Tackling kidney disease

A national action plan to reduce Australia’s kidney disease burden

Reducing the kidney disease burden through:

☑ Smarter, earlier detection
☑ Increased organ donation
☑ A national approach to dialysis
☑ Supporting those who need it most

Living with signs of Kidney Disease

Number of people (percentage of population)
Check List for Change

- Efficient, effective early detection at the primary care level by introducing an Integrated Health Check and associated training and support
- Create a better system for living organ donation by funding the Organ and Tissue Authority to develop a national approach, and making the Supporting Leave for Living Organ Donors Programme permanent
- Tackle kidney disease in Indigenous Australians through prevention, treatment, education and governance, led by the establishment of a taskforce
- Create a national approach to kidney disease and dialysis, including better support for those who choose more cost effective dialysis modalities

Action Plan for Positive Change

Kidney Health Australia has developed this action plan to provide policy makers with ways to address the growing burden of kidney disease. These initiatives seek to improve the health of those at-risk or living with kidney disease, while delivering improved efficiency and effectiveness to an already burdened health system. Each is grounded in persuasive evidence that action is needed, and where there are clear potential benefits for people living with kidney disease. They are also informed by those living with kidney disease.

The priority initiatives identified in this proposal focus on improving health outcomes, removing barriers to care and are aimed at making savings to the national health budget through a reduced need for dialysis.

**Firstly**, it outlines practical, clear and achievable policy changes to reduce and delay the onset of end stage kidney disease through more efficient, effective early detection through a quality Practice Incentive Payment (PiP) and MBS item to enable the Integrated Health Check.

**Secondly**, this action plan supports a continued system for living organ donation, moving the Supporting Leave for Living Organ Donors Programme out of a bi-annual budget trial phase and made a permanent initiative, supported by funded communications. It calls for a national, funded approach to increase living donation, led by the Organ and Tissue Authority.

**Thirdly**, this action plan highlights to the need for a National Taskforce to advise how we can overcome barriers to tackling kidney disease in Aboriginal and Torres Strait Islander communities, while reiterating the need to adopt all the recommendations of our Kidney Health for All report.

**Finally**, Kidney Health Australia is calling for a national strategy for kidney disease, including a national approach to dialysis. It outlines how significant savings can be made to the health budget by better supporting home dialysis.

“This action plan presents a package of evidence-based and cost-effective interventions spanning improved early detection, living organ donation, hospital services and helping those most in need.”
The Rising Burden of Kidney Disease

Chronic Kidney Disease (CKD) is a major health problem and it is growing.

Kidney Health Australia estimates that 1 in 3 Australians are at an increased risk of developing CKD, with the risk being even higher in those most vulnerable in our community. Approximately 1.7 million Australians aged 18 years and over - a striking 1 in 10 – have at least one clinical sign of CKD, and the situation is much worse for ‘at risk groups’. Perhaps even more startling is that 1.5 million Australians are unaware they have clinical signs of CKD.

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

In 2012, the total costs attributable solely to CKD were estimated at $4.1 billion, made up of $2.5 billion in direct healthcare costs, $700 million in direct non-healthcare costs, and $900 in government subsidies. The cumulative cost of treating all current and new cases of end stage kidney disease from 2009 to 2020 is conservatively estimated to be between approximately $11.3 billion and $12.3 billion (in 2009 dollars). The most recent data from the Australian Bureau of Statistics (ABS) show that kidney disease is a significant cause of death. In 2014, diseases of the kidney and urinary tract were the 10th leading cause of deaths in Australia, with 3,136 deaths.

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1. **More efficient, effective early detection**

CKD is often regarded as a ‘silent’ killer, as up to 90% of kidney function can be lost before symptoms are evident. Data highlights that 10% of people attending general practice have CKD, but most do not know it.

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

Despite these facts, if CKD is detected early and managed appropriately, the risk of cardiovascular events can be controlled, and the rate of deterioration in kidney function can be reduced by as much as 50%, and in some cases reversed.

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

An Integrated Health Check should be included in the proposed quality-focused Pip, and an MBS item should be established to support its uptake. Such a move would also meet the recent recommendations of the Inquiry into Chronic Disease Prevention and Management in Primary Health Care and the Government’s draft National Strategic Framework for Chronic Conditions which outlines the need for integrated risk assessments.

Australia’s general practitioners also need to be supported in their efforts to detect kidney disease. That’s why Kidney Health Australia has also been providing education to primary care health professionals since 2001 through our Primary Care Education Program. This one of a kind, evidence-based program aims to educate health professionals on best-practice approaches for the detection and management of kidney disease and related chronic conditions such as diabetes and cardiovascular disease. To date, we have utilised limited funds to educate over 27,000 health professionals through over 1000 face to face workshops and online learning.

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4 Thomas MC, Weekes AJ. Type 2 diabetes from the GP’s perspective. Kidney Health Australia, Melbourne, Vic; 2007.
7 BEACH Report. 2011-12, p.7
In addition, Kidney Health Australia has developed the ‘Chronic Kidney Disease Management in General Practice’ handbook, a key resource on the management of chronic disease for General Practitioners and other primary care health professionals. Now in its 3rd edition, this handbook has been provided free-of-charge to every general practitioner in the country, with an additional 5,000 copies ordered by health professionals every year. In 2016 we have also released CKD-GO! – An app to complement the handbook that is available for both iPhone and android. The app provides easy access to individualised care plans.

However, the detection and management of CKD in general practice remains suboptimal. Further work is needed to integrate early detection and management of CKD into routine clinical care, including the funding of the above programs.

**What needs to be done?**

- **Better Detection:** Introduce a comprehensive Integrated Health Check for kidney disease, heart disease, stroke and diabetes in primary care.

- **Improved Education:** Expand the existing Primary Care Education Program to develop education resources for general practitioners, practice nurses and other health practitioners, to address the following areas of need:
  - **Support:** Support practice nurses and general practitioners through increasing confidence to utilise the latest clinical tools and action plans
  - **Provide Resources:** Provide resources to practice nurses to enhance their ability to detect and manage chronic diseases
  - **Address Identified Gaps:** Re-focus education materials to meet gaps in knowledge as identified in national GP survey
  - **Translation into Practice:** Support practices to overcome hurdles that prevent implementation of knowledge into practice.

**Causes of CKD**

- **Diabetes:** 37%
- **Glomerulonephritis:** 20%
- **Other:** 34%
- **Hypertension:** 13%
- **PKD:** 6%

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2. A better system for living organ donation

The work program by the Australian Organ and Tissue Authority (DonateLife) has seen a substantial and sustained increase in the number of deceased donors being made available for kidney transplantation. This change has however not been accompanied by an increase in the total number of kidney transplant operations, due to a 33% fall in the number of living kidney donors over the same time. While live donor kidney transplantation has existed in Australia from the earliest days of transplantation, it peaked in 2008 when it accounted for 44% of the total transplant activity. Since then the number of living donors has steadily fallen.

Living donor kidney transplantation is associated with an increase in patient survival of 27% at 20 years (over that observed with deceased donors), highlighting that it is a critical component of the wider push for increased organ donation in Australia.

Kidney Health Australia welcomes the announcement in the Federal Budget that the Supporting Leave for Living Organ Donors Programme will be supported with a communications campaign. However we call upon the major parties to fund the communications campaign, and to commit to making this important program ongoing – currently it is reliant upon two year funding cycles.

Kidney Health Australia also welcomes the recent moves to have the Australian Organ and Tissue Authority (AOTA) consider the issues regarding the drop in living donation. We note the ‘Review of the implementation of the national reform agenda on organ and tissue donation and transplantation’ includes the recommendation that “The number of living kidney donations should be reported and reviewed by the DonateLife Network and reported on the AOTA’s website”.

Kidney Health Australia urges all parties to fund AOTA to not just report living donor numbers, but to place the living organ donation agenda under their remit, and develop a national approach to increasing living organ donation rates. This 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.

Kidney Health Australia agrees with the statement in the budget that “the financial benefits of a successful kidney transplant are huge to the recipient, community and government – improving life expectancy and quality of life and reducing healthcare costs”, and for that reason call for an adequate increase in funding to AOTA to enable them to undertake this critical work.

17 Ernst & Young. Review of the implementation of the national reform agenda on organ and tissue donation and transplantation. Canberra, Australia; 2015
What needs to be done?

☐ **Consistent National Policy:** Living donation policy should become the responsibility of the Australian Organ and Tissue Authority (AOTA), to better align with existing organ donation activity, draw upon existing staff networks and link with current awareness and education campaigns. The AOTA should be funded in order to undertake this activity.

- **Improve the System:** Address the issues surrounding surgical shortages and mismatched resources by making living donation a priority
- **Fund Reporting:** Fund the ongoing work of the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and the Australian New Zealand Organ Donor Registry (ANZOD) to increase the timeliness of living organ donation reporting
- **Educate:** Fund an education program for potential live donors that provides a balanced account of the pathway, process and procedure.

☐ **Support Live Donors:** Make the *Supporting Leave for Living Organ Donors Programme* ongoing, and further support it with a fully funded communication and education campaign.
3. Tackling kidney disease in Indigenous communities

Nationally, an estimated 59,600 (1 in 5) Aboriginal and Torres Strait Islander adults are living with biomedical markers of CKD[^1]. Alarmingly, 90% of these Aboriginal and Torres Strait Islander people who have indicators of CKD are not aware they have the killer disease[^2].

The increased incidence of CKD in Aboriginal and Torres Strait Islander communities is multi-factorial. The high incidence of risk factors, increased levels of inadequate nutrition, alcohol abuse, streptococcal throat and skin infection and poor living conditions are contributing factors[^3]. These factors all contribute to diabetes and high blood pressure, which were the cause for 80% of those starting dialysis in 2014[^4].

Addressing these factors is complex and requires cross-portfolio government engagement and coordination. That’s why Kidney Health Australia is calling for a National Taskforce on Aboriginal and Torres Strait Islander Kidney Health to provide leadership, and policy suggestions regarding coordination with States & Territories to address the gaps in access and quality of health, housing, transport and support services.

Across Australia, there is variation in the clinical management of Aboriginal and Torres Strait Islanders with CKD. This contributes to sub-standard care and adverse health outcomes due to the complex nature of Indigenous disadvantage. There are no national clinical guidelines specific to the prevention, early detection and best-practice management of the full spectrum of CKD among Aboriginal and Torres Strait Islanders.

The Kidney Health Australia Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines group are seeking to develop new clinical guidelines for the “Management of CKD among Aboriginal and Torres Strait Islander Peoples and Māori”[^5] that will improve quality of health care and outcomes in these at-risk populations.

The Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 provides significant opportunities to improve the prevention, detection and management of CKD among Aboriginal and Torres Strait Islander people. Kidney Health Australia calls on all parties to commit to provide more national focus on the prevention and detection of CKD.

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[^1]: ABS. Customised report. 2015.
[^2]: ABS. Australian Aboriginal and Torres Strait Islander Health Survey: Biomedical Results, 2012-13. 2014. Report No.: 4727.0.55.003, Canberra.
What needs to be done?

- **National Taskforce**: A National Taskforce be convened by the Federal Government with the States and Territories to address the complex issues leading to the devastating impact of kidney disease in Aboriginal and Torres Strait Islanders. The Taskforce will provide strategic advice on interventions across the spectrum of awareness, prevention, detection, education, treatment and transplantation.

- **KHA-CARI Clinical Guidelines**: Fund the development of new national clinical guidelines for the “Management of CKD among Aboriginal and Torres Strait Islander Peoples and Māori” – that follow best practice and improve the quality of health care and outcomes.

- **NATSIHP Implementation Plan**: Federal Government to provide more national focus on the prevention and detection of CKD.
4. **National Kidney Disease Strategy and Home Dialysis Package**

With the development of a National Chronic Conditions Framework underway, Kidney Health Australia argues that it is now time to commence the development of a National Kidney Disease Strategy.

A National Kidney Disease Strategy would outline the necessary actions to improve 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. It would focus on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.

There are deeply entrenched variations 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

Secondly, there are immediate actions that such a strategy can put in place to better support, and increase, the rates of people who choose home dialysis.

Dialysis is the most common single reason for hospital care, and accounts for 1.3 million separations from public and private hospitals (13% of all hospital separations). This includes all types of dialysis – in hospital and at home.

Yet home dialysis is proven to be $30,000 per person a year cheaper than in hospital dialysis. And this saving does not include the fact that those on home dialysis may be able to return to work (due to being able to undertake nocturnal dialysis) and also experience a range of health benefits.

Yet we currently don’t invest in what is needed to encourage this cheaper and often better option.
Sadly, we have seen a decline in our home dialysis rates – from 38.4% in 2000 down to 30% now. We also have a wide variation in uptake across Australia – ranging from 13% to 36% across the States and Territories.

Kidney Health Australia therefore calls on government to fund four specific policy measures to solve these issues. We believe addressing these concerns could make a considerable difference to Australia’s national home dialysis outcomes.

Firstly, education and involvement in decision making at the point of deciding the type and modality is critical. Ensuring that all patients across the nation have the same education, on all the benefits and limitations of each type of dialysis is critical to changing the rates. The Federal Department of Health and Ageing has previously funded the development of this education package.

Secondly, for those considering home haemodialysis, there is a considerable training component required. This can be up to nine weeks for the patient, and up to three weeks for their carer (if they have one).

Thirdly, there is not national uniformity in allowing carers of those caring for home dialysis patients to access the carer payment and/or carer allowance.

Finally, patients who choose home dialysis are often significantly out of pocket, as a result of the cost of running their dialysis machine, which use a considerable amount of electricity and water. However, those who choose to undertake dialysis in a satellite or hospital setting are not required to pay these costs, as they are covered under the hospital funding provided by the Australian and State and Territory Governments.

What needs to be done?

☐ A National Kidney Disease Strategy: Such a strategy would leverage off the previous and ongoing jurisdictional activities, accomplish equity and improve clinical and psychosocial outcomes and provide cost savings for both federal and state governments.

☐ A National Home Dialysis Package: A National Home Dialysis package would work to increase home dialysis by removing all potential barriers to the uptake of home dialysis by:
  - **Education**: Funding and rolling out the ‘My Kidneys My Choice’ decision aid tool to better educate patients on home dialysis
  - **Training Support**: Provide paid leave for patients and their carers who take the required time off work to be trained in home dialysis
  - **Supporting Carers**: Address the eligibility criteria that currently leaves some carers for those undertaking home dialysis ineligible for much needed support
  - **Removing Financial Barriers**: Offset the costs of undertaking home dialysis, noting the significant cost benefit to both the Australian Government and State Governments of home dialysis.

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