Kidney Health Australia

Submission on Indigenous kidney health issues for the Senate Select Committee on Health

Key Messages

- Chronic kidney disease (CKD) is increasing in Australia. Aboriginal and Torres Strait Islander people experience disproportionate levels of CKD regardless of urban, region or rural locality.
- There is scope for the Federal Government to provide solid leadership in Indigenous affairs and health, with the Department of Prime Minister & Cabinet (DPMC) at the centre of coordinated national policy and program implementation.
- Adequately resourced preventive programs with the primary health sector reduces the progression of chronic diseases, including kidney disease.
- A competent, qualified, culturally respectful, multidisciplinary health workforce is critical to improving Aboriginal and Torres Strait Islander health.
- A wide range of support services for Aboriginal and Torres Strait Islander kidney consumers and families need to be accessible and better integrated to limit the severity of dislocation for treatment.
- Ultimately, the recommendations below will lead to longer term savings as prevention, earlier detection, management will reduce late stage acute and high cost interventions.

Recommendations

Recommendation 1: The NATSIHP Implementation plan incorporate specific activities focussing on the prevention, intervention, management and support of chronic kidney disease and associated risk factors.

Recommendation 2: The Federal Government invest in awareness and prevention measures which tackle the main causes of chronic disease and CKD in Aboriginal and Torres Strait Islander populations = smoking, poor nutrition and lack of physical activity.

Recommendation 3: The Federal Government invest in training an Aboriginal and Torres Strait Islander health workforce, in chronic kidney disease.

Recommendation 4: The Federal Government invest in professional development and training of existing and graduate health workforce in Aboriginal and Torres Strait Islander CKD.

Recommendation 5: The Federal Government expedite plans for the $10m family-centric renal accommodation infrastructure development earmarked for Alice Springs and Tennant Creek.

Recommendation 6: The Federal Government prioritise the delivery and implementation of appropriate patient and carer support services in remote and regional locations.

Recommendation 7: The Federal Government provide leadership and coordination with NT, WA & SA Governments on the development of an implementation plan for the updated Central Australian Renal Study.

1. Introduction

Kidney Health Australia is the national peak, non-government charitable organisation representing the interests of kidney stakeholders including clinicians, individuals and their families to improve kidney health outcomes for those affected by the disease. This is achieved through promoting good kidney health through *Education*; *Advocacy*; *Research* and *Support*.

The health and well-being of Aboriginal and Torres Strait Islanders is a priority for Kidney Health Australia. Our *Aboriginal and Torres Strait Islander Kidney Health Strategy 2015-17* (the Strategy) was developed to "reduce the impact of chronic kidney disease and improve the health, well-being and support for Aboriginal and Torres Strait Islanders affected by kidney disease"[1].

The Strategy provides Kidney Health Australia with a range of specific activities and actions across the continuum of health care to support and improve the lives of those Aboriginal and Torres Strait Islanders, their families and communities impacted by chronic kidney disease.

Kidney Health Australia has provided an earlier submission to the Senate Select Committee on Health regarding kidney health. We now welcome the opportunity to provide this submission specifically focussing on the experience, issues and challenges of Aboriginal and Torres Strait Islander chronic kidney disease (CKD) and applaud the committee's decision to focus specifically on Indigenous health.

[1] Kidney Health Australia 2014, *Aboriginal and Torres Strait Islander Kidney Health Strategy 2015-17*

2. Burden of Chronic Kidney Disease impacting Indigenous Australians

Chronic kidney disease (CKD) refers to all kidney conditions where a person has evidence of kidney damage or reduced kidney function, lasting at least 3 months. CKD is common and often preventable, because many of its risk factors are modifiable, such as high blood pressure, tobacco smoking and obesity. An individual can lose up to 90% of their kidney function before symptoms are evident[2].

The burden of disease from CKD in all populations tends to be seriously underestimated given the under-recognition of the condition. Even when undiagnosed it impacts on health resource utilisation in its early stages through its associated hypertension, anaemia and other complications. The number with early CKD far outnumbers those with kidney failure. Aboriginal and Torres Strait Islander people experience disproportionate levels of CKD regardless of urban, region or rural locality. Compared with the general population, Aboriginal and Torres Strait Islanders are four (4) times more likely to have CKD and develop end-stage kidney disease (ESKD)[3] [4]. In remote and very remote areas of Australia, the incidence of ESKD for Aboriginal and Torres Strait Islander people is especially high with rates almost 18 times and 20 times higher than those of comparable non-Indigenous peoples[5]. The highest standardised incidence ratio was in the NT (17), followed by WA (11.9)[6].

Aboriginal and Torres Strait Islanders with treated ESKD are known to have earlier onset, experience a multiplicity of barriers to receiving equitable treatment and have worse prognosis[7].

The greater prevalence of CKD in some Aboriginal and Torres Strait Islander communities is due to the high incidence of risk factors including diabetes, high blood pressure and smoking, in addition to increased levels of inadequate nutrition, alcohol abuse, streptococcal throat and skin infection and poor living conditions[8] [9].

This disproportionate share of kidney disease has placed considerable demands on Aboriginal and Torres Strait Islander families and communities, including the need to attend dialysis (usually 3 times per week), to take multiple medications, and follow strict dietary

[2] KHA Fast Facts 2014
[3] AIHW 2011, *Chronic Kidney Disease in Aboriginal and Torres Strait Islander people*
[4] ABS 2014, *Australian Aboriginal and Torres Strait Islander Health Survey: Biomedical Results 2012-13*
[5] ABS 2012, *Australian demographic statistics*, March quarter 2012.
[6] ibid
[7] Preston-Thomas, Cass & O'Rourke 2007, *Trends in the incidence of treated end-stage kidney disease among Indigenous Australians and access to treatment*.
[8] KHA 2014a, *Kidney Fast Facts*
[9] O'Dea 2005, *Preventable Chronic Diseases Among Indigenous Australians: The Need for a Comprehensive National Approach*

restrictions. These demands are compounded by poor levels of access to kidney transplantation[10].

3. Term of Reference (e), with reference to improving Indigenous CKD

e. improvements in the provision of health services, including Indigenous health and rural health

While the burden of CKD and co-morbidity in Aboriginal and Torres Strait Islander populations may appear complex and overwhelming, significant progress has been made in recent years through coordinated focus by governments (Federal, State & Territory), non-government organisations (NGOs), Aboriginal Community Controlled Health Organisations (ACCHOs) and General Practice (GP) in the prevention, detection and management of chronic disease, including CKD.

3.1 What works in Aboriginal and Torres Strait Islander health, & CKD?

3.1.1 A workforce for prevention

Since 2009, the *Closing the Gap in Indigenous Health Outcomes – Indigenous Chronic Disease Package (ICDP)* established a tackling tobacco and healthy lifestyle workforce based in ACCHOs and Medical Locals (MLs) specifically targeting Aboriginal and Torres Strait Islander preventative health[11].

The *Tackling Smoking and Healthy Lifestyle Workforce* was rolled out nationally over three (3) years and comprises some 340 positions in 57 regions across Australia[12].

Regional Tackling Smoking and Healthy Lifestyle Teams work in partnership with Aboriginal and Torres Strait Islander communities and relevant organisations to tackle some of the main causes of chronic disease, early death and CKD: smoking, poor nutrition and lack of physical activity.

[10] George Institute for International Health 2008, *George Research Newsletter*, Issue 12.
[11] Australian Government 2013. Close the Gap: Prime Minister's report 2013, http://www.dss.gov.au/sites/default/files/documents/02_2013/00313-ctg-report_fa1.pdf
[12] Media Release: The Hon Warren Snowdon MP, Minister for Indigenous Health 8 December 2010 'National workforce launched to tackle indigenous smoking and improve health'

ISSUE:

A Review into the *Tackling Smoking and Healthy Lifestyle Programs* was undertaken in 2014, with the report due for submission to the Department of Health in late December 2014.

Approximately $67.3m of this funding has been marked for savings rationalisation in the Indigenous Affairs Program area.

Source: Senate Estimates Hansard 2014, Finance and Public Administration Legislation Committee, Friday 24 October 2014

ISSUE:

The *Local Community Campaigns* grant funding to enable Aboriginal and Torres Strait Islander communities to run locally-driven health promotion projects to help people make healthy lifestyle choices and reduce the risk of chronic disease ceased on 30 June 2014.

Source: Senate Estimates Hansard 2014, Finance and Public Administration Legislation Committee, Answers to Estimates Questions on Notice, Health Portfolio, Friday 24 October 2014.

3.1.2 Chronic Disease Management

An integrated care pathway has been established to screen, detect and manage a wide range of chronic diseases for Aboriginal and Torres Strait Islander people. The *Medical Assessment for Aboriginal and Torres Strait Islander people* (MBS Item 715) was established in response to the higher morbidity and mortality levels, earlier onset and more severe disease progression that Aboriginal and Torres Strait Islander people experience.

The integrated care pathway commences with a *Medical Assessment for Aboriginal and Torres Strait Islander people* and provides access to other Aboriginal and Torres Strait Islander specific health measures, including *Indigenous Health Incentive* under the *Practice Incentive Program (PIP), General Practice Management Plan (GPMP), Care Coordination and Supplementary Services* – access to MBS-rebated follow up services from specialists, allied health workers, practice nurses and Aboriginal Health Workers[13].

[13] AIHW website: http://www.aihw.gov.au/indigenous-australians/indigenous-health-check-data-tool/

Kidney Health Australia

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Kidney Health Australia is concerned that reforms to Medicare do not severely impact Aboriginal and Torres Strait Islander people and other low socio-economically and chronically ill groups, such as renal patients.

The establishment of any type of out-of-pocket expense to access health care will deter Aboriginal and Torres Strait Islanders and those with complex and chronic health issues to delay primary care prevention and management, which will increase acute presentations to emergency hospital departments.

For ACCHOs, the administration 'will cause significant burden and financial loss and will introduce a further obstacle to accessing primary health care for Aboriginal people leading to a widening of the gap in mortality[14].

ISSUE:

In May 2014, the (former) Minister for Health Peter Dutton MP announced that "from early 2016, five of the ten existing PIP incentives will be streamlined into a single incentive, focussing on continuous quality improvement in general practice and we will continue to work with the Australian Medical Association and others to finalise details of the new incentive and improvements to PIP".

Through the National Vascular Disease Prevention Alliance (NVDPA), Kidney Health Australia along with the National Heart Foundation, Diabetes Australia and the Stroke Foundation propose a new quality-focussed Integrated Health Check (IHC) in Australian general (medical) practice.

A new quality-focussed IHC PIP streamlines a number of existing PIPs into one absolute risk assessment for the early detection and risk management of developing chronic kidney disease, type 2 diabetes, heart disease or stroke.

Source: Minister Dutton speech at the Australian Medical Association National Conference – Global Practice, Australian Perspective in Canberra on 23 May 2014.

[14] AHCSA Submission to the Senate Select Committee on Health, Submission no. 111.

3.1.3 Subsidised Medications in primary care

Most Aboriginal and Torres Strait Islander people in remote areas will need medication for chronic disease by early or mid-adult life in order to manage the progression[15].

Under the provisions of *section 100* of the *National Health Act 1953*, clients of approved remote area Aboriginal Health Services (AHSs) are able to receive medicines from the AHS, without the need for a normal PBS prescription form, and without charge[16].

These special arrangements were introduced in 1999 to address a range of barriers for Aboriginal and Torres Strait Islander people with accessing medications in remote regions.

Under the *COAG National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes*, the *PBS Co-payment Measure* provided subsidised or nil patient co-payment for PBS medicines for eligible Aboriginal and Torres Strait Islanders living with, or at risk of, chronic disease[17].

3.2 What needs to be improved?

The health and well-being of Aboriginal and Torres Strait Islander people is complex and long-term strategies to address health outcomes need to be cognisant of the socio-economic, cultural aspects, health systems and medical factors that contribute to high rates of CKD and associated chronic diseases among Aboriginal and Torres Strait Islander people[18] [19].

3.2.1 Strategic Health Policy

The Australian Government Department of Health has signalled the development/update of a National Chronic Disease Strategy, which will accommodate a focus on kidney disease, an issue for which Kidney Health Australia has long been advocating. The prevention of chronic kidney disease in Aboriginal and Torres Strait Islander populations also requires a coordinated strategic response.

[15] Hoy 2013, 'Chronic disease care in remote Aboriginal Australia has been transformed' in BMJ 2013
[16] Department of Health website: http://www.health.gov.au/internet/main/publishinng.nsf/Content/health-pbs-indigenous
[17] Medicare Australia website: http://www.medicareaustralia.gov.au/provider/pbs/pharmacists/closing-the-gap.jsp
[18] Preston-Thomas, Cass, & O'Rourke 2007, Trends in the incidence of treated end-stage kidney disease among Indigenous Australians and access to treatment.
[19] National Indigenous Dialysis and Transplantation Symposium 2008

The *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* (the NATSIHP) identifies kidney disease as a significant health issue across the life course of Aboriginal and Torres Strait Islander people.

On 30 May 2014, Senator the Hon Fiona Nash, Assistant Minister for Health, announced that the NATSIHP would be updated to reflect the Australian Government's approach and priorities for Indigenous affairs and that an Implementation plan would be developed outlining the Commonwealth's coordinated efforts to improve Aboriginal and Torres Strait Islander health outcomes[20]. This was to be completed by the end of 2014.

To date, an updated NATSIHP and development of a national Implementation Plan are yet to be publicly released.

Recommendation 1: The NATSIHP Implementation plan incorporate specific activities focussing on the prevention, intervention, management and support of chronic kidney disease and associated risk factors.

3.2.2 Awareness & prevention of CKD

Link to other Terms of Reference:
(c) the impact of reduced Commonwealth funding for health promotion, prevention and early intervention;

Health promotion, prevention and early intervention are at the forefront of reducing the development and progression of chronic diseases.

There remains a lack of awareness and prevention by Aboriginal and Torres Strait Islander people and communities about chronic disease, CKD and the associated risk factors[21]. Aboriginal and Torres Strait Islander people are less likely to be aware that they have CKD than non-Indigenous Australians. The Australian Bureau of Statistics (ABS) Australian Health Survey Aboriginal and Torres Strait Islander biomedical survey found that nine in ten Aboriginal and Torres Strait Islanders do not know they have signs of CKD[22]. This is due to the commonality of multiple risk factors with other chronic disease, such as diabetes, hypertension and other cardiovascular disease[23] [24].

[20] Department of Health website: http://www.health.gov.au/natsihp
[21] Hoy et al 2010, 'Chronic disease profiles in remote Aboriginal settings and implications for health services planning' in *Aust NZ J Public Health*
[22] ABS 2014, *Australian Aboriginal and Torres Strait Islander people Health Survey: Biomedical Results*
[23] Stumpers S, Thomson N 2013. *Review of kidney disease among Indigenous people*.
[24] O'Dea 2005, *Preventable Chronic Diseases Among Indigenous Australians: The Need for a Comprehensive National Approach.*

The development of end stage kidney disease (ESKD) requiring dialysis is closely associated with diabetes, high blood pressure and related conditions. Appropriate preventive primary health services are essential to identify and treat the early stages of chronic diseases in Aboriginal and Torres Strait Islander communities before they become more disabling and costly to treat.

Any reduction to preventative health funding in Aboriginal and Torres Strait Islander chronic disease, such as the proposed $67.3m savings rationalisation of the *Tackling Smoking and Healthy Lifestyle* Programs will see a stagnation in efforts to manage risk factors, which will later present as more complex and acute conditions.

Recommendation 2: The Federal Government invest in awareness and prevention measures which tackle the main causes of chronic disease and CKD in Aboriginal and Torres Strait Islander populations = smoking, poor nutrition and lack of physical activity.

3.2.3 Workforce

Link to other Terms of Reference:
(g) Health workforce planning

A competent, qualified, culturally respectful, multidisciplinary health workforce is critical to improving Aboriginal and Torres Strait Islander health.

It is essential to implement different strategies to develop:

- An Aboriginal and Torres Strait Islander health workforce at all levels of the health system; and
- A health workforce that has the requisite skills and training to work effectively to improve Aboriginal and Torres Strait Islander health.

In order to improve Aboriginal and Torres Strait Islander CKD, this requires:

1. Training Aboriginal and Torres Strait Islander Health Workers, Nurses, GPs, Nephrologists, clinic managers, health policy managers, researchers and other key areas;
2. Training and professional develop about Aboriginal and Torres Strait Islander CKD and chronic illness for existing and graduate health professionals and policy managers.

For example, of the existing Aboriginal and Torres Strait Islander health workforce, there is only 1 Aboriginal Nephrologist based in the Northern Territory.

Recommendation 3: The Federal Government invest in training an Aboriginal and Torres Strait Islander health workforce, in chronic kidney disease.

Recommendation 4: The Federal Government invest in professional development and training of existing and graduate health workforce in Aboriginal and Torres Strait Islander CKD.

3.2.4 Integration of Support Services

Link to other Terms of Reference:
(b) the impact of additional costs on access to affordable healthcare and the sustainability of Medicare
(d) the interaction between elements of the health system, including between aged care and health care
(f) the better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners, pharmaceuticals, optometry, diagnostic, dental and allied health services

Aboriginal and Torres Strait Islanders with ESKD are more likely to have to relocate to access treatment. The lack of treatment available in remote areas and the availability of transplant facilities create geographical barriers to treatment with 78% of patients in remote areas having to relocate, compared with 39% of those who live in rural areas and 15% of urban Indigenous ESKD patients[25].

The dislocation of renal patients has significant biological, psychological, social and economic consequences on the health and wellbeing of consumers, their families, communities and the wider health and welfare system.

A wide range of support services for Aboriginal and Torres Strait Islander kidney consumers and their families need to be accessible and better integrated to limit the severity of dislocation including[26]:

- Psychological support services
- Housing and accommodation
- Travel and transport
- Respite Care

For example, in the Northern Territory (NT), housing and accommodation remains a significant barrier for Aboriginal and Torres Strait Islanders from homelands that are required commence dialysis in either Darwin or Alice Springs.

[25] Stumpers & Thomson 2013, *Review of kidney disease among Indigenous people*.
[26] Harvey, M; Salisbury, A & Hoy, W 2012, *Closing the Gulf in Renal Healthcare: A Collaborative Workshop Report*

Cost barriers to affordable accommodation are forcing some Aboriginal renal patients to move in with other family (creating overcrowding), town camps (lacking water, power & basic hygiene) or long-grassing (roughing it in the riverbed)[27].

Recommendation 5: The Federal Government expedite plans for the $10m family-centric renal accommodation infrastructure development earmarked for Alice Springs and Tennant Creek.

In addition, in Alice Springs, it was reported that there are no support services (including psychological) for younger adults to manage diagnosis, compliance with dialysis treatment and the changes in lifestyle needed[28].

Recommendation 6: The Federal Government prioritise the delivery and implementation of appropriate patient and carer support services in remote and regional locations.

Commonwealth/ State & Territory relationships

Link to other Terms of Reference:
(a) the impact of reduced Commonwealth funding for hospital and other health services provided by state and territory governments, in particular, the impact on elective surgery and emergency department waiting times, hospital bed numbers, other hospital related care and cost shifting;

State and Territory Governments are the predominant provider of haemodialysis services in Australia. Haemodialysis services are usually provided in a hospital-based setting (renal unit) or stand-alone (satellite centre).

Aboriginal and Torres Strait Islander people are more frequent users of hospital care and more reliant on public hospital services compared to other Australians.

In 2012–13, hospitalisation rates for regular dialysis (as the principal diagnosis) were much higher for Indigenous Australians than for other Australians (10 times as high), particularly for females[29].

In a previous AIHW report 2011, it was found that Indigenous Australians accounted for 54-97% of CKD hospitalisations as the principal diagnosis in Remote & Very Remote areas despite only making up 15% of the population[30].

[27] Kidney Health Australia 2014, Overview of visit to Northern Territory – meeting with service providers
[28] Kidney Health Australia 2014, Overview of visit to Northern Territory – meeting with service providers
[29] AIHW 2014. *Cardiovascular disease, diabetes and chronic kidney disease— Australian facts: Morbidity–Hospital care*
[30] ibid

Reductions in hospital funding will disproportionately affect Aboriginal and Torres Strait Islander people and can be expected to slow, stagnate or even reverse progress towards improving health outcomes.

The cross-border region between Western Australia, South Australia and the Northern Territory has for many years seen an increase in the number of Aboriginal renal patients requiring haemodialysis and hospital services moving to Alice Springs.

In 2010, the Federal Government commissioned the *Central Australia Renal Study* to inform governments in the cross-jurisdictional region to make evidence based policy decisions, in order to better meet the health and service needs of Aboriginal dialysis patients in the region, in affordable and sustainable ways[31].

The Australian, Northern Territory, South Australian and Western Australian Governments agreed the Terms of Reference for the Study, which was completed in 2011.

Currently in Alice Springs, there are approximately 300 patients accessing haemodialysis through NTG renal unit, Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) or the Fresenius dialysis clinic. It has been advised that the forecasted scale of demand has been underestimated in Alice Springs and facilities are currently at full capacity[32].

The Australian Government Department of Health has indicated that the Central Australian Renal Study is currently being updated with forecasted demand figures.

Recommendation 7: The Federal Government provide leadership and coordination with NT, WA & SA Governments on the development of an implementation plan for the updated Central Australian Renal Study.

Other Comments

The Federal Government has undertaken significant changes to the bureaucratic administration and management of the Indigenous Affairs portfolio. Indigenous Affairs has been identified as one of the Top 5 priorities. The Department of Prime Minister & Cabinet has central policy coordination responsibility working with Department of Health, Department of Social Services, Department of Human Services and other agencies.

Kidney Health Australia recognises the adjustments and significant time required for new changes to the machinery of government and flow-on effects for public sector management, which at present has impacted on decision-making and roll-out of new programs and initiatives.

[31] Department of Health & Ageing 2011, Central Australian Renal Study: Executive Summary.
[32] Kidney Health Australia 2014, Overview of visit to Northern Territory – meeting with service providers

For example, the first funding round for the Indigenous Advancement Strategy (IAS) was scheduled to announce successful applicants in December 2014. This has been delayed until end March 2015, leaving those services with lapsing funding agreements at 30 June 2015, who were forced to apply due to the streamlining of other Indigenous programs, in very stressful and dire circumstances.

There is scope for the Federal Government to provide solid leadership in Indigenous affairs and health. Kidney Health Australia will welcome the opportunity to work with key areas of government to assist with the roll-out of new programs and initiatives.

4. References

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