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.
**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) (Holwell 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.cari.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 (ACSQHC, 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 Carrie 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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