered for all educational resources accompanying the guidelines. The '8 [Aboriginal] Ways of Learning' framework (Regional Aboriginal Education Team, Western area 2012, *8 ways: Aboriginal pedagogy from Western NSW*, RAET, Dept. of Education and Communities, Dubbo, N.S.W) has been widely utilised in Aboriginal education and provides a structure of teaching that is culturally competent, reflecting key processes (summary fact sheet <https://www.painaustralia.org.au/static/uploads/files/8-aboriginal-ways-of-learning-factsheet2-wfklwmnralub.pdf>). Non-verbal approaches, story-telling, pictorial learning maps, use of symbolism and connection with community are key aspects of “8 Ways” to incorporate.
- “Learning from each other” is a common form of learning for Aboriginal and Torres Strait Islander peoples by sharing of stories. The value of narrative (story-telling) as means of communication and learning was considered particularly important, particularly when it comes from someone who has kidney disease (see below re: patient preceptors).
- Information in the guidelines should be accessible to patients (written format, video, translated into languages). A multifaceted approach should occur to ensure the information is suited to varied settings – for example different communities, primary care settings, and hospital settings.
- While this is complex, different levels of health literacy should be catered for, with “layers” of information ranging from simple to more complex depending on the patient needs.
- Language barriers should be actively addressed, with a focus on trained interpreters and translated material. Local community input will assist this (see below).
- Novel / innovative means of communication with patients about kidney disease and kidney care should be developed. These may include:
 - Visually-based materials as useful adjuncts to written material. For example, the visual aid “Feltman®” is commonly used for teaching Indigenous Australians about diabetes management and the prevention of type 2 diabetes, and was emphasised as a well-evaluated and widely used tool for discussions about disease that could potentially be adapted to kidney disease.
 - Video content (with translations, animations).
 - Conversation cards to facilitate questions and enable health workers to identify key points for education and discuss common misconceptions.
 - Fact sheets and consumer versions of guidelines (as already prepared for recent KHA-CARI guidelines).

- Decision-support tools specific to the needs of Aboriginal and Torres Strait Islander patients and their extended family / community, developed and evaluated in conjunction with consumers

Family support:

- This was considered highly valuable in-patient education. A family centred care approach to healthcare is more impactful and successful.
- Family members at appointments can assist patients in the decision-making process. Inclusion of extended family is essential, as they are often involved in the care of patients. Although time-consuming, this process should be facilitated by health professionals. Cultural responsibilities have an impact on the ability to engage in health care.
- The KHA-CARI guidelines group should ensure the guidelines are supported by educational information for patients and their family members.

Patient Preceptors:

- The model of care practiced by The Purple House (www.purplehouse.org.au) was cited by panel members as an example of patient preceptorship aiding implementation of clinical practice recommendations and leading to improved health outcomes.
- The preceptors (patient navigators) were effective in providing support to other patients, and new clinicians and health workers working with Indigenous patients and communities. Within the NT, the preceptor role has evolved in to a paid position.
- The preceptor role strongly complements the roles of liaison officer, health worker, nurse, and nephrologist. They provide input on cultural safe care and aspects of delivering appropriate education within the context of the local community, addressing language and cultural barriers.
- In addition, preceptors can serve as local champions for kidney disease awareness.
- Survival on dialysis in Central Australia is the highest in Australia even accounting for younger age of onset of kidney disease. This is surprising given the poverty and difficult life circumstances in this region. Effective primary health care, social and cultural support along with increasing opportunities for either permanent or respite dialysis on country are likely to be factors in this positive outcome, along with the high standard of dialysis services.

Community Reference and Governance Groups:

- Ongoing local Community input and engagement (patient and health professional) was identified as a key facilitator of uptake of guidelines.

- Continued culturally appropriate communication to inform the community and demonstrate how the implementation of the guidelines is benefiting them is an important component of implementation of any practice change. Gaining support and engagement from the community will enable follow up and feedback to assess progress of implementation.
- Local Community Reference Groups also can advise healthcare professionals about cultural and other local factors that would enhance doctor-patient communication and health outcomes for patients with CKD, and ensure adaptations of the guidelines are relevant to the community.
- Engagement of State-wide renal and Aboriginal Health networks, Aboriginal leadership and governance groups, Aboriginal Community Controlled Health Organisations and Aboriginal Medical Services, and other governing bodies will also facilitate guideline adaptation and more coordinated implementation.

3. Facilitating Health Care Professional Use and Engagement

Individualised and Adapted Care:

- Guidelines should assist practitioners to make decisions, but leave room to individualise care based on circumstance and clinical skills. The ability to vary and adapt guidelines to individual or community context was viewed as highly important.
- Regional and local variations of the guidelines will ensure use within specific areas and demographic groups.
- Guidelines are useful when organically developed by the group they are intended for. An example is the CARPA Standards Manual which was driven by general practitioners. They are used widely and routinely with the NT areas for which it was specifically developed, and is also used by some regions of WA and SA.

Coordination of Chronic Disease Care:

- The Guidelines Writing Group should develop a multisystem approach by reviewing the evidence base across cardiovascular, diabetes, and kidney disease, to identify the common approaches in addressing these chronic diseases. For example, the next edition of the Kidney Health Australia Handbook will address diabetes, cardiovascular disease and CKD cohesively, in keeping with frameworks developed by the National Chronic Disease Prevention Alliance and other groups supporting integrated health reviews.
- At every possible point, the impact of CKD on other chronic diseases (and vice versa) should be highlighted and integrated into algorithms for care of Aboriginal and Torres Strait Islander patients.

Promotion of guidelines – Local Clinical Champions:

- It was noted that once developed, guidelines are not consistently promoted to health care professionals, particularly in areas of high staff turnover. Some local jurisdictions achieve awareness of guidelines more successfully but usually when there is a strong local clinical lead or champion for kidney disease.
- Local Community input and engagement (patient and health professional) was identified as a key facilitator of uptake of guidelines. The establishment and support of local clinical champions was considered an important aspect of guideline promotion and regular use.
- For example, the Kidney Health Australia Primary Care initiative “Kidney Health Australia CKD Ambassador Program” <https://kidney.org.au/ckd-ambassador> is designed to help practices become CKD Ambassador amongst their peers and patients, through supported implementation of the recommendations of the Kidney Health Australia Handbook. This program also facilitates measurement of impact of practice change through a “do and review” process. Although this new program is in a pilot phase and has not been developed specifically for indigenous health centres, it may develop as potential model for supporting local health professional CKD champions.

Promotion of Guidelines – Health Professional Education and Support and Workforce

- Resources should be provided to train health professionals to optimally use the guidelines, including a cultural safety module. This is particularly important for health services that are not experienced in indigenous care, but may see indigenous patients on occasion.
- Aboriginal Health workers should have specific training relevant to kidney disease (and chronic disease) and these Guidelines.
- There is great variation in how local Aboriginal Medical Services and Community Controlled Health Services function. Therefore, standards of care and clear pathways for guidelines implementation are recommended, and should be actively promoted.
- Aboriginal Health professional clinical care workforce issues will need to be addressed in the longer-term. High staff turnover in many indigenous health services, lack of trained and qualified local health staff and resource constraints are identified as potential limitations to be addressed. Clinicians suggested that Aboriginal Health professional clinical care workforce is an important priority to move forward.

4. Use of Technology to Support Guidelines

Access to Technology and Digital Platforms for Guidelines Content:

- Technological advance was identified as a both a key enabler and potential barrier for successful guideline use.

- Thoughtful use of technology to support accessibility for both health practitioners and patients to culturally safe information and resources should be a key priority.
- Guidelines must be available in multiple formats to facilitate access e.g. hard copy, downloadable PDF, web-based, and within an application (“app”) for smart phones / tablets.
- It was important to note that many health professionals have paper-based clinical practice, and access to contemporary clinical practice technology is not always available. Security firewalls and protections within clinics may restrict downloading from “external” websites.
- Internet access is not universal – some areas of Australia and some remote health services have limited or no access. Power may also be inconsistently available on occasion. Therefore, access to guidelines in hard copy remains important for use in indigenous communities.
- Patients face a similar situation and, additionally, may not be able to afford to download a health resource due to data costs. These issues apply to those living in metropolitan areas as well as those in regional and remote parts of Australia.

Digital Content – Applications (“Apps”):

- Utilisation of technology requires user-friendly guidelines applications providing quick reference tools to all the information required for CKD management.
- Kidney Health Australia has the “My Kidneys, My Health” App for patients and the “CKD-Go” App for health professionals. While these Apps assist with navigation to external links hosted on the Kidney Health Australia website, access can be difficult in the absence of an internet connection. Therefore, it was suggested that for any future Apps containing CKD management guidelines, all of the content should be imbedded within Apps rather via external links, and updated regularly through notifications via the App.
- An App for the KHA-CARI guidelines would be welcomed, if content was specifically developed in a user-friendly format, with links to hard version of the full evidence-base that clinicians could access if required.

Medical Practice Software:

- Embedding links to guidelines in medical practice software is another potential avenue for facilitating implementation. This may be limited by the wide range of software used in practices.

Tele-health:

- Telehealth assumes that there is robust internet connectivity.

- Telemedicine was recognised as a potentially under-utilised means to support clinical guidelines implementation. It is also a mechanism to support “two-way education”.
- One successful model of care for Indigenous patients within a transplant clinic in Victoria has been a collaborative approach via a consultation between clinician, patient, Aboriginal co-opts, and other health care team (as required), via Telehealth. Working via the local healthcare provider has proven to be more successful than infrequent clinician site visits, and far more effective than letters to general practitioner or bringing the patient to metropolitan centres. Patient satisfaction with this model of care is high.
- Successful implementation of guidelines via telehealth consultations requires local staff to be engaged and to highlight successes and barriers (language, internet, mobile phone services).

G. Gaps in Existing Knowledge – Strengthening the Evidence-base

The panel suggested areas where evaluation of the evidence-base would be useful for incorporation into the proposed guidelines and where further research is urgently required.

1. Evidence-base for Workforce Education and Support

- The primary and secondary care workforce are critical to preventing and managing CKD.
 - Aboriginal and Torres Strait Islander peoples often bypass primary care and enter directly into tertiary nephrology services with advanced CKD or ESKD due to failure to implement early CKD detection guidelines in primary care
 - Knowledge and implementation of CKD guidelines is often limited for overseas-trained or recently arrived staff, or areas of high staff turnover and transient staff populations.
 - Lack of continuity of clinical care due to staff turnover undermines guidelines implementation.
 - Staff involved in CKD care may lack culturally appropriate communication skills training.
- Understanding the challenges facing the primary and secondary care workforce in regional and remote areas will be an important step in addressing the lack of awareness about early kidney checks and prevention of CKD progression, and implementing guidelines for CKD management:
 - Strategies to improve workforce capacity and staff retention are urgently required.
 - New guidelines must be accompanied by improved workforce capability through culturally appropriate education and resources. These should address early stage CKD management to improve detection rates and minimise “crash landing” to tertiary care.
 - In addition, there needs to be better education for local health professionals involved in the care of patients receiving renal replacement therapy (all modalities) and renal supportive care, to facilitate care in community and minimise evacuation / transfer.

2. Evidence-base for Geographical Variation in CKD Risk and Care

- The relationship between CKD risk and geographical location has been demonstrated (Kidney Health Australia 2016 State of the nation Report 2016).

- CKD Management Guidelines do not currently detail geographical variations in risk, and do not incorporate remoteness or other geographical parameters into clinical care algorithms.
- Biology may be the similar across cohorts but population risks and sociodemographic factors may differ, and therefore guidelines should address the geographical variation.
- The evidence-base demonstrating benefit of earlier and more aggressive screening and intervention for CKD in certain areas with the highest risk of patients developing end stage disease should be expanded.

3. Evidence-base for Patient and Community Education Strategies

- Current guidelines on CKD management do not address evidence-based strategies for culturally appropriate patient education and patient-doctor communication to facilitate CKD care. This represents a significant gap in the guidelines and barrier to implementation of care recommendations.
- The evidence-base determining barriers and facilitators of health-related culturally appropriate communication and education in Aboriginal and Torres Strait Islander cohorts has grown in recent years and should be synthesised. There are several specific projects that address this and these should be drawn upon in the proposed guidelines. For example, The Northern Territory Renal Services Integration Project and Menzies School of Health Research have had a large range of projects addressing how best to engage Indigenous people in primary care and kidney care, and barriers and enablers of indigenous engagement with health systems.
- Suitable, validated, nationally available education resources about prevention and CKD are lacking. Many regions have developed their own resources and methods of education, and successful initiatives should be identified and evaluated in other cohorts.
- Developing culturally appropriate education resources in multiple media formats (video, pictures) that facilitate translation into appropriate languages and health literacy levels is an urgent priority.
- The role of patient preceptors and models of care through peer-support should be further explored and evaluated.

4. Evidence-base for Prevention Strategies in Aboriginal and Torres Strait Islander peoples

- Fear of kidney disease diagnosis is a major barrier to preventative interventions in primary care.

- Further research is required into the best strategies for implementing disease prevention pathways without disengaging patients and communities due to fear and/or lack of understanding of illness.
- The evidence-base for community based and culturally appropriate education interventions for preventative health measures should be reviewed and successful strategies identified that may be utilised in CKD care. In particular evidence around improving diet quality, addressing obesity and cessation of smoking.

5. Evidence-base for Managing CKD Stages 1-5 in Aboriginal and Torres Strait Islander peoples

- Early stage CKD is often poorly managed, with many Indigenous people starting dialysis completely unaware that they have had kidney disease for years. Many patients fail to receive an Adult Health Check that may have identified their uncontrolled diabetes and kidney disease. Strategies for improved uptake of health checks in Primary care should be reviewed.
- Late referral to nephrology services remains a problem for a subgroup of patients and further work is required to understand the barriers to timely referral.
- Primary health care teams are crucial partners in CKD early detection and care, and the evidence-base is reasonably well-established. However, there is a distinct lack of structure for management of later stage CKD and transition to ESKD care in regional and remote communities.
- Further research should address the role of primary care and community health organisations in supporting later-stage CKD care for Aboriginal and Torres Strait Islander peoples, including pre-dialysis care, decision-making regarding renal replacement therapy options, dialysis care, pre-transplant referral and workup, and post-transplant care.
- Models of care where community, primary and tertiary renal care services are integrated should be explored.
- There is substantial practice and published evidence about successful models of care in this setting. An overview of Aboriginal renal services in Primary Health Care found that nurse-led services with strong Aboriginal workforce and community ownership were the most successful model (Reilly et al., 2016). Danila Dilba has implemented a successful multidisciplinary renal unit that has been evaluated and shown to significantly delay need for dialysis (Menzies School of Health Research, 2019). Other services such as Central Australian Aboriginal Congress have also strong programs in this area. A literature review about these successful models of care in the Northern Territory, and the work in the chronic care area by the South Australian Health and Medical Research Institute (SAHMRI) and Menzies School of Health Research during the past 15 years of collaboration that evaluates models of care in the Indigenous space was recommended.

- Establishing a coping mechanism for transition to dialysis is a real challenge for Indigenous patients and the health professionals engaged in their care. The evidence-base for spiritual and psychological counselling and addressing the grieving process for the loss of kidney function and transition to ESKD is very limited for Indigenous and non-Indigenous cohorts. This is an area where further knowledge is urgently required.

H. Suggested Guidelines Scope and Content

The expert clinician consultation has led to the following recommendations for topics to be included or considered for inclusion in the proposed Guidelines.

Guidelines to underpin all aspects of CKD Management for Aboriginal and Torres Strait Islander Cohorts:

1. Strategies for CKD education and support including
 - a. Patient education strategies
 - b. Community approaches and engagement strategies
 - c. Models of patient support – peer-to-peer support systems
2. Psycho-social and spiritual support for Aboriginal and Torres Strait Islander living with CKD including Management of grief associated with kidney disease
3. Strategies for Health Professional Education and Support of Workforce including
 - a. Promotion of Guidelines and local adaptation
 - b. Recommendations for culturally-safe communication with patients
 - c. Strategies for workforce training
 - d. Strategies for workforce retention
 - e. Telemedicine in CKD Care
4. Models of care for Aboriginal and Torres Strait Islander peoples across all CKD stages
 - a. Integrated models of care
 - b. Role of primary care services in supporting advanced CKD and ESKD
 - c. Multidisciplinary care models

Guidelines for Specific Aspects of CKD Management

5. Chronic Disease Prevention in Aboriginal and Torres Strait Islander Populations
 - a. Diet including salt
 - b. Smoking
 - c. Obesity management
 - d. Exercise
 - e. Blood pressure
 - f. Other primary prevention measures
6. Screening for CKD – recommendations in the Aboriginal and Torres Strait Islander cohort
7. Child and maternal health including the first 1000 days of life – reducing the impact on future CKD risk

8. Management of Acute Kidney Injury in Aboriginal and Torres Strait Islander peoples
 - a. Relationship to future CKD risk
 - b. Recommendations for prevention, management, and follow up

9. Management of Pre-dialysis CKD stages
 - a. Blood-pressure, lipid and diabetes management (and medical therapies)
 - b. Strategies for self-management
 - c. Models of care in the community (integrated care with renal services)
 - d. Referral recommendations

10. Management of Transition to End-stage CKD care in Aboriginal and Torres Strait Islander people
 - a. Psychosocial care and cultural needs
 - b. Culturally appropriate communication, education and engagement of family and community
 - c. Dialysis Modality – treatment choices
 - d. Vascular access – timing, type

11. Management of ESKD – Dialysis Care and Transplantation
 - a. Remote dialysis models of care
 - b. Management of relocation, separation from community
 - c. Addressing barriers and facilitators of treatment attendance
 - d. Referral for transplantation
 - e. Infection management

12. Management of end-of-life care with ESKD
 - a. Cultural and community aspects
 - b. Renal Supportive care

Appendix A

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A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease

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Abstract

The Kidney Health Australia — Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines aims to develop an inaugural clinical guideline for the "Management of Chronic Kidney Disease (CKD) among Aboriginal and Torres Strait Islander Peoples and Māori". In this article we highlight why this clinical guideline is needed at this time, and the pertinent history of Australian and New Zealand nephrology clinical guidelines development. We describe the strategies that will be used in Australia to ensure the guideline is underpinned by recommendations identified from within the Aboriginal and Torres Strait Islander community, and which supports clinician need.

Three engagement strategies for the Australia consultation are outlined: 1) Engaging a panel of Aboriginal and Torres Strait Islander health clinicians; 2) Targeted site engagements, with formal evaluation, with locally based Aboriginal and Torres Strait Islander consumers and services; and 3) Consultation and feedback from the Australian national peak organisations. A separate community consultation strategy is to be implemented in New Zealand.

These consumer and community consultation strategies will precede and inform the KHA-CARI guideline technical writing team. The technical writing group includes medical, nursing, and primary health care members, and also members who are Aboriginal and Torres Strait Islander and Māori. The diverse technical writing team members will ensure that the guideline will be clinically appropriate, effective and meaningful. Such guidelines, referenced to the needs of the community, are necessary to support health services to deliver quality health outcomes for patients and families living with chronic kidney disease.

Keywords

CKD, Indigenous Australians, guidelines, health services.

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Introduction

Clinical guidelines are written to inform best practice health care. Guidelines are a strategic way to align clinical practice with best practice standards and have a purpose in identifying the resourcing required to maintain best practice standards. Clinical guidelines can be used to evaluate clinical outcomes, and thus performance of health services. Best practice can be referenced to both clinical and health care user perspectives (Miller *et al.*, 2017). Creation of best practice clinical guidelines are a critical part of the broader strategies to minimise Australia's burden of kidney disease amongst Aboriginal and Torres Strait Islander peoples (KHA, 2013).

We outline the strategies underpinning the development and writing of the inaugural bi-national Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples and Māori. In this manuscript, we detail the Australian consultation strategies. A program specific for consultation with Māori communities is to be undertaken separately and is not described here.

First we present key data about chronic kidney disease (CKD) among Aboriginal and Torres Strait Islander people.

What we know about CKD among Aboriginal and Torres Strait Islander people

- Nationally almost one in five people live with indicators of CKD (albuminuria or low eGFR) but most (90%) are unaware of this (ABS, 2014).
- Albuminuria is a powerful and early predictor of rapid decline in kidney function (eGFR) (Howell *et al.*, 2017; Maple-Brown *et al.*, 2016).
- There is geographic variation in the burden of CKD, which affects a higher proportion of people living in remote Australia (ABS, 2014).
- Aboriginal and Torres Strait Islander people with end-stage kidney disease (ESKD) are more likely to commence haemodialysis treatment (ANZDATA, 2017) and have lower access to kidney transplantation than non-Indigenous patients (Lawton *et al.*, 2017).
- Advancing Aboriginal and Torres Strait Islander kidney health is a priority for governments, clinicians, patient advocacy groups and Indigenous Australians. Improving health requires culturally competent care and a willingness to partner (Hughes *et al.*, 2018; KHA, 2015; NMBA, 2018; RACP, 2003).
- The development of a best-practice set of guidelines for use by the nephrology community for the management of

CKD among Aboriginal and Torres Strait Islander peoples will support the key recommendations for education, prevention, early detection and management, and workforce education, arising from the 2015 Policy Round Table and Parliamentary Meeting which was hosted by Kidney Health Australia (KHA, 2015).

KHA-CARI Guidelines Group

The Kidney Health Australia — Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines Group is currently funded by Kidney Health Australia (KHA), the Australian and New Zealand Society of Nephrology (ANZSN) and BEAT-CKD (an NHMRC-funded program). KHA-CARI is managed by a steering committee, and since 1999, the KHA-CARI Guidelines Group has produced evidence-based clinical practice guidelines for the Australian and New Zealand region.

Guideline convenors are experts who volunteer their time after selection by the KHA-CARI Steering Committee. The guideline convenor leads a technical writing group. KHA-CARI supports the technical writing group members with a secretariat, provides training in evidence rating, and provides the systematic review of the evidence to support the technical writing group. The KHA-CARI guideline process follows a best practice approach for the development of reliable and trustworthy clinical practice guidelines (see Guideline Development Manual at www.carl.org.au). Following this approach, KHA-CARI guidelines embed best available published evidence into a framework for standard clinical care which benefits the health care user. KHA-CARI guidelines therefore have an important role in supporting high-quality health care and clinical outcomes for patients with kidney disease in Australia and New Zealand.

The majority of KHA-CARI guidelines have been disease- or treatment-specific, and have been delivered by the technical writing group with little external consultation. However, KHA-CARI has recently established a program for partnering with patients and their carers to ensure that guidelines are relevant and meaningful to both patients and clinicians. Two recent examples of the consultation process are the Autosomal Dominant Polycystic Kidney Disease and Infectious Diseases clinical practice guidelines (Miller *et al.*, 2017; Tong *et al.*, 2012; Tong *et al.*, 2016). Partnering with consumers is a priority identified by the Australian Commission on the Safety and Quality of Health Care (ACSOHC, 2016), and provides a powerful opportunity to ensure guidelines are relevant and meaningful for both health care users and the health caring clinical community. Effective partnering also increases community awareness, which supports effective translation of best clinical evidence into health care.

KHA-CARI Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander Peoples and Māori

The KHA-CARI Steering Committee prioritised this population-specific guideline, in response to a persisting and disproportionate burden of advanced kidney disease among Aboriginal and Torres Strait Islander peoples and Māori (ANZDATA Registry, 2017). Two Australian convenors (one is Torres Strait Islander) and two New Zealand convenors (one is Māori) were appointed. The guidelines technical writing group has also been appointed, comprising Australian and New Zealand members (and which includes Aboriginal and Torres Strait Islander and Māori members). For the first time in KHA-CARI history, this guideline will be preceded by community consultation.

Australian Guideline engagement strategies

In Australia, the engagement will comprise three strategies within a targeted, respectful and consultative process with Aboriginal and Torres Strait Islander peoples living with kidney disease. There are two goals of the community consultation:

1. To seek feedback and advice on the focus and content of new clinical guidelines, specifically the priorities for clinical care.
2. To determine the appropriate methods for translation of the new clinical guidelines into consumer information, tools and education materials. This will support a meaningful and relevant guideline, which can be efficiently implemented into clinical practice.

Strategy 1: Engaging a panel of Aboriginal and Torres Strait Islander health clinicians

The Aboriginal and Torres Strait Islander health clinician panel will comprise community-based practitioners (Indigenous or non-Indigenous) at the interface of patient care. This panel will be well placed to advise any issues with the utilisation of existing clinical guidelines, gaps and considerations for implementation within a variety of settings and with complex conditions. The panel will be multidisciplinary and representative of jurisdictions with a high prevalence of CKD, whilst including perspectives from metropolitan, regional, rural and remote settings.

We recognise the potential for overlapping perspectives from the Aboriginal and Torres Strait Islander kidney health workforce. This might include the 'on the ground' health clinicians who are also Aboriginal or Torres Strait Islander people (Strategy 1), who may be involved in this panel,

but who might also represent an 'on the ground' clinician who is providing patient care for a peak body (Strategy 3) or government-funded renal service (Strategy 3), whilst is also serving on community governance boards, and/or operating in a family-caring role for someone living with kidney disease (Strategy 2). Individual Strategy 1 panel members will also facilitate and assist with strategy 2, the targeted site engagements with Aboriginal and Torres Strait Islander consumers and services.

Strategy 2: Targeted site engagements with locally based Aboriginal and Torres Strait Islander consumers and services

The targeted site engagements are anticipated to occur in 15 sites across Australia, involving five states and the Northern Territory, and require 18 months to two years. The proposed community engagement sites will also be aligned to: 1) the location of dialysis centres with high numbers of Aboriginal and Torres Strait Islander people; and 2) those sites which have Aboriginal community-controlled health organisations with staff actively working in kidney health, or staff engaged in managing CKD risk factors.

Strategy 2 seeks to value participation and minimise the burden on communities, which was a priority highlighted by plenary speaker, Professor Carle Bourassa, at the 6th Annual NHMRC-Lowitja Institute Research Translation Symposium (Bourassa, 2017). The KHA-CARI consultation will be initially delivered in Darwin, Alice Springs, and Thursday Island in 2018 by the Catching Some Air project (funded by the Lowitja Institute), and led by a team from Menzies School of Health Research (Catching Some Air, 2018). This local team is ideally placed given their long-standing community relationships and proven track record in Aboriginal and Torres Strait Islander community engagement, capacity building and working with reciprocity. Subsequent consultation at other sites will be coordinated by KHA using local partners. The consultation methodology will likely evolve after each consultation and will be adaptable rather than iterative. Therefore, with secured funding, a developed methodology and an evaluation team, we will ensure the consultation process occurs, is documented, evaluated and gives reference, ownership and control of information to Aboriginal and Torres Strait Islander local communities.

Strategy 3: Consultation and feedback from the Australian national peak organisations

Strategy 3 includes engaging with members of Australian national peak health organisations who are working in kidney health on the ground. These peak organisations and affiliates include, but are not limited to, the Australian Indigenous Doctors Association, The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, Indigenous Allied Health

Australia, The National Aboriginal and Torres Strait Islander Health Worker Association, The National Aboriginal Community Controlled Health Organisation.

Feasibility and risk management

Several challenges are anticipated. The first challenge is delivering a coordinated consumer engagement process (Strategy 2) across Australia, which may feed into the clinical guideline writing phase in an acceptable time frame. Therefore, commencing the writing process has been strategically deferred to allow sufficient time for consultation and feedback with each of the Aboriginal and Torres Strait Islander health services and sites.

Delivering consultation on this scale is a further challenge, but precedence is being set. KHA partnered with the Menzies School of Health Research and the ANZSN to host the Indigenous Patient Voices — Gathering Perspectives, Finding Solutions to Chronic and End Stage Kidney Disease Symposium, in September 2017 (Hughes *et al.*, 2018). This Symposium provided a vital rehearsal to Strategy 2 — meeting logistics, identifying the most appropriate meeting facilitator, patient and carer support (some who travelled from interstate), budget requirements and learning from over 30 patients and carers who clearly articulated their priorities for care. These knowledge-sharing meetings which engage with renal patients must include consideration of ethics, remuneration and intellectual property.

A key priority is to secure adequate funding for the remaining Strategy 2 engagement sites. Potential sources of funding include traditional research funding streams, discretionary government funding and philanthropic sources. On October 25th 2018, the Hon Ken Wyatt AM MP Minister for Indigenous Health announced a \$300,000 grant to Kidney Health Australia over 2 years, to deliver the Aboriginal and Torres Strait Islander-led and culturally appropriate consultation process that seeks to meet the needs of our community. The subsequent guidelines will complement the Minister's national renal roadmap which is currently under development.

Working together with trust for community advancement through better health

Research and clinical guidelines and understanding community priorities for better health are not isolated activities. It is envisaged that the community consultation for these guidelines will have substantial added value for renal care of Aboriginal and Torres Strait Islander patients. These are not limited to bringing together, for the first time, a national Aboriginal and Torres Strait Islander renal consumer voice, with potential to maintain into the future. This is a key priority for KHA who will

coordinate and maintain the community voice links, and will also inform advocacy for Aboriginal and Torres Strait Islander renal health across many organisations.

Respecting the distinctiveness of First Nations peoples through guidelines development

The guideline consultation will respect the distinctiveness between Aboriginal and Torres Strait Islander people living with kidney disease who have varying contexts and values regarding health. Following the community consultation period, the recommendations for guidelines development from Australia and New Zealand will converge. Respect for the distinctiveness of Aboriginal, Torres Strait Islander and Māori communities will be framed at all levels of the guidelines development from inclusion of both Aboriginal and Torres Strait Islander and Māori leaders in the design and delivery of the community consultation; visiting both Aboriginal and Torres Strait Islander and Māori communities; and valuing the contribution of peak organisations who reference the needs of both Aboriginal and Torres Strait Islander and Māori people living with kidney disease. In addition, the technical writing group has actively sought inclusion of Indigenous Australian and New Zealand and Māori members.

Delivering health care framed around population-specific need

We emphasise the value of the guidelines writing process for advocating and delivering health framed around population-specific need. Given the opportunity, the health caring community who were present at the Indigenous Patient Voices Symposium, looked patients and carers in the eye, learned the impact of their illness and made an appropriate response. Patients' feedback included a pervasive and persisting experiences of bias in the delivery of kidney health services, a desire for more holistic care and services to be more available close to home (Hughes *et al.*, 2018). We are delighted the 2018 Australian Federal Government Budget has outlined a new Medicare Benefits Schedule item number for assisted dialysis in very remote Australia. This health care system transformation was directly linked to the strong collaboration of health care users (who had the opportunity to identify their most important priorities for care), and a kidney health caring community committed to health advancement. This consumer engagement method demonstrates the desire and willingness of many Aboriginal and Torres Strait Islander people to provide feedback in order to support the necessary health care transformation (Hughes *et al.*, 2018) and, more importantly, the willingness and ability to achieve health care change where these are given voice.

Conclusion

It is an expectation that people of Australia and New Zealand benefit from high-quality health care. Clinical guidelines are a strategic way to align clinical practice with best practice standards, in order to support healthy communities. Australia and New Zealand are well positioned to achieve kidney health advancement for Aboriginal and Torres Strait Islander and Māori communities through delivery of this guideline based on effective engagement. There is strong clinical and community desire to achieve kidney health advancement for Aboriginal and Torres Strait Islander Peoples through guideline development, notwithstanding the significant challenges around funding and logistics of such an unprecedented scale of consultation across Australia and New Zealand. Success in this initiative will have far-reaching importance and will embed the indigenous patient voice into clinical kidney care, policy and service delivery — for the betterment of all.

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Appendix B

Contributing Health Professionals

Name	Role, organisation	State/Territory
Dr William Majoni	Senior Consultant Nephrologist & Clinical Lead, Renal Unit, Royal Darwin Hospital	NT
Ms Heather Hall	Renal Project Manager, Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (aka Purple House)	NT
Ms Sarah Brown	CEO, Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (aka Purple House)	NT
Dr Sajiv Cherian	Nephrologist and Head of Renal Services	NT
Dr Jaquelyne Hughes	Nephrologist and Co-Chair, KHA-CARI Guidelines Writing Group	NT
Professor Alan Cass	Director of Menzies School of Health Research (Menzies)	NT
Dr Elizabeth Moore	Public Health Officer, Aboriginal Medical Services Alliance NT (AMSANT)	NT
Dr Marianne Wood	Public Health Officer, Aboriginal Health Council of WA (AHCWA)	WA
Mr Phillip Jarvis	Kimberley Aboriginal Medical Service Ltd.	WA
Ms Jenny Cutter	Executive Manager, Kimberley Renal Services Executive Manager, Kimberley Aboriginal Medical Service Ltd.	WA
Ms Melanie McNiece	Manager, Broome Renal Health Centre	WA
Ms Kerrie Parker	CKD Educator, Kimberley Aboriginal Medical Service Ltd.	WA
Dr James Stacey	GP, Kimberley Aboriginal Medical Service Ltd.	WA
Prof Mark Thomas	Professor, Nephrologist	WA
Ms Lesley Salem	Indigenous Renal Nurse Practitioner	QLD
Ms Rochelle Pitt	Care Coordinator Area South, Apunipima Cape York Health Council	QLD
Ms Valerie Nancarrow	Indigenous Liaison Officer, Cairns and Hinterland Health Service	QLD
Prof David Johnson	Director of the Metro South and Ipswich Nephrology and Transplant Service (MINTS) and Medical Director of the Queensland Renal Transplant Service at Princess Alexandra Hospital, Chair, PEAK Committee, Kidney Health Australia	QLD
Prof Tim Usherwood	Professor, General Practice, Westmead Clinical School, University of Sydney School of Medicine	NSW
Dr Emma Webster	School of Rural Health, Dubbo, University of Sydney	NSW
Dr Liz Rix	Lecturer/Academic, Gnibi College of Indigenous Australians	NSW
Ms Kylie Wyndham	Chronic Disease Nurse, North Coast (NSW) Primary Health Network, Casino Bulgarr Ngaru Aboriginal Medical Service	NSW

Dr James Collette	Nephrologist, Dubbo Base Hospital	NSW
Ms Barbara Harvie	Nephrology Nurse, Nurse Unit Manager, Dialysis Unit Queanbeyan Hospital	NSW
Dr Paul Snelling	Renal Physician & Director of Dialysis, The Royal Prince Alfred Hospital	NSW
A/Prof Ivor Katz	Senior Staff Specialist / Consultant Nephrologist The St George Hospital	NSW
Dr Richard K S Phoon	Senior Staff Specialist in Nephrology, Western Renal Service (WSLHD & NBMLHD), Senior Lecturer, University of Sydney, Westmead Hospital	NSW
Dr Angus Ritchie	Nephrology Staff Specialist, Concord Repatriation General Hospital NSW Clinical Lead, HealthPathways Sydney, Physician Informaticist, Sydney Local Health District	NSW
Dr John Saunders	Consultant Nephrologist, Royal Prince Alfred Hospital	NSW
Dr Sheena Wilmot	General Practitioner, Benchmark Medical, Sydney	NSW
Dr Martin Howell	KHA-CARI Guidelines Group	NSW
Dr Pamela López		
Dr Talia Gutman		
Ms Libby Teki	Cardiovascular, Diabetes & Kidney Unit, Australian Institute of Health and Welfare	ACT
Ms Jess Styles	Senior Policy Officer, National Aboriginal Community Controlled Health Organisation (NACCHO)	ACT
A/Prof Craig Nelson	Nephrologist, Sunshine Hospital, Clinical Director, Healthlinks, Western Health, Associated Professor, University of Melbourne	VIC
Dr Katherine Barraclough	Nephrologist, Royal Melbourne Hospital	VIC
Ms Kathryn Godwin	Primary Care Nurse, APNA	VIC
Prof Robyn Langham	Professor and Head, School of Rural Health, Faculty of Medicine, Nursing and Health Sciences, Monash University	VIC
Prof Kevan Polkinghorne	Nephrologist, Department of Nephrology, Monash Medical Centre, Adjunct (Clinical) Associate Professor, Department of Medicine, Monash University	VIC
Ms Wendy Shepherdley	Credentialed Diabetes Educator, Woodend	VIC
Mr Peter Williams	Consumer Representative, Peak Committee, Kidney Health Australia	VIC
Dr Lisa Murphy	General Manager, Prevention and Advocacy, Kidney Health Australia	VIC
Prof Stephen McDonald	Nephrologist, Royal Adelaide Hospital	SA
Dr Janet Kelly	University of Adelaide	SA

Dr Susan Crail	Royal Adelaide Hospital, Central Northern Adelaide Renal and Transplantation Service	SA
Ms Verity McTaggart	Pika Wiya Health Service Aboriginal Corporation	SA
Ms Laurel Dodd	Pika Wiya Health Service Aboriginal Corporation	SA
Dr Chris Bollen	General Practitioner, Oakden Medical Centre	SA
Dr Caitlin Sum	General Practitioner, Medical HQ	SA
A/Prof. Shilpa Jesudason	Clinical Director, Kidney Health Australia	SA
Dr Marie Ludlow	General Manager, Community Programs, Kidney Health Australia	SA
Ms Breonny Robson	National Education Manager, Kidney Health Australia	SA
Ms Dora Oliva	National Manager, Indigenous Kidney Health, Kidney Health Australia	SA
Mrs Claire Sheeky	National Primary Care Education Officer, Kidney Health Australia SA	SA
Ms Joanna Stoic	Executive Support Officer, Community Programs, Kidney Health Australia	SA

Appendix C

Framework of Questions for Discussion: Expert Panel tele/video conferences

TOPIC	CONSIDER THESE ISSUES
Usefulness of Existing CKD Guidelines	
1. Which guidelines / evidence bases are routinely used in practice?	Local, Kidney Health Australia CKD Handbook, KHA-CARI, International (KDIGO), Cochrane Awareness of these Guidelines Barriers to Awareness
2. Are these guidelines useful in ABORIGINAL AND TORRES STRAIT ISLANDER cohorts?	Biological factors Cultural issues Social / demographic factors Gaps in the guideline topics
3. What are the key barriers to guideline usefulness?	Consumer factors Health Care Professional Health service factors Guideline Factors
4. What would make guidelines more useful?	Format and delivery Accessibility Consumer engagement Health Care professional engagement Resources Technology
Gaps in Care	
1. Which gaps in care need to be addressed most urgently?	Prevention Strategies Early Detection Prevention of progression Comorbidities Pre-dialysis care Transition to End-stage Consumer education Health professional Education
2. What is the best way to address these?	
3. What has been successful in your experience?	

TOPIC	CONSIDER THESE ISSUES
CKD Guidelines Scope and Content	
<ol style="list-style-type: none"> 1. What should be included in these Guidelines? 2. How should the content be prioritised? 3. What should be left out? 	<p>As for Gaps in Care Also consider: Consumer involvement Delivery of education to consumers / communities Delivery of Education to Health professionals</p>
Strategies for Implementation	
<ol style="list-style-type: none"> 4. How should these Guidelines be implemented? 5. What has previously been successful? 6. What has been unsuccessful? 	<p>Education and dissemination Peer-peer mentoring Technology support Resourcing Community engagement Stakeholder engagement</p>

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Disclaimer

The recommendations contained in this report were formed from feedback obtained through consultation with expert, community-based health practitioners from metropolitan, rural and remote regions, who were actively involved in clinical care delivery for kidney disease, and primary health care professionals. It is designed to provide information and assist decision-making. The authors assume no responsibility for personal or other injury, loss or damage that may result from the information in this publication.