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**KIDNEY
HEALTH
AUSTRALIA**

Patron-in-Chief
Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

Patrons
Sir Jack Brabham, AO, OBE
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6 November 2012

Attention:
Ms Cathie O'Neill
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Kidney Health Australia Submission: *ACT Strategy for Improving Care and Support for those Living with Chronic Conditions.*

Kidney Health Australia welcomes the opportunity to comment on the ACT Health Directorates 'Strategy for Improving Care and Support for those Living with Chronic Conditions 2012-2017' (the Strategy). 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).

The State of Kidney Disease in Australia

It is estimated that approximately 1.7 million Australians over the age of 25 years have at least one clinical sign of existing CKD¹. 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 2010 a total of 10,590 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 Australia².

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 billion³. Noting that the Strategy highlights that chronic conditions account for approximately 80% of the total burden of disease and injury in the ACT in 2007-08, it is clear that CKD has, and will continue to have, a significant impact.

¹ White SL, Polkinghorne KR, Atkins RC, Chadban SJ. Comparison of the prevalence and mortality risk of CKD in Australia using the CKD Epidemiology Collaboration (CKD-EPI) and Modification of Diet in Renal Disease (MDRD) Study GFR estimating equations: The AusDiab (Australian Diabetes, Obesity and Lifestyle) Study. *Am J Kidney Diseases* 2010;55(4):660-70.

² www.anzdata.org.au

³ Cass A et al. The Economic Impact of End Stage Kidney Disease in Australia: projects to 2020. Published 2010. Available at: <http://www.kidney.org.au/LinkClick.aspx?fileticket=vave4WFH73U%3d&tabid=635&mid=1837>



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General Comments on the Strategy

Kidney Health Australia therefore believes that the Strategy represents another opportunity to reflect upon the increasing prevalence of chronic disease and the burden it places on the health system, while providing an avenue to address these issues within the ACT.

Kidney Health Australia acknowledges and commends the achievements realised under the *ACT Chronic Disease Strategy 2008-2011*, including the Home Tele-monitoring Service, the Improving Care for People with Chronic Conditions (Chronic Care) Program and the Chronic Disease Management Unit's Register. These programs are provided for people with chronic obstructive pulmonary disease, diabetes, heart failure and help to support them through their difficult circumstances.

However these programs currently do not extend to those suffering from chronic kidney disease. While it is recognised that chronic kidney disease often has co-morbidity with the three major chronic diseases of interest, it should be noted that in 51% of the time, it occurs separate to these, and as such these patients may go without the support of the above programs. For example, while diabetes is the primary cause of 35% of kidney disease, and hypertension is the primary cause for 14% of kidney disease, 33% of kidney disease⁴ amongst new patients in Australia (as at 31 December, 2010) is caused by non-related issues such as glomerulonephritis, polycystic kidney disease, reflux nephropathy and analgesic nephropathy. In light of these statistics, Kidney Health Australia believes that CKD should be included as one of the major chronic diseases of interest that are recognised as having a major impact on the burden of disease in the ACT, and that appropriate access to the above outlined programs follows from this.

In addition, the current draft strategy includes 'Box 1: An Indicative list of chronic conditions' referenced on page six, which includes reference to 'renal failure'. While recognising the statement in the strategy that it is not an exhaustive list, Kidney Health Australia is of the view that this should be changed to 'Chronic Kidney Disease (CKD) in all its stages'. This will ensure that those with CKD, but not on dialysis, can access the programs and support they need, at the appropriate time in the treatment of their condition rather than just those suffering 'renal failure'.

Kidney Health Australia welcomes the six Goals and Priorities outlined in the draft, and provides the below specific comments on some of the key areas.

Specific Comment on Six Key Goals and Priorities

Kidney Health Australia supports the statement regarding the need to see 'chronic disease management' as a 'dynamic state', which should start at the point of health promotion and prevention, particularly noting

⁴ www.anzdata.org.au



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as per page eight that ‘most people living with chronic conditions only consider themselves ‘sick’ when their condition flares’. This is particularly problematic for chronic kidney disease where it is possible to lose up to 90% of kidney function before experiencing any symptoms. To that extent, Kidney Health Australia strongly advocates for appropriate screening and early detection for signs of kidney disease, particularly for those with co-morbidities or risk factors, such as diabetes.

Goal two of the Strategy states that ‘Every person with a chronic condition receives the right care, in the right place, at the right time from the right team’. Kidney Health Australia agrees with this in principle, however it is essential to include the detail to outline accessibility to this care in the form of equitable access to transportation, either personal, public or community based, so that this is not a barrier to treatment or care. This is particularly important as outlined in the strategy on page seven, ‘people from vulnerable population groups are more likely to experience chronic conditions because of the many factors including poorer socio-economic status, social isolation, high rates of tobacco and alcohol usage physical inactivity and poor nutrition’. Anecdotally this holds true for those on dialysis who also face the additional hurdles of a large time away from work, additional expenses and often additional health issues, all of which further complicate their ability to maintain full time work and associated commitments. It follows from both these statements that this group of people would potentially also have greater issues regarding access to transport. In addition, in relation to the management of CKD, home therapies such as home dialysis should be promoted by health practitioners and patients should be educated about this option. Home dialysis not only offers an alternative mode of dialysis (relating to access), but can offer improved health benefits for the patient and reduced cost for the service provider.

In regards to goals three, four and five Kidney Health Australia supports the principles outlined within. Indeed, Kidney Health Australia works with patients to provide a range of support mechanisms, including a range of resources to assist them in understanding their condition, providing them links to relevant support options and advice to improve their wellbeing in living with CKD, and finally, information on how to avoid if possible, further health complications. Kidney Health Australia currently supports residents of the ACT through advocacy undertaken by Kidney Health Australia’s ACT Consumer Committee and through a support network provided through various activities such as the Kidney Health Information Service and the Kidney Club⁵ model, and in that respect would request that we be added to the list of organisations willing to assist those with chronic disease, as outlined in the draft strategy.

On the issue of integration outlined in the first priority, Kidney Health Australia would like to express support for this approach as patients with CKD are often required to move between multiple health professionals and providers. Furthermore, Kidney Health Australia supports the statement that chronic conditions are not confined to only ‘specialist roles’ but rather is one of the mainstays of primary health care.

⁵ <http://www.kidney.org.au/ForPatients/KidneyCommunity/tabid/615/Default.aspx>



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In regards to priority two 'improving access', Kidney Health supports the statements and would like to add that in the case of dialysis, the increased provision of home dialysis not only represents a desirable situation for patients, but can also represent a more economical alternative for service providers and government grappling with meeting the community dialysis need.

Kidney Health Australia supports the principles outlined in priorities three to six, in particular the priority regarding the 'development of a culture of evidence based opportunistic screening and risk identification' as outlined on page 22. In regards to priority six, 'Enhance governance and system enablers' and specifically the 'Establishment of a discrete Chronic Care Steering Committee' Kidney Health Australia notes that it will be important to have an appropriate balance of consumer (both patient and carer) representation, as well as allied health, included within this Committee to ensure there's a holistic approach.

Conclusion

Kidney Health Australia appreciates the opportunity to comment on the development of this strategy, and would welcome the chance to provide additional information to further its finalisation and linkages with other key strategic guiding documents, as we work together to tackle the chronic disease burden facing our community.

Yours Sincerely,

Anne Wilson
MD/Chief Executive Officer
Kidney Health Australia

Dr Timothy Mathew AM
Medical Director
Kidney Health Australia