Pre-Budget Submission
2015-2016 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

Executive Summary – The Rising Burden of Kidney Disease .............................................................. 3

Executive Summary – New Policy Proposals ...................................................................................... 4

The Cost to the Health System ............................................................................................................ 5

Indigenous Kidney Health ................................................................................................................... 8

The case for change ........................................................................................................................ 8

Budget Proposal for Consideration ................................................................................................. 8

A National Integrated Renal Pathway ............................................................................................... 11

The case for change ...................................................................................................................... 11

Budget Proposal for Consideration ............................................................................................... 12

A New Integrated Health Check in Primary Care and Review of Cardiovascular disease risk guidelines ............................................................................................................ 14

The case for change ...................................................................................................................... 14

Budget Proposal for Consideration ............................................................................................... 15

Education to Support the Increased Detection of all causes of CKD .............................................. 18

The case for change ...................................................................................................................... 18

Budget Proposal for Consideration ............................................................................................... 19

Awareness, Education and Self-Management for Patients .............................................................. 21

The case for change ...................................................................................................................... 21

Budget Proposal for Consideration ............................................................................................... 22

An improved Live Organ Donor System in Australia ......................................................................... 24

The case for change ...................................................................................................................... 24

Budget Proposal for Consideration ............................................................................................... 25

Improved Access to Palliative Care Services ..................................................................................... 29

The case for change ...................................................................................................................... 29

Budget proposal for consideration ............................................................................................... 30

The need for further research .......................................................................................................... 31

The case for change ...................................................................................................................... 31

Budget Proposal for Consideration ............................................................................................... 31
Executive Summary – The Rising Burden of Kidney Disease

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 CKD. Approximately 1.7 million Australians – a striking 1 in 10 – over the age of 18 years have at least one clinical sign of CKD. And 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 end-stage kidney disease continues to cost governments in Australia approximately $1 billion 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. The cost of treating those with stage 4 CKD – the stage prior to consideration of dialysis- has been shown to be 8 times higher than in those without kidney disease. 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 population. 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 community. Kidney Health Australia therefore presents this submission with a range of initial suggested actions to help address the increasing burden of CKD and ESKD. First among those is the need to stem the future tide of kidney disease through early detection, supported by primary health care organisations. It is also the most logical location for such an intervention – 83 percent of Australians visit their GPs at least once a year.

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. The priority initiatives identified in this proposal focus on improving health outcomes, removing barriers to care for people with CKD, 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. Each initiative addresses an area where there is good evidence that action is needed, and where there are clear potential benefits for people with CKD across the continuum of care.

6 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
7 BEACH Report, 2011-12, p.7
Executive Summary – New Policy Proposals

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 primary care sector, organ donation, palliative care and of course 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.

<table>
<thead>
<tr>
<th>Proposed Policy</th>
<th>Investment</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>Low cost, drawing upon Departmental resources, similar to the development of the New Chronic Disease Strategy.</td>
</tr>
<tr>
<td>A coordinated approach to Indigenous Kidney Health, comprising:</td>
<td></td>
</tr>
<tr>
<td>3. The development of a National Action Plan on Indigenous chronic kidney disease, under the National Aboriginal and Torres Strait Islander Health Plan 2013-23.</td>
<td>3. Dependent on Government priorities.</td>
</tr>
<tr>
<td>Integrated Health Checks to streamline current approaches and promote early detection of those at high risk of developing cardiovascular disease, diabetes and chronic kidney disease and ensure effective, on-going management; and an update of the Absolute Risk Guidelines.</td>
<td>Potentially cost-saving.</td>
</tr>
<tr>
<td>Education to support General Practitioners with the increased detection of CKD in people from all causes</td>
<td>Low cost ~ $250,000-$500,000, depending on scope agreed by government (scalable).</td>
</tr>
<tr>
<td>Awareness, Education and Self-Management Resources for Patients to address current gaps, assist those in rural and regional Australia and remove a burden on health professionals.</td>
<td>Low cost – each initiative varies and is scalable – from $250,000 to $500,000.</td>
</tr>
<tr>
<td>Improvements to the live organ donor system to better support live donors and continuation and expansion of the Federal Government’s Supporting Leave for Live Organ Donors Scheme.</td>
<td>~Costing for existing leave scheme already known by agencies, approx $2 million.</td>
</tr>
<tr>
<td>Improved Access to Palliative Care Services</td>
<td>~ $143,000</td>
</tr>
<tr>
<td>Address research funding for kidney disease through focussed priorities</td>
<td>Match the relative cost spent on treating kidney disease.</td>
</tr>
</tbody>
</table>
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). 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 CKD. Australians are at increased risk of CKD if they are:

- Are 60 years or older
- Are of Aboriginal or Torres Strait Islander origin
- Have diabetes
- Have a family history of kidney disease
- 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 billion, 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. 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).

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 the top cause of end stage kidney disease in Australia at 35%, while hypertension causes an additional 14% of cases.

Data from the Australian Bureau of Statistics (ABS)\(^12\) shows that kidney failure is a significant cause of death. In 2012, disease of the kidney and urinary tract were the 9\(^{th}\) leading cause of deaths in Australia, with 3,711 deaths\(^13\). This represents a 17\% increase in deaths from kidney disease since 2002 – it kills more people each year than breast cancer, prostate cancer,\(^14\) or even road deaths. Furthermore, the ABS statistics for multiple causes of death indicates that diseases of the kidney and urinary tract contributed as a ‘multiple cause’ to the deaths of 20,300 people in Australia in 2012 – a striking average of around 56 deaths per day.

The most recent data that is available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry\(^15\) shows that 2,544 people started kidney replacement therapy (dialysis or transplant) in 2013. The number of people on dialysis increased by 3\% from 2012 to 2013, resulting in 11,774 people receiving dialysis treatment at the end of 2013.

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 49\% of Australians on dialysis undertake haemodialysis at a satellite centre, 22\% at a hospital, and 29\% undertake dialysis at home (20\% peritoneal dialysis, 9\% home haemodialysis). 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, 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 the rate of new patients coming onto dialysis programs significantly lower than many of our international counterparts. In 2012 Australia ranked 37\(^{th}\) out of 48 countries in the incidence of people starting dialysis or transplant programs\(^16\).

\(^15\) ANZDATA. Australia and New Zealand Dialysis and Transplant Registry 2013 Interim Summary. 2014. www.anzdata.org.au
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 therefore provides below 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.
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.

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. 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 peoples.

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

---

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
increased levels of inadequate nutrition, alcohol abuse, streptococcal throat and skin infection and poor living conditions\textsuperscript{21, 22}.

**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 sustainable\textsuperscript{23}.

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 activity\textsuperscript{24}.

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 people\textsuperscript{25}.

**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 chronic kidney disease in Aboriginal and Torres Strait Islander communities:

1. **Development of a National Action Plan on Aboriginal and Torres Strait Islander chronic kidney disease**

The development of an overarching National Action Plan on Aboriginal and Torres Strait Islander chronic kidney disease, can wrap up a range of activities in chronic kidney disease and align with implementation of the *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* implementation and the update of the *Central Australian Renal Study*.

\begin{quote}
A National Action Plan on Indigenous Chronic Kidney Disease 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.
\end{quote}

\textsuperscript{21} KHA 2014a, *Kidney Fast Facts*
\textsuperscript{22} O’Dea 2005, *Preventable Chronic Diseases Among Indigenous Australians: The Need for a Comprehensive National Approach*
\textsuperscript{23} Department of Health & Ageing 2011, *Central Australian Renal Study: Executive Summary.*
\textsuperscript{25} Commonwealth of Australia 2013. *National Aboriginal and Torres Strait Islander Health Plan 2013-2023.*
2. Investing in chronic kidney disease 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.

Currently, nine in ten Aboriginal and Torres Strait Islanders do not know they have signs of CKD\textsuperscript{26}. The development of an educational resource for Aboriginal and Torres Strait Islanders and health professionals will increase awareness, early detection and self-management.

\textit{Transplant Story: A Personal Journey} is a 52 minute documentary that follows a real-life journey of an Indigenous family dealing with kidney disease. Ronno, is a young man who had a living donor transplant when he was a child which lasted 24 years. When his transplanted kidney began to fail, Ronno had to relocate for haemodialysis and is now on peritoneal dialysis waiting for a transplant. This film provides a unique opportunity to develop a high-quality, appropriate and easy to use educational resource for patients and health professionals.

Source: Menzies School of Health Research 2014

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 patients\textsuperscript{27}. 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.

\textit{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.

\textsuperscript{26} ABS 2014, \textit{Australian Aboriginal and Torres Strait Islander people Health Survey: Biomedical Results}

\textsuperscript{27} Stumpers & Thomson 2013, \textit{Review of kidney disease among Indigenous people}. 

A National Integrated Renal Pathway

The current National Chronic Disease Strategy, designed to provide an overarching framework of the national direction for improving chronic disease prevention and care across Australia, is now in need of revision. Agreed at the Australian Health Ministers’ Conference 2005, the Strategy represents a national agenda to encourage coordinated action in response to the growing impact of chronic disease on the health of Australians and to guide a response to the increasing burden on the health care system.

Kidney Health Australia welcomes the news that a new National Chronic Disease Strategy will be developed by the Commonwealth to replace the outdated Strategy. Kidney Health Australia remains committed to working with the project team to address kidney disease and related issues within it.

Stemming from a revised National Chronic Disease Strategy (the Strategy), Kidney Health Australia hereby argues that work should commence on the development of a National Integrated Renal Pathway, as a way of operationalising the Strategy 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 Integrated Renal Pathway 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 State based Renal Health Networks and the Australia and New Zealand Society of Nephrology 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 predicted tide of new cases 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 inefficient
- A marked variation by State in the uptake of home dialysis programs, 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 comparison
- A marked variation by State in the demographics being offered dialysis therapy

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.

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
- 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 2006

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 Integrated Renal Pathway focuses on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.*

A National Integrated Renal Pathway 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 Integrated Renal Pathway 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 Integrated Renal Pathway would be cost effective for government.

Framework for a National Integrated Renal Pathway would be:
- Evidence-based
- Patient-centred
- Cost-effective
- Able to be resourced and implemented
- Provide governance, including measuring, monitoring, reporting, and lead to quality improvement

**Components of the National Integrated Renal Pathway**

The National Integrated Renal Pathway 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 Integrated Renal Pathway would:

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

The development of a National Integrated Renal Pathway 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 National Integrated Renal Pathway 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 Integrated Renal Pathway would accomplish equity and improved outcomes for patients, with cost savings for government.
A New Integrated Health Check in Primary Care and Review of Cardiovascular disease risk guidelines

Many heart attacks and strokes can be prevented through routine cardiovascular ‘absolute risk’ assessments, conducted for eligible patients in general practice. These should be done as part of an ‘Integrated Health Check’, combining risk assessment for heart disease and stroke, a type 2 diabetes check and a kidney disease check. Although the Integrated Health Check is considered good clinical practice, it is not routinely done.

A major opportunity is being missed to detect people at risk of major chronic diseases and vascular events and keep them alive and well and out of hospital. The Australian Government is looking to create a quality-focussed Practice Incentive Payment (PIP) and it is hereby proposed that a quality PIP should include the Integrated Health Check and on-going management of those at high and moderate risk as a key component.

The case for change
Integrated Health Check in Primary Care

Well-established NHMRC approved-guidelines call for general practitioners to conduct assessments for eligible patients to detect those at risk of having a heart attack stroke or developing type 2 diabetes or CKD. Because these diseases often co-exist and share many risk factors, the NVDPA recommends that these assessments be done concurrently as part of an Integrated Health Check.

However, relatively few GPs routinely conducts these checks for eligible patients, therefore missing the opportunity to ensure people at high risk are managed to ensure they stay alive and well and out of hospital. 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, 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.

The Coalition’s Policy to Support Australia’s Health System: Australia’s health system is under increasing pressure from rising levels of chronic disease. We need a strong primary care workforce in order to provide better care and earlier interventions for people with complex and chronic health conditions. This is essential to improving the quality of life for patients, but will also alleviate demand on hospital services. Australia’s health system faces challenges due to demographic changes, increasing prevalence of chronic disease and the tyranny of distance faced by many rural and remote communities.

August 2013
Review of cardiovascular disease risk guidelines

Secondly, to support the Integrated Health Check, Kidney Health Australia, along with the National Vascular Disease Prevention Alliance call for a review of the cardiovascular risk guidelines. The NHMRC approved guidelines for the management of absolute cardiovascular disease risk (2012) support clinicians to assess risk of heart attack or stroke 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 within a specified period. This guideline, developed with the assistance of Australian Government funding, is a lynchpin to preventive initiatives to reduce the incidence of heart attack and stroke across Australia.

Each year, around 55,000 Australians suffer a heart attack (which equates to one heart attack every 10 minutes) and around 430,000 Australians are living with stroke. The extent of this pressing problem is illustrated by the following Australian statistics:

- Around 3.7m Australians had a long-term cardiovascular disease (2011-12)
- There were 44,006 deaths attributed to CVD in Australia in 2012
- CVD was responsible for more deaths than any other disease group (30% of the total)
- CVD was the main cause for more than 520,000 hospitalisations in 2011-12
- CVD has the highest level of health-care expenditure of any disease group
- Days of reduced activity for people with CVD were 1.4 times the average Australian
- Lower rates of employment and absenteeism due to CVD in 2004 were estimated to cost the economy around $2.2bn

Clinical recommendations that improve detection and underpin evidence-based medicine to reduce CVD events is 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 Australia28. Without updated evidence-based guidelines, patient care could be compromised, leading to increased hospitalisations, and a reduced workforce.

Budget Proposal for Consideration
Integrated Health Check in Primary Care

A new quality-focussed Practice Incentive Payment (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;

- 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.

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 CKD, type 2 diabetes, heart disease or stroke. The Integrated Health Check would link into already existing systems. For example, it would form an integral part of chronic disease management as an entrance point into the current Chronic Disease Management Plan mechanism.

This integrated approach to detection and prevention of vascular and related disease incorporates the recommendations of existing guidelines and policies of the National Health and Medical Research Council (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.

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;
- Improved quality systems in general practice through targets and audits to measure adherence to guidelines.

The inclusion of the Integrated Health Check in a quality-focussed PIP is supported by the National Vascular Disease Prevention Alliance, which comprises the Heart Foundation, National Stroke Foundation, Diabetes Australia and Kidney Health Australia.
Review of cardiovascular disease risk guidelines

Secondly, Kidney Health Australia, together with the National Vascular Disease Prevention Alliance, recommend an investment of $800,000 to review the current guidelines for the management of absolute CVD disease risk, developed according to NHMRC requirements.

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 CVD;
- equip clinicians with advanced risk assessment and management algorithms, supporting earlier detection and management of CVD risk;
- reduce the cardiovascular disease burden on the Australian healthcare system.

An investment of $800,000 to fully update the clinical recommendations over two years will help to establish and maintain the new online resource ensuring that health professionals are able to maintain a commitment to continuous professional quality improvement. 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.

Kidney Health Australia, along with the National Vascular Disease Prevention Alliance call for the inclusion of the integrated health check and on-going management of patients at risk as part of the development of a new, quality-focused Practice Incentive Program.

Kidney Health Australia, together with the National Vascular Disease Prevention Alliance, recommend an investment of $800,000 to review the current guidelines for the management of absolute CVD disease risk, developed according to NHMRC requirements.
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 adults\textsuperscript{29}. 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 it\textsuperscript{30}. 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 outcomes\textsuperscript{29}.

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 therapy\textsuperscript{31}. Furthermore, the AusHeart study recently concluded that CKD is common, significantly under-recognised and under-treated in primary care\textsuperscript{32}.

Kidney Health Australia has recently published the 3rd edition of its guidance booklet “Chronic Kidney Disease – Management in General Practice” to all practitioners in Australia\textsuperscript{33}, 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 opportunisticly 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 85-88% of all adults attend their GP each year, this approach has the potential to be both effective and affordable. Yet,

\textsuperscript{29} AIHW 2009. An overview of chronic kidney disease in Australia 2009. Cat no. PHE 111. Canberra: AIHW
\textsuperscript{31} Pilotto LS et al. Electronic records suggest sub-optimal management of CKD in general practice. Aust J Rural health 2012:20; 195-199
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 47% of all new people commencing dialysis in 2010 had diabetes (35% of the total had diabetes as the coded cause of their kidney failure). 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)\textsuperscript{34}.

**Budget Proposal for Consideration**

*A report has indicated that in rural general practice in Australia, there are significant shortfalls in the recording of eGFR and the recorded prescribing of appropriate kidney protective therapy.*

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.

![Graph showing diabetes as the likely growth factor in ESKD in the next decade](image)

By leveraging off the existing program, Kidney Health Australia proposes rolling out an education program to GPs, to be delivered over two years, commencing on 1 July 2015. 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 Medicare Locals 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 trialled 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 first proposal would involve the expansion 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 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 Chronic Kidney Disease 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.
An improved Live Organ Donor System in Australia

Live donor kidney transplantation (LDKT) peaked in 2008 when it accounted for 44% of the total transplant activity. The availability of a live donor also allows “pre-emptive” transplantation to occur without the requirement to go onto dialysis. This pre-emptive pathway is associated with the best clinical outcome and is the most cost-effective approach in the renal replacement pathway. LDKT is associated with an increase in patient survival of 27% at 20 years (over that observed with deceased donors).

The case for change
The work undertaken by the Australian Organ and Tissue Authority (AOTA) over the last 5 years has seen a substantial and sustained increase in the number of deceased donors being made available for kidney transplantation. Currently, despite having some of the highest success rates for organ transplantation in the world\textsuperscript{35}, Australia’s rate of deceased organ donation has failed to keep abreast with demand for transplantation\textsuperscript{36}. Indeed, the number of deceased organ donors will never meet the demand, no matter how efficient the retrieval process - therefore there is a need to increase the rates of kidney transplantation by increasing the number of living donors.

The increase in deceased donations has however not been accompanied by an increase in the total number of kidney transplant operations due to a co-incident 33% fall in the number of live kidney donors in the same time period. The reasons for the fall in the live donor numbers are not evident and were the subject of a review by the Australian Government in late 2013, and a series of recommendations have been developed, to which Kidney Health Australia has provided advice to Government on these. However, an announcement on the response to the recommendations is yet to be made.

The first 6 months of the scheme’s operation, July to December 2013 saw not only the reversal of the downward trend for the last five years, but a slight increase. Kidney Health Australia believes that this is, in part, a result of the introduction of the ‘Supporting Leave for Living Donors Scheme’ in July 2013, and our ongoing media, communication and education efforts. Kidney Health Australia believes that the 2014 live donor figures will indicate a further reversal of this trend and provide evidence that the scheme has had a positive effect on donor numbers, despite only having a very small financial investment and no significant education or communication program. Kidney Health Australia hereby argues that this is evidence of a well designed scheme, ready to be made ongoing.

However, there are a number of issues Kidney Health Australia believes can be considered as further ‘contributors’ to be undertaken to address the performance of live donation in this country. The rate of


uptake of live donor kidney transplantation varies significantly between units, regions and States in Australia. The reason for this variation (documented to vary tenfold between units) is not well studied but is believed to largely reflect the attitude of health professionals to live donor transplantation and the variable resourcing of units with staff such as a dedicated LDKT workup nurse. There is a significant deficiency in education and communication materials for both the medical profession and the community regarding live donation – a deficiency that becomes even starker when compared to the efforts put into deceased organ donation. While the issue of deceased organ donation is being handled through a dedicated agency (with extensive communication and education materials, a national register and a network of dedicated DonateLife staff), no such support exists in the area of live donation. Even the government’s ‘Supporting Leave for Live Donors’ Scheme is run by the Department of Health, not AOTA, and has no communication, awareness raising or education funding to support it – despite this being essential to its ongoing success.

The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) (together with its “sister” registry, the Australian and New Zealand Organ Donor Registry (ANZOD)) have the responsibility for reporting on the number and characteristics of live donor kidney operations. In contrast to the remit for ANZDATA/ANZOD to report on deceased donor activity on a monthly basis by the 2nd Monday of each month (thereby ensuring that all stakeholders can monitor performance effectively) there are no such requirements in the live donor area.

Budget Proposal for Consideration

Currently, despite having some of the highest success rates for organ transplantation in the world, Australia’s rate of deceased organ donation has failed to keep abreast with demand for transplantation. Live donation will for the foreseeable future be an essential component of broader organ donation efforts.

Firstly, Kidney Health Australia is of the view that Live Donation policy should be the responsibility of the Australian Organ and Tissue Authority (AOTA). The establishment of AOTA in 2009 and the consequent changes to deceased donor procurement centring on the organisation’s engagement with hospitals, the establishment of the DonateLife network, public communication, education, awareness, activities, events and engagement with civil society, including through the Advisory Council, has led to significant increases in the deceased donation rate.

In addition AOTA are responsible for the Australian Paired Kidney Exchange Program (AKX) ‘an initiative of the Organ and Tissue Authority to increase the options for living kidney donation’37 – a scheme which is clearly a living donor policy in action. However, this means there is a clear division and split within the way in which live donation policy is being administered and run in this country, with the Department of Health taking on a large part of the policy role and the leave scheme. By placing this aspect of organ donation under AOTA it would better align it with existing activities and therefore create an economical and efficient mechanism for moving this issue forward, by leveraging off all the work and structures already in place.

It is envisaged that AOTA would be charged with establishing standard clinical protocols (including guidance about clinical suitability of would be live donors), minimum performance criteria, education material for staff and patients and the responsibility for reporting the rate of, and the long term follow-up of, live donors.

The limited education and communication materials around live donation is in part driven by the absence of high quality education material that informs new or existing dialysis patients about LDKT in a positive, yet balanced manner. Noting the strong focus by AOTA on improved education, marketing and awareness activities for organ donation, it could be considered both economical and efficient to include information regarding live donation in current donation communication and donation efforts. Such channels exist to inform key target markets regarding donation, such as patients, carers, medical professionals, renal networks, clinics and the broader kidney network. Such a strategy could also leverage AOTA’s already existing presence at key organ donation related events, social media campaigns and online activity. Kidney Health Australia is currently developing high quality patient education material in the area of dialysis (through an Australian Government grant) and a similar initiative is needed in LDKT.

Secondly, Kidney Health Australia is of the view that there is a strong case for Australia to document the long term outcome of live kidney donation. Live kidney donation has generally been documented as a low risk, although recent overseas studies have highlighted that there may be some risks to the donor. The risk in the long term can be significantly impacted by the tendency in recent years in Australia to relax the live kidney donor acceptance criteria to include some donors with obesity, pre diabetes and hypertension. It is clear that living donation forms an essential part of broader Australian organ donation efforts, yet currently live kidney donor follow-up is not mandated - and in many areas is left in the hands of the primary care system.

Such an outcome could be improved through an expanded live kidney donor registry. Australia has a registry, established by ANZDATA in 2003 to accomplish the purpose of long term follow-up of Australian donors, and suggested annual follow-up data recording. Participation in this registry is on the basis of opting in with a formal consent process in place. However, the existing register contains no assessment of quality of life, it is not systematic, and experiences significant drop off in follow-up – the loss to follow-up percentage is over 70%. In short, it is both inadequate and incomplete.

Through mandating improved follow-up, the registry should take into account an assessment of the ‘quality of life’ of the donor over the long-term, post-surgery. This would also include bringing back remotely based donors for a central follow-up through providing a mechanism to pay the physician. Kidney Health Australia would suggest such follow up could be limited to a 5 yearly period, thereby not creating an excessive cost. Furthermore, by injecting a small amount of funds into the registry and a physician payment mechanism, it should also be possible to make a system that is physician independent – something critical to ensuring follow up over the longer term (20-30 years).

Thirdly, there is a need to address the issues surrounding surgical shortages and mismatched resources – stemming in part from the Federal / State divide between organ donation and transplantation. Kidney Health Australia has been made aware of direct reports from renal units where there have been issues in some jurisdictions of:

- A shortage of surgeons resulting in the need for interstate short term recruitment
- A shortfall in theatre allocation to LDKT, resulting in ‘gating’ the maximum number of operations
- A lack of dedicated LDKT workup nurses, resulting in delays and inefficiencies

Kidney Health Australia calls on the Australian Government to address this issue through an AHMAC driven process of review.
There is a need to bring live donation reporting up to the same level as we currently see for deceased reporting. As outlined above, live donation reporting is usually many months after the annual close of the database before any report is issued. This means that it is often 18 months behind in documenting monthly activity. This seriously impairs any timely analysis and the opportunity to address problems impacting live donation. Kidney Health Australia suggests that AOTA be required (as the funding body for ANZDATA/ANZOD) to be given responsibility for creating and monitoring reporting timelines. A modest increase in resources for these Registries would be required to allow additional staff time to be allocated to this process, but would remove the stark disparity between deceased and living organ donation reporting.

And finally, noting the success of the ‘Supporting Leave for Living Donors Scheme’ and the strong levels of uptake, the strong positive media it generated towards organ donation, it’s very limited cost compared to benefit, and the passionate community support it has gained, Kidney Health Australia calls on the Government to extend the Scheme beyond it’s two year pilot ending June 2015, and make the scheme ongoing.

In the first 18 months of operation (up until 31 December 2014), the Scheme has resulted in 191 people registering and 109 claims already being paid following surgery, which considering it is only available to those who are employed, is a considerable achievement for a policy in its infant/pilot period.

Furthermore, as experienced with AOTA and the drive to increase deceased donation, increased education and communication to the general public is critical. The Scheme has generated significant free media coverage of the option of live donation, and shone a light on the Government’s support for live donors. Key media coverage for the ‘Leave for Living Donors Leave Scheme’ in 2014 included the story of a Queensland family who had registered for the Scheme, as the father was taking time off of work to donate his kidney to his son. The family’s story and the concept of the Scheme received strong interest from Queensland metro media, as well as national outlets, with the highlights being a four-and-a-half minute segment on Sunrise and a near full-page run in the Courier Mail39, and additional coverage of similar stories was achieved in major metropolitan papers.

Therefore, and most importantly, we call on the Australian Government to consider extending the scheme from its current level of 6 weeks and minimum wage to 8 weeks and average weekly earnings. Finally, noting that the scheme relies upon awareness, we request a small amount of money be put aside for education, communication and awareness raising regarding the existence of paid leave for living donors. Even with these additions, the cost of the Scheme remains far below the levels of expenditure directed towards deceased organ donations. Furthermore and as per past submissions, we call on the Government to fund communication activities to support the live donor leave scheme, including the creation of an employer charter which could be signed by peak employee and business organisations.

39 Worth approximately $69,437 and $29,592 respectively in PR values.
Kidney Health Australia believes that in order to improve the live organ donor system in Australia the following policy responses should be considered:

- Live Donation policy, including the Supporting Leave for Live Donors become the responsibility of AOTA. This will allow:
  - Increased communication, awareness and education to be efficiently leveraged off existing, funded activity and networks, such as the DonateLife network;
  - Consistency in messaging and policy development, all aimed at improving the overall organ donation rate in Australia
- Addressing, in conjunction with the States to address clinical and resource constraints that currently impede live donations.
- An improved live donor registry to provide for regular, systematic follow-up of live donors to assess their quality of life, describe practice patterns of living kidney donation in Australia, describe the relationship between donor factors and recipient outcomes and monitor risks associated with kidney donation.
- Remove the significant delay that currently exists in live donation reporting and make it consistent to bring it more in line with deceased donation reporting, and therefore allow timely analysis and the opportunity to address any problems identified.
- Continuation of the Supporting Leave for Living Donors beyond the two year pilot period, with consideration given to extending the leave period, increasing the payment rates and providing some small funding to facilitate communication, education and awareness raisings.
Improved Access to Palliative Care Services

Joint Kidney Health Australia and Palliative Care Association proposal - Collaborative Web-based Education Resource

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.\(^{40}\)

Patients with CKD and ESKD experience an average of seven symptoms affecting their daily life.\(^{41}\) Symptoms can include itching, fatigue, depression, constipation, insomnia, nausea, vomiting, shortness of breath and pain.\(^{42}\) 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.\(^{43}\) Access to specialist palliative care services and information about palliative care in rural and remote communities is limited for both patients and health professionals.\(^{44}\) 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.

\(^{40}\) Australian Institute of Health and Welfare. “Palliative care services in Australia” HWI 123, Canberra: AIHW; 2013.
\(^{41}\) 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
\(^{42}\) Phipps, L. et al “Educational Needs in Supportive and End-of-life Care” *Nephrology*
\(^{43}\) 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
\(^{44}\) 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
PCA and Kidney Health Australia developed a joint position statement on palliative care and
CKD/ESKD\(^{45}\) 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, 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 site\(^{46}\) 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.

---


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

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.

Budget Proposal for Consideration

"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.