

Pre-Budget Submission

2016-2017 Federal Budget

Charting a Comprehensive Approach to Tackling Kidney Disease

"Proposals to guide increased risk assessment, support early detection and improve the treatment of kidney disease".



Prevent, Detect, Support.

Contents

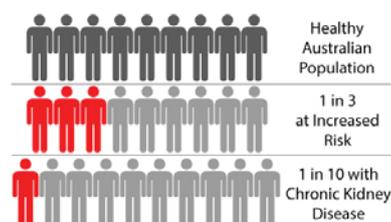
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Executive Summary – New Policy Proposals

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.

Kidney Health Australia therefore presents this submission with a range of suggested actions to help address the increasing burden of CKD and end stage kidney disease (ESKD). First among those is the need to stem the future tide of kidney disease through early detection, supported by pharmacy and primary health care organisations². Primary care is the most logical location for such an intervention – 83 percent of Australians visit their GPs at least once a year³, and the distribution of community pharmacy around Australia is comprehensive.

How much CKD in Australia?



1 in 1400 on dialysis or living with a transplant.

Kidney Health Australia has included proposals to address the full spectrum of the health sector – from strategic planning and early detection, to education and support in the pharmacy and primary care sector, organ donation, palliative care and Indigenous health. All of the proposals are realistic, designed to be low-cost, no-cost or generate savings and have one principle in common – they are all designed to improve the lives of those with kidney disease through smart, targeted interventions, which seek to support existing efforts and policy.

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). 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 renal community and with significant input from our national network of consumers. Kidney Health Australia has captured the results of this ongoing consultation in this budget submission, which ensures that the proposals have acceptance from our stakeholders and are implementable.

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 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

³ BEACH Report, 2011-12, p.7

Proposed Policy	Investment
<p>A coordinated approach to Indigenous Kidney Health, comprising:</p> <ol style="list-style-type: none"> 1. Education and training in Aboriginal and Torres Strait Islander CKD 2. Patient support services in remote and regional locations to assist patient journey and transition 3. The development of a National Action Plan on Indigenous CKD, under the <i>National Aboriginal and Torres Strait Islander Health Plan 2013-23</i>. 	<ol style="list-style-type: none"> 1. Low cost – adaptation and scaling of existing. Potential cost-saving in long-term. 2. Dependent on locations: Potential cost-saving in long-term. 3. Dependent on Government priorities.
<p>The Government introduce a national early detection ‘KidneyCheck’ program, which provides information to at risk Australians and directs them to Community Pharmacy.</p>	<p>Low cost – a letter to those at risk, as well as expanding the already existing ‘KidneyCheck’ scheme.</p>
<p>Integrated Health Checks to streamline current approaches and promote early detection of those at high risk of developing cardiovascular disease, diabetes and CKD and ensure effective, on-going management.</p>	<p>Potentially cost saving</p>
<p>Review and update of the Absolute Cardiovascular Risk Guideline.</p>	<p>\$1.2 million</p>
<p>Development of a new National Framework specific for CKD, devolving from the new National Chronic Disease Strategy and aimed at improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.</p>	<p>Low cost, drawing upon Departmental resources, similar to the development of the New Chronic Disease Strategy.</p>
<p>Education to support primary care health professionals with the increased detection of CKD in people from all causes.</p>	<p>Low cost ~ \$250,000-\$500,000, depending on scope agreed by government (scalable).</p>
<p>Awareness, education and self-management resources for patients to address current gaps, assist those in rural and regional Australia and remove a burden on the health system.</p>	<p>Low cost – each initiative varies and is scalable – from \$250,000 to \$500,000.</p>
<p>Provide a national paid leave scheme for patients and carers needing to train for home haemodialysis</p>	<p>Low cost – with potential long term savings</p>
<p>Improved access to palliative care services for people with end stage kidney disease</p>	<p>~ \$143,000</p>
<p>Address research funding for kidney disease through focussed priorities</p>	<p>Increase the research to be more relative to the cost spent on treating kidney disease.</p>

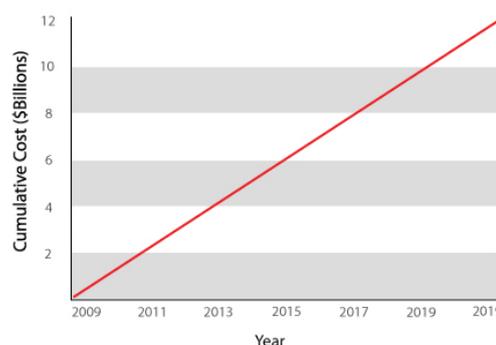
The Cost to the Health System

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 or the presence of proteinuria (protein in the urine) or haematuria (blood in the urine)⁴. Perhaps even more startling is that 1.5 million Australians are unaware they have indicators of CKD.

In addition, 1 in 3 Australians is at an increased risk of developing CKD⁵. Australians are at increased risk of CKD if they:

- have diabetes
- have high blood pressure
- have established heart problems (heart failure or heart attack) and/or have had a stroke
- have a family history of kidney failure
- are obese
- are a smoker
- are 60 years or older
- are of Aboriginal or Torres Strait Islander origin
- history of acute kidney injury

Projected treatment costs for all new & existing kidney patients



Recent costing analyses have shown that in 2012 the total costs attributable solely to CKD in Australia were an estimated \$4.1 billion, made up of \$2.5 billion in direct healthcare costs, \$700 million in direct non-healthcare costs, and \$900 million in government subsidies. Furthermore, 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 billion⁶. Individuals with CKD incur 85% higher healthcare costs and 50% higher government subsidies than individuals without CKD, and costs increase by CKD stage⁷.

The Australian Institute of Health and Welfare estimates that the rate of people starting dialysis or transplant is expected to increase by 80 percent by 2020 – rising from 11 to 19 per 100,000 of the Australian population⁸. 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 community⁹. Indeed, the Central Australian Renal study estimated that just for the

⁴ 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 Dis* 2010;55(4):660-70.

⁵ 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.

⁶ 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>

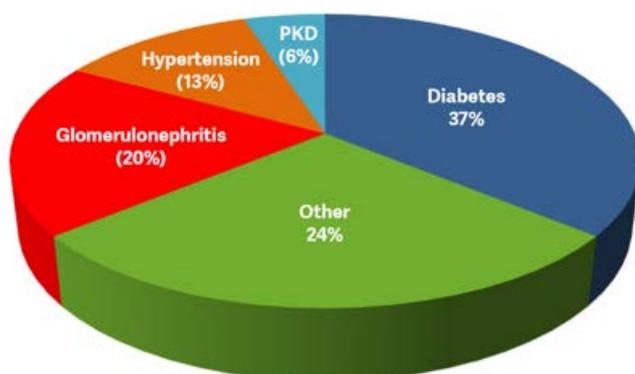
⁷ Wyld M, Lee CMY, Chadban SJ, Zhuo X, White S, Shaw J, Morton R, Colagiuri S. Cost of CKD in Australia. Abstract ANZSN Annual Scientific Meeting. *Nephrology*: 2014. **19** (Suppl. 4), 23.

⁸ AIHW 2011. Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020. Cat. No. PHE 150. Canberra.

⁹ 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>.

areas relevant to its report, that the whole of service costs for those with ESKD would be \$240 million to \$302 million for the period 2009 to 2020¹⁰.

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. Two of the most common causes of ESKD requiring renal replacement therapy (dialysis or transplant) in Australia in 2014 were diabetes (accounting for 37% of cases) and hypertension (13%)¹¹.



Data from the Australian Bureau of Statistics (ABS)¹² shows that kidney disease is a significant cause of death, with around 56 people dying every die with kidney-related disease. Kidney-related disease kills more people each year than breast cancer, prostate cancer, or road traffic accidents. The mortality rate from CKD has not improved over the last decade, in contrast with the improvement in death rates that is recorded for cardiovascular disease and stroke, which are decreasing at a rate of 4.5% and 3.6% each year respectively¹³.

The most recent data available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry¹⁴ shows that 2,610 people started kidney replacement therapy (dialysis or transplant) in Australia in 2014. The number of people on dialysis increased by 3% from 2013 to 2014, resulting in 12,091 people receiving dialysis treatment at the end of 2014. While the majority of people still dialyse in a hospital or satellite dialysis unit, a number of interventions are impacting on the previous downward spiral of rates of home dialysis and this method of treatment now showing an upwards trend back to 30% of all people on dialysis¹⁵.

With dialysis estimated to cost up to \$79,072 per person per year for hospital haemodialysis, \$65,315 for satellite, \$49,137 for home haemodialysis and \$53,112 for peritoneal dialysis (2009 prices), dialysis is clearly an expensive treatment. Despite the cost effectiveness to government and potential health benefits of home dialysis (peritoneal dialysis and home haemodialysis) for the patient, there are significant state-by-state variations in uptake. Furthermore, in Australia there is an

¹⁰ Cass A, Brown A, Togni S, et al. Australian Department of Health and Ageing; 2011. Central Australia Renal Study. June 2011. *Part 2: Final Report, p.4.*

¹¹ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2015

¹² Australian Bureau of Statistics. Causes of death, Australia, 2013. 2015

¹³ Australian Institute of Health and Welfare. Cardiovascular disease, diabetes and chronic kidney disease - Australian facts: Mortality. Cardiovascular, diabetes and chronic kidney disease series no. 1. Cat. no.CDK 1. Canberra: AIHW; 2014

¹⁴ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2016

¹⁵ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2016



overall lack of dialysis capacity, with the rate of new patients coming onto dialysis programs significantly lower than many of our international counterparts. In 2013 Australia ranked 40th out of 51 countries in the incidence of people starting dialysis or transplant programs¹⁶.

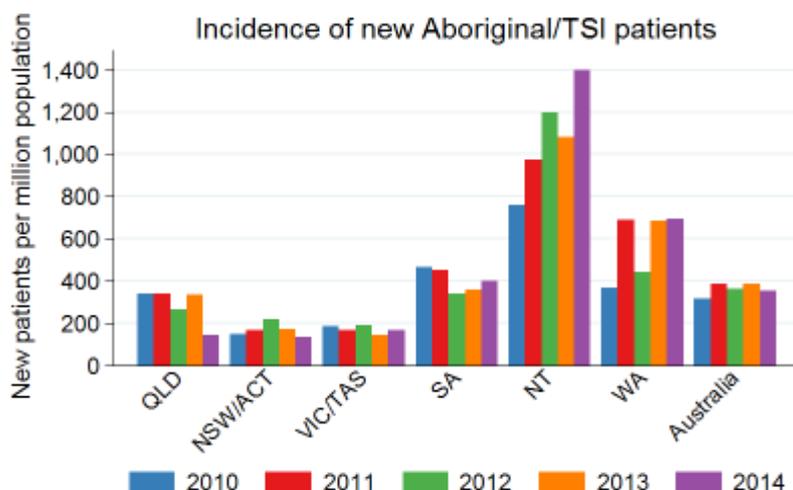
Even when averaging out the different modalities and their respective usage, Kidney Health Australia estimates that the average cost of supplying dialysis is still a considerable \$65,000 per person (based on 2009 prices), per year. Moreover, this does not take into account the lost productivity dividend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

In light of these considerable costs, Kidney Health Australia provides a number of policy proposals, which together form a comprehensive 'next step' for policymakers in the federal government to consider. Kidney Health Australia's aim in presenting this budget submission is to ensure that funding is being spent as effectively and efficiently as possible within the health system.

¹⁶ United States Renal Data System. Annual Data Report: Atlas of Chronic Kidney Disease in the United States. 2015

Indigenous Kidney Health

Aboriginal and Torres Strait Islander health is a national priority that has been recognised by all sides of government. The gross disadvantage experienced by many Aboriginal and Torres Strait Islander people may appear to be complex and overwhelming. There are however, many examples of community-level innovation that are a modest cost to operate, offer the opportunity for scalability and have the potential to provide long-term savings to the health system. Improving the health outcomes of Aboriginal and Torres Strait Islanders requires coordination and commitment by governments, partnership and community-level investment in capacity.



Incidence of new Indigenous patients starting kidney replacement therapy, 2010-2014¹⁷

The case for change

Aboriginal and Torres Strait Islander people experience disproportionate levels of CKD regardless of urban, region or rural locality. Compared with the general population, Aboriginal and Torres Strait Islanders are four times more likely to have CKD and develop ESKD^{18, 19}. In remote and very remote areas of Australia, the incidence of ESKD for Aboriginal and Torres Strait Islander people is especially high with rates almost 18 times and 20 times higher than those of comparable non-Indigenous peoples²⁰.

The greater prevalence of CKD in some Aboriginal and Torres Strait Islander communities is due to the high incidence of risk factors including diabetes, high blood pressure and smoking, in addition to increased levels of inadequate nutrition, alcohol abuse, streptococcal throat and skin infection and poor living conditions^{21 22}.

¹⁷ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2016

¹⁸ AIHW 2011, Chronic Kidney Disease in Aboriginal and Torres Strait Islander people

¹⁹ ABS 2014, Australian Aboriginal and Torres Strait Islander Health Survey: Biomedical Results 2012-13

²⁰ ABS 2012, Australian demographic statistics, March quarter 2012.

²¹ KHA 2014a, *Kidney Fast Facts*

²² O'Dea 2005, *Preventable Chronic Diseases Among Indigenous Australians: The Need for a Comprehensive National Approach*

Previous and ongoing activity

The *Central Australian Renal Study*, commissioned by the Federal Government in 2010, informed the Northern Territory, South Australian and Western Australian Governments about the scale of health and service needs of Aboriginal dialysis patients in the cross-jurisdictional region, in order to make evidence based policy decisions that are affordable and sustainable²³.

The *Closing the Gap in Indigenous Health Outcomes – Indigenous Chronic Disease Package (ICDP)* established a range of preventative health measures and workforces positions specifically targeting the risk factors of chronic disease – smoking, poor nutrition and lack of physical activity²⁴.

The *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* (the NATSIHP) identifies kidney disease as a significant health issue across the life course of Aboriginal and Torres Strait Islander people²⁵.

Budget Proposal for Consideration

Kidney Health Australia provides the following recommendations of key targeted activities which can have a significant effect on the burden of CKD in Aboriginal and Torres Strait Islander communities:

1. Development of a National Action Plan on Aboriginal and Torres Strait Islander CKD by putting in place a time limited National Taskforce

The development of an overarching National Action Plan on Aboriginal and Torres Strait Islander CKD, can wrap up a range of activities in CKD and align with implementation of the *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* implementation and the updated *Central Australian Renal Study*. This action plan can be developed by establishing a time limited *National Aboriginal and Torres Strait Islander Kidney Health Taskforce* of experts. Such a Taskforce would bring together experts in Indigenous health, kidney disease, general practice, health systems, consumer representation and health program delivery.

A National Action Plan on Indigenous CKD, developed by a National Aboriginal and Torres Strait Island Kidney Health Taskforce, will focus on coordinating cross-portfolio efforts on improving Aboriginal and Torres Strait Islander health and well-being outcomes, removing barriers to care and overall cost savings to the health system. The Federal Government can work with States and Territory Government to implement and coordinate activities to ensure that Aboriginal and Torres Strait Islander kidney consumers have adequate information, screening, management, access to treatment, and support.

2. Investing in CKD education and training for the Aboriginal and Torres Strait Islander health workforce.

Training of the existing health workforce and developing an Aboriginal and Torres Strait Islander health workforce to detect, educate and support Aboriginal and Torres Strait Islander kidney consumers will delay the progression of CKD ESKD requiring dialysis or transplant services.

²³ Department of Health & Ageing 2011, *Central Australian Renal Study: Executive Summary*.

²⁴ KPMG 2013, *National Monitoring and Evaluation of the Indigenous Chronic Disease Package First Monitoring Report 2010-11*, Australian Government Department of Health, Canberra

²⁵ Commonwealth of Australia 2013. *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*.

Currently, nine in ten Aboriginal and Torres Strait Islander adults do not know they have signs of CKD²⁶. The development of training and educational resources for Aboriginal and Torres Strait Islanders professionals and those health professionals seeing Indigenous clients will increase awareness, early detection and self-management.

The development of an educational resource and training is low cost and can be adapted, scaled nationally and delivered through existing channels, in partnerships with key Indigenous health agencies. There is potential cost-savings in the long-term, as the result of increased awareness, early detection and self-management.

3. Investing in appropriate patient support services in remote and regional locations

In remote areas, 78% of patients have to relocate to access dialysis or transplant services, compared with 39% of those who live in rural areas and 15% of urban Indigenous ESKD patients²⁷. Separation from country creates significant biological, psychological, social and economic consequences on the health and wellbeing of consumers, their families, communities the wider health and welfare system. At present, there is inadequate support for Aboriginal and Torres Strait Islander patients to assist and support the renal pathway journey, including emotional and social support.

Preceptors: patients supporting patients concept will be trialled in two locations in 2015 (NT & regional NSW). Existing Aboriginal renal patients will be employed part-time/casual to support new renal patients and health staff on the renal pathway journey.

Source: Rix EF, Barclay L, Stirling J, et al. 'Beats the alternative but it messes up your life': Aboriginal people's experience of haemodialysis in rural Australia.

Federal Government funding for appropriate patient support services in remote and regional locations to assist patient journey and transition is low cost, depending on the specific locations identified by need. There is potential cost-savings in the long-term, as the result of greater self-management, compliance with regimes, streamlining of processes.

²⁶ ABS 2014, *Australian Aboriginal and Torres Strait Islander people Health Survey: Biomedical Results*

²⁷ Stumpers & Thomson 2013, *Review of kidney disease among Indigenous people*.

A National Rollout of 'KidneyCheck' in Community Pharmacy

Kidney Health Australia has developed the KidneyCheck™ Program, an Australian first program, which utilises a three-pronged approach targeted at people who have already been diagnosed with diabetes or hypertension and others at increased risk of developing kidney disease. The Program consists of a package of urine testing strips that allow individuals to monitor for protein in their urine (an early sign of kidney damage) in the privacy of their own home. KidneyCheck™ is a self-management program that assists in setting health goals and monitoring results, and includes a health professional education package targeted at community pharmacists and pharmacy assistants.

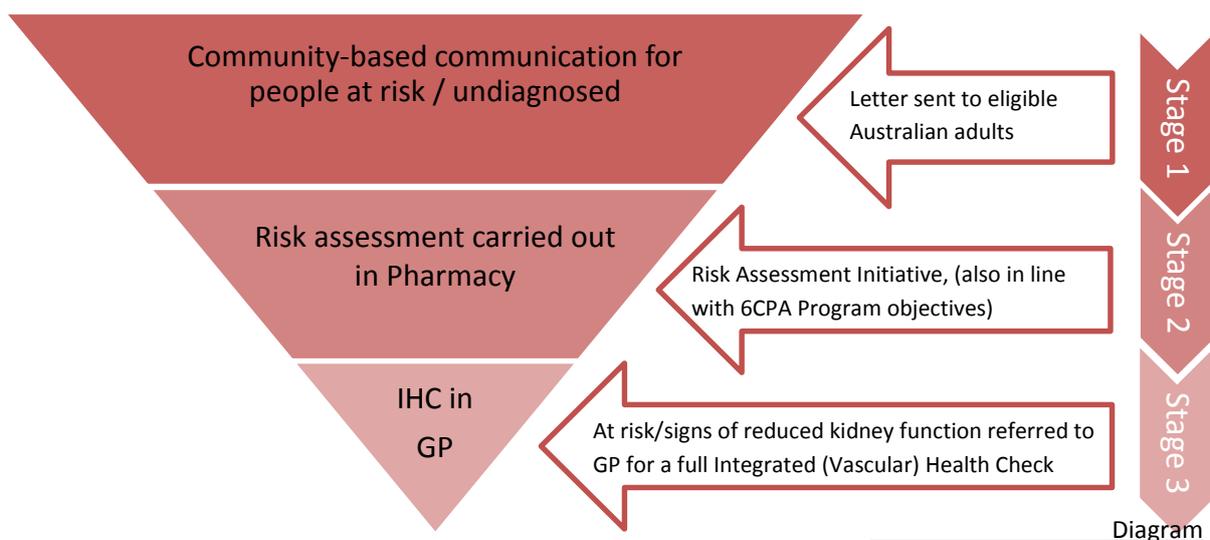
Establishing links between community pharmacy and primary care is integral to the KidneyCheck™ Program. Regardless of the result of the urine dipstick test, the correct action in this population with documented high risk of CKD is to ensure they have had a urine albumin creatinine ratio, eGFR and blood pressure test performed by their GP at least every two years. The pharmacy education package focuses on identifying high risk individuals, educating consumers on the requirement to supplement KidneyCheck™ results with tests performed by their GP, and adopting evidence-based referral pathways to primary care.

The case for change

Recent economic analyses show that people with CKD incur 85% higher healthcare costs and 50% higher government subsidies than individuals who do not have CKD³.

We believe that primary prevention strategies should target the key risk factors for CKD, including prevention, detection and best practice management of diabetes and cardiovascular disease as an integrated approach. Consumer self-management strategies form an important part of best practice management for chronic disease. Consumer awareness and coaching equips patients with the necessary skills and information to make lifestyle changes, and can provide practical information and pathway suggestions as required. Kidney Health Australia proposes the following approach, leveraging off three existing Government-funded initiatives, which when combined work increase consumer awareness of prevention and management of CKD.

Budget Proposal for Consideration



1: Cost effective pathway to engage 'at risk' and undiagnosed through a 'tiered' approach.

Stage 1: Broad Population Awareness

Kidney Health Australia suggests a process similar to that utilised for Bowel Screen. A letter would be sent to Australian adults at increased risk of CKD, informing them of their increased risk, and the relationship between kidney disease and other chronic diseases such as cardiovascular disease and diabetes. Furthermore, Kidney Health Australia would recommend that the letter encourage people take one of two actions: visit their pharmacist for a risk assessment, or visit their GP for an Integrated (Vascular) Health Check.

The eligible population for the letter would be people who have one or more of the following risk factors for kidney disease:

- have diabetes
- have high blood pressure
- have established heart problems (heart failure or heart attack) and/or have had a stroke
- have a family history of kidney failure
- are obese
- are a smoker
- are 60 years or older
- are of Aboriginal or Torres Strait Islander origin
- history of acute kidney injury

Stage 2 in Detail: Cost Effective Community Level Pharmacy Risk Assessment

Kidney Health Australia believes that opportunistic primary prevention is possible when high-risk individuals attend community pharmacies to obtain their prescription medicines, or follow a potential prompt via the mailed information outlined above.

Community pharmacies, with their recognised trust and expertise, close links to local populations and widespread geographical distribution, can potentially provide a high quality, and readily accessible location for opportunistic urine testing to provide a measure of kidney function, and do so while also assessing the risk for other cardiovascular diseases, such as heart disease and diabetes.

The benefit of this approach is that it provides an avenue to implement improved primary care in Australia by drawing on community pharmacy, and potentially the direction set by the Government's recent the 6th CPA. It provides a controlled environment where only those at risk are consulted, and such an environment removes much of the risk that can occur with self-testing, without support. Furthermore, the urine test is very quick and cost effective – it does not require the patient to mail a sample off to a lab and await results, before being in a position to take action.

The KidneyCheck™ Program provides the education to the pharmacist, the appropriate advice via a medical professional, the ability to target those at risk, and most importantly, it is already in place – it simply needs to be put at the heart of a pharmacy risk assessment in a manner, similar to the Health Navigator tool (which is already developed)²⁸.

The in-pharmacy risk assessment and referral program would consist of informed consent to record standardised information including participant demographics, personal and family history, lifestyle

²⁸ Health Navigator is an online tool for health screening at a community level, which has already been trialled in Queensland. It provides an online assessment tool (www.healthnavigator.org.au) that assists consumers to identify their risk of developing CKD, cardiovascular disease and diabetes using evidence-based and validated risk assessment tools.

and medication, with a focus on type 2 diabetes, cardiovascular disease and CKD risk factors. The risk assessment for all three conditions and a printout of personalised recommendations would be provided to the participant and their nominated GP.

A pilot program will demonstrate how best to implement this pathway in an integrated and cost-effective manner. Participant follow-up of outcome measures will evaluate if the pathway is leading to appropriate referral of new patients, or people previously not assessed for chronic disease risk, to primary care.

Stage 3 in Detail: Integrated (Vascular) Health Check at the General Practice Level

Should a pharmacist then identify a consumer to be at increased risk of CKD, cardiovascular disease or diabetes, or the KidneyCheck™ combined with the risk assessment suggests reduced kidney function, then they will be referred to their local GP, along with a supporting letter / documentation from the pharmacy. Other evidence-based primary care referral criteria as stipulated in the RACGP Red Book⁵ (for example Penumovax, overdue pap smear) would also apply.

This ensures that the right people are being funnelled into primary care, and establishes a relationship between the consumer, the pharmacist, and primary care. Kidney Health Australia would argue that it also ensures consistency – as the pharmacy based ‘Health Navigator’ and the Integrated (Vascular) Health Check have both been endorsed by the NVDPA.

The proposed Integrated Health Check is outlined in an earlier chapter in this submission.

Currently, despite 83% of Australian’s visiting their GP at least once a year, 1.5 million Australians are unaware they have signs of CKD. The issue isn’t that the diagnostic tools don’t exist – the issue is a lack of awareness and a lack of risk assessments and kidney checks being undertaken.

Kidney Health Australia therefore recommends that the Australian Government consider the national rollout of the KidneyCheck™ program in Pharmacy. Building on the principles that Community Pharmacy can contribute to improved primary care and early detection efforts, such a program, when combined with an Integrated Health Check, can make a significant impact on the early detection of chronic kidney disease.

A New Integrated Health Check in Primary Care

Well-established, National Health and Medical Research Council (NHMRC) approved-guidelines call for GPs to conduct assessments for eligible patients to detect those at risk of cardiovascular disease, diabetes or CKD.

Because these diseases often co-exist and share many risk factors, it is recommended that these assessments be done concurrently as part of an integrated health check.

The case for change

Together cardiovascular disease, diabetes and CKD are three of the more prevalent chronic conditions in Australia. These three conditions have a substantial impact on the health of Australians, affecting almost 1 in 4 adult Australians, or an estimated 3.7 million people²⁹. Combining a risk assessment for heart disease and stroke, a type 2 diabetes check and a kidney disease test into an 'Integrated Health Check' is considered best practice as it consolidates the necessary checks a patient can request from their doctor.

During 2014, the then Health Minister, Peter Dutton, announced that the government would develop a new quality-focussed Practice Incentive Payment (PIP), by consolidating five existing PIP schemes into a single program.

Undertaking Integrated Health Checks and ensuring on-going management of patients at risk should be incorporated into the proposed quality-PIP.

Budget Proposal for Consideration

A new quality-focussed PIP which includes detection and prevention of vascular and related diseases should require general practices to:

- 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;
- Maintain a patient register, with recall and reminder system for patients eligible for assessment and those who require management of risk; and
- 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 quality PIP should be linked to Primary Health Networks, with the Networks charged with promoting uptake of the integrated health check through education, systems support, creating linkages with relevant prevention services in the Network, measurement, and reporting and evaluation via quality improvement audits.

²⁹ Australian Institute of Health and Welfare. Cardiovascular disease, diabetes and chronic kidney disease- Australian facts: risk factors. Cardiovascular, diabetes and chronic kidney disease series no. 4. Cat. no. CDK 4. Canberra: AIHW.; 2015.

A new quality-focussed PIP would complement existing PIPs and encourage general practice to implement an integrated health check for the early detection and risk management of people at increased risk of developing cardiovascular disease, diabetes or CKD.

The Integrated Health Check would link into existing systems, for example, forming an integral part of chronic disease management as an entrance point into the current Chronic Disease Management Plan mechanism. In addition to inclusion in the proposed quality-focused PIP, an MBS item should be established to support uptake and implementation of the integrated health check

This is a unique and important opportunity to ensure significantly greater adherence to existing evidence-based guidelines for the detection and prevention of the major vascular and related diseases and prevention of heart attack and stroke in people at high risk.

The potential benefits include:

- Improved detection of people at increased risk of vascular and related disease;
- Improved management of risk for people who have not developed disease;
- Reduced prescribing and reduced use of publicly funded health coaching and health promotion services for those at low risk, with more targeted, evidence-based prescribing for medications, including statins and anti-hypertensives and behaviour change/lifestyle interventions;
- Fewer avoidable hospitalisations;
- Reduced red tape, due to integration with existing primary care initiatives and a system which complements other mechanisms; and
- Improved quality systems in general practice through targets and audits to measure adherence to guidelines.

This integrated approach to detection and prevention of vascular and related disease incorporates the recommendations of existing guidelines and policies of the NHMRC, Royal Australian College of General Practitioners (RACGP), Australian Primary Care Collaboratives program (APCC), the National Prescribing Service (NPS) and other government agencies and primary care organisations. It is also supported by the National Vascular Disease Prevention Alliance (NVDPA), which comprises the Heart Foundation, National Stroke Foundation, Diabetes Australia and Kidney Health Australia.

Include the Integrated Health Check and on-going management of patients at risk as part of the development of a new, quality-focussed Practice Incentive Program. Provide an MBS item to support uptake of the integrated health check, with the absolute cardiovascular risk guidelines.

Review of Cardiovascular Disease Risk Guidelines

As part of a call for an Integrated Health Check, Kidney Health Australia, together with the NVDPA, recommends a review the current guidelines for the management of Absolute Cardiovascular Disease Risk.

The case for change

The NHMRC-approved Guidelines for the Management of Absolute Cardiovascular Disease Risk³⁰ support clinicians to assess the risk of cardiovascular disease among the general population (45 years and over). Absolute Cardiovascular Disease Risk assessment is the probability, expressed as percentage, that a person may experience a cardiovascular event (heart attack or stroke) within a five-year period. This guideline, developed with the assistance of Australian Government funding, is a lynchpin to preventive initiatives to reduce the incidence of cardiovascular disease across Australia, key diseases that must be tackled as part of any improvement in broader vascular health.

These guidelines were published in 2012 and are overdue for an update to incorporate new evidence reflecting international best practice care.

Clinical recommendations that improve detection and underpin evidence-based medicine to reduce cardiovascular events are a priority in Australia. Emerging evidence from comparative assessment programs in New Zealand and overseas will inform new clinical guideline recommendations. New Zealand Primary Healthcare Organisations have achieved 86% assessment rates of the eligible population, drawing on clinical guidelines as the basis for detection and management of risk, compared to 25% in Australia³¹. Without updated evidence-based guidelines, patient care could be compromised, leading to increased hospitalisations, and a reduced workforce.

Uptake of the new guideline will be strengthened by the support of the Improvement Foundation (Australian Primary Care Collaboratives) and colleges of general practice to ensure wide communication and to encourage broad clinical involvement. A better quality workforce delivers better outcomes for patients, more efficient care and dramatically lower health costs.

Budget Proposal for Consideration

There is an opportunity for significant positive change with limited investment. New evidence-based recommendations with the updated guideline will:

- Guide clinicians in evidence-based practice to prevent the onset of cardiovascular disease;
- Equip clinicians with advanced risk assessment and management algorithms, supporting earlier detection and management of cardiovascular risk; and
- Reduce the cardiovascular disease burden on the Australian healthcare system.

To underpin the Integrated Health Check with fully updated management of cardiovascular disease guidelines would require an investment of \$1.2 million and would ensure that health professionals are able to maintain a commitment to continuous professional quality improvement.

³⁰ National Vascular Disease Prevention Alliance. Guidelines for the management of absolute cardiovascular disease risk. 2012.

³¹ Heart Foundation General Practitioner Annual Survey, 2012

A National Kidney Disease Strategy

Kidney Health Australia welcomes the ongoing development of a new National Chronic Disease Framework, replacing the outdated Chronic Disease Strategy. Kidney Health Australia remains committed to working with the project team to address kidney disease and related issues within the revised high level Framework.

However, stemming from a revised National Chronic Disease Framework, Kidney Health Australia argues that is now time to commence the development of a National Kidney Disease Strategy (similar to the work that has already been done on a National Diabetes Strategy), as a way of operationalising the Framework, as it relates to kidney disease. Structured to reflect the patient journey, ranging from the reduction of risk, early detection, managing acute conditions, ensuring adequate access to long-term care and to care in the advanced stage of the disease, a National Kidney Disease Strategy would focus on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.

The case for change

Kidney Health Australia, the Australia and New Zealand Society of Nephrology (ANZSN), along with leading clinicians and networks believe that there is much that can be done to improve the early detection - and more efficient treatment - of kidney disease to help stem the growing prevalence of ESKD, putting downward pressure on the usage of high cost dialysis treatment.

There are deeply entrenched problems with the planning and delivery of renal replacement services throughout Australia. There is an overall shortfall in the capacity of dialysis services resulting in:

- A lack of choice for many people facing dialysis leading to the allocation of people to a type of dialysis that is not their preferred option and is often cost inefficient³²
- A marked variation by State in the uptake of home dialysis programs³³, despite this treatment modality being associated with lower cost, reduced need for specialist personnel, improved quality of life, flexibility in quantum of dialysis treatment and probable increased survival
- A low number of people being treated on dialysis programs by International comparison³⁴
- A marked variation by State in the demographics being offered dialysis therapy³⁵

In addition it is noteworthy that for a high cost therapy, largely performed in public health facilities, there is a surprising lack of timely public accountability of dialysis activity and no systematic auditing of adequacy of care, safety or patient outcomes. There is a need for smart, evidence based management and future planning for delivery of dialysis services.

³² Fortnum D, Grennan K, Ludlow M. Dialysis Consumer Perspectives Survey Two: Complete dataset report. Kidney Health Australia. Available at www.kidney.org.au; 2015

³³ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2016.

³⁴ United States Renal Data System. Annual Data Report: Atlas of Chronic Kidney Disease in the United States. 2015

³⁵ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2016.

Previous and ongoing jurisdictional activity

These jurisdictional plans are characterised by variable uptake and implementation, and have resulted in mixed outcomes.

- NSW: Published Renal Dialysis Service Plan to 2011, written in 2007
- Victoria: Published a Renal Directions Discussion Paper in 2013.
- SA: Recently published a paper on Initiation of Dialysis but has not developed a formal Renal Plan. SA does list KPIs for dialysis within documents for the SA Renal Clinical Network written in February 2014
- Qld: Published a Renal Services Plan in 2008-2017, written in 2007
- Tasmania: Published a Renal Services Plan in 2010-2020, written in 2009
- WA: Published a Model of Care for Renal Services in 2007 (new version under review)
- ACT: Published Renal Health Services Plan in 2010-2015, written in 2010
- NT: Published Renal Services Strategy 2004-2009, written in 2004

Previous and ongoing national activity

- National: Federal Government published National Chronic Disease Strategy and five supporting National Service Improvement Frameworks in 2005, with a new Strategy currently under development
- National: Kidney Health Australia published National CKD Strategy in 2006³⁶

The 2006 National CKD Strategy was based on wide consultation with stakeholder organisations and individuals, and an extensive review of the national and international CKD literature. This process identified 18 National Priority Actions across the CKD continuum of care, but was not funded to develop the necessary implementation plans.

Budget Proposal for Consideration

The National Kidney Disease Strategy focuses on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.

A National Kidney Disease Strategy would:

- leverage off the previous and ongoing jurisdictional activities
- accomplish equity and improve clinical and psychosocial outcomes
- provide cost savings for both federal and state governments

It is critical to establish an agreed, robust, evidence-based pathway to manage people along the continuum of CKD. The advantages of a National Kidney Disease Strategy are the opportunity to develop recommendations on key areas of national importance such as early detection, role of primary care, choice of dialysis location and transplant options. If implemented, the likely recommendations in a National Kidney Disease Strategy would be cost effective for government.

A National Kidney Disease Strategy would be:

- Evidence-based
- Patient-centred
- Cost-effective
- Able to be resourced and implemented

³⁶ Kidney Health Australia. National Chronic Kidney Disease Strategy. www.kidney.org.au 2006

- Provide governance, including measuring, monitoring, reporting, and lead to quality improvement

Components of the National Kidney Disease Strategy

The National Kidney Disease Strategy would focus on key areas such as:

- Early detection of CKD and closing the gap in appropriate management in primary care
- Evidence based interventions being applied appropriately to all those identified to have CKD
- Strong focus on patient education and self-management at all stages of CKD
- A smooth entry into renal replacement therapy with an emphasis on an educated patient making an informed choice
- A policy of home dialysis or pre-emptive transplantation first
- The role of supportive care for people on either the dialysis or non-dialysis pathway

The National Kidney Disease Strategy would:

- Contain an environmental scan (events, trends, issues, expectations) and identify opportunities for improvement
- Embrace workforce issues and recommend minimum ideal staffing levels with an emphasis on the need for expanded allied health capacity in the kidney arena

The development of a National Kidney Disease Strategy with its expected recommendations would serve little purpose if there is not engagement with the Commonwealth and State Governments from the beginning. Failure to get their support would mean the project had limited likelihood of having any impact on the kidney sector.

Therefore, the ideal approach to this project would be to put together a proposal for the consideration of AHMAC who would then fund and contract the work. Kidney Health Australia would be a potential tenderer for this contract. An AHMAC supported project carries with an increased likelihood of ownership of the findings, and thus would lead to successful implementation.

The proposed National Kidney Disease Strategy focuses on improving health outcomes, removing barriers to care for people with CKD and ensuring equity of access to all treatments, and making savings to the national health budget through either low-cost or no-cost initiatives, initiatives that return direct savings to the budget, or those which could be expected to alleviate a strain from the health system over time and improve national productivity.

The current fragmented approach to renal service delivery and health care funding is a significant threat to many current attempts seeking to improve CKD outcomes. Without an overall guiding agreement there is a risk that the more effective and efficient outcomes sought through future reforms may not be achieved. A National Kidney Disease Strategy would accomplish equity and improved outcomes for patients, with cost savings for government.

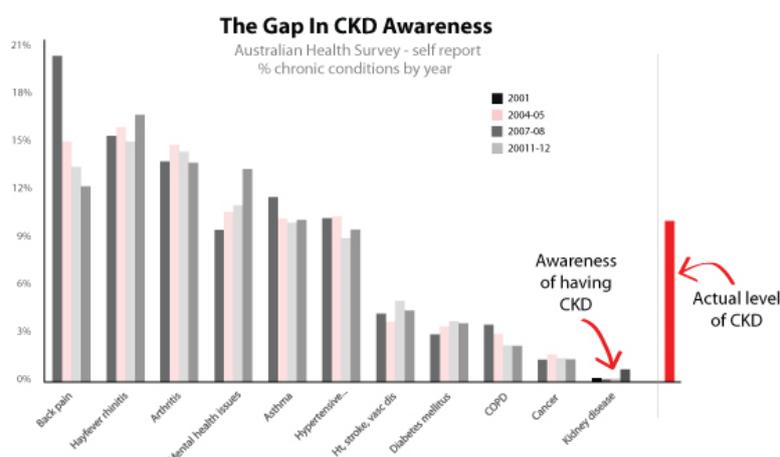
Education to Support the Increased Detection of all causes of CKD

The case for change

Population surveys have consistently shown that clinical evidence of CKD is present in about 11% of all adults³⁷. The recent Australian Health Survey for the first time asked the question “do you have kidney disease?” Only 0.8% responded “yes”, indicating that only one in 12 of those who had CKD was actually aware of it³⁸. The low rate of awareness of CKD, particularly when compared to other chronic conditions, is highlighted in this figure and indicates a great deal more is required to be done in terms of education and awareness.

The last decade has seen the development of an International definition of CKD, which has led to a staging scheme with clinical action plans aligned to each stage. The recently amended staging scheme emphasises the need to ascertain the underlying diagnosis, establish the degree of kidney dysfunction and assess the presence of protein in the urine. This new staging scheme offers improved correlation with kidney and cardiovascular outcomes²⁹.

Yet a recent report indicated that in general practice in Australia, there are significant shortfalls in the recording of kidney function and the recorded prescribing of appropriate kidney protective therapy³⁹. Furthermore, the AusHeart study recently concluded that CKD is common, significantly under-recognised and under-treated in primary care⁴⁰.



Kidney Health Australia has recently published the 3rd edition of its guidance booklet “Chronic Kidney Disease – Management in General Practice” to all practitioners in Australia⁴¹, in part to address this shortfall. This booklet captures the latest changes to the staging and management recommendations for people with CKD. This initiative was developed by the Kidney Check Australia Taskforce (KCAT) program that Kidney Health Australia has conducted for the last 10 years. The program, the only one of its kind in Australia, seeks to educate health professionals in primary care on the advances in knowledge and management of CKD. This program with limited funds has focussed its educational effort on face to face workshops, on-line learning and written material.

The broader Kidney Health Australia vision has been that all people identified to be at high risk of having CKD should be opportunistically offered a kidney health check (blood test, urine test and BP check) in primary care on a regular basis. Given that it has been estimated that 83% of all adults attend their GP each year, this approach has the potential to be both effective and affordable. Yet,

³⁷ AIHW 2009. An overview of chronic kidney disease in Australia 2009. Cat no. PHE 111. Canberra: AIHW

³⁸ Australian Health Survey, 2012. Accessed Dec 5, 2012

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/DC337D37739BC7BDCA257AC9001A845D?opendocument>

³⁹ Pilotto LS et al. Electronic records suggest sub-optimal management of CKD in general practice. Aust J Rural health 2012 :20; 195-199

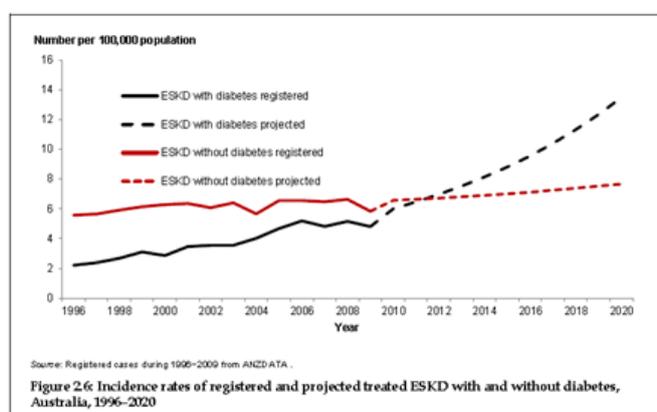
⁴⁰ Razavian M et al. Cardiovascular risk management in CKD in general practice (the AusHeart study). Nephrol Dial Transplant. 2012;27(4):1396-402.

⁴¹ Chronic Kidney Disease (CKD) Management in General Practice. (3rd edition) Kidney Health Australia, Melbourne 2015.

despite the obvious mechanism to carry out a kidney health check through such cost effective means by consolidating with existing GP consultations, Australia remains a long way from achieving this vision, given the facts outlined in this submission.

One special focus of GP education for Kidney Health Australia has been in people with diabetes. Studies have shown 50% of people with type 2 diabetes in general practice will have CKD, and 49% of all new people commencing dialysis in 2010 had diabetes (37% of the total had diabetes as the coded cause of their kidney failure)⁴². Projections indicate that the number of people with kidney failure secondary to diabetes will double in the next decade and will account for almost **all** growth in Australian dialysis numbers (Figure)⁴³.

Diabetes is the likely growth factor in ESKD in the next decade



Budget Proposal for Consideration

Kidney Health Australia, through its existing KCAT project is well positioned to roll out an enhanced national education program to support the Government's recent policy change to introduce a measure of kidney function as part of the diabetic annual cycle of care PIP payment, and do so cost effectively and with minimal start up time.

⁴² ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2015

⁴³ Projections of the incidence of treated end-stage kidney disease in Australia. 2010-2020 AIHW . September 2011.

By leveraging off the existing KCAT program, Kidney Health Australia proposes rolling out an education program to GPs, to be delivered over two years, commencing on 1 July 2016. The program would deliver face to face workshops at each Primary Healthcare Network. These face to face workshops would be one-to-two hour workshops using a local nephrologist as the facilitator, and would be accredited by the Royal Australian College of General Practitioners (RACGP) and offer a high quality, evidence-based presentations backed up with hardcopy takeaway resources for participants. The program would have specific learning objectives for GPs, specifically:

- Knowing the eight major risk factors for CKD
- Knowing how to measure kidney function and interpret the results
- Being able to outline the optimal management of diabetic kidney disease
- Gaining a better appreciation of the need to screen high risk individuals for CKD
- Being able to implement a practice based system to perform a kidney health check for patient at increased risk of CKD

In addition, the program would involve developing a supplement to existing on-line learning modules on CKD and diabetes and hypertension

The Kidney Health Australia's publication "*CKD Management in General Practice*", already well recognised and used within primary care has been updated and includes new sections on kidney stones and acute kidney injury and a special section on CKD care in the elderly.

By leveraging off Kidney Health Australia's existing publications and through the delivery in Primary Health Networks the total cost could be limited to approximately \$260,000 for low level intervention but could be scaled up to \$500,000. This represents a relatively small cost to support the Australian Government's decision to include a measure of CKD as part of the existing PIP payment.

Awareness, Education and Self-Management for Patients

Life with kidney disease can be an isolating experience. It can be difficult to navigate the health system, to raise awareness of the issues surrounding the ongoing treatment of kidney disease, and to find a way to seek further information. The below proposals are modest in cost but designed to be significant in impact and utilise existing and proven models.

The case for change

There is a clear need for a comprehensive kidney education program that focuses on delivering self-management education and increased capacity for people living with kidney disease.

There is also increasing demand for an enhanced service to provide information, clarify issues and help people through the emotional journey of living with kidney disease, and understanding its impact on lifestyle and family with practical information and pathway suggestions. The health care system is increasingly strained in providing health and medical services to the growing number people with chronic illness, and information provision and patient understanding can often fall by the wayside.

A medical appointment offers only a small window of opportunity to discuss complex health queries and as a result, people often leave their health provider seeking additional information and support. Kidney Health Australia has the only service that exists in Australia that has understanding of, or offers support for, kidney disease and currently responds to more than 2100 enquiries a year, without promotion of the service. The service, called the Kidney Health Information Service (KHIS) provides information, support and referral advice relating to kidney health. It is often the case that the KHIS service is the first point of human contact after diagnosis of kidney failure, helping people through the emotional journey of understanding kidney disease and its impact on lifestyle and family with practical information and pathway suggestions. Noting that you can lose 90 percent of kidney failure before symptoms appear, the realisation that they will now require dialysis for the remainder of their life (or until such time as a transplant, if that is an alternative that is available) can be a significant shock.

No other service exists in Australia that has understanding of or offers support for kidney disease. This service is particularly useful to rural and regional Australians due to lack of primary health services locally, and limited direct access to information, support or referral services in their areas.

Many of the mechanisms to enable greater self-care by patients exist – already having been trialed and proven. In many cases, they simply need the recognition and funding to enable them to be rolled out nationally, so that all Australians living with kidney disease can access low cost resources that will empower them to better care for themselves.



Budget Proposal for Consideration

Kidney Health Australia has prepared the below recommendations to assist in supporting patients, their carers and their families through the journey of living with kidney disease. Each of these proposals is low cost and designed to work to address areas where, based on our observations, current support is lacking.

The health care system is increasingly strained providing health and medical services to the growing number of people with chronic illness. A doctor's appointment offers only a small window of opportunity to discuss complex health queries – the KHIS service can provide that information.

The first proposal would involve the adaptation of an already successfully trialled interactive resource – the 'Kidney Kiosk'. The kiosk is an interactive, online touch screen digital educational tool that allows those living with kidney disease to learn about their kidney disease, treatment, and the best possibilities for self-management.

Kidney Kiosk is a particularly useful model for demonstrating how to overcome the absence of support for regional and rural Australians living with kidney disease, and could be readily expanded and be applied to other portable devices. Using online technology, it is cheap, scalable and updatable. Kidney Health Australia estimates that such a service could be rolled out nationally, online, through dedicated national project management, content creation, production and through leveraging off existing partnerships for \$200,000. This would place the content online, so would not include the hardware costs – meaning each hospital or health service provider is not locked into purchasing specific hardware, but rather could determine the best mechanism to suit their circumstances.

Secondly Kidney Health Australia would recommend the development of an education resource – specifically a CKD Community Education Package, which would be distributed through existing networks such as Local Health Networks to educate the 'at risk' general public on kidney disease. The goal would be for this education to then encourage those at risk to visit their GP to ascertain their kidney status, thereby contributing to both earlier detection, and a reduction in health costs arising from late detection. This could be packaged with training for volunteer speakers and has the capacity to provide essential regional and rural coverage. The total cost, including a fulltime resource, content development, production and evaluation would only be \$385,000 for a program to run nationally.

Thirdly, Kidney Health Australia would recommend enhanced telephone support and information, by expanding our national KHIS to respond to greater call volumes and provide understanding, support, information and pathways for people living with kidney disease. The current service is beyond capacity and has no ability for additional call volume – a significant concern noting the predicted increase in kidney disease. CKD is increasing in prevalence and research indicates there is a critical level of undiagnosed disease in the community. As promotion of risk factors increase, we anticipate more awareness and diagnosis resulting in increased demand on the service. Upgrading the service will ensure it is more efficient and responsive and will more effectively meet stakeholder needs, particularly those living in rural or regional Australia. Future demand could be met by an additional dedicated staff member, appropriate training, a digital online education resource and a modest upgrade to the current telephony system for \$250,000.

The Australia Government provide a small amount of funding to the following education and support mechanisms to address identified gaps in the patient experience, improve earlier detection, patient understand and reduce burden on the health system, particularly GPs.

- Fund an online expansion of the 'Kidney Kiosk' initiative – helping those with kidney disease learn about their condition and assist in understanding self-management options (\$250,000).
- Development of an educational resource targeted at those 'at risk' of developing kidney disease and distribute through existing networks, such as the Local Hospital Networks, complemented by a volunteer speaker program (\$385,000).
- Fund an expansion of the Kidney Health Information Service to meet current and future demand and address an area where there is currently a significant gap in information provision (\$250,000).

More detailed costings for each of these initiatives can be provided at any stage.

Providing Paid Leave for Home Haemodialysis Training

Dialysis represents 15% of hospitalisations in Australia.⁴⁴ Consumers who undertake hospital based dialysis contribute the highest per patient cost within ESKD to the health system. Introducing a federal home haemodialysis training leave scheme has the potential to contribute to reducing the variation in home haemodialysis uptake amongst all jurisdictions.

Kidney Health Australia recommends introducing nine weeks of minimum wage, federally funded paid leave for a home haemodialysis training patient, and three weeks of federally funded paid leave for a carer in training, in order to remove a major financial barrier to the uptake of home dialysis, and to alleviate a significant financial burden.

The case for change

Dialysis consumers living with ESKD not only face physical but also emotional strain caused by the need for ongoing treatment.

There are two main types of dialysis: peritoneal and haemodialysis. Peritoneal dialysis is usually performed at home, while haemodialysis can be undertaken either at home or at a dialysis centre. Eighty percent of people on dialysis use haemodialysis with the majority using centre-based dialysis. Haemodialysis involves the consumer being attached to a machine filtering their blood for at least five hours, three times per week. This centre-based treatment is enough to live but does not completely replace the work of the kidneys.

There is a significant cost and burden of travel required to regularly attend the dialysis centre for treatment. Dialysis affects employment opportunities, with many consumers unable to maintain “normal” working hours. In-centre dialysis has a fixed regime with little flexibility.

Research has shown a clear benefit of undertaking home haemodialysis over the in-centre alternative; results show improved quality of life in areas such as freedom of daily diet and fluids, opportunities to travel, and reduced medications⁴⁵. In addition, improved sexual drive and higher quality interactions with family, improved sleep patterns⁴⁶, and the ability to return to work are reported⁴⁷. The medical benefits of home haemodialysis are most often attributed to the ability to increase frequency of sessions and the length.

The roadblock in commencing home haemodialysis is extensive training on a hospital or training site, needed over a nine week period – much longer than any annual or sick leave entitlement provides. There is often the need for a carer to participate in a substantial portion of this training.

The impact of chronic disease on labour force participation is significant. Kidney Health Australia’s National Consumer Survey sought feedback on the direct impact of dialysis for consumers⁴⁸. In the

⁴⁴ <http://www.kidney.org.au/kidneydisease/fastfactsonckd/tabid/589/default.aspx>

⁴⁵ Mowatt, G., Vale, L., & Macleod, A. (2004). Systematic review of the effectiveness of home versus hospital or satellite unit hemodialysis for people with end-stage renal failure. *Int J Technol Assess Health Care*, 20, 258-268.

⁴⁶ Jaber, B. L., Lee, Y., Collins, A. J., Hull, A. R., Kraus, M. A., McCarthy, J. et al. (2010). Effect of daily hemodialysis on depressive symptoms and postdialysis recovery time: Interim report from the FREEDOM (Following Rehabilitation, Economics and Everyday-Dialysis Outcome Measurements) study. *Am J Kidney Dis*, 56, 531-539.

⁴⁷ Mowatt, G. Et al.

⁴⁸ Fortnum D, Grennan K, Ludlow M. Dialysis Consumer Perspectives Survey Two: Complete dataset report. Kidney Health Australia. Available at www.kidney.org.au; 2015

age bracket of 45-64 year olds, 53 percent indicated that home dialysis done by themselves or the carer had reduced the household income, and that hours at work were reduced, a position was changed or work was given up all together. Forty-five percent in this cohort indicated that the spouse or family had to alter their work or study. In the younger age group of 24-44 year olds, it found that 42 percent of respondents indicated home dialysis reduced the household income, and 50 percent found home dialysis meant a reduction of hours, a change in position or giving up work all together. Thirty-eight percent of consumers in this age group found that their spouse or family members had to alter their work or study.

One consumer, called Christine, mentioned to Kidney Health Australia that in order to train for home dialysis she exceeded her leave entitlements so has had significant periods with little or no pay. Christine tried to work what hours she could around her training and ill-health but was forced to rely on her parents and savings to pay the mortgage.

Kidney Health Australia believes the introduction of paid leave for home dialysis would remove a significant financial strain for those considering their dialysis modality options. There is also precedence for introducing a period of paid leave for medical purposes, particularly when it involves removing a financial barrier to better (and more economical) health outcomes.

In the case of providing paid leave, the Commonwealth has set a precedent with the case of the *Supporting Leave for Living Organ Donor Programme*. The aim of the program was to alleviate the financial stress/barriers that can be experienced by living donors and also to reimburse employers for payments or leave credits provided to their employees for leave taken to donate an organ and recover from the procedure.

From a Government perspective, the introduction of a paid leave for home dialysis training would be administratively efficient, as the payments would be made within an existing structure, such as Centrelink, Medicare or the Department of Health.

International Experience

Other jurisdictions have moved towards the use of temporary leave for training purposes. The United States Department of Labor, through the *Family and Medical Leave Act (1993)*, provides the allowance for employers to grant eligible employees 12 weeks of time off within a 12-month period for medical training purposes. Some states have dovetailed the allowance by enabling this time to be taken as 'paid' leave. States that have adopted paid leave under the *Family and Medical Leave Act* include California (*Paid Family Leave Insurance Program 2004*)⁴⁹, New Jersey (implementing California's model in 2008) and Washington (*Family and Medical Leave Program 2007*).

Budget Proposal for Consideration

Providing paid leave for home haemodialysis training can generate savings to the Government in a number of ways. Firstly, a patient who is able to undertake a home haemodialysis method versus an 'in-centre' method can save up to \$29,935 per patient, per annum in treatment costs⁵⁰. This is due to the fact a patient not 'in-centre' would have reduced staffing and no hospital overhead costs.

Secondly, providing paid leave for consumers who wish to undertake home haemodialysis would be a small cost up-front that would pay for itself in time, once considerations such as the person being

⁴⁹ <https://ca.db101.org/ca/situations/workandbenefits/rights/program2b.htm>

⁵⁰ Cass A et al. The Economic Impact of End Stage Kidney Disease in Australia: projects to 2020. Published 2010.

able to return to work⁵¹ (therefore contributing income tax), a reduction in claims for patient travel assistance, and general increases in productivity levels and economic contribution from being active in the workforce. ANZDATA has identified that on average for the past three years, 188 people have started home haemodialysis in Australia, so the numbers are not significantly high and would therefore not create an unrealistic upfront cost, if a policy were introduced to support these patients.

The annual cost of dialysis per patient per year is: \$79,072 for hospital dialysis, \$65,315 for satellite dialysis, \$53,112 for peritoneal dialysis, and \$49,137 for home haemodialysis (2010 prices). Current analyses indicate that 71% of Australians receive dialysis at a hospital or satellite centres, and 29% are dialysing at home. Despite the cost effectiveness to government and the potential health benefits of home dialysis, there are significant state-by-state variations of uptake, ranging from 37% (home haemodialysis and peritoneal dialysis) in NSW to as little as 13% in the Northern Territory and 22% in South Australia, Tasmania and the Australian Capital Territory.

Kidney Health Australia estimates 'that increasing the use of home haemodialysis over the next 10 years would lead to an estimated net savings of between \$378 and \$430 million for our health system'.⁵²

A large part of the savings for home dialysis is that a carer is the 'would-be' nursing support that would otherwise be paid for by Government if the dialysis was occurring in a unit setting. Working carers may be required to give up employment and apply for Government support, and our experience has been that carers are already disadvantaged because they are not eligible for the higher 'Carer Payment' (\$589.60 per fortnight) currently administered by Centrelink.

In the case of the already unemployed or those who are currently receiving a level of Centrelink benefit, they could simply maintain their benefits during the training period. However, as the system stands, many of the eligible unemployed registered with Centrelink are considered as 'active job seekers' and must be seeking employment for six months each year. Under this circumstance the net financial effect would be the same, and we would seek an exemption to the job seeking requirements for financial support.

There is negligible risk involved for fraud claims given the intensity and length of the training involved, and also given that the training is hospital administered. It would be virtually impossible for someone who is not the dialysis patient, undergoing dialysis, or caring for a dialysis consumer, to claim funding under this scheme.

⁵¹ If an individual chooses to undertake in-centre dialysis, full-time (37.5 hours per week) paid employment is close to impossible to coordinate with strict appointment times and dialysis occurring three days per week for at least six hours per session.

⁵² Kidney Health Australia, Jan 2012, A Model for Home Dialysis, Australia, (page 14)

Home haemodialysis is associated with improved health outcomes and a higher quality of life that includes more flexibility. Providing federally funded, paid leave at minimum wage for training purposes means individuals may be able to return/maintain their role in the workforce. The cost to the Government would be minimal, and would return through taxation, productivity gains to the economy, and overall savings from choosing home dialysis over the significantly more expensive in-centre option. Without access to reasonable carer and medical leave policies for training purposes, consumers are at risk of being forced to choose between their jobs and their families, or their health, and it places an unnecessary barrier to home dialysis.

Improved Access to Palliative Care Services

Joint Kidney Health Australia and Palliative Care Association

Life-expectancy is greatly reduced for those with kidney disease and despite dialysis the symptom burden is often poorly managed. Kidney Health Australia and the Palliative Care Association (PCA) are collaborating to improve access for those with kidney disease to palliative care services. The first step would be to consolidate and provide easy access to information and education for both the general public and health professionals.

The case for change

In Australia kidney failure (as a principal or additional diagnosis) is the third most common cause of palliative care related hospital separations (behind secondary cancer and lung cancer), and kidney failure as the principal diagnosis accounts for 36% of all palliative care patient deaths.⁵³

Patients with CKD and ESKD experience an average of seven symptoms affecting their daily life.⁵⁴ Symptoms can include itching, fatigue, depression, constipation, insomnia, nausea, vomiting, shortness of breath and pain.⁵⁵ These symptoms are frequently under-diagnosed or inadequately treated which reduces a person's quality of life.

The highest incidence rates of CKD and ESKD in Australia occur within remote, regional and Aboriginal and Torres Strait Islander communities. Although not all groups are affected equally by ESKD, there are some communities where the rates are approximately twenty times higher than the national figure.⁵⁶ Access to specialist palliative care services and information about palliative care in rural and remote communities is limited for both patients and health professionals.⁵⁷ Palliative care in rural and remote areas is generally delivered by primary care physicians and community nurses and not palliative care specialists. The limited support, education and information provided to these health professionals makes the management of palliative care and renal support difficult.

To achieve the best quality of life for a person with CKD/ESKD, health care professionals need to communicate with and properly inform, understand and support the person, their family and carer/s. By raising awareness and providing information and support, the person, their family and carer/s will be able to make informed decisions on their future care, including dialysis withdrawal while being aware of, and having access to relevant support networks. Additionally, symptom management should be improved.

PCA and Kidney Health Australia developed a joint position statement on palliative care and CKD/ESKD⁵⁸ which drew attention to the need for health professionals, patients and carer/s to be provided with accurate information and education about palliative care and renal disease. It called for a central national resource point for written, digital information and education for patients,

⁵³ Australian Institute of Health and Welfare. "Palliative care services in Australia" HWI 123, Canberra: AIHW; 2013.

⁵⁴ Murphy, E., Murtagh, F., Carey, I., Sheerin N. "Understanding Symptoms in Patients with Advanced Chronic Kidney Disease Managed without Dialysis: Use of a Short Patient-Completed Assessment Tool" *Nephron Clinical Practice* 2009;111 pp. 74–80

⁵⁵ Phipps, L. et al "Educational Needs in Supportive and End-of-life Care" *Nephrology*

⁵⁶ Sajiv, C. "Cultural Considerations when providing care to Aboriginal and Torres Strait Islanders option for conservative care" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.430

⁵⁷ May S. "Issues and Models of Renal Supportive care in Rural Areas" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.435

⁵⁸<http://www.palliativecare.org.au/Portals/46/Position%20Statements/WEB%20Palliative%20Care%20CKD%20Position%20Statement.pdf>

carers and health professionals on palliative care associated with kidney disease; and for more accessible information and education for health professionals, patients, their family and carer/s on palliative care and kidney disease.

Budget proposal for consideration

Education resources are limited for people with ESKD and those that are available are not widely marketed. One central national resource point for written, digital information and education for patients, carers and health professionals on palliative care associated with kidney disease would bridge this gap. A collaboratively developed website between PCA and Kidney Health Australia would ensure more accessible information and education for health professionals, patients, their family and carer/s on palliative care, and kidney disease including symptom management and dialysis withdrawal. Centralising resources would also allow for the identification of gaps in existing materials and future standardisation.

A website would support the up-skilling 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 people including the promotion of advance care planning. A website could host education and ongoing support for renal specialists, renal medicine trainees and general practitioners by palliative care specialists on the benefits and practical delivery of a palliative approach for people with CKD/ESKD, their families and carer/s.

It is estimated that developing the website would be a 6 month project, with existing website developers for Kidney Health Australia conducting the work. There would be ongoing costs for maintaining the website and its content. The website would operate like the Kidney Cancer site⁵⁹ accessed via the Kidney Health Australia website, which presents extensive information on Kidney Cancer via a special site to support those with kidney cancer, their families, carers and health professionals – but with strong links and branding to the primary Kidney Health Australia and PCA websites.

Kidney Health Australia and the Palliative Care Association believe this measure will allow improved access to authoritative information on palliative care options for CKD/ESKD and particularly end-of-life kidney disease patients, families and health providers, with particular benefits to remote and regional communities.

Aboriginal and Torres Strait Islanders

Culturally appropriate and supported closer-to-home dialysis models are needed to enable Aboriginal and Torres Strait Islanders to remain with their families, on country and to achieve better health outcomes.

Without this, patients face significant dislocation from home and Government's bear the burden of increased costs resulting from late presentation to treatment, increased travel and accommodation costs, and a less than optimum health outcomes (see Kidney Health Australia's submission).

The high burden of chronic disease, the complexity and co-morbidity of illness for Aboriginal and Torres Strait Islanders and the provision of care in rural and remote settings are significant

⁵⁹ <http://www.kidney.org.au/KidneyCancer/tabid/799/Default.aspx>

challenges. Aboriginal and Torres Strait islander people in remote and very remote regions experience end stage kidney disease at a rate 18 to 20 times higher than that of the wider Australian population. They are also on average at least 20 years younger when commencing renal dialysis treatment. It is estimated that over 75% of patients in these remote areas have to relocate to access life-saving renal dialysis treatment. Aboriginal and Torres Strait Islanders are almost four times more likely to die with kidney disease as a cause of death than non-Indigenous Australians.

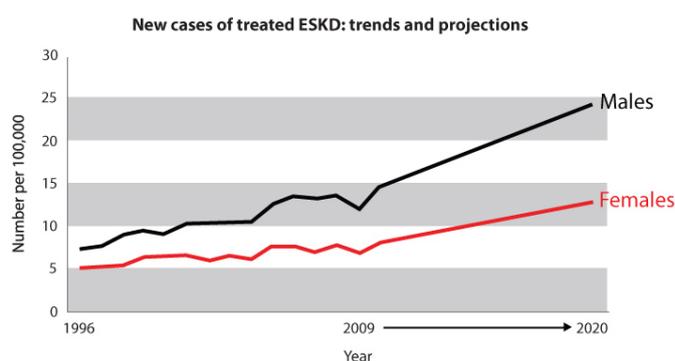
As the result, the impact of CKD is significant and devastating on Aboriginal and Torres Strait Islander communities. Many families are dislocated and often separated and in unfamiliar surroundings. Many Aboriginal and Torres Strait Islanders choose to withdraw from treatment and return to their families, communities and cultural homelands.

Inequity of access to palliative care services is experience by many Aboriginal and Torres Strait Islanders in these circumstances. This may be the result of lack of culturally appropriate information and support services, fragmentation of care and the transition between primary and acute care, fragmentation between public and private care, and geographical issues.

PCA and Kidney Health Australia call on the Commonwealth Government to provide national coordination, consistency and culturally appropriate support for those Aboriginal and Torres Strait Islanders who choose a conservative care pathway, to return home for end of life care, or to ensure that support exists for those who may approach the end of their dialysis treatment possibilities once having returned home.

The need for further research

Recent advances in the clinical area offer a new hope – to those living with kidney disease, their doctors and those administering the health system – and these benefits flow directly from research. For example, for the first time an effective therapy has been proven for polycystic kidney disease (an inherited condition that accounts for ten per cent of kidney failure in Australia), a direct result of research. Significant advances have also been made in understanding the processes causing damage and scarring inside the kidney that result in the progression of most kidney diseases. These advances have the potential to flow into the clinical arena in the next few years and will likely reduce the numbers of patients needing treatment. Further advances can only come from increasing this investment.



The case for change

Without improved research outcomes, the cost of treating kidney disease is simply going to grow.

The completed Australian Government-sponsored 'Strategic Review of Health and Medical Research'⁶⁰ 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.

Budget Proposal for Consideration

From Homer Smith "From fish to philosopher" (1953)

"Recognizing that we have the kind of blood we have because we have the kind of kidneys we have, we must acknowledge that our kidneys constitute the major foundation of our philosophical freedom. Only because they work the way they do has it become possible for us to have bones, muscles, glands and brains. Superficially, it might be said that the function of the kidney is to make urine; but in a more considered view one can say that the kidneys make the stuff of philosophy itself."

Firstly, Kidney Health Australia believes that Australia needs a greater national focus on kidney disease, and should appropriately fund kidney research to a level commensurate with the burden on the health system.

The increased funds from this research should be focussed on the following principles:

- **Leading Internationally:** Developing world leading kidney research programs that include programs in prevention and better management of established disease
- **Kidney Specific:** Ensure that NHMRC and Australian Research Council establish focussed kidney-specific research programs, separate and additional to broader vascular research
- **Partnership:** Work collaboratively with organisations such as Kidney Health Australia to multiply the impact of available funds

- Patient Focussed: Broad-based research that covers the kidney spectrum but with a special emphasis on patient centred outcomes in the area of kidney failure treatment
- Translate and Implement: Emphasise and facilitate the translation of research findings into clinical practice

Kidney Health Australia believes a modest increase in Research funding could be targeted at the following areas to have greatest, practical effect:

- National Plans: The creation of a national evidence based renal services plan (including a model of care) that focuses on the increased prevalence of kidney failure in the elderly and its adverse impact on quality of life and social status;
- Cost-effectiveness: Improved cost-effective approaches to the early detection of chronic kidney disease;
- Target Specific Needs: The development of specific therapies for common kidney conditions such as glomerulonephritis, diabetic kidney disease and vascular disease;
- Pursue Pathways: The development of therapies that address the pathway of progression to kidney failure through inflammation and scarring that is common to most kidney conditions;
- Vascular Approach: The impact of CKD on other conditions, such as heart disease, where CKD is not only an independent risk factor but a major determinant of patient outcome; and
- Patient Centred: Better understanding of the patient experience leading to a focus on improved patient outcomes as the marker of success particularly in the area of dialysis and transplantation.