Indigenous Kidney Health

Project Title: Kidney Health Australia - Indigenous Kidney Health Program

Applicant: Kidney Health Australia

Primary contact: Dr Shilpa Jesudason
Clinical Director, Kidney Health Australia
M: 0403 131 670
Email: Shilpa.jesudason@kidney.org.au

Secondary contact: Dr Lisa Murphy
Interim Chief Executive Officer, Kidney Health Australia
M: 0457 070 506
Email: lisa.murphy@kidney.org.au

Address: 125 Cecil Street
South Melbourne Victoria, 3025
www.kidney.org.au

L M Murphy

Dr Lisa Murphy
Interim Chief Executive Officer
Kidney Health Australia

S Jesudason

Dr Shilpa Jesudason
Clinical Director
Kidney Health Australia

KHA ask for funding support

Kidney Health Australia (KHA), the only national body dedicated to assisting Australians living with kidney disease to improve their health outcomes and quality of life, seeks funding of $1 million to develop an Indigenous Program for kidney health with the remit of support, education and advocacy for equity in health care for Aboriginal and Torres Strait Islander people living with chronic kidney disease.

Patient population

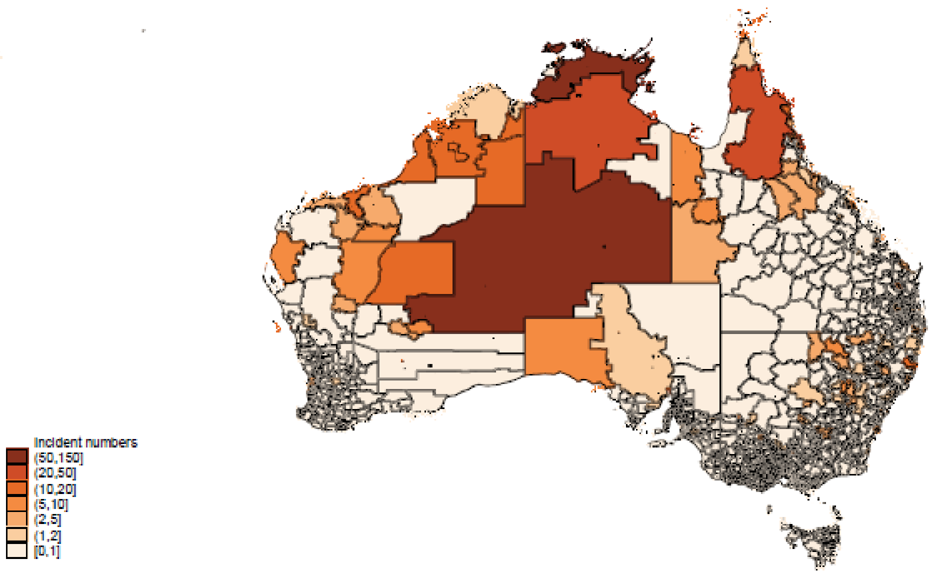
Australian Bureau of Statistics (ABS) census data from 2016 indicate that the adult (over 15 years of age) population of Aboriginal and Torres Strait Islanders in Australian was approximately 428,453 people. [1] ABS data, has also found that the actual prevalence of chronic kidney disease (CKD) in Aboriginal and Torres Strait Islander adults is approximately 18%. If we use this percentage and apply that to the approximate adult Indigenous population, it can be estimated that approximately 77,122 people currently have signs of CKD. [2]

Self-reporting of CKD remains low at around 1.7%. This figure coupled with the actual prevalence CKD of around 18%, indicates that about 9 out 10 Aboriginal and Torres Strait Islander adults are unaware that they have kidney disease. This statistic is of massive significance for the impact of prevention and intervention strategies.

Precise figures for end stage kidney disease (ESKD) are available through The Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA). [3] The number of Aboriginal and Torres Strait Islander Peoples with treated ESKD at the end of 2015 was 1888. There is a year-on-year increase of approximately 4%.

Aboriginal and Torres Strait Islander adults living in remote areas are more than twice as likely as those living in non-remote areas to have signs of chronic kidney disease. Amongst Aboriginal and Torres Strait Islanders, the heaviest disease burden impacts on people living in very remote (36.7%) and remote (27.6%) regions. Outer regional areas (17.7%) remains high. Inner regional (10.7%) and major cities (11.8%) are less likely to be impacted as greatly. The incident of indigenous kidney disease patients is shown in Figure 1.[3]

Figure 1: Incident indigenous kidney patients 2011-2015 by postcode



Issues

The unique challenges of kidney disease in Indigenous Australians when compared to non-Indigenous Australians

When compared to non-Indigenous Australians, CKD presents more frequently, is more severe at an earlier age, is more strongly associated with diabetes and multiple co-morbidities, the frequency of the treatment options are different, and has greater social and medical impact on Aboriginal and Torres Strait Islanders. For this reason, addressing Aboriginal and Torres Strait Islander kidney health is a major priority for government, clinicians, patient advocacy groups and indigenous Australians.

Disparities in rates of kidney disease

Kidney disease is a significant health problem for all Australians, but severe kidney disease is more common among Indigenous people than among non-Indigenous people. In particular, the prevalence of CKD and the overall levels of ESKD among Aboriginal and Torres Strait Islander peoples are consistently reported as significantly higher than among other Australians. [2] Aboriginal and Torres Strait Islander people represent less than 2.5 percent of the national population, however they account for approximately 11% of people commencing kidney replacement therapy each year.

Disparities in age of onset of chronic kidney disease

The median age of Indigenous people with ESKF is about 30 years less than for non-Indigenous people and occurs within the ages of 35 and 65. [4] This is traditionally the period of maximum family responsibilities, productivity, community contribution and leadership. This creates significant life-changing challenges for many young Aboriginal and Torres Strait Islanders, particularly young families.

Disparity of co-morbidities

For Aboriginal and Torres Strait Islander Australians with ESKD, there is an increased prevalence of significant medical co-morbidities, including complications of diabetes and vascular disease.

Disparities in treatment

The incidence rates of renal replacement therapy (RRT-dialysis and transplant) are 8 - 9 times those of non-Indigenous Australians.[3] There are differences in type of RRT used in indigenous people compared with non-indigenous people.[5] The predominant type of dialysis used is haemodialysis, performed in satellite and hospital units. The proportion of indigenous patients receiving dialysis in a home setting (either peritoneal or haemodialysis) is much lower than for non-indigenous patients. While peritoneal dialysis theoretically is attractive for patients living remotely, high rates of peritonitis, technique failure and mortality are reported.[6] Rates of kidney transplantation are substantially lower. Living donors are few, due to the high background prevalence of kidney disease and of risk of development of CKD in donors,[7] and outcomes of deceased donor transplants are worse, with a high burden of comorbidities and infectious complications.[8] There are important barriers arising from communication and other difficulties.[9]

Disparities in outcome

For Aboriginal and Torres Strait Islanders, there are markedly higher rates of transplant loss, particularly evident at 3 years after transplantation. Indigenous Australians experience higher mortality rates throughout the first five years after transplantation. The difference in survival worsens over time.

Disparities in social impact

For the majority of remote and very remote patients, the need to re-locate to treatment centres to receive RRT and other treatments, often hundreds of kilometres from their community and country, has a devastating impact on families. Families are often separated or whole families relocate, sometimes across State and Territory borders in order to access dialysis treatment. For some, the need to relocate from family and country may lead to a decision to forego treatment. In almost all people, the impact of kidney failure on the patient and their family is severe with prolonged ill health, a heavy symptomatic burden, loss of job opportunities and ability to work, financial hardship and very real social disruption. There are major challenges in the health and social support area for Aboriginal and Torres Strait Islanders accessing renal dialysis services away from home. From a provider and a patient perspective, the patient pathway particularly for Aboriginal and Torres Strait Islander kidney patients is often fragmented, confusing, isolating and burdensome.[2]

KHA Proposal

The proposal is for a full Indigenous Program to educate, support and advocate for Indigenous Australians affected by kidney disease. There are two major elements to the proposal:

- Kidney Health Australia Indigenous Program
- The Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines

1. Kidney Health Australia Indigenous Program

KHA seeks funding to build and implement an Indigenous peer support and education program to improve the quality of life and health outcomes of Aboriginal and Torres Strait Islanders affected by kidney disease and work towards 'Closing the Gap'.

A number of factors will ensure that our programs are relevant, powerful and respectful for Aboriginal and Torres Strait Islander history, culture, worldviews, health beliefs & behaviours and kidney health issues. These factors include:

- Kidney health Australia has well established and strong partnerships with key external stakeholders in the Indigenous Health arena
- The program will be overseen by a project officer of Aboriginal or Torres Strait Islander heritage
- Every program will be informed by consultation with the Aboriginal and Torres Strait Islander communities to ensure relevance and acceptance
- Indigenous communities do not recognise state or territory boundaries and as a national rather than state based organisation Kidney Health Australia has the infrastructure to support these communities

Kidney Health Australia will build on and enhance its existing Aboriginal and Torres Strait educational resources. Patient and carer education will be through the patient preceptorship model where experience patients and carers are trained by health care professionals to teach other members in their communities with kidney disease. This model has been shown to not only improve the outcomes of patient or carer but also the trainer themselves. This method will also support the development of peer-to- peer support groups.

BUDGET	
Educational Resource Development	100,000
Training of patient preceptors	400,000
Communications and Marketing (ongoing)	75,000
Design and Printing	75,000
Travel	25,000
Total Year 1	**675,000**
Ongoing support per annum	**75,000 pa**

2. The Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines

The Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines [10] are an evidence-based project that began in 1999. KHA-CARI Guidelines seek to improve the quality of care and outcomes for patients living with kidney disease in Australia and New Zealand by facilitating the development and implementation of clinical practice guidelines based on the best available evidence and effectiveness. The guidelines cover three disease areas; Kidney Disease, Dialysis, and Transplantation. This project is funded by Kidney Health Australia and is managed by the CARI Guidelines Steering Committee.

To address the unique challenges of Indigenous Australians with kidney disease and to improve kidney health in Indigenous Australasians, the KHA-CARI Guidelines group is developing a new specific guideline for management of CKD for Aboriginal and Torres Strait Islander peoples and Māori – *KHA-CARI Indigenous Guidelines*. This guideline aims to generate best practice guidelines to improve processes and outcomes of care Aboriginal and Torres Strait Islander Peoples and Māori.

The development of a best-practice set of guidelines SPECIFIC to indigenous 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 KHA. [2]

A novel feature in the development of the KHA-CARI Indigenous Guidelines will be a nationwide community consultation of Aboriginal and Torres Strait Islanders consumers and communities to ensure the guidelines are aligned with community preferences. This process is imperative to ensure appropriateness, effectiveness, and integration in order to have maximum impact on quality of health outcomes.

Given the experience that Kidney Health Australia has in the kidney community, Kidney Health Australia are to fund and conduct the nationwide community consultations – the vital first step in development of the KHA-CARI Indigenous Guidelines.

Goals of the Community Consultation

1. Seek feedback and advice on the focus and content of new clinical guidelines for the management of CKD among Aboriginal and Torres Strait Islanders; specifically the priorities for clinical care
2. Seek feedback and advice on the appropriate methods for translation of the new clinical guidelines into consumer information, tools and education materials, to facilitate implementation in clinical practice.

Community Consultation Method

The CARI guideline will be developed using validated and established methods of the KHA-CARI guidelines development manual http://www.cari.org.au/docs/KHACARI_Guideline_development_%20manual.pdf

The engagement of consumers and communities as part of the KHA-CARI Guideline development is a *new* component to the existing methodology. Engagement, consultation and participation of Aboriginal and Torres Strait Islanders is very important to ensure the appropriateness, effectiveness, integration and impact on quality of health outcomes.

Summary of Methodology:

Strategy 1: Establish a Panel of Aboriginal and Torres Strait Islander health clinicians
Strategy 2: Local Site Consultations with Aboriginal and Torres Strait Islander consumers and services
Strategy 3: Consultation with Aboriginal and Torres Strait Islander health peak bodies

Strategy 1: Panel of Aboriginal and Torres Strait Islander health clinicians

The Panel of Aboriginal and Torres Strait Islander health clinicians will comprise those community-based practitioners at the interface with Aboriginal and Torres Strait Islander patients. They will be well-placed to advise of the 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 representative of the key States/Territories with high CKD prevalence, with regard to metropolitan, rural and remote regions. Individual panel members will also facilitate contacts and assist with *Strategy 2: Targeted site engagements with Aboriginal and Torres Strait Islander consumers and services*.
The Panel of Aboriginal and Torres Strait Islander health clinicians will provide advice and feedback on defining the scope of the new clinical guidelines.

Strategy 2: Targeted site engagements with Aboriginal and Torres Strait Islander consumers and services
The consultation will occur locally via community partners. Community partners will be selected based upon the location of dialysis centres with high numbers of Aboriginal and Torres Strait Islanders and Aboriginal Community Controlled Health Organisations (ACCHOs) with staff working in kidney health or managing risk-factors.

In addition, we will aim for efficiency and avoidance of resource waste, duplication by partnering with organisations with existing access and processes for community consultation. A total of 20 consultations will occur focusing on the Northern Territory, Western Australia, South Australia and New South Wales and will include a cross section of rural, remote and urban communities. Details of the proposed sites, consumers and services are given in Appendix A.

Method for Community Consultation:

- To be developed with each site based on local community pathways and processes, but will essentially involve a workshop in each local community.
- Workshops will be co-convened by a lead clinical contact or researcher, and local community contact. Participants will be invited by the local community contact. Facilitators for the workshops will be identified by the local community contact.
- Logistics of the meeting will be arranged by the local community contact with support from KHA and CARI.
- Workshops will be recorded and transcribed; transcripts will be provided to participants for feedback via the local community contact for correction
- Transcripts will be analysed and feedback collated
- Participants will evaluate the process (evaluation form to be developed)

The outcomes of the Community Consultation will then directly be fed back to the KHA-CARI Guidelines working group which has already been appointed to write the guidelines. These recommendations will shape the Guideline writing.

Following generation of Draft Guidelines:

- Draft Guidelines (or any issues that arise requiring further input) will be circulated to participants via the local community contact for further input
- The final guidelines will be disseminated in accordance with the community feedback
- The final guidelines will be made available in language and formats suitable for all Indigenous peoples to access and understand.

Strategy 3: Consultation with Aboriginal and Torres Strait Islander health peak bodies

As part of the public consultation process, the Aboriginal and Torres Strait Islander health peak bodies will be directly contacted to seek feedback regarding the guidelines. These organisations include *but will not be limited to*:

- Australian Indigenous Doctors’ Association (AIDA)
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)
- Indigenous Allied Health Australia (IAHA)
- National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA)
- National Aboriginal Community Controlled Health Organisation (NACCHO) and Affiliates

Timeframe

The project started in the second quarter of 2017 with KHA-CARI Committee Working Group meetings to discuss guideline development and consultation process. In 2018 the planning of the community consultation will take place and workshops eventuate. In 2019 the results of the community consultation will be used to inform the development of the KHA CARI Indigenous guidelines. A detailed summary of the timeframes and duration of the project is given in Appendix A.

References

1. 2016 Census Counts - Aboriginal and Torres Strait Islander Peoples (by State/ Territory and Capital City/ 'Rest of State'). Australian Bureau of Statistics. Available from URL http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/2075.0Main%20Features52016?opendocument&tabname=Summary&prodno=2075.0&issue=2016&num=&view=

2. Kidney Health for All: A report on policy options for improving Aboriginal and Torres Strait Islander Kidney Health, September 2015. Retrieved [18th Feb 2018] Available from http://kidney.org.au/cms_uploads/docs/september-2015-kidney-health-for-all.pdf

3. ANZDATA Registry. 38th Report, chapter 12: Indigenous people and end stage kidney disease. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2016. Retrieved [18th Feb 2018] Available from URL: http://www.anzdata.org.au

4. Stumpers S, Thomson N (2013) Review of kidney disease among Indigenous people. Retrieved [18th Feb 2018] Available from: www.healthinfonet.ecu.edu.au/chronic-conditions/kidney/reviews/our-review

5. Hoy, W. E., Mott, S. A., and Mc Donald, S. P. (2016) An expanded nationwide view of chronic kidney disease in Aboriginal Australians. Nephrology, 21: 916–922. doi: 10.1111/nep.12798.

6. Lim WH, Boudville N, McDonald SP, Gorham G, Johnson DW, Jose M. Remote indigenous peritoneal dialysis patients have higher risk of peritonitis, technique failure, all-cause and peritonitis-related mortality. Nephrol. Dial. Transplant. 2011; 26 (10): 3366–72.

7. Rogers NM, Lawton PD, Jose MD. Indigenous Australians and living kidney donation [letter]. N. Engl. J. Med. 2009; 361: 1513–6.

8. Rogers NM, Lawton PD, Jose MD. Kidney transplant outcomes in the indigenous population in the Northern Territory of Australia. Transplantation 2006; 82: 882–6.

9. Devitt J, Cass A, Cunningham J, Preece C, Anderson K, Snelling P. Study protocol–Improving access to kidney transplants (IMPAKT): A detailed account of a qualitative study investigating barriers to transplant for Australian Indigenous people with end-stage kidney disease. BMC Health Serv. Res. 2008; 8: 31.

10. KHA-CARI Guidelines. Available from URL http://www.cari.org.au/

Attachment A: Site Engagements with Consumers & Services (Draft)

	Name	Position	Location
Queensland			
1	Dr Mark Wenitong	GP, Apunipima	Cairns, QLD
2	Maurice Serico	KHA Indigenous Rep	Brisbane, QLD
3	Sam Mills	Unit Manager, TI Hospital	Thursday Island, QLD
4	(2 people)	Aboriginal Health Workers	Yarrabah, QLD
5	Tracey Cuthbertson	Kidney Health Project Officer	Saibai Island, Torres Strait
6	Dr Slav	WuChopperen Health Service	Cairns, QLD
Northern Territory			
7	Heather Hall	Renal Nurse, Panuku	Darwin, NT
8	Beth Amega & 2 others	Renal Nurse Coordinator Danila Dilba	Darwin, NT
9	Lockie & Co.	Panuku Consumers	Darwin, NT
10	Sarah Brown	EO, The Purple House	Alice Springs, NT
11	Donna Ah Chee & Staff	CAAC	Alice Springs, NT
Western Australia			
12	Jenny Cutter	Manager, KRS	Broome, WA
13	Sharon Carlin	Renal Nurse Coordinator, KRS	Broome, WA
14	CEO	Derby AMS	Derby, WA
15	CEO	Kununurra AMS	Kununurra, WA
16	Corina Abraham	KHA Indigenous rep	Perth, WA
New South Wales			
17	Lesley Salam	Renal Nurse	Kempsey, NSW
18	Elizabeth Rix	Renal patient group	Nth NSW
South Australia			
19	Nola Butler	KHA Indigenous rep	Adelaide, SA
20	SAHMRI (OG, JK, SJ)		

Appendix B: Timeline and Duration of KHA-CARI Indigenous Guidelines

Abbreviations:

KHA:	KHA staff – in kind support from SJ / staff
CARI:	CARI Office Staff
WG:	Writing Group led by Australian Chairs
Panel:	Panel of Clinicians Expert in Indigenous Health (Strategy 1)
Community Partners:	Organisations enlisted to facilitate consultation at local sites

Date	Task	Responsible
June – Dec 2017	Guideline Group Face-to-face meetings and T/C with all new members to discuss guideline development and consultation process	CARI, WG
Jan-March 2018	KHA applications for discretionary funding for community consultation	KHA
Jan-April 2018	Confirm methodology for Stage 1 Community Consultation	KHA, CARI, WG
Jan-Feb 2018	Identify panel members for Strategy 1	KHA
March –May 2018	Meetings (TC/VC) of Strategy 1 panel	KHA, CARI
March 2018	Guideline Working Group TC	CARI
July-August 2018	Strategy 1 panel report on priorities / questions	Panel, CARI
May-July 2018	Commence Strategy 2: Community Consultation NT / FNQ sites	Menzies (JH), KHA
August-Sept 2018	Refine Priorities / Consultation Process	CARI, WG
Sept 2018	WG Face-2-face meeting at ANZSN, Sydney	CARI
Sept 2018-March 2019	Conduct Community Consultation across all other sites	KHA, CARI, Community Partners
December 2018	Guideline Working Group TC	CARI
December 2018	Strategy 1 Panel TC for feedback	CARI
2018-2019	Literature search; identify evidence-base; guideline writing as per usual methods	CARI, WG
2020	Draft Guidelines – Community Stakeholders; Strategy 1 Panel Input; Public Consultation	KHA, CARI, Community Partners, WG
2020	Strategy 3 Peak Body Consultations	KHA
Late 2020	Finalise Guidelines	CARI
2020-2021	Disseminate Guidelines	KHA, CARI