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Senate Select Committee on Health

Kidney Health Australia Submission Regarding Terms of Reference

Introduction

Chronic Kidney Disease (CKD) is a major health problem, and one that is growing. Without greater focus from the Australian Government, there is clear evidence based on current trends that the situation has the potential to worsen. Kidney Health Australia estimates that 1 in 3 Australians are at an increased risk of developing CKD¹. Approximately 1.7 million Australians – a striking 1 in 10 – over the age of 18 years have at least one clinical sign of CKD. The situation is much worse for ‘at-risk-groups’.

Yet to date, CKD has received little attention, particularly when compared to other chronic diseases. The treatment of those with kidney failure continues to cost governments in Australia approximately \$1 billion², per year, and an economic study by Kidney Health Australia estimates that the cumulative cost of treating all current and new cases of end-stage kidney disease (ESKD) from 2009 to 2020 is between approximately \$11.3 billion and \$12.3 billion. It is clear that kidney disease is a measurable cost to the health system, not to mention a considerable cost in 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 population³. The burden of CKD is distributed unequally and unfairly, as evidenced by the high rates of the condition in the lower socio-economic groups and in the Aboriginal and Torres Strait Islander community⁴.

Kidney Health Australia therefore presents this submission on a range of issues to the Senate Select Committee on Health for consideration, as they relate to the Terms of Reference. As the peak national body representing the needs of those with kidney disease in Australia, Kidney Health Australia is well placed to identify the current policy impediments to improved health outcomes, and offer evidence-based, sensible and cost-effective solutions for consideration by government. First among those is the need to stem the future tide of kidney disease through early detection, supported by primary health care organisations⁵. It is also the most logical location for such an intervention – 83 percent of Australians visit their GPs at least once a year⁶.

Kidney Health Australia advocates on matters relating to the welfare of kidney stakeholders and the delivery of services to people affected by CKD in all its stages. Furthermore, Kidney Health Australia

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 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>

³ AIHW 2011. Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020. Cat. No. PHE 150. Canberra.

⁴ Kidney Health Australia, Chronic Kidney Disease Summit: The Need for Action in Australia, 2007. Available at <http://www.kidney.org.au/HealthProfessionals/PublicationsforHealthProfessionals/tabid/635/Default.aspx>

⁵ To see Kidney Health Australia's further views on this, please refer to our 'Submission into the Review of Medicare Locals – December 2013' at www.kidney.org.au

⁶ BEACH Report, 2011-12, p.7

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)*. Kidney Health Australia is committed to achieving its mission through engaging with renal sector professionals and consumer stakeholders in all initiatives and linking with other key chronic illness programs in an integrated way. Kidney Health Australia's work is carried out in consultation with the nephrological community and with significant input from our national network of consumers.

In its 46-year history, Kidney Health Australia has built a substantial evidence base to support its activities, and strong support from the community to continue to initiate efforts to reduce the incidence and impact of CKD. This submission represents areas where we believe current out of pocket costs are negatively impacting improved treatment of those with kidney disease, as well as the more efficient use of our limited health dollars.

The Cost to the Health System

Approximately 1.7 million Australians - a striking 1 in 10 - over the age of 18 years have at least one clinical sign of existing CKD, such as reduced kidney function and the presence of proteinuria (protein in the urine) or haematuria (blood in the urine)⁷. Perhaps even more startling is that an estimated 1.5 million Australians are unaware they have indicators of CKD⁸.

In addition, 1 in 3 Australians is at an increased risk of developing CKD⁹. Australians are at increased risk of CKD if they:

- Are 60 years or older
- Are of Aboriginal or Torres Strait Islander origin
- Have diabetes
- Have a family history of kidney failure
- Have established heart problems
- Have high blood pressure
- Are obese
- Are a smoker

As outlined above, CKD continues to cost governments in Australia approximately \$1 billion¹⁰, per year, and the cumulative cost of treating all current and new cases of end-stage kidney disease (ESKD) from 2009 to 2020 is estimated to be between approximately \$11.3 billion and \$12.3 billion. In addition, a study from the UK confirmed the sizable funding required to support treatment for kidney disease highlighting that the National Health Service (NHS) in England's annual spend on kidney care was estimated at £445 million in 2002 (£566 million in 2009-10 prices, or \$852 million Australian dollars). Furthermore the study indicated that program budget analysis by the Department of Health in England estimated that 'the total NHS expenditure on kidney care, including CKD, at £1.64 billion in 2009-10' (\$2.4 billion Australian dollars)¹¹.

The nature of kidney disease with its complex co-morbidities 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. Indeed, diabetes is

⁷ Australian Bureau of Statistics. Australian Health Survey: Biomedical Results for Chronic Diseases, 2011-12. ABS, Canberra; 2013.

⁸ Australian Bureau of Statistics. Australian Health Survey: First results 2011-12. 2012. Report No. 4364.0.55.001.

⁹ 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.

¹⁰ 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>

¹¹ Kerr M, Bray B, Medcalf J, O'Donoghue DJ and Matthews B. Estimating the financial cost of chronic kidney disease to the NHS in England. *Nephrol Dialysis Transplantation*

the top cause of kidney failure in Australia at 36%, while hypertension causes an additional 12% of cases.

The most recent data from the Australian Bureau of Statistics (ABS)¹² shows that kidney failure is a frequent cause of death. Around 56 people die every day with kidney related disease. And in 2012, diseases of the kidney and urinary tract were the 9th leading cause of death in Australia, with 3,711 deaths. The number of deaths from kidney-related disease has increased 17% since 2002. While there has been significant progress over the past 15 years, kidney-related disease still kills more people a year than breast cancer, prostate cancer or even road traffic accidents¹³. On a global basis there has been an 82% increase in the number of deaths from chronic kidney disease between 1990 and 2010¹⁴.

Sadly there has been a 45% increase in deaths from chronic disease since 2000. More people die from diseases of the kidney and urinary tract each year than breast cancer, prostate cancer and even road deaths.

The most recent data that is available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry¹⁵ shows that 2,534 people started kidney replacement therapy (dialysis or transplant) in 2012. The number of people on dialysis has increased by 4.1% from 2011 to 2012, resulting in 11,446 people receiving dialysis treatment at the end of 2012.

With dialysis costing up to \$79,072 for hospital haemodialysis, \$65,315 for satellite, home haemodialysis \$49,137 and peritoneal dialysis \$53,112 (2009 prices), it is clearly an expensive treatment. Current breakdowns indicate that 22% of Australians receive dialysis at a hospital, 29% were dialysing at home and 49% 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 37% in NSW to as little as 13% in the Northern Territory. Furthermore, in Australia there is an overall lack of dialysis capacity – with Australia ranking 10th of 42 countries listed in the incidence of new end-stage renal disease patients in 2011¹⁶, with the rate of new patients coming onto dialysis programs significantly lower than many of our international counterparts.

Even when averaging out the different modalities and their respective usage, Kidney Health Australia estimates that the average cost of supplying dialysis is still a considerable \$65,000 per person (based on 2009 prices), per year. And of course, this does not take into account the lost productivity dividend resulting from these patients either being forced to reduce their work hours, or leave employment altogether.

Terms of Reference

Kidney Health Australia would like to take the opportunity to highlight briefly a number of the issues pertaining to kidney disease, as they relate to selected clauses in the Terms of Reference.

As previously mentioned, Kidney Health Australia is a member of both the *Australian Chronic Disease Prevention Alliance* (membership of which is the Cancer Council, the National Heart Foundation, the National Stroke Foundation, Diabetes Australia and Kidney Health Australia) and the *National Vascular Disease Prevention Alliance* (membership of which is the National Heart Foundation, the National Stroke Foundation, Diabetes Australia and Kidney Health Australia). Both of

¹² Australian Bureau of Statistics. Causes of death, 2011. 2013.

¹³ Causes of Death, Australia 2010, published 2011
(<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3303.0.55.001main+features42010>)

¹⁴ Lancet 2912; 380:2095-128

¹⁵ ANZDATA. Australia and New Zealand Dialysis and Transplant Registry 2013 Annual Report – 36th edition www.anzdata.org.au

¹⁶ U.S. Renal Data System. Annual Data Report: Atlas of Chronic Kidney Disease in the United States. 2013.

these alliances have a wealth of information that may be of particular use to the Committee in considering the outlined terms of reference.

For that reason Kidney Health Australia in our submission has focussed on issues that are largely specific to kidney disease below, as they relate to the Terms of Reference.

Impact of Reduced Hospital Funding

In regard to point (A):

Variation of Hospital Service Delivery

Regional variation of the supply and quality of dialysis, and critical enabling services of patient transport, requires attention and goes to the heart of the issues of hospital funding. Kidney Health Australia has been advocating for the Safety and Quality Commission to include kidney disease in their Atlas of Variation in health service delivery, and believe this report, and the ABS Health Survey will offer significant insights into the state of Australia's kidney health. As the peak body, Kidney Health Australia has documented that the supply, quality and support for dialysis varies greatly, as does the level of home dialysis vs in-centre dialysis nationally – resulting in significant equity issues.

Equally concerning is Australia's current performance as it relates to the provision of dialysis currently, in which Australia is ranked in the lowest quarter in terms of the number of those with end-stage renal disease on dialysis, in the developed world. This is outlined in the diagram.

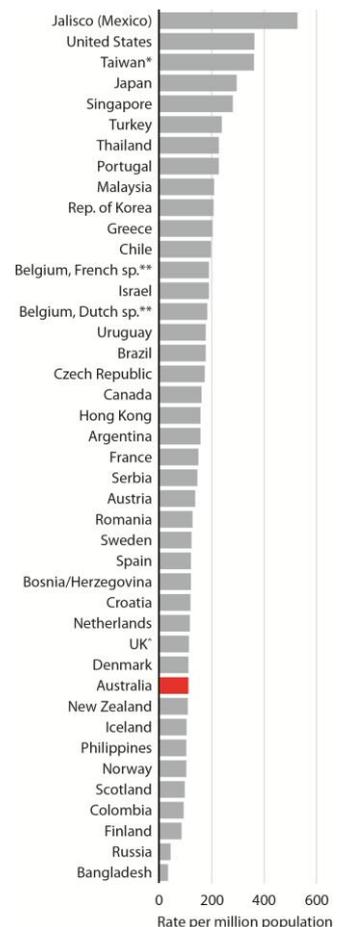
Since the majority of dialysis – regardless of modality – is funded by the hospital system, any cuts to hospital funding are likely to further deteriorate Australia's already low standing by international standards. Furthermore, Kidney Health Australia is aware through our links to medical professionals, renal units and consumers that the supply of dialysis and associated services is already significantly constrained, suggesting there is no room to 'absorb' any further downgrading of hospital funding.

Graph: Incidence of ESRD, 2011.

Kidney Health Australia is committed to the principle of patient choice of their dialysis pathway. We are aware that choice is not offered in all regions of Australia in large part due to financial and resources constraint. In particular the lack of ready access in some regions to home dialysis is regarded as inequitable and leads to the deprivation of those patients from the cheapest, most flexible and most successful form of dialysis.

Out-of-Pocket Costs for Dialysis Patients

For those living with kidney disease and undertaking dialysis, there are a number of out-of-pocket costs incurred. These costs create a burden on those already suffering physically, mentally and financially. Current breakdowns indicate that 71% of Australian's receive dialysis at a hospital or satellite centres, and 29% are dialysing at home. 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 37% in NSW to as little as 13% in the Northern Territory and 22% in South Australia, Tasmania and the Australian Capital Territory.



Therefore, the use of home dialysis, where appropriate, results in a considerable saving to governments – up to \$30,000 per patient, when compared to hospital based dialysis. 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.

Many patients undertaking home dialysis are able to return to or continue in the workforce, where previously this was not possible as the ability to undertake dialysis outside work hours was restricted. For those who do not live within distance short distance of a dialysis unit 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, resulting in potentially further savings for governments.

Increasing the uptake of 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 reduce the cost to State, Territory and Commonwealth governments. Indeed, Kidney Health Australia's 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 achieved¹⁷. This is crucial not just to the State and Territory Governments who run dialysis services, but to the Commonwealth who under the mature model of Activity Based Funding (ABF), will be funding 50% of these hospital costs going forward.

Yet despite this, the capital set-up costs for home dialysis machines and the associated water and electrical costs are only partially reimbursed or discounted, in varying degrees, through differing means 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.

Utility costs for those on home dialysis – water and electricity, set-up and waste disposal – can act as a significant barrier to increased uptake, despite the health and economic benefits of home dialysis. As these costs rise, they could also act as a major consideration for patients to return to hospital or satellite dialysis in an effort to defray these expenses. This is because these costs – set-up, electricity, water and waste removal are covered in full, by the service provider for those who undertake satellite and in-centre dialysis.

Therefore for those whom home dialysis might reduce the burden of travel, may result in better health outcomes, may increase participation in the workforce and may save governments up to \$30,000 per year, we don't support nearly well enough. A small payment – less than 10% of what government could potentially save, would greatly assist home dialysis patients and remove this significant financial barrier and burden. Furthermore, the current process is not an administratively efficient manner of providing financial support. One single, direct payment from the government would thereby remove some significant transaction costs. To that end, Kidney Health Australia would recommend adopting a model of one single, annual payment as is currently provided in Victoria.

Activity Based Funding (ABF)

The three modalities of dialysis need to be priced appropriately and Kidney Health Australia has been working closely with the Independent Hospital Pricing Authority (IHPA), over a number of

¹⁷ 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>

years, to ensure that in setting pricing levels, and therefore hospital funding, due consideration was given to each modality, uptake, preferred clinical outcomes and the need to avoid inadvertent and unintended economic disincentives.

Long term introduction of ABF also provides an opportunity to work with State and Territory governments to standardise the manner in which financial support is provided to those who undertake home dialysis, noting a lack of support can act as a barrier to increased home dialysis uptake. Currently in many states and territories, home dialysis patients bear a significant cost, which is only partially reimbursed. 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 and reduced transaction and administration costs.

Kidney Health Australia therefore advocates that not only should all modalities of dialysis continue to be included within ABF, but that like hospital and satellite dialysis, the cost of running the home dialysis machines be included in the price weightings. This would ensure consistency between the different modes of dialysis and their respective pricing under ABF, and provide an efficient means of funding these costs for patients. Further to this, Kidney Health Australia would advocate that the Commonwealth ensure that the revised funding arrangements take into account rural and Indigenous loadings for location of those undertaking home dialysis.

Submissions regarding this matter can be provided to the committee, or found here: <http://www.kidney.org.au/Whoweaare/PolicyandAdvocacy/tabid/846/Default.aspx>

Transplantation

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, with the latest figures showing that transplants from live donors account for 28 percent of total transplant activity. 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 – a potential saving in excess of \$80,000 in direct health care costs, per patient, per year, not to mention the productivity benefits as the individual returns to employment.

Live transplantation in Australia relies upon the Australian hospital system, yet does not receive the same priority, attention or resourcing that deceased organ donation does. Kidney Health Australia is well aware that there have been examples of where shortages of surgeons, theatres, or resources have delayed live donation. Furthermore, live donation as a policy issue does not sit with the Australian Organ and Tissue Authority, and it is the strong view of Kidney Health Australia that it should. Previous submissions regarding this matter by Kidney Health Australia can be provided to the committee.

The interaction between elements of the health system, including between aged care and health care

In regard to point (D):

Aged Care

Kidney disease is a disease that disproportionately impacts on those who are older. In 2012, some 5,091 (45%) of people on dialysis were over the age of 65. Only 20% over 65 years used home peritoneal dialysis (PD), 22% of all patients were new to dialysis, with 73% of those aged over 65. Sadly, 14% of patients withdrew or died on dialysis; 19% of those who died were 65-84 years and 40% were aged over 85¹⁸. Furthermore, 60% of the aged on dialysis use the more expensive HD, which in addition requires transport to treatment each week. It is also known that with support 30% would be willing and able to do PD.

The prognosis of those aged over 60 on dialysis is worse than that of most cancers with only 46% on dialysis surviving 5 years. It is also calculated that for every person who starts dialysis there are a similar number who do not start dialysis. They are deemed to be on a conservative or supportive care pathway. Research suggests those with two or more co-morbidities choosing conservative care will have an equal life expectancy to those who choose dialysis.

There are many gaps in holistic care and information for aged with ESKD. The aged with CKD require a comprehensive programme that supports healthy living, shared decision making, enhanced quality of life, supported dialysis options and planning for the end of life. Currently there is an inadequate approach to dealing with this issue in an aged care setting. This places pressure on transport services, often ambulance based, who may need to assist in transporting those from an aged care setting to dialysis, three times a week.

Furthermore there is a clear need for national action to address areas where support is needed – appropriate support and training, advance care planning, linkages to community services, decision support when it comes to choosing the modality of dialysis. Furthermore, there is a need to increase information and tools that can be used by all relevant health-care professionals from primary care to tertiary care to support the aged with late stage CKD.

Palliative Care

Kidney Health Australia and Palliative Care Australia recently released a joint position statement outlining the key areas for action and investigation federally.

Despite technological and medical improvements, renal replacement therapy has its limitations. Transplantation is not suitable for many people. The transplants have a limited lifespan and the associated medications may cause severe side-effects, including a 2.5 times greater risk of cancer. Similarly, dialysis fails to provide a cure for kidney disease, offers limited symptom reduction, and incurs significant treatment burdens¹⁹.

It is estimated that 5,000 new people present annually with ESKD. Of these patients, approximately half choose to commence renal replacement therapy, and half do not receive dialysis for a variety of reasons. These people should typically access a non dialysis supportive care pathway (also referred to as conservative care). Around 20% of patients who initially choose renal replacement therapy

¹⁸ ANZDATA Australia and New Zealand registry report(2013) www.anzdata.org.au

¹⁹ Masterson, R & Foote, C. *Perspective – the issues surrounding end-stage kidney disease and dialysis in the elderly and those with comorbidities*. ANZSN Renal Supportive Care Guidelines 2013. Nephrology 18 p.403

change to palliative care at a later date²⁰. There is currently a 4% increase in ESKD prevalence per annum, with 11,446 people receiving dialysis treatment in December 2012.

Palliative care is a valuable part of treatment and support for people with CKD/ESKD. Whether carrying out dialysis or opting for a supportive non-dialysis pathway, palliative care teams aim to provide holistic, person centred supportive care for the person, their family and carer/s.

To that end, we have called for improved access to palliative care services for people with CKD/ESKD, their family and carer/s through:

- Education for renal health professionals and general practitioners about the articulated pathways and referral systems, in all jurisdictions, to palliative care services for people with CKD/ESKD.
- Up-skilling and appointment of specialist doctors or nurse practitioners to improve access to treatment and palliative care services for remote, rural and regional patients, particularly for Aboriginal and Torres Strait Islander peoples.
- A central national resource point for written, digital information and education for patients, carers and health professionals on palliative care associated with kidney disease.
- Education and ongoing support for renal specialists, renal medicine trainees and general practitioners by palliative care specialists on the benefits of a palliative approach for people with CKD/ESKD, their families and carer/s.
- National implementation of a validated tool to objectively measure the symptom burden associated with ESKD with an associated quality improvement indicator, such as the Palliative Outcome Scale – Symptoms Renal (POS-S Renal).
- Targeted implementation strategies to promote advance care planning amongst renal health professionals, people with CKD/ESKD, their families and carer/s.
- More accessible information and education for health professionals, patients, their family and carer/s on palliative care and kidney disease.
- A national project/research to evaluate which delivery model(s) of palliative care for someone with CKD/ESKD are cost and resource effective and enhance the patient's quality of life.

Improvements in the provision of health services, including Indigenous health and rural health;

In regard to point (E):

The provision of appropriate health services commensurate with need is an ongoing challenge in Indigenous and rural communities. Approximately 6.7 million people living in rural and remote Australia do not enjoy the same access to health services and health-related infrastructure as other Australians²¹. There is plethora of evidence to indicate that health outcomes, as exemplified by higher rates of death, tend to be poorer outside major cities, due to differences in access to services, risk factors and the regional/remote environment²².

²⁰ ANZDATA Australia and New Zealand registry report(2013) www.anzdata.org.au

²¹ National Rural Health Alliance 2013. Knowing the Issues. <http://www.ruralhealth.org.au/advocacy/knowning-the-issues>

²² AIHW 2013. Impact of rurality on health status. <http://www.aihw.gov.au/rural-health-impact-of-rurality/>

The past several years have seen significant inroads in the provision of health services to Indigenous and rural communities. This is the result of increased workforce positions, technology, funding health promotion & services and strategic policy directions developed with Indigenous and rural community input.

Increased Workforce

Since 2009, the *Closing the Gap in Indigenous Health Outcomes – Indigenous Chronic Disease Package* (ICDP) has established a new health workforce specifically targeting Aboriginal and Torres Strait Islander health, including²³:

- 143 Aboriginal and Torres Strait Islander Outreach workers
- 31 Practice Managers
- 22 Additional Health Professionals
- 94 Indigenous Health Project Officers
- 138 Registrars training in Indigenous health posts

The ICDP aims to provide direct support to the health sector and better access to health care by Indigenous Australians²⁴. While chronic kidney disease is not directly identified and prioritised with the ICDP, there is capacity for health services to prioritise the needs of their community. Through the additional health workforce, local health services are able to increase health checks, deliver chronic disease self-management programs, and deliver community health education on chronic disease risk factors.

Technology

Rural and remote health services face geographic challenges and stand to benefit significantly from eHealth technologies.

For example, the arrangements under Medicare support telehealth consultations with specialists for patients living in rural and remote areas. Using special Medicare item numbers, eligible health professionals and aged care service providers can organise and support real-time online appointments with specialist clinicians in a larger centre²⁵.

Funding Health Promotion & Services

It is recognised that promotion, education and awareness of chronic disease and risk factors are vital to preventing the impact of morbidity and mortality for Aboriginal and Torres Strait Islander people. The ICDP funding is flexibly administered targeting prevention, early intervention and chronic disease management.

There was scope for non-government agencies and Indigenous communities to identify their health priorities and develop appropriate local level strategies for intervention. Indeed, the AIHW²⁶ found that successful programs for Indigenous Australians are underpinned by community involvement and engagement in the development and delivery of programs and possessed flexibility in the design and delivery for local contexts.

²³ Commonwealth of Australia 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

²⁴ Department of Health and Ageing 2012. Closing the Gap: Tackling Indigenous Chronic Disease Package, <http://www.health.gov.au/internet/main/publishing.nsf/Content/work-ab-gap>

²⁵ National Rural Health Alliance 2013. Knowing the Issues. <http://www.ruralhealth.org.au/advocacy/knowing-the-issues>

²⁶ Closing the Gap Clearinghouse (AIHW, AIFS) 2013. *What works to overcome Indigenous disadvantage: key learnings and gaps in the evidence 2011-12*. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.

Strategic Policy

The *National Aboriginal and Torres Strait Islander Health Plan* (the Health Plan) is an evidence-based policy framework designed in partnership with Aboriginal and Torres Strait Islander organisations to guide policies and programmes to improve Aboriginal and Torres Strait Islander health over the next decade until 2023²⁷. While chronic kidney disease is not a specific, identified health priority in the health plan, a strengths-based approach to Aboriginal and Torres Strait Islander cultural wellness sets it apart. The Health Plan fills the void of previous lapsed Indigenous health plans, which failed to be accepted by Aboriginal and Torres Strait Islander organisations or fully implemented.

Kidney Health Australia calls for the Australian Government, in partnership with States & Territories maintain strategic focus and investment on workforce, technology, funding health promotion & services and strategic policy directions that improve rural and Indigenous health.

At present, the review and rationalisation of Federal Government programs, especially within the Indigenous Affairs portfolio threatens the focus, sustainability of investment and effort to improve Indigenous health outcomes.

The *Indigenous Advancement Strategy 2014* while consolidating policies and programmes into five overarching programmes²⁸ fails to elevate the importance of Aboriginal and Torres Strait Islander health.

Federally-funded Aboriginal Community Controlled Health Organisations (ACCHOs) and other non-government organisations providing services to Aboriginal and Torres Strait Islander communities hold 12-month extended funding agreements to 30 June 2015 pending review and rationalisation of programs. This impacts significantly on the sustainability of front-line services, especially in remote and rural communities where they are often the only service providers and struggle to attract and retain quality health staff.

We call on the Australian Government to ensure that any further funding rationalisation does not adversely affect the delivery of front-line health services to Indigenous and rural communities and that these services and programs are exempt in order to improve outcomes for these already disadvantaged groups.

The better integration and coordination of Medicare services, including access to general practice;

In regard to point (F):

Integrated Health Checks at the GP level

Kidney Health Australia, as part of the National Vascular Disease Prevention Alliance (NVDPA) has been calling for an Integrated Health Check at a GP level which would:

- Check eligible patients for vascular and related conditions through an ‘integrated health check’ which includes an absolute cardiovascular risk assessment, diabetes check and kidney disease check;
- Manage the overall risk profile of patients, stratify risk (high, moderate, low) and address their combined risk factors through advice about healthy eating, healthy physical activity and healthy weight, medical management and/or facilitating and coordinating access to evidence-based prevention programs;

²⁷ Department of Health 2014. National Aboriginal and Torres Strait Islander Health Plan, <http://www.health.gov.au/natsihp>

²⁸ Programs: Jobs, Land & Economy, Children and Schooling, Safety and Wellbeing, Culture and Capability, Remote Australia Strategies

- Maintain a patient register, with recall and reminder system for patients eligible for assessment and those who require management of risk;
- Record and report proportion of eligible patients who are checked, who have their risk managed according to the relevant practice guidelines, who have a GP management plan, and who access evidence-based prevention programs.

The NVDPA is well placed to call for this adoption of such a check, as it has led the development of guidelines for an absolute cardiovascular risk approach to cardiovascular disease prevention that takes into account an individual's overall risk profile, rather than a traditional clinical focus on single risk factors, in predicting the likelihood of later disease events and in treating the risk factors

Kidney Health Australia strongly advocates for this to occur as we know 1 in 10 have at least one sign of CKD, yet only 1 in 10 of those people have been informed of it. This is particularly concerning considering that 83 percent of Australians visit their GPs at least once a year – clearly the current suite of MBS item and PIP payments are not working in effectively identifying kidney disease.

The key development that is required for improved clinical management of the early stages of CKD (and in fact all chronic diseases) is to facilitate self-management and efficient communication by either a hand held electronic device or by a standardised hard copy template. Either way, the responsibility for data entry to the hand-held format must be with the patient and the data contained must be readily available to all health practitioners consulted by the patient.

Health workforce planning

In regard to point (G):

The workforce assessment recently completed by the Australian and NZ Society of Nephrology shows that there are about 500 practising nephrologists in Australia. It can be seen that if all known CKD was identified and managed then this workforce cannot begin to manage CKD in this country (with 1.7 million people affected).

The nephrology and nursing workforce is currently largely committed to the care of kidney failure patients and is adequate. There is a large shortfall however in the Allied Health area. All dialysis patients require dietary advice, pharmacy counselling and many would be advantaged by access to social workers along with exercise trainers, and podiatrists. The vast majority of dialysis have no access to these health professionals due to a lack of numbers.

Kidney Health Australia calls on the Commonwealth Government to urgently review and address the lack of health workforce to manage the raising rates of kidney patients in Australia.

Any related matters:

In regard to point (H):

Carer Support

Despite the significant saving home dialysis provides governments, many dialysis Carers are currently excluded from accessing carer support. The Commonwealth can address this roadblock by better supporting the Carer who enables home dialysis through access to Carer's income. 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. This contribution varies from completely performing the dialysis, to being present during dialysis to assist

during clinical emergencies which can be potentially life-threatening. During dialysis the person undergoing treatment is connected to the machine or dialysis equipment and therefore is completely dependent on their Carer for all support related to provision of daily living. The average time spent for this role is around 20 hours a week, which compromises the ability of the carer to work. 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.

Yet despite this, Carers of those on home dialysis are usually not considered eligible for the Carers payment, as there is not a specific category for provision of complex medical care on the current carers form.

Transport

End stage kidney disease requires dialysis is a long-term treatment to stay alive. Dialysis is available as a self-managed home therapy or in a centre (hospital or satellite) where health professionals perform the dialysis. The majority of patients with end stage kidney disease require three haemodialysis treatments per week and require transport to attend in-centre based dialysis. This is a significant cost barrier for many dialysis patients. It is exacerbated in the elderly, those with poor social networks and those who live great distances from dialysis units, such as rural and regional Australians.

In 2007 Kidney Health Australia (KHA) undertook a consumer survey that determined the distances being travelled, the associated costs and the preferred modality of transport²⁹. In 2010, KHA undertook the Consumer Perspectives on Dialysis survey which included questions regarding transport³⁰. Both surveys confirmed an ongoing issue with transport availability and the financial commitment required to attend dialysis.

Our survey has shown that overall it is private transport by car that accounts for 74.4% of transport to life saving dialysis – 39.5% being driven by another person and 34.9% driving themselves. For dialysis patients however, unlike patients who may travel less regularly for treatments of other illnesses, dialysis for in-centre patients is characterized by a never ending cycle of travel – at minimum, three times a week, every week, to stay alive.

The fact that such regular treatments often means reduced working hours, or unemployment, and on top of the added associated medical costs, it soon becomes very clear that the level of financial reimbursement available to patients for travel becomes very significant to their ongoing financial viability. It should come as no surprise that our survey highlighted that for the nearly 75% of consumers who drive or who are driven, incur costs for travel that comprise approximately 15% of their pension. Furthermore, those who pay the most for travel – over \$50 per week – are disproportionately represented in regional areas³¹.

As PATS is administered by State and Territory Governments, each state has a differing scheme, payment rates and eligibility requirements. It should be noted that the NRMA estimate that the actual cost of running a small car is at minimum 56 cents per kilometre, and large car can be in excess of 97 cents per kilometre³². For taxation purposes, the Australian Tax Office currently offers

²⁹ Kidney Health Australia 2007 Dialysis Consumer Transport Survey

³⁰ Kidney Health Australia 2010 Consumer Perspectives on Dialysis

³¹ Dialysis Transport Survey, National Results and Recommendations, Kidney Health Australia, 2007.

³² <http://www.mynrma.com.au/motoring/buy-sell/buying-advice/car-operating-costs/about-car-operatingcosts.htm>

claiming rates of 63 cents for a small car and 75 cents for a large car³³. Both of these figures far exceed the rates of even the most generous State and Territory schemes, highlighting that these schemes are at best, a contribution to assisting in the covering of costs, rather than representing a true measure of reimbursement.

As demonstrated above Kidney Health Australia's concerns are that the current schemes simply do not adequately reimburse dialysis patients for the true cost of their travel. Furthermore there is no national consistency in the level of the payments, the distance thresholds and in particular, the introduction of cumulative weekly distance thresholds to address the particular circumstances of dialysis patients.

Finally, the same applies to the payments made under PATS for accommodation, where overnight or continued travel away from home is needed. These payment rates range from \$35 per night up to \$60 (or \$75 for a couple) to cover commercial accommodation³⁴. Again both the levels of payment, and the significant state by state variation, cause issues for patients and their carers. Furthermore, there remain a myriad of different eligibility requirements and differing rules, application and claim procedures.

Kidney Health Australia calls on the Australian Government to work with the State and Territory Governments to increase the payment rates, lower thresholds and work towards greater national consistency between the schemes, thereby removing the significant inequity between the current schemes.

Need for Live Donor Support

One of the barriers to live kidney donation is the financial cost to the donor, with international experience indicating that 45% of living donors experience some form of financial hardship³⁵ and one international study highlighting that 24% of potential living donors choose not to donate because of anticipated financial hardship³⁶. The continuing tightening of economic conditions will likely have an impact on live donors seeking to self-fund their operation and time away from work. These financial strains have been eased, to some degree, by providing donors who work with the ability to access paid leave, for a specified period, via a reimbursement to the employer through the announcement of the '*Supporting Leave for Living Donors*' Scheme – something that Kidney Health Australia has advocated for quite strongly.

It is important to note however that the scheme is only a two year pilot and that no funds have been put aside for wider public awareness and campaigning. Noting that the scheme relies upon the awareness and education of the donor, their employer and their doctor, Kidney Health Australia believes a longer trial period, or ideally making the scheme ongoing, noting its modest cost and significant social and economic benefit it brings.

Furthermore, we would argue that a small amount of funds be put aside to undertake education and communication campaigns is necessary. In the absence of that funding yet being made available, Kidney Health Australia has undertaken our own communications campaign, advertising the scheme online, through our newsletters, through an online forum, and by writing to State and Territory

³³ <http://www.ato.gov.au/individuals/content.aspx?doc=/content/33874.htm>

³⁴ http://www.wacountry.health.wa.gov.au/fileadmin/sections/pats/WACHS_G_PATS_GuideForPatientsAndCarers.pdf

³⁵ Stothers L, Gourlay W and Liu W, 2005, *Attitudes and predictive factors for live kidney donation: A comparison of live kidney donors versus nondonors*, Kidney International; 67: 1105-1111.

³⁶ Sickand M, Cuerden M, Klarenbach S, Ojo A, Parikh C, Boudville N and Garg A, 2009, *Reimbursing Live Organ Donors for Incurred Non-Medical Expenses: A Global Perspective on Policies and Programs*, American Journal of Transplantation; 9: 2825-2836.

Public Service Commissioners, major industry groups and unions, to let them know this type of paid leave now exists. However, if this scheme is going to be widely accessed, more needs to be done.

Kidney Health Australia would also advocate for the Australian Government to work to develop, in bilateral discussion with the States and Territories, a standardised policy as to what costs – such as transport and medical – are covered for the patient, as there is currently inequity occurring not only between jurisdictions, but between different renal units.

Need for Increased Research

The relative level of support flowing to kidney research has never matched the expenditure devoted to treating 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 about 2 percent of the total health budget. Without improved research outcomes, this cost is simply going to grow.

The completed Australian Government-sponsored 'Strategic Review of Health and Medical Research' Report stresses the need for support of the research workforce over the long term. Kidney Health Australia remains one of the main non-government supporters of kidney research in Australia, recently redirecting its program towards the public health arena in an attempt to address a clear shortfall.

In light of the recently announced Medical Research fund, Kidney Health Australia remains hopefully that this funding research disparity will be addressed, but would encourage further discussion and consideration into this issue by the Committee.

Conclusion

Quite clearly, it can be seen that kidney disease has a significant impact on the health system in terms of direct treatment costs; in lost employment; in travel and accommodation costs; 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 committee inquiry provides an opportunity to consider options to target a number of key areas within the scope of the Terms of Reference regarding Australia's health system.

Kidney Health Australia would be happy to expand upon the views outlined in here in person, should the Committee wish to discuss further. We thank you in advance for your consideration of the issues raised above. If you have any questions, please feel free to contact Luke Toy, General Manager Public Affairs on luke.toy@kidney.org.au