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Her Excellency Ms Quentin Bryce, AC
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Kidney Health Australia submission to the National Commission of Audit Health Portfolio

26 November 2013

Kidney Health Australia hereby responds to the invitation to provide a submission to the National Commission of Audit (the Audit). Kidney Health Australia recognises the importance of undertaking a review of current activities and believes that such a review offers an opportunity to better address areas of need in prevention and treatment of chronic disease, as outlined by the Government's election commitments.

Introduction

This submission recognises the key points raised in the Audit's Terms of Reference (ToR), particularly around the 'scope for efficiency and productivity improvements', and especially in relation to the need 'to make recommendations to achieve savings'. These can be summarised into three broad themes, covering seven specific areas:

- Kidney Health Australia believes that there is much that can be done to improve the early detection - and more efficient treatment - of kidney disease to help stem the predicted tide of new cases of end stage kidney disease (ESKD), **putting downward pressure on the usage of high cost dialysis treatment.**
- As per the ToR which seeks suggestions on the adoption of new technologies in service delivery, and the consideration of alternative service delivery mechanisms to improve productivity and service quality, **Kidney Health Australia has highlighted the role that better supporting and funding home dialysis, home dialysis patients and their carers can have in reducing real health expenditure in a significant, realistic manner.**
- As per the ToR, this submission also seeks to highlight where there is 'a compelling case for the activity' to be undertaken by the Commonwealth, and in doing so highlights where a series of **investments in Aboriginal and Torres Strait Islander health programs, increased research and live donor transplantation could reap significant health and economic benefits in the medium and longer term.**



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The Current Impact of Kidney Disease

Chronic Kidney Disease (CKD) is a major health problem and its incidence is growing. Kidney Health Australia estimates that 1 in 3 Australians are at an increased risk of developing CKD¹, with the risk being even higher in those most vulnerable in our community. Approximately 1.7 million Australians aged 18 years and over – a striking 1 in 10 – have at least one clinical sign of CKD. And the situation is much worse for ‘at risk groups’. There has been a 45 percent increase in deaths from chronic kidney disease since 2000. More people die from diseases of the kidney and urinary tract each year than breast cancer, prostate cancer or even road deaths.

Kidney disease represents a significant and growing burden to the health system. It carries a considerable cost in health expenditure and forgone productivity. The Australian Institute of Health and Welfare estimates that the number of people on dialysis is expected to increase by 80 percent by 2020 – rising from 11 to 19 per 100,000 of the Australian population². Depending upon the mode of dialysis this can cost in excess of \$80,000 per person, per year.

Despite costing governments in Australia approximately \$1 billion per year, kidney disease has received little attention³. The cumulative cost of treating all current and new cases of end stage kidney disease from 2009 to 2020 is conservatively estimated to be between approximately \$11.3 billion and \$12.3 billion (in 2009 dollars), representing potentially more than 30,000 people on dialysis.

The most recent data from the Australian Bureau of Statistics (ABS) shows that kidney failure is a significant cause of death. In 2011, diseases of the kidney and urinary tract were the 10th leading cause of deaths in Australia, with 3,386 deaths⁴.

A common misconception is that kidney disease is wholly the result of an unhealthy lifestyle and that it is therefore ‘caused’ by inactivity, in-appropriate diet or a combination these factors. The most common causes of end stage kidney disease in Australia are diabetic nephropathy, and hypertensive vascular disease. However, many other diseases and conditions can damage the kidneys, including glomerulonephritis (where the body’s immune system attacks the kidney filters causing swelling and scarring), reflux nephropathy (a defect present from birth, in which the kidneys are damaged by the backward flow of urine), inherited conditions such as polycystic kidney disease (characterised by thousands of cysts developing in the kidneys), or a range of other disorders, traumas or congenital disorders.

¹ Chadban SJ, Briganti EM, Kerr PG et al. Prevalence of kidney damage in Australian adults: The AusDiab kidney study. J Am Soc Nephrol 2003 July;14(7 Suppl 2):S131-S138.

² AIHW 2011. Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020. Cat. no. PHE 150. Canberra

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?lleticket=vave4WFH73U%3d&tabid=635&mid=1837>

⁴ Australian Bureau of Statistics. Causes of death, 2010. 2012.



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1. More efficient and effective early detection

Firstly, Kidney Health Australia believes that greater efficiencies and better health outcomes can be achieved through detecting kidney disease earlier, particularly through the implementation of an integrated health assessment, taking into account someone's absolute risk levels. CKD is often regarded as a 'silent' killer, as up to 90 percent of kidney function can be lost before symptoms are evident. Data highlights that 10 percent of people attending general practice have CKD, but most do not know it⁵.

Similarly, every second patient that visits their general practitioner with type 2 diabetes will also have CKD⁶. CKD is a significant risk factor for vascular complications and for progression to kidney failure. Strikingly, among those with CKD, the risk of dying from cardiovascular events is up to 20 times greater than the risk of requiring dialysis or transplantation⁷.

Despite these facts, if CKD is detected early and managed appropriately, the risk of cardiovascular events can be controlled, and the rate of deterioration in kidney function can be reduced by as much as 50 percent. In some cases the deterioration may even be reversible⁸. Importantly, effective prevention and management of one condition can lead to reduction in the risk of related diseases⁹.

Early detection of CKD at the primary care level is therefore critical to stemming the tide. It is also the most logical location for such an intervention - 83 percent of Australians visit their general practitioner at least once a year¹⁰.

To address this issue Kidney Health Australia is advocating for the introduction of a comprehensive Integrated Health Assessment for kidney disease, heart disease, stroke and diabetes in primary care. This would also address the issues surrounding multiple, separate screening tests for those currently at risk. The first step would be the greater uptake of the absolute risk guidelines and the measurement of such through an indicator.

The current suite of government-funded health checks are not effectively identifying those at risk. This is primarily because of low access rates, non-integrated approaches to CVD risk assessment and the absence of a national program to support better management of risks for CVD and related diseases, like type two diabetes and kidney disease. Consolidating the current existing primary

⁵ SAND abstract No. 163 from the BEACH program: Chronic kidney disease in general practice patients. Sydney: FMRC University of Sydney, 2011.

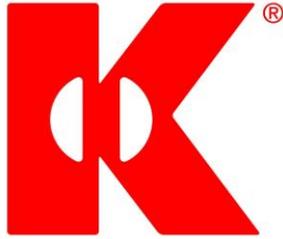
⁶ Thomas MC, Weekes AJ. Type 2 diabetes from the GP's perspective. Kidney Health Australia, Melbourne, Vic; 2007

⁷ Keith DS, et al. Longitudinal follow-up and outcomes among a population with chronic kidney disease in a large managed care organization. *Archives of Internal Medicine*. 2004;164:659-663.

⁸ Johnson DW. Evidence-based guide to slowing the progression of early renal insufficiency. *Intern Med J* 2004;34(1-2):50-7.

⁹ Australian Institute of Health and Welfare (2009) *Prevention of cardiovascular disease, diabetes and chronic kidney disease: targeting risk factors*

¹⁰ BEACH Report, 2011-12, p.7



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health care approaches into an integrated health assessment will help GPs determine a person's absolute risk of a cardiovascular event and the most appropriate preventive measure for people who are at risk, but not yet showing symptoms, of disease. This will have potentially significant benefits to those at risk as well as to the healthcare system. The direct health cost of CVD (currently \$7.9bn a year) and of CKD could be contained with early identification and management of those at high risk before they develop disease, particularly for those aged over 45.

2. Promoting home dialysis to improve productivity and health outcomes while reducing costs

Living with kidney disease is an ongoing struggle. Dialysis, at a minimum, takes four to five hours at a time, three times a week. It requires either travelling to a satellite centre or hospital frequently, or undertaking dialysis at home.

For those with kidney disease, dialysis is a necessary, albeit high cost, treatment. Without dialysis or transplantation, death will occur. An economic study commissioned¹¹ by Kidney Health Australia in 2010 highlighted that on average dialysis costs \$79,072 for hospital haemodialysis (2009 prices), \$65,315 for satellite, home haemodialysis \$49,137 and peritoneal dialysis \$53,112; it is clearly an expensive treatment. Current breakdowns indicate that 22% of Australian's receive dialysis at a hospital, 27% were dialysing at home and 50% in satellite centres. However, despite the cost effectiveness to government and potential health benefits of home dialysis for the patient, there are significant state-by-state variations, ranging from 38% in NSW to as little as 12% in the Northern Territory and 19% in South Australia.

Clearly, increasing home dialysis in the patients for whom it is reasonable and appropriate will potentially not only improve their quality of life and productivity, but also the cost to both state and territory and the Commonwealth. Indeed, the aforementioned economic study notes the expected costs to the health system in the future; Kidney Health Australia estimates that \$378 to \$430 million could be saved over the next 10 years if the increased use of home dialysis was achieved¹². This is crucial to the Commonwealth who under the mature model of Activity Based Funding (ABF), will be funding 50% of hospital costs.

In addition to reduced costs, dialysis in the home results in less travel for the patient which is a considerable benefit for those living in regional, rural and remote localities, or for patients lacking access to public or alternative transport. Some patients undertaking home dialysis are able to return

¹¹ 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>

¹² Sted



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to the workforce, where previously this was not possible as the ability to undertake dialysis outside work hours was not possible. It also creates a cost saving as patients will not need to seek travel reimbursements, or accommodation assistance, if a switch to dialysing at home is made.

3. Better support to increase home dialysis to improve productivity and health outcomes while reducing costs

Mobility and independence is dramatically reduced while undergoing dialysis. Transport to and from medical appointments, plus attendance at appointments, is often an added responsibility, as is the need to often limit work and recreational activities in favour of fulfilling their role as Carer.

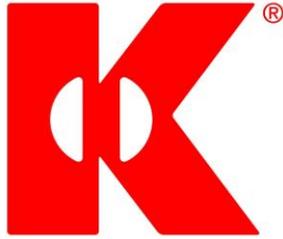
Carers play a particularly pivotal role in supporting an increased home dialysis uptake, especially if the patient is a young child, has limited mobility, dexterity or movement or has failing memory. Whilst the majority of Carers for dialysis patients believe their caring role is rewarding, caring is not always easy and comes at a cost. Carers have poorer health and well-being than non-Carers, and their responsibilities can adversely impact on family relationships, social networks, employment opportunities and finances.

Despite the significant saving home dialysis provides governments, many dialysis Carers are currently excluded from access carer support. The Commonwealth can address this roadblock by better supporting the Carer who enables home dialysis through access to Carer's income.

In a similar vein, currently the capital set-up costs for home dialysis machines and the associated water and electrical costs are partially reimbursed or discounted, in varying degrees, to differing levels across States and Territories. The present structure of accountabilities between the Commonwealth and the States and Territories within the Health portfolio, and the differing delineation of responsibilities in service delivery, has resulted in inequitable and inadequate responses across jurisdictions.

Furthermore, it has led to complicated and sub-optimal policy responses in the way in which some financial support is provided. For example, an administratively efficient manner of providing financial support for associated water or electrical costs to support home dialysis would be to provide a single payment to the patient. However, currently many jurisdictions do this through the use of complex partial rebates, provided through the utility provider rather than directly from the government, thereby increasing transaction costs, creating issues regarding accessibility, and causing inconsistency across regions.

The introduction of ABF provides an opportunity to work with State and Territory governments to standardise the manner in which this financial support is provided, noting a lack of support can act as a barrier to increased home dialysis uptake, and that they are currently unnecessarily



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administratively complex for both the government and the patient. By ensuring that home dialysis is funded appropriately, including through appropriate and effective levels of support for the costs borne by the home dialysis patient, significant savings could be potentially gained through increased home dialysis usage.

4. A better system for live organ donation

The work program by the Australian Organ and Tissue Authority (DonateLife) over the last four years has seen a substantial and sustained increase in the number of deceased donors being made available for kidney transplantation. This remarkable result of a 43% increase in the last four years highlights the improvements made as a result of the Commonwealth's investment.

This change has however not been accompanied by an increase in the total number of kidney transplant operations, due to a 33 percent fall in the number of live kidney donors over the same time.

While live donor kidney transplantation has existed in Australia from the earliest days of transplantation, it peaked in 2008 when it accounted for 44 percent of the total transplant activity. Since then the number of live donors has steadily fallen.

The availability of a live donor allows 'pre-emptive' transplantation to occur without the requirement to start dialysis – generating a significant saving in dialysis treatment costs (dialysis costs are outlined above). This pre-emptive pathway is associated with the best clinical outcome and is the most cost-effective approach in the renal replacement pathway.

In fact, live donor kidney transplantation is associated with an increase in patient survival of 27 percent at 20 years (over that observed with deceased donors), highlighting that it is a critical component of the wider push for increased organ donation in Australia. Again this removes or significantly delays an ongoing high cost treatment through dialysis.

To that end, Kidney Health Australia believes that the inclusion of live donation policy within the remit of the Australian Organ and Tissue Authority (DonateLife) would better align with existing organ donation activity, draw upon existing staff networks and link with current awareness and education campaigns. Currently there is a lack of policy initiatives in the live donation space federally.

Furthermore, by continuing and expanding upon the current very modest levels of support for live donors (which has been met with overwhelming support from patients and the sector), along with improved reporting of live donor transplantation, the Commonwealth should be able to make a considerable difference in the live donation rate, and thus the overall donation rate. Furthermore, if



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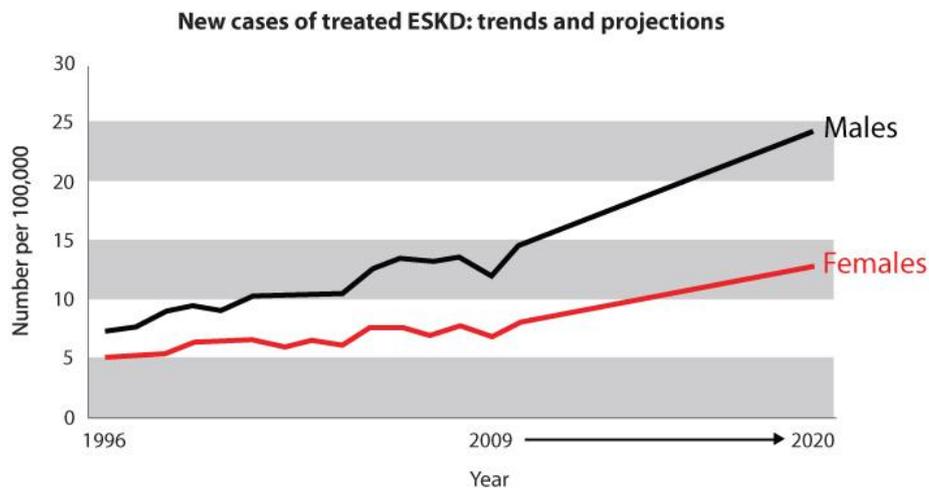
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the Commonwealth were also to develop, in bilateral discussion with the States and Territories, a standardised policy as to what costs – such as transport and medical – are covered, the current inequity which occurs not only between jurisdictions, but between different renal units, could be overcome.

5. The need for further research

The relative level of support flowing to kidney research in Australia has never matched the expenditure on kidney disease. This continues to be true with the National Health and Medical Research Council (NHMRC) allocating about 1 percent of its funds to the kidney area when it consumes approximately 2 percent of the total health budget.

Without improved research outcomes, this cost to our health system is simply going to grow, as outlined in the table below.



Australia needs a national focus on kidney disease, and should appropriately fund kidney research to commensurate with the burden on the health system – failure to do so is only going to increase the potential burden on our health system. Kidney Health Australia also believes that there is an opportunity to work collaboratively with organisations outside of government to multiply the impact of available funds, particularly within the current budget context.

6. Tackling kidney disease in Aboriginal and Torres Strait Islander communities

The high prevalence of kidney failure in Aboriginal and Torres Strait Islander people in Australia has been recognised for many years. A recent report by the AIHW summarises and outlines the size and scope of this major influence on Indigenous health and well-being, with an emphasis on the



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increased prevalence of kidney disease in remote communities¹³. One telling statistic is that Aboriginal and Torres Strait Islander people make up 2 percent of Australia's population but comprise 10 percent of the dialysis population. Indigenous Australians are almost four times as likely to die with chronic kidney disease as a cause of death than non-Indigenous Australians. Although the cause of the increased prevalence of CKD in Indigenous people is multi-factorial, the impact of diabetes is major and exemplified by the lifetime risk of end-stage kidney failure in Indigenous people increasing from 7 percent to 49 percent, if diabetes is present.

To that end, Kidney Health Australia would call on the Commonwealth to use the Audit to examine areas where action can be taken to reduce the incidence of CKD in Aboriginal and Torres Strait Islanders, through improved screening and treatment and through awareness and education. Included in this is for consideration of how the Commonwealth could better support dialysis, including the concepts of self-care dialysis that enables people from remote areas to return to their communities.

Conclusion

Quite clearly it can be seen that kidney disease has a significant impact on the health system in terms of treatment costs; in lost employment; and most importantly, on people's ability to lead productive, healthy lives. This is the case not only for those living with kidney disease, but for those caring for people with kidney disease, noting that the caring responsibilities for those on dialysis are significant.

The nature of kidney disease dictates that it needs health initiatives to be ingrained across the full spectrum of the health policy making sphere, and done so in consideration with other chronic diseases, such as diabetes and vascular disease.

Kidney Health Australia believes that this Audit provides an opportunity to consider options to target a number of key areas – all designed to greatly improve the lives of those with kidney disease, while also reducing the significant and increasing burden on our health system. This can be achieved through reducing costs to the national health budget through a reduced need for dialysis (early detection, increased organ donation) or where dialysis is necessary through more efficient modes (such as home dialysis for those whom it is appropriate). Finally by investing in key areas as outlined above, action can be taken to address the rising burden of disease much earlier, and therefore reduce the strain on the health system in the years ahead.

¹³ Australian Institute of Health and Welfare. Chronic Kidney Disease in Aboriginal and Torres Strait Islander people 2011. Canberra Australia: AIHW; 2011. Report No.: Cat. No. PHE 151.