Kidney Health Australia Submission: National Aboriginal and Torres Strait Islander Health Plan.

Kidney Health Australia welcomes the opportunity to comment on the National Aboriginal and Torres Strait Islander Health Plan (the Plan). Kidney Health Australia is the only peak national body representing the needs of those with kidney disease in Australia. As the lead organisation in the kidney sector, Kidney Health Australia advocates on matters relating to the welfare of kidney stakeholders and the delivery of services to people affected by chronic kidney disease (CKD), in all its stages. Furthermore, Kidney Health Australia has close ties with consumers, the medical community, renal units around the nation and is a member of the Australian Chronic Disease Prevention Alliance (ACDPA) and the National Vascular Disease Prevention Alliance (NVDPA). To that end, Kidney Health Australia was an active contributor to the consultations underpinning the development of the Plan, taking part in those held in Canberra, Launceston and Brisbane.

The State of Kidney Disease in Indigenous Communities

It is estimated that approximately 1.7 million Australians over the age of 25 years have at least one clinical sign of existing CKD. CKD may further deteriorate into end-stage kidney disease (ESKD), when renal replacement therapy (RRT) - dialysis or transplantation - is required to stay alive. Without kidney function death will occur in a matter of days. At the end of 2011 a total of 10,998 Australians were on dialysis, and according to the Australian Institute of Health and Welfare this figure is expected to increase 80 per cent by 2020. Currently, 1,068 people are waiting for a kidney transplant in Australia.

The situation is much worse for Aboriginal and Torres Strait Islanders, who are at an increased risk of developing CKD. The first detailed, comprehensive analysis by the Australian Health and Welfare Institute (AIHW) in 2011 indicated that over the period from 2007 to 2008, almost 11% of new cases of treated ESKD were for Indigenous Australians, despite comprising only 2.5% of the total population. The situation is worse when you consider the fact that the hospitalisation rate for regular dialysis treatment among Indigenous Australians was 11 times as high for other Australians, and Indigenous Australians are four

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2 Australian Institute of Health and Welfare. Chronic kidney disease in Aboriginal and Torres Strait Islander People. Published 2011. Available at: www.aihw.gov.au
times more likely to die with CKD as a cause of death. The situation for Indigenous Australian’s living in rural and remote locations is considerably worse.

The cost of treating CKD is equally daunting. Economic modelling commissioned by Kidney Health Australia conservatively estimates that the cumulative cost of treating all current and new cases of ESKD from 2009 to 2020 Australia wide to be between $11.3 billion and $12.3 billion\(^3\). The AIHW estimates that in 2006-07 12% of hospital admitted patient expenditure on CKD was for Indigenous Australians, and that the cost of treating Indigenous Australians would continue to increase as a proportion of the total expenditure. This is based on the fact that over the period 2001 to 2008, the number of Indigenous Australians receiving treatment for ESKD had increased by 72%, where as the increase for non-Indigenous Australians was only 41% by comparison\(^4\).

In light of the significance of kidney related health issues within the Indigenous and Torres Strait Islander community, Kidney Health Australia welcomes the opportunity to comment on the development of the National Aboriginal and Torres Strait Islander Health Plan (NATSIHP).

**General Comments on the Plan**

Kidney Health Australia believes that the Plan represents another opportunity to reflect upon the increasing prevalence of chronic disease and the burden it places on the health system, while providing an overarching roadmap to combat it. The below comments seek to provide a general response to the issues raised in the online consultation survey, as well as a number of additional suggestions.

Kidney Health Australia believes that prevention and early intervention through the establishment and maintenance of healthy environments is vital to stopping the increasing rates of CKD and ESKD. This can be achieved by improving access to quality food, increased education and awareness, and early diagnosis in the primary care space. Addressing the social determinants of health is therefore critical in addressing the health gap.

In regards to implementing meaningful change in the Indigenous health space, Kidney Health Australia ascribes to a partnership approach of collaboration in order to improve the health of all Australians. This is particularly so in respect to Indigenous Australians, where it must be pursued in a culturally respectful manner, and importantly, community led.

It is important to introduce a degree of flexibility into any national response – the variation across regions, levels of remoteness and socio-economic status is significant and any plan must continue to recognise this.

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Finally, the practical impediments to improved chronic disease management, and in particular, CKD and ESKD can make a considerable impact if dealt with appropriately. Issues such as transport, accommodation, follow-up care and access to medication – particularly for rural and remote locations – cannot be underestimated, and are elaborated further below under the relevant headings.

Response to main themes based on survey questions:
Harnessing strengths and making a difference in health outcomes
Kidney Health Australia agrees with the points raised in a number of the face to face consultations that Indigenous people need to be the drivers of solutions to health issues, and that partnering and collaboration remain a key facet of this community led approach. Specifically, there was a strong focus on the need to develop the capacity of communities to advocate and successfully manage their health and social affairs and that this should be reflected within the plan.

With regard to making a difference in outcomes, it is clear that a strong focus on public health measures will continue to be required, and backed by appropriate resourcing. Importantly, the provision of a wide range of treatment options in remote, regional and urban settings should not result in significant variations in quality or safety, despite a potential differential in the mode of delivery.

However, it remains true that social determinants will still play the most significant role in improving health outcomes. Indeed, a number of reasons that kidney disease and other chronic conditions can take hold include a lack of appropriate sanitation, the increased use of alcohol or tobacco, the inability to secure fresh, healthy food (which drives substitution to less healthy alternatives), housing, overcrowding and a combination of other conditions. It is essential to continue to focus on the social determinants, and do so within future health plans and through the broader ‘Closing the Gap’ initiatives, if meaningful health outcomes are to be achieved.

What Governments need to do
There has in the past been an effort to harness the knowledge, skills and capabilities of people outside of government more effectively to work with Indigenous Australians. This process needs to continue and be engrained in the plan, if Aboriginal and Torres Strait Islander people are to proactively manage their health – in this respect funding to support communities in this task would enable a greater pro-active approach.

From a governance and policy making perspective, the key inhibitor to addressing the full spectrum of social determinants remains the delineation between different departments, agencies and portfolios at both a federal and state level. Building on the efforts through the ‘Close the Gap’ initiatives, different departments and agencies could further improve to work more effectively together, so as to ensure that overlaps in some areas and gaps in others do not emerge. This is particularly true when looking at the links between education, social support services and health services, as discussed below.
Health System - Workforce

One of the key areas of interest for Kidney Health Australia going forward is the greater development of an Aboriginal and Torres Strait Islander health workforce – which requires a recommitment by all levels of government to improve the entire education pipeline. At the current time there is no competency module on early CKD available for Aboriginal health workers and work has only just begun to correct this.

Obviously such a comprehensive approach, as drawn out in the face to face consultation, requires improved literacy and numeracy rates in primary school, progressing to active after school groups, through to a career development focus and tertiary study. Improving the number of opportunities through scholarships, cadetships for University and ABSTUDY funding improvements are important in achieving this. Likewise, in this age bracket, supporting those who choose to become parents through flexible and continuing engagement with education, will assist in stemming the loss of educated young people from potential career pathways. For mature aged students, consideration of multiple pathways to university and mentoring (using local Indigenous leaders/elders) and support programs will also be important in helping to facilitate the transition from school to university or TAFE to a career.

In relation to supporting mainstream health services to provide improved, culturally appropriate health care, programs such as the Remote Area Health Corps (RAHC) offer a good model for introducing people to working in Indigenous communities. One possible solution may be to expand it to all regions and Aboriginal Community Controlled Health Services (ACCHS) where there is a workforce shortage. Such an approach that builds in appropriate preparation and support will likely generate more favourable outcomes, rather than just offering straight financial incentives as a method of recruitment and retention.

Health System – Primary Care

With regard to the questions relating to integration and coordination of comprehensive care, improved accessibility and cultural competency, it is clear that imbedding robust integrated chronic disease prevention, surveillance and treatment programs into primary care could make a significant difference. Some Aboriginal Medical Services (AMS) undertake this already, but this should be increased significantly and across the differing modes of primary care delivery as the burden of chronic disease continues to grow.

As part of this, linking primary care screening with existing health services is an area that should be further explored. For example, those who travel from rural or remote communities to undertake dialysis may often do so with family and friends, which would provide an opportunity for parallel, robust screening of those already at high risk for indicators of chronic disease, such as CKD. Indeed Kidney Health Australia has developed a number of projects and processes to demonstrate the viability of screening those at risk of CKD, and models such as our Kidney Evaluation for You (KEY) could present a valuable example for consideration.
A key part of encouraging greater screening and treatment services is also appropriate reimbursement to the provider. However, such reimbursements should not be seen as ‘high cost’ as they will may indeed save the cost of late and often more intensive, intervention and treatment. In addition, for rural areas the reimbursement for pharmacy advice and dispensing, coupled with supply issues, continues to be an issue. For those suffering from chronic conditions, such as CKD, a reliable, sustainable supply of medications, coupled with appropriate advice is critical. This is particularly the case for middle aged patients who may be on multiple medications and will need advice and support regarding drug interactions and ongoing dosage management.

For those in rural and remote locations a continued approach to funding outreach models of care for those who choose not to - or more likely cannot - travel are particularly important. This can take the form of travelling vehicle (such as a dialysis bus, such as exists in Central Australia and which Kidney Health Australia is currently further implementing in Victoria), increased transport options to a satellite clinic, or mobile eHealth solutions. Furthermore, it has been the experience of Kidney Health Australia that the current levels of subsidies to support those who travel are inadequate, and in the case of those who undertake dialysis at home (thus saving a considerable expense to government) the levels of reimbursement for water and electricity usage continue to be inadequate.

Equally, transport and accommodation remain critical issues for those with kidney disease – currently families travel to locations to undergo dialysis and there is more often than not no available housing. As a result they either suffer in less than adequate conditions, or do not travel for dialysis and thus suffer the health consequences. Therefore greater interaction between health, housing, social portfolios are critical to address this gap, and this includes working with State governments who bear some of the policy and program responsibility.

**Health System – Integration**

The greater integration of IT systems for recording clinical care – both as a mechanism for continuous improvement of the patient experience, but also data collection should be pursued. Ultimately, the ability for all health providers that work in the Indigenous health space to allow a patient’s record to move between them would be highly desirable. For example, the ability of a patient to move between an AMS, a state health service, the Royal Flying Doctor Service and local GPs, with an underlying shared record and linkages, would ensure a much greater continuity of care.

**Principles and Priorities**

As outlined above, Kidney Health Australia ascribes to a partnership approach and collaborative efforts to improve the health of Indigenous and Torres Strait Islanders. As such, Kidney Health Australia recognises and supports culturally appropriate engagement to empower Indigenous Australians to implement quality approaches to improving their health.
In relation to key priorities, there needs to be greater awareness and education to prevent chronic conditions, and in particular, CKD. For an enduring and improved Indigenous Health system a social determinants approach that clearly advocates for cross portfolio linkages is critical. Furthermore, overcoming the Federal / State divide is critical – particularly for those with CKD as the cross border issues between Western Australia, the Northern Territory and South Australia highlight acutely. A plan that therefore seeks to overcome these and support solutions that are suitable and adaptable for remote, regional and urban settings and promotes practical solutions – such as parallel screening for CKD while family members undergo dialysis – should be pursued. In addition, addressing the shortfall in transport, accommodation at the point of care, pharmacy supply, and water and electricity reimbursements for dialysis patients would likely result in a marked improvement in health outcomes and disease management.

Finally, Kidney Health Australia believes that a Plan that encourages the greater collaboration between key peak health organisations in a supporting role, but with a community and Indigenous lead approach is needed. In that respect, the national consultation process is a positive first step in the development of a national plan, and Kidney Health Australia remains eager to continue to engage with government on its continued development, additional policy development and eventual resourcing. Should you have any questions or would like to follow up any of the above please contact us on the above numbers. Thank you again for this opportunity to comment.

Yours Sincerely,

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Kidney Health Australia          Kidney Health Australia