Evidence Document
A compendium to the National Strategic Action Plan for Kidney Disease
Quote from front page: Phil Carwsell OAM, Patient Partner

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

The National Strategic Action Plan for Kidney Disease was led by Kidney Health Australia with funding from the Australian Government Department of Health.

For enquiries about the National Strategic Action Plan for Kidney Disease, and for information about kidney health and support, please contact the Kidney Health Australia Kidney Helpline on 1800 454 363 or visit the website www.kidney.org.au.

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The National Strategic Action Plan for Kidney Disease and the compendium documents were managed and written by Dr Emma Tinning, Dr Lisa Murphy and A/Prof Shilpa Jesudason of Kidney Health Australia.
Introduction

The National Strategic Action Plan for Kidney Disease (the Action Plan) provides a blueprint for transforming kidney health in Australia over the next ten years. The Action Plan articulates a vision for preventing chronic kidney disease (CKD) and improving the lives of those affected by CKD, underpinned by the effective use of research, evidence and data.

The Action Plan includes three priority areas with nine corresponding objectives, each with a range of detailed actions designed to address the most pressing needs in kidney disease (Table 1). These are supported by robust evidence and developed through extensive stakeholder consultation.

Table 1: Priority Areas and Objectives

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<th>Priority One</th>
<th>Prevention, Detection and Education</th>
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<td>Develop a nationally coordinated approach to increase the effectiveness of the prevention of chronic conditions in Australia</td>
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<td>Increase early detection and management to slow the progression of kidney disease and empower people to self-manage their conditions</td>
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<td>Raise community and healthcare professional awareness and understanding of CKD and other chronic diseases to support prevention and early detection targeted at priority groups</td>
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<td>Improve support for people affected by CKD</td>
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<td>Reduce the disproportionate burden of kidney disease on Aboriginal and Torres Strait Islander communities</td>
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<th>Research and Data</th>
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<td>Establish a well-funded collaborative kidney research program to increase strategic research investment, foster cross collaboration and translate cutting edge research into real world outcomes</td>
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<td>3.2</td>
<td>Use data, evidence and research to drive improvements in kidney disease prevention, treatment and outcomes</td>
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This document provides the background and evidence base for the strategy, including information about kidney disease and treatment; the health, psychosocial and economic impact of CKD on Australia; and the evidence supporting the priorities and actions. Additional supporting information is available in the compendium documents *Consultation Summary* and *Stocktake of Existing Initiatives* also accompanying the Action Plan.
Kidney Disease

Functions of the kidneys
Kidneys 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. Kidneys have a number of other less well-known functions that are central to health, including producing hormones essential for red blood cell production and controlling blood pressure, and activating vitamin D.

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 three months. There are five recognised CKD stages. Stage 1 is the mildest form, gradually progressing through to stage 5 also known as end stage kidney disease (ESKD). Table 2 on the following page describes the symptoms and treatment of each of these stages.

Diagnosis
Kidney damage is diagnosed 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)
- pathological abnormalities (e.g. renal biopsy).
- abnormal kidney function.

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 GFR < 60mL/min/1.73m.

Causes of CKD
There are many different and varied causes of kidney disease. Currently in Australia, 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 (18%) and hypertension (14%). Other causes include immune diseases, conditions people may be born with (congenital) or genetic disorders. The most common genetic cause of kidney disease is polycystic kidney disease (PKD) accounting for 6% of all new cases of ESKD.

Risk factors for chronic kidney disease
1 in 3 Australians are at risk of developing CKD. The main risk factors include:

- Diabetes
- Cardiovascular disease (CVD) - heart attack, heart failure and vascular disease
- High blood pressure
- Being of Aboriginal and Torres Strait Islander origin
- Family history of kidney failure
- History of acute kidney injury
- Obesity
- Age (60 years or older)
- Tobacco smoking
- Lifestyle factors (sedentary lifestyle, alcohol excess, high salt and sugar diets).

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.
Symptoms and complications

Kidney disease is a largely asymptomatic condition and up to 90% of kidney function can be lost before symptoms are evident. Symptoms typically appear very late in the disease course; a person with stage 4 kidney disease may not have any symptoms or may only have vague, non-specific symptoms such as feeling tired or slightly “off colour”. Symptoms may be present earlier in the disease course in some causes of kidney disease (for example PKD), or symptoms may be present as a result of damage to other organs such as the heart or blood vessels.

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.

CKD affects every organ system in the body, and damage accumulates over time. There are many serious complications of CKD that greatly affect overall health and wellbeing. These include cardiovascular disease, hypertension, bone disease, anaemia, sleep apnoea, hyperlipidaemia, and malnutrition. Some of these problems, for example the increased risk of cardiovascular disease, are already evident at an early stage of CKD.  

Management

If CKD is detected early, effective management can not only slow or even halt the progression to ESKD but also reduce the damage from complications.  

This management may include general treatments that help all kidney diseases (lifestyle changes, blood pressure control, medications). It may also include specific treatments for certain conditions (for example, immune suppressing drugs for immune conditions).

In late stages kidney function is severely reduced, requiring symptom control and intensive intervention in preparation for stage 5. 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. There are two main types of dialysis – haemodialysis and peritoneal dialysis (PD) and haemodialysis. Haemodialysis is where blood travels through a special filter called a ‘dialyser’ before being returned cleaned to the body. Peritoneal dialysis is where a special fluid is put into the peritoneal cavity through a soft plastic tube, and then drained out of the body. Neither of these treatments completely restores health and patients may still have many symptoms, particularly fatigue. Patients remain at risk of health problems and increased mortality. The burden of dialysis is overwhelming - no other disease requires life-sustaining treatment that patients and their carers must actively participate in for years.

Whilst transplantation is an effective treatment for ESKD it is not a cure and does not reverse all complications. Powerful immune-suppressing medications need to be taken regularly and indefinitely to avoid organ rejection. These can have serious and deadly side effects, including increased risks of some forms of cancer, infection, and cardiovascular disease. Transplants do not last forever and some patients will return to dialysis.

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.

The choice of treatment for ESKD should be made in partnership with the patient and their doctor. The choice is based on personal preference, lifestyle, daily schedule, and activities. Many factors such as age, location, other medical conditions and available support system may also impact the choice. The Kidney Health Australia decision aid tool ‘My Kidneys, My Choice’ is a useful aid that supports people make the right choice of treatment for them.
The triad of chronic kidney disease, cardiovascular disease and diabetes

More than half of people living with CKD also have cardiovascular disease (CVD) and/or diabetes\(^7\). 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 each other. CKD independently increases the risk of hypertension and other cardiovascular events, including heart attack, angina, coronary artery disease, stroke and heart failure.\(^8\)

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.\(^9\)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
<th>eGFR</th>
<th>Kidney Function Deterioration</th>
<th>Interventions and Treatment</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Kidney damage (protein in urine) and normal GFR</td>
<td>&gt; 90</td>
<td>90% - 60%</td>
<td>→ identify and treat specific underlying diseases or causes of CKD - weight reduction if overweight/obese - cholesterol management - balanced and adequate diet - physical exercise - tobacco use prevention and control (including smoking cessation) - hypertension management - diabetes management - medications to reduce urine protein leak</td>
<td>No symptoms *Symptoms can appear earlier in some causes of CKD such as PKD, immune conditions</td>
</tr>
<tr>
<td>2</td>
<td>Kidney damage and mild decrease in GFR</td>
<td>60 – 89</td>
<td>60% - 70%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Moderate decrease in GFR</td>
<td>30 – 59</td>
<td>70% - 77.5%</td>
<td></td>
<td>Symptoms unlikely</td>
</tr>
<tr>
<td>4</td>
<td>Severe decrease in GFR</td>
<td>15 – 29</td>
<td>77.5% - 85%</td>
<td>As above plus: - preparation for ESKD - symptom management - management of anaemia</td>
<td>Symptoms more likely</td>
</tr>
<tr>
<td>5</td>
<td>Kidney failure, ESKD</td>
<td>&lt; 15 or on dialysis</td>
<td>≥ 85%</td>
<td>As above plus: - transplant - dialysis (peritoneal dialysis or haemodialysis) - supportive care</td>
<td>Symptoms highly likely</td>
</tr>
</tbody>
</table>
Burden of chronic kidney disease
1 in 3 are at risk of developing CKD<sup>10</sup> and a striking 1 in 10 are currently living with biomedical markers of CKD. However less than 10% of people with CKD know they have the condition, meaning there are over 1.7 million Australians who are unaware that they are living with indicators of CKD.<sup>11</sup> This burden is growing - between 2003-2015 there was a 26.9% increase in years lost to ill health from CKD and a 32.7% increase in years of life lost.<sup>12</sup>

Burden of end-stage kidney disease
The Australia and New Zealand Dialysis Transplant (ANZDATA) Registry collects and reports the incidence, prevalence and outcome of dialysis treatment and kidney transplantation for patients with ESKD across Australia and New Zealand. The most recent data<sup>13</sup> shows that 3056 people started RRT (dialysis or transplant) in Australia in 2017 resulting in a total of 24,738 people on RTT in Australia. Of these, 13,051 people were receiving dialysis treatment and 11,687 living with a functioning kidney transplant. The number of people on dialysis increased by 2.6% from 2016 to 2017. These numbers are only for patients on RRT, they do not include the data for supportive care. The true burden of ESKD in Australia is therefore significantly greater than 24,738.

Aboriginal and Torres Strait Islander kidney disease
An estimated 1 in 5 (18%) Aboriginal and Torres Strait Islander adults have biomedical signs of CKD,<sup>14</sup> more than double that of non-Indigenous Australians. They are 3 times as likely to have indicators of Stage 1 CKD, and more than 4 times as likely as non-Indigenous people to have indicators of Stages 4-5 CKD.<sup>15</sup> The incidence rate of ESKD among Aboriginal and Torres Strait Islanders is almost 5 times as high as the non-Indigenous rate with an earlier age of onset.<sup>16</sup>

Deaths from chronic kidney disease
CKD contributed to 11% of all deaths in 2017, which is over 17,000 deaths. CKD was the underlying cause of death in around 4,400 deaths, and an associated cause of death in a further 13,100 deaths. Kidney disease is a significant cause of death with around 56 people dying every day with kidney-related disease,<sup>17</sup> more than breast cancer, prostate cancer, and road traffic accidents combined. The mortality rate from CKD has not improved over the last decade. In contrast death rates for cardiovascular disease and stroke are decreasing at a rate of 4.5% and 3.6% each year respectively.<sup>18</sup> For people who do not receive a transplant or go on to dialysis, the survival rate at five years is worse than most common cancers.<sup>19</sup>

Psychosocial burden of kidney disease
People living with kidney disease, in particular those with ESKD<sup>20</sup> but also earlier stages of CKD, suffer severe and debilitating psychological burden, in addition to and exacerbating the physical symptom burden.<sup>21</sup>

The psychosocial and emotional distress stems from a number of factors including: physical and functional effects of kidney failure and RRT, large burden of physical symptoms, impairment in quality of life (QOL), cognitive impairment, dependence on a chronic life-sustaining treatment, loss of vocational capacity, financial stress, and unfavourable effects on marital and familial roles and social support. The burden is not limited to the patient but extends to their carers and family.<sup>22</sup>

Whilst the psychosocial burden of living with CKD is increasing being recognised, in particular through patient reported outcome measures,<sup>23</sup> the emphasis is still very much on the physical care.<sup>24</sup>

Economic burden of kidney disease
CKD is a considerable burden on Australian society. In 2012 the total costs attributable solely to CKD in Australia were an estimated $4.1 billion, made up of $2.5 billion in direct healthcare costs, $700 million in direct non-healthcare costs, and $900 million in government subsidies.<sup>25</sup> Note that these costs are for pre end-stage kidney disease (ESKD) only, as people receiving dialysis or transplant were excluded from these cost estimates. In Australia, dialysis and transplantation for ESKD are estimated to cost over $1 billion each year.<sup>26</sup>

Much of these costs relate to dialysis. Of the 10.2 million admissions to hospitals in 2014-15, dialysis for ESKD was the most common single reason for care (over 1.3 million admissions). Dialysis currently represents 13% of
hospitalisations in Australia. Between 2010-11 and 2014-15, admissions for dialysis increased by 3.6 per cent on average each year.\textsuperscript{27}

Furthermore, the cumulative cost of treating all current and new cases of ESKD from 2009 to 2020 is estimated to be between approximately $11.3 billion and $12.3 billion\textsuperscript{28}. Individuals with CKD incur 85\% higher healthcare costs and 50\% higher government subsidies than individuals without CKD, and costs increase by CKD stage.\textsuperscript{29} These costs are set to grow, with the rate of people starting dialysis or transplant expected to increase by 80\% by 2020 – rising from 11 to 19 per 100,000 of the Australian population.\textsuperscript{28}

Approximately 70\% of people dialyse in a hospital or satellite dialysis unit and 30\% at home.\textsuperscript{30} With dialysis estimated to cost up to $79,072 per person per year for hospital haemodialysis, $65,315 for satellite, $49,137 for home haemodialysis and $53,112 for peritoneal dialysis (2009 prices), dialysis is clearly an expensive treatment. Despite the cost effectiveness to government and potential health benefits of home dialysis (peritoneal dialysis and home haemodialysis) for the patient, there are significant state-by-state variations in uptake.
Evidence Base

Priority 1. Prevention, Detection and Education

1.1 Develop a nationally coordinated approach to increase the effectiveness of prevention the prevention of chronic conditions in Australia

- Chronic conditions are the main causes of premature death and illness in Australia, responsible for two thirds of the country’s burden of disease.
- Australia is ranked 16th out of 31 Organisation for Economic Co-operation and Development countries for per capita expenditure for preventive health, with only 1.7 percent of health care expenditure going to prevention and public health.\(^{31}\)
- Australia’s success in smoking cessation policy demonstrates the impact of a coordinated, multi-tiered approach. A national strategy, underpinned by regulation, education, health promotion and supportive health systems has resulted in significant reductions in smoking rates over the past few decades.

Obesity

- There has been a significant increase in processed, energy dense, nutrient poor food consumption in children and adults over the past three decades. Today over two thirds of the Australian population are overweight or obese.\(^{32}\)
- Obesity is an independent risk factor for CKD. An estimated one-third of CKD cases in Australia are related to excess weight, and obesity doubles the risk of developing CKD in comparison to someone of healthy weight.\(^{33}\)
- Obesity also increases the risk of developing diabetes and high blood pressure, which are the two most common causes of ESKD in Australia.\(^{34}\)

Salt intake

- On average, Australian adults eat significantly more than the recommended upper limit of salt intake.\(^{35}\)
- Around 80% of the salt in Australian diets comes from processed food.\(^{36}\)
- Excess dietary salt increases the risk of high blood pressure, which is a leading cause of death and disability, including CKD cause and progression.\(^{37}\)

Policies targeting unhealthy food and beverage consumption

- Dietary factors contribute almost ten percent of the global health burden.\(^{38}\) Policies include taxing and regulating unhealthy foods and subsidies for health foods.
- Australian modelling has found taxation of alcohol, tobacco and unhealthy food and beverages to be one of the most cost effective health prevention interventions available and limiting salt in processed foods one of the most cost-effective and even cost-saving preventive health measures in Australia.\(^{39}\)
- Modelling has also found food and beverage taxes and subsidies might avert as many as 470,000 disability-adjusted life years (DALY - a measure of overall disease burden) in the Australian population of 22 million, with a net cost saving of AU$3.4 billion to the health sector.

Unhealthy food marketing to children

- Unhealthy food marketing to children influences food preferences, consumption and purchase requests.\(^{40}\)
- Internationally marketing restrictions are shown to significantly reduce children’s exposure to unhealthy food advertising.\(^{41}\)
- Marketing to children in Australia is largely self-regulated and there is little evidence that this approach reduces the amount of marketing to which children are exposed.
- Progress is hampered by the lack of a single definition of “unhealthy” foods that cannot be marketed to children in Australia.\(^{42}\)

Promoting, and addressing barriers to, physical activity
Currently 70 percent of children and nearly 60 percent of adults in Australia do not meet recommended levels of physical activity.\textsuperscript{43} The burden of disease attributable to inactivity could be reduced by more than a quarter if Australians increased their activity levels by just thirty minutes, five days a week.\textsuperscript{44} Physical inactivity is a significant burden on the Australia economy, costing $13.8 billion in 2008 and causing an estimated 16,000 premature deaths every year.\textsuperscript{45}

**Tobacco control**

- Tobacco smoking is a significant modifiable risk factor for kidney disease\textsuperscript{46} as well as a range of other diseases, including numerous cancers, stroke and heart disease.\textsuperscript{47}
- Tobacco smoking is the leading cause of preventable death in Australia and economic and social costs of smoking were estimated to be approximately $31.5 billion in 2004/05 (more recent figures are not available).\textsuperscript{48}
- Reducing tobacco smoking rates has significant economic and social benefits for Australia.\textsuperscript{49}
- Australia is a Party to the World Health Organisation (WHO) Framework Convention on Tobacco Control (FCTC).\textsuperscript{50} Under the FCTC, Australia must adopt and implement effective measures for preventing and reducing tobacco consumption, nicotine addiction and exposure to tobacco smoke. The FCTC also obliges Australia to take steps to protect its tobacco control setting and implementation from interference from the tobacco industry and its interests.

**Primordial and primary prevention - the role of social determinants**

The WHO defines social determinants as “the conditions in which people are born, grow, work, live, and age, and the set of forces and systems shaping the conditions of daily life.” Social factors determining health include income, wealth, education, occupation and social inequality based on race and ethnic group membership.\textsuperscript{51}

- Lower socioeconomic status is associated with a higher prevalence of CKD; 13.5% of people with the lowest socioeconomic status have clinical evidence of CKD compared with 8.4% of people with the highest socioeconomic status.\textsuperscript{52}
- Lower socioeconomic status is also associated with poorer dialysis outcomes.\textsuperscript{53}
- CKD related deaths in the lowest socioeconomic populations in society are almost twice that of those in the highest socioeconomic group.
- Between one-third and one-half of the health gap between Aboriginal and Torres Strait Islander people and non-Indigenous people is attributable to differences in social determinants of health.\textsuperscript{54} Addressing chronic disease prevention, including CKD, in Australia requires addressing the social determinants that influence Indigenous health including:
  - Connection to family, community, country, language and culture
  - Racism
  - Early childhood development, education and youth
  - Employment and income
  - Housing, environment and infrastructure
  - Interaction with government systems and services
  - Law and justice
  - Health choices
  - Food security

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

**Early primary care risk assessment, detection and intervention**

- Up to 90% of kidney function can be lost before symptoms are evident.
- Around 10% of people attending general practice have CKD, but most do not know it.\textsuperscript{55}
- Primary care is the logical location for assessment and detection of CKD given 83% of Australians visit their general practitioner at least once a year.\textsuperscript{56}

A key benefit of primary care detection and effective primary care management is early nephrology referral.
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Early referral is associated with:

- significant improvements in mortality, morbidity and hospitalisations, better uptake of peritoneal dialysis and earlier placement of arteriovenous fistulae.\(^5^7\)
- lower overall treatment costs and reduced likelihood of progressing to the next CKD stage.\(^5^8,5^9\)

However among patients who reach ESKD requiring dialysis in Australia, around quarter present to nephrologists late and commence dialysis within 90 days.\(^6^0\)

Risk assessment is most effective when coordinated with referral with primary health services and lifestyle modification for follow up of those found to be high risk.\(^6^1\)

**Health assessments**

The Medical Benefits Scheme (MBS) Health Assessment items are the key mechanism for detecting chronic disease in primary care settings. Health assessments may include the use of risk assessment tools and tools to establish diagnosis of chronic disease, as well as the development of a management plan. The Medicare Benefits Taskforce Review Report from the General Practice and Primary Care Clinical Committee: Phase 2, made a number of recommendations regarding the suite of Health Assessment items (701, 703, 705, 707 and 715)\(^7^0\) aimed at improving the quality of health assessments, including:

- Include a requirement that the GP must personally explain the findings and implications of the Health Assessment to the patient, and agree with the patient a plan for health promotion and disease prevention based on these findings.
- Include the requirement that the Health Assessment be uploaded to My Health Record, unless patient consent is withdrawn, and where reasonably achievable.
- Expand eligibility of Health Assessments to new at-risk populations and modify existing populations to better align with clinical and service needs.
- Ensure that the content of Health Assessments should conform to guidelines generally acceptable to the wider body of the profession such as the Guidelines for preventive activities in general practice.\(^8^3\)

The National Vascular Disease Prevention Alliance (NVDPA) has been calling for an ‘Integrated Health Check’ at a GP level, which would:

- Check eligible patients for vascular and related conditions through an ‘Integrated Health Check’ which includes an absolute cardiovascular risk assessment, diabetes check and kidney disease check.
- Manage the overall risk profile of patients, stratify risk (high, moderate, low) and address their combined risk factors through advice about healthy eating, healthy physical activity and healthy weight, medical management and/or facilitating and coordinating access to evidence-based prevention programs.
- Maintain a patient register, with recall and reminder system for patients eligible for assessment and those who require management of risk.
- Record and report proportion of eligible patients who are checked, who have their risk managed according to the relevant practice guidelines, who have a GP management plan, and who access evidence-based prevention programs.

In February 2019 the Commonwealth Government announced primary care Heart Health Checks lasting at least 20 minutes would be made available from 1 April 2019.\(^6^4\) The two new interim items (699 and 177) are available to patients with cardiovascular disease, or patients at risk of developing cardiovascular disease Cardiovascular disease including: people aged 45 years and above Aboriginal or Torres Strait Islander persons who are aged 30 years and above. The eligibility criteria and scope of and these items is narrower than the recommendations of the Medicare Benefits Taskforce Review Report from the General Practice and Primary Care Clinical Committee. The committee recommended expanding the availability of health assessments to people 40 years and over and deleting the short (20 minute) health assessment items 701 (224*).

**Lifestyle modification**

Lifestyle modification programs are aimed at are people identified at high risk or in the early stages of chronic diseases, such as CKD. Such programs typically focus on healthy eating, physical activity, weight loss and
smoking cessation and can be delivered online, in person, by telephone or a combination. Lifestyle modification is shown to be effective in reducing a key risk factor for CKD, diabetes, particularly when directed by a dietician and when founded on recognised guidelines. These effects are shown to last up to 20 years.

Inherited kidney diseases
A number of forms of kidney diseases are genetic. These include cystic diseases, such as autosomal dominant and recessive polycystic kidney disease, metabolic diseases, such as Bartter and Gitelman syndromes and immune glomerulonephritis.

- Polycystic Kidney Disease (PKD) is the most common serious genetic disorder of the kidneys, with 1 in 1,000 Australians likely to be affected.
- In 90 percent of Autosomal Dominant Polycystic Kidney Disease (ADPKD) cases there is a known family history of the disease.
- People with PKD have a one in two chance of passing the condition on to their children.

Currently genetic testing for inherited kidney diseases is not widely accessible in Australia, with access varying between states and individual hospitals. The Action Plan for Critical Change in Polycystic Kidney Disease Outcomes in Australia recommends Medicare-rebatable genetic testing to provide equitable access to testing across Australia. The Medical Services Advisory Committee (MSAC) recently supported the application (1449) for MBS funding of genetic testing for the diagnosis of Alport’s Syndrome (a disease affecting the kidney function, sight and hearing).

The benefits of genetic testing include:
- Earlier diagnosis
- Personalised treatment
- Earlier intervention and better outcomes
- Providing information to allow for family planning and other decisions
- Enabling identification of appropriate living kidney donors.

1.3 Raise community and health professional awareness and understanding of CKD and other chronic conditions to support prevention and early detection targeted at priority groups

Health literacy
Health literacy is the capacity to absorb the health information necessary to make appropriate health decisions.

- Both chronic disease awareness and overall health literacy in Australia are relatively low.
- Low health literacy is associated with lower levels of health knowledge, poorer health outcomes and higher use of health services.
- Both disease awareness and overall health literacy are important determinants of chronic disease self-management.

Kidney disease awareness in Australia
1 in 3 are at risk of developing CKD and over 1.7 million Australian adults – a striking 1 in 10 - are currently living with biomedical markers of CKD. However less than 10% of people with CKD know they have the condition, meaning there are over 1.5 million Australians who are unaware that they are living with indicators of CKD.

There is relatively little recent evidence regarding knowledge of CKD among the Australian general public although a national study found understanding of kidney disease is extremely low, with less than 10% of respondents aware of the causes of the disease. Equally concerning is that understanding of kidney disease in people diagnosed with CKD is also low. A survey of patients referred to an Australian nephrology clinic found:
- almost 40% were unable to identify causes of CKD
- 51% were unsure of how the disease is managed
• 16% were unsure why they had been referred to a nephrologist
• most participants believed they had received insufficient information regarding kidney disease from primary care.

A follow up study of a subsection of these patients 12 months later found little improvement in overall knowledge,79 highlighting gaps in the education offered in both primary and tertiary care. This finding reflects research showing a large number of people diagnosed with chronic diseases in Australia have limited understanding of their disease.80

Primary care education

CKD is significantly under-recognised and under-treated in primary care, leading to late diagnosis and specialist referral.

• Among people with abnormal kidney function, only an estimated 18% are correctly identified as having CKD in primary care settings.81
• There are large shortfalls in the recording of kidney function and the recorded prescribing of appropriate kidney protective therapy.82 For example it is estimated every second person with CKD receiving blood pressure medication does not have their blood pressure controlled to target levels.83
• The high proportion of CKD patients failing to be diagnosed in primary care highlights the need for ongoing primary care health professional education to improve knowledge of CKD and appropriate treatment.84
• There is variation in kidney disease patient education practices Australia. Inconsistencies are evident in: the method and delivery format; time devoted to education; the timing of information delivery; and the provision of information, such as dialysis type and location.85,86

Priority 2. Optimal Care and Support

2.1 Deliver high quality, equitable kidney care across Australia

While overall people in Australia affected by CKD receive high quality care, disparities in access to and outcomes of care across the country. These differences are evident in disparities for people experiencing economic and social disadvantage, those in regional and remote areas and Aboriginal and Torres Strait Islander populations.

Optimal Care Pathways

Optimal Care Pathways (also known as standardised care pathways, care pathways, care maps) are guides that describe the best possible care for patients with particular condition or with particular needs. They aim to improve patient outcomes by promoting consistent, coordinated and quality care regardless of where they live.

Optimal Care Pathways provide healthcare professionals and health service providers with an agreed consistent nationwide approach to basic standards of care that is based on current best practice including clinical guidelines, consensus statements, standards and research. The Optimal Care Pathways must allow for healthcare professionals to use their own professional judgement as appropriate and be flexible to accommodate non-standard situations such as the presence of complex comorbidities.

Optimal Care Pathways:
• Provide a mandate for service improvement priorities such as identifying gaps in current services and reducing unwanted variations in practice
• Are useful in deciding how best to organise service delivery to achieve the best outcomes for patients
• Are relevant across all jurisdictions
• Use by healthcare professionals as an information resource and tool to promote multidisciplinary discussion
• Patient versions ("what to expect" guides) can help patients, carers and family members understand their disease and treatment and what they should expect in terms of management. They also support collaboration and communication between people affected by a disease.

Optimal Care Pathways are well established and have generally been shown to improve patient outcomes, reduce health care costs, promote patient satisfaction, foster healthcare professional collaboration and improve process outcomes.87,88

Cancer care in Australia has been improved through the national adoption of Optimal Care Cancer Pathways through the Australian Health Ministers’ Advisory Council (AHMAC). The pathways have been developed through consultation with a wide range of expert multidisciplinary teams, peak health organisations, consumers and carers and are nationally endorsed by the National Cancer Expert Reference Group (includes representation from each jurisdiction and nationally), Cancer Australia and Cancer Council Australia.89 Evaluation of the Optimal Care Cancer Pathways is currently underway. The findings will help inform the development of the proposed Optimal Care Kidney Pathways.

Resource planning
There is a clear need to address planning and delivery of renal replacement services throughout Australia. The biggest growth in service needs is likely to be for those with pre-dialysis stage CKD, where preparation for ESKD is crucial to prevent hospitalisations, comorbidity and costs. The non-RRT cohort with ESKD also need specific resources around conservative management, management of symptom burden and palliative care. The resources required here may be largely community based and in primary care.

Increasing demands for RRT are placing an additional strain on existing services and 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 inefficient90
• A marked variation by state in the uptake of home dialysis programs91
• A low number of people being treated on dialysis programs by international comparison92
• A marked variation by state in the demographics being offered dialysis therapy.93

In addition there is there is a lack of public accountability of dialysis activity and no systematic auditing of adequacy of care, safety or patient outcomes. Some of the data needed to support the development of performance indicators and benchmarking is currently available through the ANZDATA. However there is a lack of nationally consistent data collection for detection and pre-dialysis stage CKD, hindering the measurement and reporting of early stage patient outcomes. Data collection throughout the entire patient journey is required to effectively monitor and evaluate quality of care and patient outcomes.

Kidney care in regional, rural and remote communities
People living in rural areas of Australia have poorer health outcomes than those living in cities.

• Mortality rates in regional areas are higher than major cities and increase further with increasing remoteness.94
• The CKD related death rate in remote areas is twice that of the death rate in cities.95
• While socioeconomic and demographic factors (including being Aboriginal and Torres Strait Islander) contribute to the disparity in health outcomes, the gap remains even after controlling for these factors. For example people in rural areas undergo fewer diagnostic96,97,98 or therapeutic interventions99,100 than Australians in major cities.
• Patients in metropolitan areas are more likely to access dialysis than regional and remote areas. In 2016 there were 12,706 people in Australia on dialysis. Around 80% of these people live in major cities, 20% of these are located in inner regional areas, 8% in outer regional and 2% in remote or very remote areas.101
• Patients commencing dialysis in rural and remote settings have worse outcomes than those in metropolitan areas. In 2012-13, the hospitalisation rate where CKD was recorded as the principal and/or additional diagnosis (excluding dialysis) was twice as high in remote and very remote compared with major cities.102
Commencing dialysis in regional or remote areas of Australia is an independent predictor of mortality. Commencing dialysis in regional or remote areas of Australia is an independent predictor of mortality. Regional and remote patients with ESKD are less likely to undergo transplants. Distance from healthcare facilities is associated with lower attendance at renal specialist or multidisciplinary care clinics and lower overall quality of care. Telehealth has the capacity to improve CKD care in regional and remote areas and reduce costs to both for both patients and the health system. A review of telehealth at Royal Melbourne Hospital transplant unit found remote clinical reviews resulted in significant time and costs savings for patients and reduced greenhouse emissions. Similarly a retrospective audit of paediatric nephrology telehealth consultations through the Queensland Telepaediatric Service over 10 years found 318 paediatric telenephrology consultations had been conducted with regional remote patients, with an average saving of $505 per consultation.

Living donation and transplantation

Recipients of living donor transplants have better morbidity and mortality outcomes, with donor kidney transplantation associated with a 27 percent increase in patient survival at 20 years over that observed with deceased donors. Rates of living donation vary markedly across the country, with lower rates of living donation outside major cities. A barrier to live kidney donation is the financial cost to the donor, with international experience indicating that 45% of living donors experience some form of financial hardship and that nearly a quarter of potential living donors choose not to donate because of anticipated financial hardship. In Australia donors who work can access paid leave, for a specified period, via a reimbursement to the employer through the ‘Supporting Living Organ Donors’ program. The program also allows donors to claim reimbursement for some out of pocket expenses, enabling donors who are not employed to participate.

Transplant access and outcomes

Kidney transplants are associated with a five to ten fold reduction in mortality in comparison with dialysis. The Organ and Tissue Authority (OTA) was established in 2009 to manage the implementation of the Australian Government’s national program for increasing organ and tissue donation for transplantation in partnership with the DonateLife Network, state and territory governments, the donation and transplantation clinical sectors, eye and tissue banks, and the community. Between 2009 and 2017 the number of deceased organ donors more than doubled (106%) and the number of transplant recipients increased by 75%.

Access to the kidney transplant waiting list is via individual transplant programs based on set eligibility criteria – including meeting the medium to long term life expectancy eligibility criteria from the Transplantation Society of Australia and New Zealand (TSANZ) and as well being eligible for Medicare. States and individual transplant unit may also have differing approaches that account for differences in populations and geography.

There is evidence of disparities in access to transplants between population groups. Aboriginal and Torres Strait Islander patients are less likely to be added to transplantation waiting list, a disparity not explained by patient or disease related factors. Aboriginal and Torres Strait Islander patients and people living in rural Australia also experience poorer transplant outcomes, including higher vascular rejection rates and/or lower patient survival post-transplantation.

The TSANZ Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia report includes 35 recommendations to address these disparities. A further Review of Organ Donation, Retrieval and Transplantation System undertaken by the Department of Health for all governments through the Council of Australian Governments Health Council will be publicly available in 2019.

Paediatric to adult transition

Over 150,000 young Australians (aged <25 years) have biomedical markers of kidney disease. In 2018 almost 700 were on RRT for ESKD. Of these, 190 young Australians were receiving dialysis and 506 living with a transplant.
Transition to adult health care is challenging for young people, their families and health care workers. Apart from the normal developmental factors influencing young people, there are additional factors associated with having a chronic disease including anger and resentment, denial of severity of illness and/or questioning authority leading to rejecting medical advice and treatment. Patients in the 15-24 age range have to cope with treatment in an adult clinic dominated by a significantly larger and older cohort with medical teams often ill-equipped and under-resourced to tailor services to support younger patients. These factors mark the transition from to adult care as high risk of non-adherence to medication and/or complex transplant medication compliance regimes.

Consequently adolescent and young adult kidney transplant recipients have a worse transplant outcome than any other age group up to 70 years of age, with higher rates of dangerous late acute rejection and reduced 5-year graft survival. Dedicated clinics for young adults transitioning to adult care or presenting with kidney disease for the first time are designed to improve outcomes for these patients, with evidence from a UK service demonstrating a 67% reduction in transplant failure associated with transition to adult care.

2.2 Reduce the financial impact of kidney disease on patients carers and families and the health system

The financial impact of kidney disease

CKD takes a significant toll on the lives of patients and their families. Advanced kidney disease is associated with increased odds of falling into relative poverty, beyond social determinants. An Australian study of CKD patients found over 70% of participants faced out of pocket cost exceeding 10% of their household costs, with over half reporting economic hardship as a result.

These costs were found to have severe consequences for people with low financial resources, with:

- 13% of participants going without meals
- 11% unable to heat their homes
- 12% increasing the amount owing on their credit cards by greater than $1000
- 19% missing medical appointments or failing to fill prescriptions because they were short of money.

The financial impact of kidney disease relate to:

- treatment and medication associated costs
- transport for treatment and specialist appointment costs
- impact of the disease on capacity to work
- the need for ongoing care from a family member, further impacting on family income.
- Difficulty accessing carers support payments.

Costs of home dialysis and the role of carers

- Currently 30% of total dialysis patients dialyse at home.
- Home dialysis is a considerable cost saving to government – annually up to $30,000 per patient.
- Greater uptake of home dialysis has the potential to reduce strain on renal unit resource and the costs of dialysis treatment to the healthcare system.
- Many patients undertaking home dialysis are able to return to or continue in the workforce, where previously this was not possible as the ability to undertake dialysis outside work hours was restricted.
- Other savings include decreasing need for travel and accommodation assistance.
- An estimated $378 to $430 million could be saved over the next 10 years if the increased use of home dialysis was achieved.

Despite this, the capital set-up costs for home dialysis machines and the associated water and electrical costs are only partially reimbursed or discounted, in varying degrees, through differing means across states and territories.
In addition uptake of home dialysis frequently depends on carer management especially if the patient is a child, has limited mobility, dexterity or movement, or has failing memory. Carer contribution varies from completely performing the dialysis, to being present during dialysis to assist during clinical emergencies (which can be potentially life-threatening). During dialysis the person undergoing treatment is completely dependent on their carer for all support related to provision of daily living. The average time spent for this role alone, is around 20 hours a week, which compromises the ability of the carer to work.

**Estimated cost of expanding finance support to patients and carers**

Deloitte Access Economics was engaged by Kidney Health Australia to provide indicative costings for two of the proposed actions in the Action Plan:

- **Action 2.2.3** Increase access to the Commonwealth funded Carer Allowance for carers of patients with ESKD
- **Action 2.2.4** Increase access to government support for people with ESKD

Note that conservative eligibility assumptions have been made to estimate an ‘upper bound’ cost of the actions. In addition, it is assumed that the entire eligible population would receive the payments, which is unlikely in practice.

The estimated cost of expanding the Commonwealth-funded Carer Allowance for carers of ESKD patients from 2019 to 2029 is $467.2 million. If the allowance were limited to eligible patients undergoing home haemodialysis the cost of the allowance from 2019 to 2029 would be $56.0 million (assuming that the growth rate of home dialysis remains constant relative to other modalities).

The estimated cost of a medical allowance for ESKD patients from 2019 to 2029 is $355.4 million. The estimated average annual cost of implementing actions (between the period of 2019 to 2029) would be $104.6 million. The total cost of the actions from 2019 to 2029 in net present value terms is $822.7 million.

**Transport costs**

Travel for care represents a significant ongoing cost for people living with ESKD. Unlike most other chronic illnesses, travel for in-hospital/renal unit dialysis requires frequent and ongoing travel – a minimum of three times weekly – to stay alive.

Eligibility for and rates of travel assistance varies between the State and Territory administered Patient Transport Assisted Schemes (PTAS). For example, there is no national consistency in the distance thresholds or the per kilometre subsidies for those who travel by car. None of the schemes sufficiently reimburse patients for the true cost of their travel for care, exacerbating the financial burden of living with ESKD. Those in regional and rural areas and the elderly disproportionately feel the impact of travel costs. Research by Kidney Health Australia found:

- 74.4% of transport to dialysis are car trips – 39.5% being driven by another person and 34.9% driving themselves
- driving to dialysis incur costs for travel that comprise approximately 15% of the pension
- costs are highest for people in regional areas, with people who pay over $50 per week disproportionately represented in regional areas.

Payments made under PTAS for accommodation, where overnight or continued travel away from home is needed, also vary significantly between states, and none reflect the true cost of staying away from home. For rural and remote patients, such as Indigenous communities, accommodation costs can represent a significant barrier to treatment. These payment rates range from $35 per night up to $60 (or $75 for a couple) to cover commercial accommodation. Again both the levels of payment, and the significant state-by-state variation, cause issues for patients and their carers.
2.3 Improve support for people affected by chronic kidney disease

**Psychosocial support**

People living with kidney disease, in particular those with ESKD but also earlier stages of CKD, suffer severe and debilitating psychological burden, in addition to and exacerbating the physical symptom burden.\textsuperscript{130} Treatment poses a significant burden on patients and is frequently associated with additional stresses such as changes in family dynamics, social life, employment and finances,\textsuperscript{131} affecting quality of life and leading to high levels of anxiety and depression.\textsuperscript{132}

Whilst the psychosocial burden of living with CKD is increasing being recognised, in particular through patient reported outcome measures, the emphasis is still on the physical care. Psychosocial support needs to become more of a focused component of CKD treatment.

- Around a quarter of people living with CKD suffer from depression.\textsuperscript{133}
- Psychosocial stresses are associated with both lower quality of life and worse prognostic outcomes.\textsuperscript{134} For example, depression is associated with lower levels of treatment adherence and higher rates of hospitalisation\textsuperscript{135} as well as higher rates of withdrawal from dialysis and mortality.\textsuperscript{136}
- Psychosocial interventions impact on depression anxiety and improve quality of life for both people with kidney disease and carers.\textsuperscript{137}
- Telephone and other telehealth psychosocial support services for patients and carers are associated with\textsuperscript{138,139}
  - enhanced psychological health (reduced anxiety, depression, stress, burden, irritation and isolation)
  - increased self-management
  - improved caregiving knowledge/skills/patient management
  - higher quality of life
  - more social support/social function/need met
  - improved coping/problem solving skills/goal attainment/decision-making
  - better communication with providers
  - more cost saving
  - enhanced physical health
  - productivity.

**Peer support**

Peer support programs are an important element in chronic disease management. Peer support is associated with increased self-management and improvement in health related quality of life.\textsuperscript{140} Benefits of peer support include:

- Access practical information based on real work experience
- Social support and reduced sense of isolation
- Positive role modelling for managing disease
- Increasing empowerment and sense of agency.\textsuperscript{141}

**Dialysis travel in Australia**

- Travel while on dialysis is challenging and options are limited but travel is not impossible. Provision of water and electricity is also a major consideration.
- Travel limitations depend on what mode of dialysis a person is on. Peritoneal dialysis (PD) offers the least restrictive options for travel but still requires meticulous planning in particular for dialysis equipment and supplies. Haemodialysis (HD) in-hospital or satellite is the most restrictive option.
- Options for travel on dialysis include:
  - take equipment and supplies (in a caravan or trailer for home haemodialysis) – PD or home HD
  - fixed dialysis house or campervan that has a machine – home HD
  - dialysis at a dialysis unit close to your destination - HD
  - the Kidney Health Australia Big Red Kidney Bus - HD
  - a special holiday tour organised with dialysis included – HD.
The option of using a fixed dialysis unit at the holiday destination is limited by availability of free dialysis chairs and the lack of a consistent agreement between states for funding arrangements.

### 2.4 Reduce the disproportionate burden of kidney disease on Aboriginal and Torres Strait Islander communities

The prevalence of CKD and the overall levels of ESKD among Aboriginal and Torres Strait Islander peoples are consistently reported as significantly higher than among other Australians.

- Aboriginal and Torres Strait Islander people represent less than 2.5 percent of the national population, however they account for approximately 11% of people commencing kidney replacement therapy each year.1
- Aboriginal and Torres Strait Islander adults living in remote areas are more than twice as likely as those living in non-remote areas to have signs of chronic kidney disease. Amongst Aboriginal and Torres Strait Islanders, the heaviest disease burden impacts on people living in very remote (36.7%) and remote (27.6%) regions. Outer regional areas (17.7%) remains high. Inner regional (10.7%) and major cities (11.8%) are less likely to be impacted as greatly.
- The median age of Indigenous people with ESKF is about 30 years less than for non-Indigenous people and occurs within the ages of 35 and 65.142
- CKD disproportionately causes or contributes to Indigenous deaths, responsible for 215.8 percent of deaths between 2008 and 2012143 and contributing to 5 percent of the total disparity between Indigenous and non-Indigenous mortality.144

#### Disparities in treatment

- Indigenous Australians with kidney disease are more reliant on dialysis and less likely to receive a transplant than non-Indigenous Australians.
- Indigenous patients are 10 times less likely than non-Indigenous patients to be added to the waiting list for a kidney donation transplant.
- In 2017 87% of Indigenous Australians with kidney disease were reliant on dialysis and 13% had received a kidney transplant, in comparison to 49 percent and 51% respectively in the non-Indigenous population.145
- The incidence of ESKD for Indigenous peoples in remote areas of Australia is 18-20 times higher than that of comparable non-Indigenous peoples. Despite this only 241 of 10,551 patients with a functioning kidney transplant are Indigenous.146
- In remote areas, 78% of patients have to relocate to access dialysis or transplant services, compared with 39% of those who live in rural areas and 15% of urban Indigenous ESKD patients.147
- Separation from country creates significant biological, psychological, social and economic consequences on the health and wellbeing of consumers, their families, communities the wider health and welfare system. At present, there is inadequate support for Aboriginal and Torres Strait Islander patients to assist and support the renal pathway journey, including emotional and social support.

The **Renal Roadmap for Aboriginal and Torres Strait Islander Health** was developed in 2018 to address to enormous burden of kidney disease on Aboriginal and Torres Strait Islander communities. The Roadmap is the blueprint for a comprehensive, coordinated and sustained multi-sectoral campaign that addresses the social determinants underpinning the disproportionate burden of CKD on Indigenous communities. The Roadmap focuses on five domains:

- Primordial Prevention
- Primary Prevention
- Primary Healthcare, including secondary and tertiary prevention
- Tertiary Health Care
- Research and Data

The TSANZ Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia was commissioned to examine available evidence around:

- Evidence and gaps around steps to waitlisting and to long term transplant function
- Improving Indigenous dialysis patients’ health to improve their capacity to be listed
- Measures to address these gaps.

The report includes 35 recommendations, with the three nominated highest priority being:

1. Establishing a resourced National Indigenous Kidney Transplantation Taskforce
2. Enhancing data collection and reporting processes on pre- and post-transplant outcomes
3. Improving the equity and accessibility of transplantation for Indigenous patients.
Priority 3. Research and Data

3.1 Establish a well-funded collaborative kidney research program to increase strategic research investment, foster cross collaboration and translate cutting edge research into real world outcomes

The relative level of support flowing to kidney research has never matched the expenditure devoted to treating kidney disease. This continues to be true with the National Health and Medical Research Council (NHMRC) allocating about 1 percent of its funds to the kidney area when it consumes about 2 percent of the total health budget. The rates for CKD as the underlying and/or associated cause of death remained relatively stable for over twenty years. Without improved research outcomes, this cost is simply going to grow. The benefits of targeted investment are evident in other diseases. Funding for cancer research has increased steadily over the past several decades, and there have been associated improvements in survival rates across a number of cancers, including breast and prostate cancers. Kidney disease requires this same targeted investment.

Consumer voices

Internationally there is growing recognition of the importance of patient led research. Despite this, Australia lags behind on integrating consumer engagement into health and medical research. While consumers may participate in clinical trials, a review of health and medical research in Australia identified a need leadership to ensure meaningful consumer involvement in the early stages of research, such as identifying and shaping research topics. The need for increased consumer engagement in research is reflected in the Australian Medical Research and Innovation Priorities 2018-2020, which includes “consumer driven research” The priority recommends establishing programs “that can pair researchers to consumers, carers and clinicians and through a joint priority setting methodology design grant opportunities that enable consumer-driven targeted research” This approach underpins Canada’s CAN Solve CKD program, a patient oriented kidney research network that has set key kidney research priorities and funded 18 patient centred research projects.

There have been significant advances in bringing the consumer voice to CKD research in Australia over the past 10 years. In 2014 Kidney Health Australia held a consumer workshop to explore research priorities in kidney disease. Subsequently, Better Evidence and Translation in Chronic Kidney Disease (BEAT-CKD) in partnership with Kidney Health Australia have convened a series of consumer workshops to discuss principles and strategies for patient involvement in research identified a number of themes including:

- Respecting consumer expertise and commitment in research
- Being aware of the individual needs of consumers and reducing the burden of being involved
- Harnessing existing relationships with clinicians and exposing consumers to clinical research
- Developing a coordinated approach to ensure all voices are heard, equitable access to information and opportunities to participate
- Fostering a patient centred culture, with research a two-way partnership between researchers and the kidney community.

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

Monitoring and evaluation are essential for measuring progress in kidney health. High quality data is essential to understanding the natural history, epidemiology, and burden of disease, quality of care and treatment outcomes, information that can be used as part of a continuous quality improvement process. High quality data will underpin the development and evaluation of Optimal Care Kidney Pathways, which will include pathways from detection and early stage disease through RRT and conservative care.

The ANZDATA registry, which collects data about the 24,738 people in Australia and New Zealand on RRT for ESKD, is an essential tool for kidney research and treatment improvements. ANZDATA is used by government agencies, including the Organ and Tissue Authority, health services and researchers. Data is used to review practice, determine variation in practices between health services and jurisdictions, evaluate treatment outcomes, aid in decision making around treatment and support options, monitor long term survival and mortality for kidney failure and variability in access to care. 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.\textsuperscript{164}

However while a number of states collect CKD data, there is no nationally coordinated dataset to capture non-ESKD care, which impacts on the capacity of researchers to follow the natural progression of disease and evaluate the efficacy of models of care to manage early stage disease.\textsuperscript{165,166} Given the high disease and cost burden associated with CKD and that the majority of people with CKD are at pre-RRT stage, capturing data at every stage of the patient journey will be essential to improve patient outcomes.

**Australian Health Survey**

High quality comprehensive national health data is essential in providing decision makers, health professionals and researchers with an understanding of the status of the key diseases and risk factors.\textsuperscript{167} Measuring the impact of health interventions allows governments to ensure the most effective use of limited resources. The first Australian Health Survey (2011-13), with critical biomedical data coming from the National Health Measures Survey – has been the most comprehensive health survey ever conducted in Australia.\textsuperscript{168} It has collected information such as health status, behavioural risk factors (e.g. smoking, physical inactivity), service use, medications, and the prevalence of biomedical risk factors, such as high blood pressure, high blood cholesterol and overweight/obesity. It is important that this survey be repeated every 5-6 years, to ensure timely information to support policy decisions. The cost of the survey is minimal compared to the cost of the chronic disease burden. Failure to continue investment in the survey, especially the biomedical component, would lead to sub-optimal investment of resources (waste and inefficiency) and poorer health outcomes for Australians.

**Clinical guidelines**

Clinical practice guidelines (or simply “clinical guidelines”) are recommendations on how to diagnose and treat a medical condition. They are mainly written for healthcare professionals but some guidelines have been adapted for patients.

Guidelines summarise the current medical knowledge, weigh the benefits and harms of diagnostic procedures and treatments, and give specific recommendations based on this information. They should also provide information about the scientific evidence supporting those recommendations. Healthcare professionals don’t have to follow the recommendations if they don’t think they are suitable for certain patients. But deviations from guidelines must be justified.

Clinical guidelines are essential tools for delivering consistent, best practice kidney care. The efficacy of guidelines depends on both the extent to which they are underpinned by rigorous and up to date research and the effectiveness with which they are utilised by the clinical community.

The Kidney Health Australia-Caring for Australasians with Renal Impairment guidelines group (known as KHA-CARI) are the to key evidence based clinical practice guidelines for the management of chronic kidney disease in Australia and New Zealand.

Clinical guidelines must be updated regularly. New improvements in treatment may not to be incorporated into clinical practice, due to guidelines that fail to keep pace research or failure to adequately disseminate/communicate new best practice to the clinical community. Cochrane Australia identifies a number of key barriers to the effective use of guidelines including:

- Poorly targeted research
- Inefficient evidence synthesis
- Information overload due to the enormous amount of research produced
- Lack of co-ordination between stakeholders and limited stakeholder involvement
- Research produced in inaccessible formats.\textsuperscript{169}

In an effort to overcome these barriers Cochrane Australia and the Australian Living Evidence Consortium are developing Living Evidence – living systematic reviews and guidelines – a new methodology for guidelines
development that facilitate rapid real-time synthesis of new evidence into guidelines. Living Evidence uses continuous evidence surveillance and rapid response pathways to incorporate new relevant evidence into systematic reviews and clinical practice guideline recommendations as soon as it becomes available.
## Appendices

### Appendix 1: Glossary

A list of medical terms used in this Action Plan is provided below in alphabetical order.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ALBUMINURIA</td>
<td>Protein in the urine.</td>
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<tr>
<td>CARDIOVASCULAR DISEASE</td>
<td>Includes all diseases and conditions of the heart and blood vessels, such as arteries and veins.</td>
</tr>
<tr>
<td>CHRONIC KIDNEY DISEASE (CKD)</td>
<td>All kidney conditions where a person has evidence of kidney damage and/or reduced kidney function that lasts for three months.</td>
</tr>
<tr>
<td>SUPPORTIVE CARE</td>
<td>Also known as non-renal replacement therapy. Active treatment for ESKD that does not involve dialysis or a transplant. Uses diet and medication to manage symptoms of kidney failure.</td>
</tr>
<tr>
<td>CREATININE</td>
<td>A breakdown product of protein metabolism. The concentration of creatinine in the blood is used as a measure of kidney function.</td>
</tr>
<tr>
<td>DIABETES</td>
<td>Is a chronic disease caused by problems with the production and/or action of insulin in the body.</td>
</tr>
<tr>
<td>DIALYSIS</td>
<td>A treatment for kidney failure, which removes wastes and extra fluid from the blood by filtering through a special membrane. There are two types of dialysis, haemodialysis and peritoneal dialysis.</td>
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<tr>
<td>eGFR</td>
<td>‘estimated glomerular filtration rate’ measures how well the kidneys filter wastes from the blood.</td>
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<tr>
<td>END-STAGE KIDNEY DISEASE (ESKD)</td>
<td>Also known as end-stage renal disease (ESRD). It is when the kidneys have totally or almost totally stopped working. People with ESKD must either have regular dialysis (use a machine that filters the blood) or have a kidney transplant to stay alive.</td>
</tr>
<tr>
<td>GLOMERULONEPHRITIS</td>
<td>A range of diseases that cause Inflammation of the kidney.</td>
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<tr>
<td>HAEMATURIA</td>
<td>Blood in the urine.</td>
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<tr>
<td>HAEMODIALYSIS</td>
<td>Blood travels through a special filter called a ‘dialyser’ before being returned cleaned to the body.</td>
</tr>
<tr>
<td>HYPERTENSION</td>
<td>High blood pressure.</td>
</tr>
<tr>
<td>NEPHRONS</td>
<td>Filtering units of the kidneys.</td>
</tr>
<tr>
<td>OEDEMA</td>
<td>Swelling caused by the accumulation of fluid in body tissues.</td>
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<tr>
<td><strong>OSTEOPOROSIS</strong></td>
<td>Reduction in bone mass and density, also known as brittle bones.</td>
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<tr>
<td><strong>PERITONEAL DIALYSIS</strong></td>
<td>Is where a special fluid is put into the peritoneal cavity through a soft plastic tube, then drained out of the body.</td>
</tr>
<tr>
<td><strong>POLYCYSTIC KIDNEY DISEASE</strong></td>
<td>A genetic kidney disorder characterised by multiple cysts in the kidneys.</td>
</tr>
<tr>
<td><strong>SIDE EFFECTS</strong></td>
<td>Unfavourable reactions to a medication.</td>
</tr>
<tr>
<td><strong>SUPPORTIVE CARE</strong></td>
<td>Also known as non-renal replacement therapy. Active treatment for ESKD that does not involve dialysis or a transplant. Uses diet and medication to manage symptoms of kidney failure.</td>
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</table>
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ACCHS</td>
<td>Aboriginal Community Controlled Health Services</td>
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<td>AHMAC</td>
<td>Australian Health Ministers’ Advisory Council</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>ANZDATA</td>
<td>Australia and New Zealand Dialysis and Transplant Registry</td>
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<tr>
<td>ANZSN</td>
<td>Australian and New Zealand Society of Nephrology</td>
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<tr>
<td>ADPKD</td>
<td>Autosomal Dominant Polycystic Kidney Disease</td>
</tr>
<tr>
<td>BEAT-CKD</td>
<td>Better Evidence and Translation in Chronic Kidney Disease</td>
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<tr>
<td>CHC</td>
<td>Council of Australian Governments Health Council</td>
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<tr>
<td>CKD</td>
<td>chronic kidney disease</td>
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<tr>
<td>DALY</td>
<td>disability-adjusted life years</td>
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<tr>
<td>CVD</td>
<td>cardiovascular disease</td>
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<tr>
<td>ESKD</td>
<td>end-stage kidney disease</td>
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<tr>
<td>FCTC</td>
<td>Framework Convention on Tobacco Control</td>
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<tr>
<td>HD</td>
<td>Haemodialysis</td>
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<tr>
<td>KHA-CARI</td>
<td>Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group</td>
</tr>
<tr>
<td>MBS</td>
<td>Medicare Benefits Schedule</td>
</tr>
<tr>
<td>MRFF</td>
<td>Medical Research Future Fund</td>
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<tr>
<td>MSAC</td>
<td>Medical Services Advisory Committee</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NVDPA</td>
<td>National Vascular Disease Prevention Alliance</td>
</tr>
<tr>
<td>OCPKD</td>
<td>Optimal Care Pathways for Kidney Disease</td>
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<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
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<tr>
<td>OTA</td>
<td>Organ and Tissue Authority</td>
</tr>
<tr>
<td>PD</td>
<td>Peritoneal Dialysis</td>
</tr>
<tr>
<td>PKD</td>
<td>polycystic kidney disease</td>
</tr>
<tr>
<td>PROMs</td>
<td>Patient Reported Outcome Measures</td>
</tr>
<tr>
<td>PATS</td>
<td>Patient Transport Assisted Schemes</td>
</tr>
<tr>
<td>RRT</td>
<td>renal replacement therapy</td>
</tr>
<tr>
<td>QOL</td>
<td>quality of life</td>
</tr>
<tr>
<td>TSANZ</td>
<td>Transplantation Society of Australia and New Zealand</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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