

# **National Strategic Action Plan for Kidney Disease**

April 2019

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We acknowledge Traditional Owners of Country throughout Australia and recognise the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders both past and present.

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## Contents

Acknowledgements	4
Abbreviations	5
Overview	6
About this Action Plan	9
Kidney Disease	13
Australian Situation	16
In the Words of the Kidney Community	18
Priority Area One - Prevention, Early Detection and Education	19
Priority Action Two - Optimal Care and Support	25
Priority Action Three - Research and Data	31
Achieving Progress	34
References	35

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The Action Plan was managed and written by Dr Emma Tinning, Dr Lisa Murphy, Dr Marie Ludlow and A/Prof Shilpa Jesudason of Kidney Health Australia.

### Advisory Group

The Advisory Group was convened to provide guidance on all aspects of the Action Plan. The Advisory Group members comprised: Karen Booth (President Australian Primary Health Care Nurses Association), Fiona Donnelly (President Renal Society Australasia), Chris Forbes (CEO Kidney Health Australia), Prof Kirsten Howard (Health Economist), A/Prof Shilpa Jesudason (Advisory Group Chair, Clinical Director Kidney Health Australia, Nephrologist), Prof David Johnson (Nephrologist), Prof Peter Kerr (Nephrologist), A/Prof Duncan Mortimer (Health Economist), David Parker (Consumer, Kidney Health Australia Board Member), Prof Carol Pollock (Kidney Health Australia Board Chair, Nephrologist) and Prof Tim Usherwood (General Practitioner).

### Expert Organisations

Australian Genomics Health Alliance  
Australia and New Zealand Dialysis and Transplant Registry  
Australia and New Zealand Society of Nephrology  
Australian Primary Health Care Nurses Association  
Deloitte  
Diabetes Australia  
The George Institute for Global Health  
The Heart Foundation  
KidGen  
Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group  
Kidney Health Australia Consumer Council

Menzies School of Health Research  
National Aboriginal Community Controlled Health Organisation  
PKD Foundation of Australia  
Primary Care Education Advisory Committee for Kidney Health Australia  
Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation)  
Renal Society of Australasia  
State Primary Health Networks  
The Stroke Foundation  
The Organ and Tissue Authority  
Transplantation Society of Australia and New Zealand

### Australian Government Department of Health

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## Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
ANZSN	Australian and New Zealand Society of Nephrology
ATSI	Aboriginal and Torres Strait Islander
CKD	chronic kidney disease
CVD	cardiovascular disease
ESKD	end-stage kidney disease
eGFR	estimated glomerular filtration rate
HD	haemodialysis
KHA	Kidney Health Australia
KHA-CARI	Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group
MBS	Medicare Benefits Schedule
NACCHO	National Aboriginal Community Controlled Health Organisation
NRHA	National Rural Health Alliance
OTA	Organ and Tissue Authority
PBS	Pharmaceutical Benefits Scheme
PD	peritoneal dialysis
POCT	point of care testing
PKD	polycystic kidney disease
RRT	renal replacement therapy
TSANZ	Transplant Society of Australia and New Zealand

## Overview

### VISION

*To prevent kidney disease, ensure optimal care for those affected by kidney disease and maximise outcomes from research - through collaboration, integration and equity.*

### Priority Areas

1. Prevention, Detection and Education
2. Optimal care and Support
3. Research and Data

**Australia is facing a kidney disease crisis – one in three adults are at risk of chronic kidney disease, one in ten have early signs of disease and more than 1.5 million have no idea that they have chronic kidney disease.**

Chronic kidney disease (CKD) contributes to over 17,000 deaths a year, more than breast cancer, prostate cancer and road deaths combined. CKD disproportionately affects the most vulnerable in our society, taking a devastating toll on Aboriginal and Torres Strait Islander communities. In addition, CKD costs the economy more than \$5 billion a year.

While early CKD is largely symptom free, end stage kidney disease (ESKD) is life altering. Without treatment, ESKD is incompatible with life. The options for treatment are dialysis therapy, transplantation or supportive (palliative) care - but each of these presents an enormous physical and psychosocial burden to patients and their families and carers. Dialysis requires daily or three times a week treatment, and does not completely remove the many debilitating symptoms of kidney failure. Transplantation is life-changing, but is an option only for some and transplant medications have significant side-effects, including severe infection and cancer. Those with ESKD often speak of loss – of identity, independence, jobs, relationships, travel opportunities, financial security and optimism about the future. People acting as carers for their loved ones with ESKD describe being nurse, taxi driver, social worker and therapist in addition to husband or wife, son or daughter, mother or father, sister, brother, partner or friend. CKD affects not just the patient and their family but often their community as well. Having kidney disease is a long journey with constant and challenging requirements for education, support and navigation through health systems.

Yet CKD is largely preventable, and progression towards end stage disease can be slowed or even halted with early detection and good management. Better management at all stages of the disease has the capacity to improve lives and reduce the enormous burden of CKD on Australia.

The Action Plan for Kidney Disease recognises the vital importance of preventing CKD, as well as the need for better detection, treatment and management for those living with the disease. It also includes actions that provide much needed support for those with CKD, their carers and families, and proposes a research agenda to support prevention, treatment and ultimately find a cure for CKD. The strategy includes three **Priority Areas** with nine corresponding **Objectives** and thirty-four individual **Action Items** for implementation by the Commonwealth, State and Territories, the healthcare and research sectors and chronic disease and consumer peak bodies.

## Priority Areas and Objectives

### Prevention Detection and Education

Develop a nationally coordinated approach to increase the effectiveness of chronic disease in Australia.

Increase early detection and management to slow disease progression and empower people to self-manage their conditions.

Raise community and health professional awareness and understanding of CKD and other chronic diseases.

### Optimal Care and Support

Deliver high quality, equitable kidney care across Australia.

Reduce the financial impact of kidney disease on patients, carers and families.

Improve support for people affected by chronic kidney disease.

Reduce the disproportionate burden of kidney disease on Indigenous communities.

### Research and Data

Establish an MRFF funded collaborative kidney research mission to increase strategic research investment, foster cross collaboration and translate cutting edge research into real world outcomes.

Use data, evidence and research to drive improvements in chronic kidney disease prevention, treatment and outcomes.

## Partnerships

Key to the success of The Action Plan is the integration and expansion of successful established services and the integration and collaboration of government and non-government organisations. The effective prevention and management of chronic conditions is strongly influenced by the contributions made by a wide range of Partners. These Partners include:

- individuals, carers and families;
- communities;
- all levels of government;
- non-government organisations;
- the public and private health sectors, including all health care providers and private health insurers;
- industry; and
- researchers and academics.

All Partners have shared responsibility for health outcomes according to their role and capacity within the health care system. Greater cooperation between Partners will lead to more successful individual and system outcomes. Actions included in this Action Plan are intended to guide Partner investment in the prevention and management of kidney disease and should be implemented collaboratively to achieve the best health outcomes.

### Expected outcomes

1. A more effective, national approach to chronic disease prevention targeting the primary causes of chronic disease, ultimately resulting in reduced prevalence of CKD.
2. Widespread awareness and understanding of CKD leading to increased early detection and effective management within primary care.
3. Increased equity of access to and outcomes from comprehensive, culturally appropriate high quality care during all stages of CKD.
4. Improved quality of life and health outcomes for people affected by CKD.
5. Reduced economic burden through reduced disease burden and prevalence.
6. A focused, targeted kidney research program leading to continuous improvements in prevention and treatment and the search for a cure.

## About this Action Plan

The Commonwealth Government tasked Kidney Health Australia with developing the country's first National Strategic Action Plan for Kidney Disease in recognition of the significant and growing impact of kidney disease on the health and wellbeing Australians as well as the economic impact on society.

The plan articulates a national vision for preventing CKD and improving the lives of those affected by CKD, underpinned by the effective use of research, evidence and data. The intended audiences for the Action Plan include the Australian and state and territory governments, health service providers and funders, clinicians, consumers, researchers and research funders. Achieving the plan's vision will require coordinated national action and partnerships across all levels of government and the health system, non-government organisations, the private sector, researchers and academics, and people affected by CKD.

The Action Plan aligns with the 2017 National Strategic Framework for Chronic Conditions<sup>1</sup> (The Framework), with its emphasis on prevention, efficient, effective and appropriate care and support and targeting priority populations. The Action Plan reflects the Framework's guiding Principles to enable the successful prevention and management of CKD in Australia, and specific Enablers for successfully achieving the Vision of the Action Plan.

This action plan is the product of three key major pieces of work, details of which are provided separately.

- Extensive consultation with and survey of the Australian kidney community – including people with kidney disease and their carers and family, health professionals, researchers, government representatives and policy makers, non-government organisations (Consultation Summary)
- A thorough review of the current landscape of Australian kidney health care services and resources, details of which are summarised in the compendium – (Services and Resources Summary).
- A review of current evidence, policies and strategies to guide and support the recommended priorities and actions. - Evidence-base Summary.

Australia has a passionate and invested kidney community eager for change, demonstrated by the overwhelming response to our stakeholder survey and consultation process. Their generous participation has resulted in actions that are a true reflection of the wishes of the kidney community.

### Addressing the impact of CKD in Indigenous communities

Reflecting the significant burden of kidney disease in Aboriginal and Torres Strait communities, the Action Plan includes a focus on addressing the inequalities in CKD, in particular the disproportionate burden of kidney disease in Aboriginal and Torres Strait people. Relevant actions draw on a number of noteworthy reviews in relation to Aboriginal and Torres Strait kidney health. These include:

- Minister Wyatt's Road Map for Indigenous Kidney Health
- the TSANZ Performance Report – Improving Indigenous Transplant Outcomes
- the Department of Health Organ Donation Retrieval and Transplantation Review
- KHA-CARI Indigenous Guidelines Community Consultation

The Action Plan does not attempt to encompass every recommendation in each of these important reports. Instead the plan includes a number of key recommendations relating to the implementation of these reports. These recommended actions can be found in Objective 2.4 *Reducing the*

*disproportionate burden of kidney disease in Indigenous communities.* Additional actions relating to Aboriginal and Torres Strait Islander people kidney health are also included in each of the priority areas throughout the Action Plan.

A strong overarching recommendation is that Aboriginal and Torres Strait Islander people are involved in:

- Setting and formulating policy affecting their communities
- Developing and implementing locally relevant programs
- Health care service delivery in the community

Finally, the importance of cultural continuity to the wellbeing of Aboriginal and Torres Strait Islander people must be forefront in all proposed actions.

### Organ donation and transplantation

Kidney transplantation is an important treatment option for ESKD and this Action Plan acknowledges the value and importance of organ donation and transplantation to the kidney community. The development of this Action Plan coincides with a major review by the Organ and Tissue Authority (OTA). While the findings of the report are not yet available, OTA have indicated that major changes to the deceased donation system, such as moving to an opt out approach, will not be a priority. Acknowledging this advice, the strategy includes actions relating to:

- Facilitating living donation
- The development of optimal care pathways for transplant (and living donation) to improve access to and outcomes from transplants
- Recommendations related to the TSANZ Performance Report – Improving Indigenous Transplant Outcomes.

## Action Plan Summary Table - Priorities, Objectives and Actions

<b>Priority 1. Prevention, Detection and Education</b>	
<b>1.1. Develop a nationally coordinated approach to increase the effectiveness of chronic disease prevention in Australia</b>	
1.1.1	Establish a national agency responsible overseeing chronic disease prevention in Australia.
1.1.2	Promote healthier eating, including reducing consumption of salt and sugar.
1.1.3	Address barriers to physical activity.
1.1.4	Build on and strengthen tobacco control initiatives to reduce smoking in the community.
1.1.5	Focus on primordial prevention.
<b>1.2. Increase early detection and management to slow disease progression and empower people to self-manage their conditions</b>	
1.2.1	Increase early chronic disease risk assessment in primary care for better identification of people at risk of chronic disease.
1.2.2	Increase uptake and effectiveness of primary care health assessments (Integrated Health check) and care planning.
1.2.3	Prevent onset and slow the progression of CKD through better access to lifestyle modification programs.
1.2.4	Provide easier, nationally consistent access to genetic counselling and testing to enable earlier detection and treatment of inherited kidney disease.
<b>1.3. Raise community and health professional awareness and understanding of CKD and other chronic diseases to support prevention and early detection</b>	
1.3.1	Improve chronic disease health literacy through nationwide, targeted awareness and education programs.
1.3.2	Raise community awareness and understanding of the function of kidneys, CKD risk factors and consequences.
1.3.3	Provide primary care education and training to encourage best practice for CKD risk assessment detection and management.
<b>Priority 2. Optimal Care and Support</b>	
<b>2.1. Deliver high quality, equitable kidney care across Australia</b>	
2.1.1	Establish nationally standardised care pathways to ensure all people receive high value care, irrespective of where they live.
2.1.2	Map current and future resource needs to improve equity of access to kidney care nationally.
2.1.3	Improve CKD care in rural and remote Australia.
2.1.4	Increase equity of access to transplant and equity of transplant outcomes.
2.1.5	Increase living donor transplantation.
2.1.6	Provide national access to multi-disciplinary renal genetics clinics.
<b>2.2. Reduce the financial impact of kidney disease on patients, carers and families</b>	
2.2.1	Reduce the out of pocket costs of home dialysis by addressing the national variation in utility subsidies for home dialysis as well as simplifying the processes for obtaining subsidies.
2.2.2	Reduce transport costs for both long distance travel to specialist care and for regular travel for treatment.
2.2.3	Better access to the Commonwealth funded carer allowance for carers of patients with end-stage kidney disease.
2.2.4	Increase access to government support for people with end-stage kidney disease.
2.2.5	Make it easier for people with kidney disease to remain in or enter the workforce by providing education resources for employers and colleagues and the implementation of an employer bonus.
<b>2.3. Improve support for people affected by chronic kidney disease</b>	
2.3.1	Increase the availability of health, wellbeing and psychosocial support for people with CKD, carers and families.
2.3.2	Create peer support networks (virtual and face to face) across Australia for people affected by kidney disease.
2.3.3	Introduce a national approach to travel dialysis to make it easier for people on dialysis to travel.
<b>2.4. Reduce the disproportionate burden of kidney disease on Indigenous communities</b>	
2.4.1	Implement the <i>Renal Roadmap for Indigenous Health</i> .
2.4.2	Implement the TSANZ <i>Improving access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander People in Australia</i> report.

### Priority 3. Research and data

#### 3.1. Establish an MRFF funded collaborative kidney research mission to increase strategic research investment, foster cross collaboration and translate cutting edge research into real world outcomes

- |       |  |
|-------|--|
| 3.1.1 | Establish a Kidney Research Collaborative to develop and implement a kidney research strategy with targeted priorities.      |
| 3.1.2 | Invest in high quality research focused on improving disease prevention and management and the search for a cure.            |
| 3.2.3 | Establish a Kidney Consumer Hub to facilitate joint research priority setting and enable consumer driven, targeted research. |

#### 3.2. Use data, evidence and research to drive improvements in chronic kidney disease prevention, treatment and outcomes

- |       |   |
|-------|---|
| 3.2.1 | Implement nationally consistent data collection at all points of care to support ongoing improvements in kidney disease prevention, detection and management. |
| 3.2.2 | Roll out an improved Australian Health Survey (AHS) in conjunction with Australian Bureau of Statistics.  |
| 3.2.3 | Translate research into practice through the strengthening of clinical guidelines and implementation of living guidelines.                                    |

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# Kidney Disease

## Functions of the kidneys

Kidneys are the unsung heroes of the body. They have a vital role in keeping the body healthy and getting rid of body wastes. Most people have two kidneys, each with over 1 million tiny filters called nephrons that clean the blood removing wastes and toxins. Excess water is added to other wastes to make urine and control water balance in the body. The kidneys have a number of other less well-known functions that are central to our health. Kidneys produce hormones that control blood pressure, they make a hormone called erythropoietin that is essential for red blood cell production and they activate vitamin D, which is essential for strong bones and muscle.

## Definition of chronic kidney disease

CKD refers to all kidney conditions where a person has evidence of **kidney damage** and/or **reduced kidney function** that lasts for 3 months.

**Kidney damage** is evidenced by one or more of: albuminuria (protein in the urine), haematuria (blood in the urine) after exclusion of urological causes, structural abnormalities (e.g. on kidney imaging tests) or pathological abnormalities (e.g. renal biopsy).

Kidney function is measured by estimated or measured glomerular filtration rate (GFR) which measures how well the kidneys filter wastes from the blood. **Reduced kidney function** is defined as an estimated or measured glomerular filtration rate (GFR)  $< 60\text{mL}/\text{min}/1.73\text{m}^2$ .

## Types of CKD

There are many different types of kidney disease. Currently the most common cause of CKD is diabetes. Diabetes accounts for 36% of all new cases of ESKD, compared with 17% in 1994. The other common causes of ESKD include glomerulonephritis (inflammation of the kidney, 18%) and hypertension (high blood pressure, 14%). The most common genetic cause of kidney disease is Polycystic Kidney Disease accounting for 6% of all new cases of ESKD.<sup>2</sup>

## Risk factors for CKD

1 in 3 Australians are at risk of developing CKD.<sup>3</sup> Adult Australians are at an increased risk of chronic kidney disease if they:

- are obese with a body mass index (BMI) 30 or higher
- have diabetes
- have high blood pressure
- have established heart problems (heart failure or heart attack) or have had a stroke
- have a family history of kidney failure
- are a smoker
- are 60 years or older
- are of Aboriginal or Torres Strait Islander origin
- have a history of acute kidney injury.

While some risk factors such as age, family history and racial background cannot be changed, risk factors such as tobacco smoking, overweight and obesity, high blood pressure and diabetes can be modified or well

managed, reducing the risk of CKD. Many of the risk factors for CKD also apply to other chronic diseases such as CVD (including CHD and stroke) and diabetes, which in turn, are risk factors for CKD.

### Stages of CKD

CKD comprises five recognised stages. Stage 1 is the mildest form, gradually progressing through to stage 5 also known as end stage kidney disease (ESKD).<sup>4</sup> ESKD is incompatible with life unless renal replacement therapy (RRT) with dialysis or a transplant is undertaken. The five stages of CKD with associated management are outlined in Table 2.

**Table 2: The Five Stages of CKD**

The Five Stages of CKD					
Stage	Description	eGFR	Kidney Function Deterioration	Interventions and Treatment	Symptoms
1	Kidney damage (protein in urine) and normal GFR	> 90	50% - 60%	-Weight reduction if overweight/obese -Balanced and adequate diet -Physical exercise	None
2	Kidney damage and mild decrease in GFR	60 – 89	60% - 70%	-Smoking cessation -Hypertension management -Diabetes management	None
3	Moderate decrease in GFR	30 – 59	70% - 77.5%	-Medications to reduce urine protein leak	Symptoms unlikely
4	Severe decrease in GFR	15 – 29	77.5% - 85%	As above plus: -Preparation for ESKD -Symptom management -Management of Anaemia	More likely
5	Kidney failure, ESKD	< 15 or on dialysis	≥ 85%	As above plus: -Transplant -Dialysis (Peritoneal Dialysis or Haemodialysis) -Supportive Care	Likely

### Symptoms

Kidney disease is a largely asymptomatic condition and up to 90% of kidney function can be lost before symptoms are evident. Symptoms appear very late in the disease course; a person with stage 4 kidney disease may not have any symptoms.

When symptoms do occur they include: oedema (swelling), fatigue, foamy dark urine, difficulty concentrating, tingling of fingers and toes, decreased appetite, sleep problems, severe fatigue and weakness, easy bruising and bleeding, anaemia, thirst, skin colour change, nausea and vomiting, and little or no urine.

### Complications

There are many serious complications of CKD these include hypertension, osteodystrophy, anaemia, sleep apnoea, cardiovascular disease, hyperlipidaemia, hyperparathyroidism and malnutrition. Many of these complications are already evident at an early stage of the disease.<sup>5</sup>

### The triad of chronic kidney disease, cardiovascular disease and diabetes

More than half of people living with CKD also have CVD and/or diabetes.<sup>6</sup> CKD, CVD and diabetes are inextricably linked. They have similar underlying causes and features and share common risk factors. These diseases have a complex relationship and each may be associated with, or exacerbate the presence of, the others. CKD independently increases the risk of hypertension and other cardiovascular events, including heart attack, angina, coronary artery disease, stroke and heart failure.<sup>7</sup> A person with CKD is more predisposed to develop premature cardiovascular disease and is more likely to die from a heart attack or stroke than they are to progress to ESKD requiring dialysis or transplant.<sup>8</sup>

## Management

Interventions to avoid or reduce the impact of kidney disease are targeted at all stages. However, the earlier in the disease course interventions are instigated, the greater the outcome. If CKD is detected, early effective management can not only slow or even halt the progression of the disease but also reduce the damage from complications.<sup>5</sup> Early detection with active risk assessment and health checks is therefore crucial in limiting the impact of CKD.

### Under-diagnosis of CKD a serious issue

- The proportion of people with CKD remaining undiagnosed by primary care physicians is as high as 50%, despite the automated reporting of estimated GFR, which was introduced to improve early detection of CKD.
- Among people reaching ESKD, a quarter present to a nephrologist so late they require dialysis within 90 days, missing the chance to slow disease progression.

Chen, Titi, and David C. Harris. "Challenges of chronic kidney disease prevention." *The Medical Journal of Australia* 203.5 (2015): 209-210.

In late stages kidney function is severely reduced, requiring symptom control and intensive intervention in preparation for Stage 5.<sup>4</sup> ESKD is incompatible with life unless renal replacement therapy (RRT) is undertaken. RRT has two forms—kidney transplant or dialysis. Dialysis is an artificial way of removing waste substances from the blood and is provided in hospitals, satellite dialysis units, and can also be provided in a home setting. Neither of these treatments completely restores health, and patients remain at risk of health problems and increased mortality. The burden of dialysis is overwhelming - no other disease has a life sustaining treatment that patients actively participate in for years. It is constant and relentless. Whilst transplantation is an effective treatment for ESKD it is not a cure. Powerful medications that can have serious and deadly side effects, including increased risks of some forms of cancer, need to be taken regularly and indefinitely to avoid organ rejection.

Not all patients with ESKD receive RRT. Non-RRT medical management of ESKD, also known as supportive care, is a treatment choice that involves ongoing active therapy to minimise the symptoms of kidney failure, without using RRT. Patients who choose a pathway without dialysis or transplantation often live with a large symptom burden and increasing frailty, ultimately requiring palliative care.

## Australian situation

### Burden of chronic kidney disease

1 in 3 are at risk of developing CKD<sup>3</sup> and over 1.7 million Australian adults – a striking 1 in 10 - are currently living with biomedical markers of CKD<sup>9</sup>. However less than 10% of people with CKD know they have the condition<sup>10</sup>, meaning there are over 1.5 million Australians who are unaware that they are living with indicators of CKD. Annually, at least 160,000 Australian adults will develop CKD.<sup>11</sup>

### Burden of end-stage kidney disease

In 2013, there were around 5,100 new cases of ESKD in Australia, including those on RRT and those undertaking non-RRT treated care.<sup>12</sup> At the end of 2017 there were 24,738 people receiving RTT (dialysis or a kidney transplant) for ESKD, with 3,056 people commencing RRT in 2017.<sup>2</sup> Projections forecast the number of people on RRT is expected to rise by 60 per cent between 2011 and 2020 (19,780 patients in 2011 to 31,589 in 2020), over four times the projected growth in the Australian population overall.<sup>13</sup> At the beginning of 2017 there were 952 people on the kidney transplant waiting list.<sup>2</sup>

### Morbidity and mortality

CKD contributed to 11% of all deaths in 2015, that is around 17,000 deaths, CKD was the underlying cause of death in around 4,300 deaths, and an associated cause of death in a further 12,800 deaths.<sup>12</sup> For people who do receive a transplant or go on to dialysis, the survival rate at five years is worse than most common cancers<sup>14</sup>. (Hutchison AJ, 2011).

### CKD in Aboriginal and Torres Strait Islander peoples

The burden of CKD disproportionately affects Aboriginal and Torres Strait Islander people. An estimated 1 in 5 (18%) Indigenous adults (59,600 people) are living with biomedical markers of CKD.<sup>15</sup> After taking age differences into account, Indigenous people are three times as likely as their non-Indigenous counterparts to have indicators of Stage 1 CKD and more than four times as likely to have Stages 4–5.<sup>15</sup> Indigenous adults living in remote areas are more than twice as likely as those in non-remote areas to have signs of CKD (34 per cent compared with 13 per cent).<sup>15,16</sup>

Aboriginal and Torres Strait Islander people progress to ESKD around 30 years earlier than non-Indigenous people.<sup>17</sup> The rate of treated-ESKD among Aboriginal and Torres Strait Islander people is around 6 times the non-Indigenous rate,<sup>2</sup> a disparity that increases with remoteness.

There are significant and persistent disparities in transplant access and outcomes for Indigenous and non-Indigenous Australians. In 2017, there were 2,161 Indigenous Australians registered for RRT. Of these, 87% were reliant on dialysis and 13% had received a kidney transplant.<sup>2</sup> In comparison, 49% of non-Indigenous Australians with ESKD were reliant on dialysis and 51% had received a kidney transplant.<sup>2</sup>

For those who are fortunate enough to receive a kidney transplant, this disparity persists, with Indigenous kidney transplant recipients experiencing significantly worse post-transplant outcomes compared to non-Indigenous recipients.

ESKD is a significant contributor to Indigenous mortality, contributing to 16% of Indigenous deaths between 2008 and 2012<sup>16</sup> and accounting for 5% of the total disparity between indigenous and non-indigenous mortality rates.<sup>6</sup>

### Hospitalisations

Of the 10.6 million admissions to hospitals in 2015-16 there were approximately 1.7 million hospitalisations (16% of all hospitalisations) where CKD was recorded as the principal and/or additional diagnosis.<sup>12</sup> Dialysis was the most common reason for hospitalisation in Australia in 2015-16, accounting for 1.4 million

hospitalisations for CKD as the principal diagnosis (13% of all hospitalisations).<sup>12</sup> The number of hospitalisations for CKD more than doubled between 2005-06 and 2015-16, with CKD as the principal diagnosis (excluding regular dialysis) increasing by 51% and regular dialysis by 58%.<sup>12</sup> Aboriginal and Torres Strait Islander peoples are admitted to hospital for dialysis at 12 times the rate for other Australians.<sup>12</sup>

### Cost

People with CKD incur 85 per cent higher healthcare costs and 50 per cent higher government subsidies than individuals without CKD. Even early stage CKD is associated with a 50 per cent increase in direct costs, with more advanced stages associated with a sixfold increase in expenditure.<sup>18</sup> In 2012, the total costs attributable solely to pre-end-stage kidney disease 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 million in government subsidies.<sup>18</sup> In Australia, dialysis and transplantation for ESKD are estimated to cost over \$1 billion each year.<sup>19</sup>

#### **CKD is one of Australia's most expensive diseases and these costs are growing**

Modelling predicts that between 2012-2020, per-patient, CKD produces a considerably greater financial impact on Australia's healthcare system, compared to CVD. This includes:

- prevalence increasing by 29 percent, compared to 7 percent in CVD
- RRT prevalence increasing by 29%, compared to 7% in CVD treatment
- Total CKD expenditure increasing to increasing by 37%, compared to 14% in CVD expenditure

A 2013 Australian study found the high unavoidable out of pocket costs for treating CKD have severe consequences for people with low financial resources, with:

- 13% of participants going without meals
- 11% unable to heat their homes
- 12% increased the amount owing on their credit cards by greater than \$AUD1000
- 19% missing medical appointments or failing to fill prescriptions because they were short of money.

Tucker, Patrick S., et al. "The increasing financial impact of chronic kidney disease in Australia." *International journal of nephrology* 2014 (2014).

## In the Words of the Kidney Community...

“The initiative I would most like to see in the Action Plan is better support and information provided to the carers. They work tirelessly seven days a week. They endure some terrible sights and watch their loved ones suffer everyday with this debilitating disease. They take us to appointments, hospital admissions, wait outside operating suites to the wee hours of the night. Why; because they suffer emotionally and mentally with no support. I know first-hand how hard it’s for the carer and how they suffer. They need support, some relief.”

“When I was finally diagnosed, I thought the renal specialist had got the wrong patient. I wish. I had no idea my kidneys had failed. And I was a fit and educated person who knew much about the body, but nothing about the kidneys and heart relationship. Please educate the public more broadly, especially children. It should be part of a lifelong health strategy.”

“From my 30 years’ experience in Indigenous renal health, the majority (of people) want to know why they have it, how they got it and how to prevent going onto the machine. The Indigenous health workers want to understand so they can better help their people. Indigenous communities, given the chance, will often have the solution.”

“Mental health... Patients feel very alone and not heard. They should be treated like cancer patients as they are on a life support machine!”

“(We need to) try to prolong patients’ time before commencing dialysis. I had a very good specialist and through good management, diet, etc, was able to last 20 years from diagnosis to dialysis and my kidney (function) was about 50% or less when I was diagnosed”

Basically ... make KIDNEY DISEASE as scary to society as Cancer is portrayed. Awareness that this disease can happen to you at any time, for any reason MUST be conveyed. There are a lot of misconceptions about the disease that need addressing

“It is difficult to manage home haemodialysis without support. As a fulltime carer (I need) greater social security benefits, as I have had to sacrifice working, superannuation and work cover protections to care. Financial hardship has resulted in not being able to afford adequate dental due to lack of funds. While it is a privilege to be my husband’s caregiver I face a future of poverty.”

“If you have kidney disease your life spirals into depression and 3 times a week going back and forth for hospital visits which impacts the whole family. More services need to be given for patient and carer and family psychology services.”

# Priority One – Prevention Detection and Education

## What we hope to achieve

- A comprehensive, nationally coordinated approach to chronic disease prevention resulting in more effective prevention funding and programs.
- Improved community and health professional chronic disease/CKD awareness, understanding of risk factors, prevention and disease management.
- Earlier detection and improved management of CKD, slowing disease progression and empowering people to self-manage their condition.

## Why is this important?

Australia's health system is facing an overwhelming challenge to manage the growing burden of chronic diseases. Chronic diseases are the main causes of premature death and illness in Australia, responsible for two thirds of the country's burden of disease. Yet, today Australia is ranked 16th out of 31 OECD countries for per capita expenditure for preventive health, with only 1.34 percent of health care expenditure going to prevention.

Reducing the burden of CKD requires addressing the shared root causes of chronic disease. More than fifty percent of Australians have at least one chronic condition and nearly a quarter live with two or more chronic diseases. In the case of CKD, more than half of people living with CKD also have cardiovascular disease and/or diabetes.

Addressing social determinants of health is vital to reducing the burden of chronic disease. Changing the social and environmental conditions that place particular populations at higher intergenerational risk of chronic disease is fundamental to this approach.

It is vital that Australia coordinates its efforts to increase the effectiveness of chronic disease prevention funding and approaches. Diseases such as diabetes, cardiovascular disease and CKD share common social and environmental determinants, behavioural and biomedical risk factors.

A disease specific approach needs to be replaced with a comprehensive, coordinated suite of national programs that tackle the causes of disease, from social determinants onwards, underpinned by widespread, targeted awareness campaigns and a focus on increasing health literacy.

In Australia, almost 60 percent of adults have low health literacy, limiting their ability to make effective health decisions. The effectiveness of preventative health programs will depend on increasing understanding of key risk factors for chronic disease and providing clear, accessible information to encourage follow up for people at risk.

Addressing low awareness of CKD is also vital. CKD is a silent disease and up to 90 percent of kidney function can be lost without symptoms. As a consequence, over 1.5 million Australians with early signs of CKD are unaware they have the disease. Widespread lack of knowledge about the role of the kidneys exacerbates the silence around CKD in the community. Preventing CKD and improving early detection and management depends on concerted efforts to raise the profile of kidneys and CKD across Australia.

Early detection and management of kidney disease can slow or halt the progression of disease, reducing the social and financial toll of CKD on the community and the health system. The overwhelming lack of awareness of the early signs of kidney disease and under-diagnosis of early stage CKD highlight the need for a widespread public and primary care education campaign and wider access to risk assessment and detection. The current suite of MBS funded primary health assessment and chronic disease management items can be used more effectively to increase early detection and improve CKD management through better patient engagement and follow up, appropriate referral and the development of appropriate treatment pathways. With the right support, the chance of making and maintaining the necessary lifestyle changes are greatly increased.

## What will be different?

A coordinated and cohesive approach to addressing chronic disease in Australia will be overseen by a powerful national body working in partnership with government agencies, chronic disease bodies, healthcare professionals, researchers and the community. A health literate population will understand chronic disease risk factors and symptoms of early stage kidney disease and seek diagnosis and care. Earlier detection and multi-disciplinary intervention will slow the progression of disease. Better primary care communication with patients will give people diagnosed with CKD the knowledge and confidence to manage their treatment.

## 1. Prevention, Detection and Education

### 1.1 Develop a nationally coordinated approach to increase the effectiveness of chronic disease prevention initiatives in Australia

	Action	Implementation
1.1.1	Establish a national body responsible for overseeing chronic disease prevention in Australia	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Establish and fund a Commonwealth agency tasked with developing a comprehensive, integrated approach to chronic disease prevention in Australia, overseeing the delivery and evaluation of evidenced based/best practice programs. This new national prevention body will: <ul style="list-style-type: none"> <li>- Develop a coordinated multi-pronged strategy among stakeholders for preventative actions against chronic disease at all stages of life course</li> <li>- Evaluate existing programs and identify a series of effective interventions that have an evidence-base where immediate roll-out may have short-term achievement of health improvement</li> <li>- Deliver co-ordinated prevention promotion interventions for immediate action and health improvement gain across a variety of services, platforms and agencies with partnerships being the key driver of delivery (see Actions 1.1.2-1.1.5 and 1.3.1 and 1.3.2)</li> <li>- Determine the research agenda for preventative strategies</li> <li>- Identify strategies for promotion of prevention within the health workforce</li> </ul> </li> </ul>
1.1.2	Promote healthier eating, including reducing consumption of salt and sugar	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop and fund a National Obesity Strategy, based on the recommendations outlined in the <i>Tipping the Scales: Australian obesity prevention consensus</i></li> </ul>

		<ul style="list-style-type: none"> <li>• Develop and fund a new National Nutrition Policy to align with recommendations from the WHO, the United Nations Steering Committee on Nutrition (UNSCN) and the Food and Agriculture Organisation (FAO), including <ul style="list-style-type: none"> <li>- Restrict marketing of unhealthy food and beverages to children;</li> <li>- Implement a national sugar and salt levy and using funds raised to support preventative health programs, including affordable food</li> <li>- Strengthen national food reformulation, including reducing dietary sodium and sugar levels as well as portion control measures</li> <li>- Invest in effective education campaigns, including a focus on early years</li> <li>- Mandate the national Health Star Rating system with enhanced consumer education measures</li> </ul> </li> <li>• These activities will be supported by a national multimedia chronic disease awareness and school chronic disease health literacy campaigns (Action 1.1.6).</li> </ul>
1.1.3	Address barriers and promote physical activity	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop and fund a National Physical Activity Strategy, building on existing successful state-based programs, with a range of programs to encourage physical activity to be developed and rolled out nationally. Programs should focus on: <ul style="list-style-type: none"> <li>- Improving access to infrastructure and open space</li> <li>- Increasing opportunities for physical activity</li> <li>- Creating infrastructure where it is lacking</li> <li>- Raising awareness of the importance of physical activity, targeting school children and the broader population</li> <li>- Targeted programs for at risk populations in a culturally appropriate manner using local knowledge and community engagement</li> </ul> </li> <li>• These activities will be supported by national multimedia chronic disease awareness and school chronic disease health literacy campaigns (Action 1.3.1).</li> </ul>
1.1.4	Build on and strengthen existing tobacco control initiatives to reduce smoking in the community	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Invest in a mass media education campaign to further reduce smoking prevalence for the life of the next National Tobacco Strategy. <ul style="list-style-type: none"> <li>- Employ a population level approach as well as complementary targeted approaches for populations with high smoking rates.</li> <li>- Investment would complement existing funding provided for the Tackling Indigenous Smoking program</li> </ul> </li> <li>• Develop national clinical guidelines and program support to embed a tobacco dependency treatment approach into health services.</li> <li>• Enhance tobacco cessation programs and support in Aboriginal Community Controlled Health Services.</li> <li>• Fund a national Quitline service.</li> </ul>

1.1.5	Focus on primordial prevention	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop a range of programs focused on primordial prevention in at risk populations/communities, in line with recommendations from the <i>Renal Roadmap for Indigenous Health</i> and the <i>Best practice primary and secondary preventative interventions in chronic disease in remote Australia</i>.</li> </ul> <p>These will focus on key time points - pre and post conception, during pregnancy, during the first ten years of a child's life and into young adulthood. Programs will address factors such as:</p> <ul style="list-style-type: none"> <li>- Food security</li> <li>- Low breastfeeding rates</li> <li>- Health in pregnancy including nutrition antenatal care</li> <li>- Smoking cessation</li> <li>- Appropriate and affordable housing</li> <li>- Obesity prevention</li> </ul> <p>Programs will be developed and rolled out based on the principles of collaboration, partnership with local communities and with a focus on community led initiatives.</p>
<b>1.2. Increase early detection and management to slow disease progression and empower people to self-manage their conditions</b>		
1.2.1	Increase early chronic disease risk assessment in primary care for better identification of people at risk of chronic disease	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop an MBS rebatable chronic disease risk assessment tool through expanding the AusDRisk tool to include Cardiovascular Risk Assessment and Kidney Disease Risk Assessment questions, to be implemented in Primary Care settings. Also make the tool available in community settings.</li> </ul> <p>Those found to be high risk will have immediate access to a primary care Integrated Health Check (Action 1.2.2).</p>
1.2.2	Increase uptake and effectiveness of primary care health assessments (Integrated Health check) and care planning	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Facilitate early detection through increasing uptake and focus of MBS funded health assessments (Integrated Health Check).</li> <li>• Improve disease management, with appropriate multidisciplinary treatment pathways, including a review the current MBS health assessment items to incorporate an Integrated Health Check by: <ul style="list-style-type: none"> <li>- Extending the current eligibility criteria for MBS rebatable health assessments to encompass those at risk of chronic disease including CKD</li> <li>- Standardizing MBS rebatable health assessments by linking them to professional guidelines outlining the expected content of those assessments, including the IHC</li> <li>- Including the IHC in the Quality Improvement Incentive (QII) Program</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>- Increasing the use of software tools to improve CKD risk factor identification, testing, diagnosis and management.</li> <li>- Improving early stage disease management through increased referral to and uptake of multidisciplinary lifestyle modifications programs (Action 1.2.3)</li> <li>• Facilitate patient self-management of early CKD</li> <li>- Developing resources for patient-centred chronic disease management in primary care to increase understanding of treatments and encourage successful self-management of early CKD. This includes developing culturally and linguistically diverse materials in multiple formats appropriate for varying literacy levels, language and cultural frameworks.</li> </ul>
1.2.3	Prevent the onset and slow the progression of CKD through lifestyle modification programs.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Lifestyle Behavior Modification Programs targeted at people identified as at high risk for chronic disease and those with early stage kidney disease. Programs will be culturally appropriate and tailored for and by different population groups. Activities include: <ul style="list-style-type: none"> <li>- Enhance existing evidence-based lifestyle modification programs to include CKD</li> <li>- Develop lifestyle behavior modification programs (based on existing successful programs) in States where there are current no such programs</li> <li>- Improve referral pathways to modification programs with a dedicated portal that links health care settings and makes referral easy and simple for patients and practitioners</li> <li>- Resource ACCHSs to develop and implement chronic disease prevention programs within their communities</li> </ul> </li> </ul>
1.2.4	Provide easier, nationally consistent access to genetic counselling and testing to enable earlier detection and treatment of inherited kidney disease.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Address the disparities in access to genetic testing for inheritable kidney disease across jurisdictions/States. Initial activities include: <ul style="list-style-type: none"> <li>- Seek in principle State agreement for a national approach to counselling and testing for inheritable kidney disease, including applications such as preimplantation genetic diagnosis (where applicable)</li> <li>- Convene an expert panel to develop nationally agreed criteria and scope of MBS funded genetic testing for patients/families affected by or at risk of inherited kidney disease and cost implications</li> </ul> </li> </ul>
<p><b>1.3 Raise community and health professional awareness and understanding of CKD and other chronic diseases to support prevention and early detection</b></p>		
1.3.1	Improve chronic disease health literacy through nationwide, targeted awareness and education programs	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• A national school education campaign to increase health literacy in young people, particularly in relation to chronic disease and healthy lifestyles. This campaign will support various state-based programs aimed at teaching healthy behaviours in school, such as healthy eating/cooking programs. Options include: <ul style="list-style-type: none"> <li>- Integration of additional chronic disease modules into existing state-based health literacy programs</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>- Development of a new national school chronic disease literacy program</li> </ul> <p>•A multi-platform, multilingual, nationally coordinated chronic disease awareness campaign to increase knowledge of the risk factors associated with kidney and other chronic diseases. This campaign will build on the range of national and state disease specific campaigns to develop a comprehensive campaign to encourage people at risk to follow up with a risk assessment (Action 1.2.1) or health assessment (Action 1.2.2). The campaign will include culturally appropriate, targeted messaging for different populations, including Indigenous communities (in line with Action 2.4.1).</p> <p>-</p>
1.3.2	Raise community awareness and understanding of the function of kidneys, CKD risk factors and consequences	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>•Develop and rollout a 2020 national multi-format kidney awareness campaign. Messaging will target different population groups, including high risk populations and be available in multiple languages.</li> </ul> <p>Content will include:</p> <ul style="list-style-type: none"> <li>- essential role of kidneys</li> <li>- risk factors for CKD</li> <li>- the need for early detection and how to do it</li> <li>- consequences of CKD and ESKD especially links to cardiovascular risk</li> <li>- simple preventative measures for chronic disease and CKD</li> </ul>
1.3.3	Provide primary care education and training to encourage best practice CKD risk assessment, detection and management	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• The national provision of chronic kidney disease education and training to primary care health professionals in line with current best practice guidelines to improve early detection of chronic kidney disease and facilitate effective and timely management (Action 1.2.2). This would build on existing primary care education and training programs and align with best practice guidelines and Optimal Care Pathways (Action 2.1.1).</li> </ul>

## Priority Two – Optimal Care and Support

### What we hope to achieve

- Standardised care and national planning to increase access to high quality, comprehensive and appropriate care, irrespective of where people live, improving health outcomes and health system efficiency.
- People affected by CKD, including patients, carers and families, have access to a range of financial and psychosocial supports, improving quality of life for patients, carers and families.
- The prevalence and impact of CDK on Indigenous communities is reduced through a comprehensive suite of programs targeting the root causes of disease and increased equity of access to treatment.

### Why is this important?

Overall, in Australia, people with CKD receive high quality care, however care standards and resources vary significantly across the country. These differences are particularly stark in rural, remote and Indigenous communities. While a number of states have developed a range of rigorous models of kidney care, more needs to be done to ensure that best practice care is rolled out nationally. Best practice kidney care has the capacity to slow disease progression, better prepare patients for treatment, improve patient quality of life and optimize the use of health resources.

Reducing the disparities in care also requires a national approach to resource planning to ensure Australia has the infrastructure and workforce to deliver care when and where it is most needed now and into the future. The disproportionate burden of kidney disease on vulnerable populations, including Indigenous communities, requires targeted and tailored models of care and resource planning, underpinned by concerted efforts to address the root causes of chronic disease.

Beyond healthcare care, people affected by kidney disease are typically offered too little in the way of support, compromising the quality of life of those living with the disease and their families. People affected by kidney disease face a range of largely unacknowledged challenges. Treatment for ESKD is typically arduous and ongoing and comes with a range of debilitating side effects. One of the most common treatments, haemodialysis, makes travelling particularly difficult, with people usually unable to access dialysis outside their local area. Expenses associated with treatment, including transport, parking, utilities and medications, frequently coupled with an inability to work, can place families in financial stress. For those well enough to work, finding an employer able to accommodate the ongoing need for lengthy treatment is an additional challenge.

Carers play an essential role in both home and hospital-based dialysis. Uptake of home dialysis, which provides a significant cost saving to government, frequently depends on carer management especially if the patient is a child, has limited mobility, dexterity or movement, or has failing memory. The average time spent overseeing home dialysis alone is around 20 hours a week, which compromises the ability of the carer to work. Despite this, carers of people with ESKD are usually not considered eligible for the Carers payment, as there is no specific category for provision of complex medical care.

Unsurprisingly ESKD takes an enormous toll on the lives of people with CKD and their families, with financial hardship, stress and depression common experiences. People affected by ESKD simply need

more support. This includes financial help and a range of psychosocial supports that account for the long-term debilitating nature of the disease and acknowledge the heavy lifting done by carers to reduce the burden on the healthcare system.

## What will be different?

Improvements in consistency of care mean people will be able to access high value care irrespective of where they live. People affected by kidney disease will have improved quality of life through reduced financial stress, increased flexibility and access to multidisciplinary support. Indigenous kidney programs will reflect the needs of communities, with prevention programs targeting the social determinants of health, care closer to home and financial and social support for those who need to travel for care.

## 2. Optimal Care and Support

### 2.1. Deliver high quality, equitable kidney care across Australia

2.1.1	Establish nationally standardized care pathways to ensure all people receive a high standard care, irrespective of where they live.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Nationally standardised best practice kidney care through developing and rolling out nationally agreed Optimal Care Pathways for Kidney Disease (OCPKDs) including pathways for:               <ul style="list-style-type: none"> <li>- People at increased risk of CKD</li> <li>- Early stage kidney disease (detection, diagnosis and management)</li> <li>- Inherited kidney disease</li> <li>- Adolescent to adult transition of care</li> <li>- End stage kidney care and transition to dialysis</li> <li>- Kidney transplants (work up, recipient eligibility, pre- and post-transplant care)</li> <li>- Living kidney donation</li> <li>- Supportive care for patients with ESKD who will not have dialysis</li> <li>- Indigenous specific kidney care pathways</li> </ul> </li> </ul> <p>Indigenous guidelines will be developed as part of the implementation of the <i>Renal Roadmap</i> (Action 2.2.1).</p> <p>Crucial to the optimal care pathways will be the ensuring the necessary workforce training and requirements to effectively implement pathways (Action 2.1.2).</p>
2.1.2	Map current and future resource needs to improve equity of access to kidney care nationally.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop a kidney workforce and resource planning tool that integrates prevalence and risks of CKD, current capacity and workforce across Australia. The tool will be used to provide a comprehensive picture of current and future needs and capacity for service planning across all levels of government. The tool will draw on a range of Commonwealth and State data.</li> </ul>
2.1.3	Improve CKD care in rural and remote Australia.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Programs that:</li> </ul>

		<ul style="list-style-type: none"> <li>- Improve resource/service planning (Action 2.1.2) so integrated health care for CKD can be delivered closer to home where possible.</li> <li>- Partner with local community health organisations and NGOs to deliver care tailored to the needs of individual communities</li> <li>- Develop innovative models of integrated care for more effective use of the rural and remote health workforce</li> <li>- Increase support for primary and community CKD care and enhancing integration with tertiary-level kidney care</li> <li>- Increase the use of telemedicine to provide access to specialist services and advice where needed</li> </ul> <p>These actions align with the activities outlined in the <i>Renal Roadmap for Indigenous Health</i> and the <i>Best practice primary and secondary preventative interventions in chronic disease in remote Australia</i>.</p>
2.1.4	Increase equity of access to transplant and equity of transplant outcomes	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>•This action includes: <ul style="list-style-type: none"> <li>- Identify barriers to selecting, working-up, referring, assessing and waitlisting patients for kidney transplantation</li> <li>- Develop clear and nationally consistent guidelines for recipient eligibility</li> <li>- Develop standardised care pathways pre-, peri- and post-transplantation (as per Action 2.1.1)</li> <li>- Support transplant specialist outreach in regional, rural and remote to augment support of individuals post-kidney transplantation (as per Action 2.1.3)</li> </ul> </li> </ul>
2.1.5	Increase living donor transplantation.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>•Promote living donation through: <ul style="list-style-type: none"> <li>- Developing nationally standardized living donor support subsidies to reduce inequities between and within states and territories</li> <li>- Providing ongoing funding for the Supporting Leave for Living Donors program beyond 2022</li> <li>- Reducing disparities in early pre-transplant work up and planning, including rolling out clear best practice guidelines for living donation</li> <li>- Increasing patient knowledge about living donation. This would include a multi-platform education campaign, providing information in a range of formats to suit different diverse levels of health literacy and languages to assist patient and potential living donor decision making</li> </ul> </li> </ul> <p>Guidelines for early transplant workup will form part of the Optimal Care Pathways for Kidney Disease program (Action 2.1.1).</p>
2.1.6	National access to multi-disciplinary renal genetics clinics.	Inherited kidney disease is a rapidly changing domain, where early diagnosis and therapeutic intervention can have major positive outcomes for patients as well as subsequent generations in their family. Multi-disciplinary renal genetics clinics (where families are seen by teams including nephrologists, clinical geneticists and genetic

		<p>counsellors and where appropriate, provided with clinical diagnostic genomics to seek a genetic diagnosis) should be available nationally with access for all Australians with inherited kidney disease.</p> <p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• National multi-disciplinary renal genetics clinics.</li> </ul>
<b>2.2. Reduce the financial impact of kidney disease on patients, carers and families</b>		
2.2.1	Reduce the out of pocket costs of home dialysis by addressing the national variation in utility subsidies for home dialysis as well as simplifying the processes for obtaining subsidies.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Reduce the inequities in out of pocket costs of home dialysis by having a nationally consistent utility subsidy, and a simpler process for accessing subsidies. An essential first step is seeking in-principle State Health Ministerial agreement to address this problem via the AHMAC.</li> </ul>
2.2.2	Reduce transport and accommodation costs for both long distance travel to specialist care and for regular travel for life sustaining treatment.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop kidney disease specific patient transport assistance schemes across the states and territories. The scheme will reduce the out of pocket costs of travel for dialysis, transplant assessment and other multiple hospital/clinic visits, which are currently not covered under existing state schemes. This includes: <ul style="list-style-type: none"> <li>- increasing payment rates</li> <li>- lowering travel thresholds</li> <li>- national consistency between the schemes</li> </ul> </li> </ul> <p>In principle State Health Ministerial agreement for this program will be sought via the AHMAC.</p>
2.2.3	Better access to the Commonwealth funded carer allowance for carers of people living with ESKD.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Extend eligibility for the Commonwealth Carers payment to include the provision of complex medical care, to acknowledge the unique burden of caring for someone with end-stage kidney disease, particularly those undergoing home dialysis.</li> </ul>
2.2.4	Increase access to government support for people with end-stage kidney disease.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Address the gaps in financial and social support for people with end-stage kidney disease. Specific activities associated with this action are still being investigated. Proposals include: <ul style="list-style-type: none"> <li>- Including patients with end-stage kidney disease in existing government programs</li> <li>- Developing a specific end-stage kidney disease allowance for under 65s to assist with out of pocket costs for care</li> <li>- Increasing access to a healthcare card to provide pharmaceutical support that reflect the costs of kidney disease treatment</li> </ul> </li> <li>• Focus on helping patients access services that are already available, through a kidney care navigator service, as part of the kidney helpline (Action 2.3.1)</li> </ul>

2.2.5	Make it easier for people with kidney disease to remain in or enter the workforce.	<p>The arduous and ongoing nature of ESKD treatment can make working a challenge. Apart from side effects, treatment requirements and ongoing healthcare commitments makes remaining in the workforce difficult for many people living with CKD.</p> <p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop education materials for employers to increase understanding of end-stage kidney disease and treatment and accommodating the needs of employees.</li> <li>• Investigate the feasibility of an employer bonus to assist employers meet the workplace requirements of people with end-stage kidney disease.</li> </ul>
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### 2.3. Improve support for people affected by kidney disease

2.3.1	Increase the availability of health, wellbeing and psychosocial support for people with CKD, carers and families.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Address the need for ongoing psychosocial support for patients and carers. It includes: <ul style="list-style-type: none"> <li>- A 24-hour support line staffed by qualified professionals including social workers, nurses and dieticians to assist consumers directly and/or link them to a range of appropriate services, such as mental health</li> <li>- Developing a web-based, downloadable information on relevant topics</li> </ul> </li> </ul> <p>The program could be delivered through expanding Kidney Health Australia’s Kidney Helpline or as part of a broader Commonwealth chronic disease helpline program. It would also draw on the patient guides developed as part of the Optimal Care Pathways for Kidney Disease (Action 4.1).</p>
2.3.2	Create peer support networks (virtual and face to face) across Australia for people affected by kidney disease.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Develop and support programs that connects kidney consumers and carers with trained mentors and others who have similar experiences living with or caring for someone with kidney disease. This would include networks targeting specific population groups, such as <ul style="list-style-type: none"> <li>- young adults</li> <li>- regional and remote populations</li> <li>- people with PKD</li> <li>- Indigenous populations, with these programs being developed by Indigenous leaders and organisations</li> <li>- carers</li> </ul> </li> </ul>
2.3.3	Introduce a national approach to travel dialysis to make it easier for people on dialysis to travel	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Investigate the implementation of a national dialysis travel program to make it easier for patients to travel. Possible solutions include <ul style="list-style-type: none"> <li>- Making spare private renal unit capacity available nationally (based on NSW’s Enable - away from home dialysis program)</li> <li>- A dialysis swap program, with state agreement for all hospitals to participate and supported by the appropriate technology.</li> </ul> </li> </ul>

		The first step in this action is obtaining in principle AHMAC commitment to facilitating better access to dialysis away from home.
<b>2.4 Reduce the disproportionate burden of CKD on Indigenous Populations</b>		
2.4.1	Implement the Renal Roadmap for Indigenous Health.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Implement the <i>Renal Roadmap for Indigenous Health</i> including the development and rollout of key actions across the five domains of the Roadmap.</li> </ul> <p>The implementation will be governed by the principle that Indigenous peoples must be key players and involved in:</p> <ul style="list-style-type: none"> <li>- Setting and formulating policies affecting their communities</li> <li>- Developing and implementing locally relevant programs</li> <li>- Health care service delivery in the community</li> </ul>
2.4.2	Implement the TSANZ Performance Report recommendations to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander People in Australia report.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Implement the key priorities identified in the TSANZ Performance Report into Indigenous transplantation. These are</li> <li>- Establish a National Indigenous Transplant Taskforce to drive policies and programs related to improving transplant access and outcomes</li> <li>- Implement programs to improve access to wait listing, including piloting a patient navigator program and the establishment of multidisciplinary pre- and post-transplant clinics)</li> <li>- Create a framework for testing post-transplantation changes through enhanced data collection and reporting</li> </ul>

## Priority Three – Research and Data

### What we hope to achieve

- A well-funded, coordinated MRFF Kidney Collaborative, resulting in significant advances in kidney research and the translation of research into real world outcomes.
- Increased engagement of consumers through a comprehensive Kidney Consumer Research Hub linking consumer and researchers in all stages of research from design to dissemination and translation of findings.
- Enhanced data collection, evidence and research drives improvements in the effectiveness and efficiency of chronic kidney disease prevention, treatment and support.

### Why is this important?

Australia is conducting ground breaking research into kidney disease, from basic and clinical research through to health services research. However Australia needs to take a more targeted, focused approach in order to ensure kidney research outcomes ultimately translate to community health gains. The benefits of making specific diseases national priorities are well demonstrated by the improvements in survival rates across a number of cancers, including breast and prostate cancers that have accompanied the steady increase in cancer research funding and public health intervention over several decades. Given the growing social and economic burden of CKD, kidney disease requires the same sustained research focus to prevent, manage, and, hopefully one day, cure kidney disease.

Kidney disease research is well aligned with key national research priorities, so there are opportunities for greater access to research funding if kidney disease is prioritised and the kidney research community coordinates its efforts. These priorities include the National Health and Medical Research Council (NHMRC) focus on prevention, management and cure and the Medical Research Future Fund (MRFF) 2018-2020 priorities.

Consumer driven research is a key MRFF priority and there is a growing recognition of the importance of patient led research internationally. Despite this, Australia lags behind on integrating consumer engagement into health and medical research. Beyond an ethical imperative to involve patients in research, there are significant advantages to consumer led research; involving patients helps optimize the design and dissemination of research and ensure the effectiveness of resulting interventions. Involving patients provides a deeper understanding of some of the key issues around kidney disease and facilitates translation into real interventions with the potential to transform the lives of those living with kidney disease.

High quality, linked up data is essential to making inroads in kidney disease prevention, management, treatment and research. Data underpins the actions across each of the priorities outlined in this action plan. Data is routinely collected and effectively used at end stage kidney disease. The ANZDATA and TSANZ databases collect a range of information about dialysis and transplantation that inform improvements in ESKD treatment and renal service planning. The TSANZ report Improving access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander People in Australia demonstrates how effectively data can be used to inform policy and practice changes, revealing the depth of the disparity in access to and outcomes of transplants in Indigenous communities and highlighting key actions for change.

However, little data is routinely captured at diagnosis and early treatment of early and mid-stage CKD, which effects the ability to effectively manage/plan and evaluate the efficacy of treatments. Better data collection and management within primary care is essential to addressing this gap.

Linking primary care data with ANZDATA and TSANZ databases as well as AIHW data will be key to building a comprehensive picture of CKD in Australia, facilitating research and the monitoring and evaluation of policies and programs.

## What will be different?

A coordinated, strategic approach to kidney disease with key priorities agreed by the kidney research community and consumers will result in better leveraging of existing funding and translation of research to improved patient outcomes. Informed and engaged consumers will collaborate with researchers in all stages of kidney disease research. Data will be used effectively to support ongoing improvements in kidney disease prevention, detection and management.

<b>3. Research</b>		
<b>3.1. Establish an MRFF funded collaborative kidney research mission to increase strategic research investment, foster cross collaboration and translate cutting edge research into real world outcomes</b>		
3.1.1	Establish a Kidney Research Collaborative to develop and implement a kidney research strategy with targeted priorities	<p>Australia needs to take a more targeted, focused approach to in order to ensure kidney research outcomes ultimately translate to community health gains</p> <p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• The Kidney Research Collaborative would develop and implement an integrated kidney research strategy with targeted priorities, focused on prevention, treatment and finding cures for kidney disease. An audit of kidney research and research capacity in Australia to identify research strengths, gaps and opportunities would be conducted to identify key strengths, gaps and opportunities to inform funding.</li> </ul> <p>This action will depend on developing strong partnerships between researchers, medical professionals and nurses, policymakers, peak bodies and community members.</p>
3.1.2	National investment in kidney disease research.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Manage targeted funding opportunities for identified priority areas from the MRFF and NHMRC</li> <li>• Coordinate collaborative funding bids</li> </ul>
3.1.3	Establish a Kidney Consumer Hub to facilitate joint research priority setting and enable consumer driven, targeted research.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Establish a National Kidney Consumer Research Hub, in line with 2018 MRFF priorities. The hub will be a key component of the national strategy for kidney disease, including research priority setting (Action 3.1.1).</li> </ul>
<b>3.3. Use data, evidence and research to drive improvements in chronic kidney disease prevention, treatment and outcomes</b>		
3.2.1	Implement nationally consistent data collection	High quality, linked up data is essential to making inroads in kidney disease prevention, management, treatment and research. Data

	at all points of care to support ongoing improvements in kidney disease prevention, detection and management.	<p>underpins the actions across each of the priorities outlined in this action plan.</p> <p><b>Actions</b></p> <ul style="list-style-type: none"> <li>• Increase CKD data collection in primary care (Actions 1.2.1, 1.2.2)</li> <li>• Increase linkages between the breadth of CKD data collected, including biospecimens and genomic, phenomic and multiomic data where available.</li> <li>• Ensure the long-term viability and currency of ANDATA /ANZOD through: <ul style="list-style-type: none"> <li>- Secure and ongoing funding for medical director and staff for ANZDATA/ANZOD</li> <li>- Investment in IT infrastructure and platforms</li> <li>- Expanding consumer engagement – including ready access through IT portals (Action 3.2.1)</li> <li>- Developing expanded outcome collections (PROMS)</li> <li>- Driving the quality &amp; safety / KPI agenda</li> </ul> </li> </ul>
3.2.2	Roll out an improved Australian Health Survey (AHS) in conjunction with Australian Bureau of Statistics.	<p>The AHS provides vital information about prevalence of kidney disease. The last survey was done in 2011-13, however no follow-up has been funded.</p> <p><b>Actions</b></p> <ul style="list-style-type: none"> <li>•The continuation of the Australian Health survey. This supports a large number of actions in this Action Plan. This would include the relevant kidney disease questions and biomarkers of CKD.</li> </ul>
3.3.3	Translate research into practice through the strengthening of clinical guidelines and implementation of living guidelines.	<p><b>Actions</b></p> <ul style="list-style-type: none"> <li>•This action includes <ul style="list-style-type: none"> <li>- Supporting the Australian Living Evidence Consortium to build and evaluate a world first, online, dynamically updated summary of evidence to guide clinical practice and policy development</li> <li>- Ongoing sustainable funding for the KHA-CARI clinical guidelines</li> <li>- A living guidelines pilot to transform the KHA CARI guidelines into living guidelines.</li> <li>- research to inform optimal approaches to translating guidelines into clinical practice</li> </ul> </li> </ul>

# Achieving Progress

## Implementing the strategy

The success of this Action Plan depends on coordination and collaboration between many stakeholders across all levels of government and the health system, the research sector and patient and community organisations. Targeted and sustainable investment will also be required to achieve the strategy's vision - preventing CKD, providing high optimal and support for those affected by the disease and maximising the outcomes of research. A vital first step in realising the actions outlined in the Action Plan is establishing a steering committee to oversee the plan's implementation. This steering committee would be tasked with prioritising actions, identifying key partners and establishing processes to implement these actions. The steering committee will also set implementation targets for the next five years as well as monitoring the progress of the Action Plan's implementation.

## Key partnerships

- People affected by kidney disease, including their families and carers
- Australian and state and territory governments, departments of health and social services, and agencies such as the Australian Institute of Health and Welfare and the Australian Commission of Safety and Quality in Health Care
- Primary, secondary and tertiary healthcare providers in both the public and the private sector
- Clinicians, renal specialists and nurses
- Rural health organisations
- Aboriginal and Community Controlled Health Organisations and other representative stakeholders of Aboriginal and Torres Strait Islander peoples
- Kidney disease consumer organisations
- Professional and peak bodies
- Research organisations and institutes
- Prevention organisations such as The Australian Chronic Disease Prevention Alliance (ACDPA)
- Industry, including the pharmaceutical industry and private health insurance

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