



Australian Government
Department of Health

“

We want to be active partners in our own care, advocates for better kidney health and finally we want to know that our efforts and the work of clinical carers and researchers will lead to better outcomes for future patients – all patients, no matter where they live, how much they earn, their age or gender or how they are valued by the wider society. Every person with chronic kidney disease deserves nothing less.

”



National Strategic Action Plan for Kidney Disease

Quote from front page: Phil Carswell 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 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 **kidney.org.au**

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The National Strategic Action Plan for Kidney Disease

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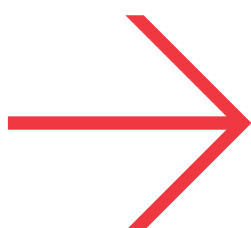
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- Members of the Advisory Group who provided their valuable time and expertise to help shape the Action Plan.
- Participants in the Roundtable held in November 2018 who identified potential actions and priorities for consideration as part of the development of the Action Plan.
- Members of the Kidney Health Australia National Consumer Council who shared their experience of living with kidney disease and provided input and feedback on the stakeholder survey and draft Action Plan.
- Our kidney community who provided input and feedback through the stakeholder survey.
- The expert organisations and individuals who provided advice during the consultation.
- The project team for the Action Plan: Dr Emma Tinning, Dr Lisa Murphy and A/Prof Shilpa Jesudason of Kidney Health Australia.

Foreword

I have worked as a nephrologist and a kidney researcher for over 30 years. In that time I have had the privilege of caring for thousands of patients, and I am constantly filled with admiration for the strength and resilience of people affected by kidney disease and the tireless support of their loved ones.

Clinicians, nurses and other health professionals strive to provide the best possible care for patients, and Australia's health system is one we are justifiably proud. However much more can be done: one in ten Australians have evidence of chronic kidney disease, yet most don't realise they have kidney problems, nor do they recognise the prognosis is worse than most other chronic conditions, including cancer. Too many people miss out on receiving the high quality, joined up care and support they deserve.

The National Strategic Action Plan for Kidney Disease (the Action Plan) offers a vision for transforming kidney disease treatment in Australia; one in which geography, socioeconomic status or culture does not determine quality of care or health outcomes. It offers a comprehensive and coordinated suite of actions designed to address the causes of kidney disease, improve care and support for those affected and build a world class kidney research community underpinned by patient voices.

Importantly, the Action Plan recognises the urgent need to move beyond disease "silos" to tackle prevention of chronic conditions in an integrated and long term way. It also highlights the ongoing and unacceptable disparity in the health and welfare of Aboriginal and Torres Strait Islander people, for whom kidney disease remains a leading cause of death and disability.

Kidney Health Australia has been a tireless advocate for the kidney community for over fifty years, and it is a privilege to develop this Action Plan on its behalf. We have been overwhelmed by the interest and investment of the kidney community, whose voices have been integral to the process. We now look forward to working with the kidney community to implement this Action Plan.

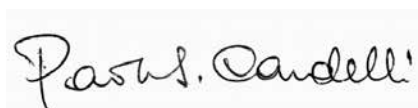


Professor Carol Pollock
Chair, Kidney Health Australia Board

I inherited polycystic kidney disease from my mother, who had inherited it from her father; I in turn have passed it on to my own youngest daughter. It is from this genetic vantage point that I have witnessed firsthand the positive impact of advancements in the detection and management of kidney disease as a direct result of research and clinical trials.

I am alive today thanks to a combination of the courage and selflessness of my kidney donor and the truly extraordinary intergenerational advances in medical science that have made stories like mine commonplace in today's world. Kidney Health Australia's National Consumer Council was formed in recognition of the value of having a formal pathway for people living with kidney disease and their carers, to contribute to a continuous improvement cycle for better health outcomes. This Action Plan will play a critical role in ensuring the needs of our kidney patients, families and their carers are identified and supported well into the future.

I commend Kidney Health Australia for delivering this important document and look forward to seeing the benefits implementing the Action Plan will bring for Australia.



Mr Paolo Cardelli
Chair, Kidney Health Australia
National Consumer Council

Overview

Australia is facing a kidney disease crisis.

- One in three adults are at risk of chronic kidney disease (CKD),^{1,2}
- One in ten have early signs of disease and more than 1.7 million have no idea that they have the disease.^{2,3}
- Currently there is no cure for CKD.
- CKD contributes to around 17,500 deaths a year, more than breast cancer, prostate cancer and road deaths combined.⁴
- Kidney disease disproportionately affects the most vulnerable in our society, and takes a devastating toll on Aboriginal and Torres Strait Islander communities.
- CKD costs the economy more than \$5 billion a year.^{5,6}

CKD is a silent and pernicious illness.

While largely symptom free in the early stages, end stage kidney disease (ESKD) is fatal without ongoing treatment.

Treatment for ESKD is arduous and debilitating, impacting hugely on quality of life.

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.

This crippling disease is too often accompanied by crippling financial hardship.

People with CKD face out of pocket costs that leave many families in financial dire straits, unable to afford basics such as heating, nutritious food and medical prescriptions. Those with ESKD may be too ill to work and many require ongoing carer support from a family member, resulting in further loss of family income.

It doesn't have to be this way.

Though some forms of kidney disease are unavoidable (such as inherited kidney disease), kidney disease is often preventable, and progression towards ESKD can be slowed or even halted with early detection and good management. Better management and support at all stages of the disease has the capacity to improve lives and reduce the enormous burden of CKD on Australia.

A strategy for the kidney community

Kidney Health Australia has developed this Action Plan on behalf of the kidney community. The community is impatient for change: the response to the development of the strategy has been unprecedented, from people with kidney disease and carers to the wide range of healthcare professionals involved in providing care and support. Over 2,500 people and organisations responded to the stakeholder survey – 1,800 of those within 48 hours of the survey going live – all asking for action. The principle that the voices of people affected by kidney disease must be at the centre of the proposed policies and programs, underpins this Action Plan.

A blueprint for change

This Action Plan provides a blueprint for transforming kidney disease in this country over the next ten years, with over thirty actions across three priority areas designed to address the most pressing needs in kidney disease. The priority areas for action and corresponding objectives are summarised on page 8. The associated actions are summarised on page 10 and 11.

What we can achieve

With the right focus, investment, collaboration and partnerships, Australia has the capacity to make lasting changes over the next ten years; slowing the tidal wave of chronic conditions, providing equitable support and care for people affected by kidney disease and using research to improve lives and ultimately find cures for this deadly disease.

About this Action Plan

Vision

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

Background

Kidney Health Australia has developed the country's first National Strategic Action Plan for Kidney Disease (the Action Plan) in recognition of the significant and growing impact of kidney disease on the health and wellbeing of Australians as well as the economic impact on society.

The Action Plan articulates a national vision for preventing kidney disease and improving the lives of those affected by kidney disease, underpinned by the effective use of research, evidence and data.

The intended audiences for the Action Plan include the Australian State and Territory governments, health service providers and funders, healthcare professionals, consumers, researchers and research funders. Achieving the Action Plan's vision will require coordinated national action and partnerships across all levels of government and the health system, non-government organisations (NGOs), the private sector, researchers and academics, and people affected by kidney disease.

The Action Plan aligns with the 2017 National Strategic Framework for Chronic Conditions⁷ (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 kidney disease in Australia, and including specific Enablers for successfully achieving the Vision of the Action Plan (see Concept Map).

Concept Map
for National Strategic
Action Plan for
Kidney Disease



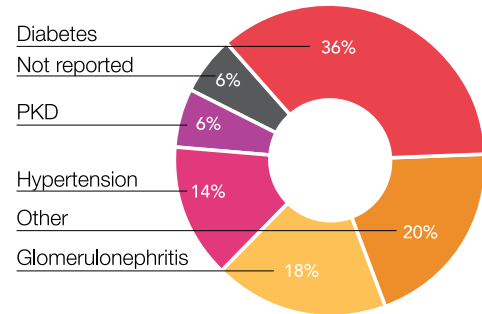
What is kidney disease?

Kidney disease (also called renal disease) is a general term for when the kidneys are damaged and don't function as they should.

If kidney damage happens quickly and the kidneys recover, for example from an accident or infection, it is called acute kidney disease. 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 or more. 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).

What are the types of CKD?

There are many different types and causes of CKD. 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 (PKD) accounting for 6% of all new cases of ESKD.⁸



Partnerships

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 best health outcome.

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 Organ and Tissue Authority
- Primary, secondary and tertiary healthcare providers in both the public and the private sector
- Healthcare professionals
- 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
- Industry, including the pharmaceutical industry and private health insurance

Building on Existing Activities

A number of major reports relevant to kidney disease have been commissioned recently. Many of the issues and recommendations raised during the consultation period for this Action Plan are addressed in these reports. The Action Plan does not attempt to encompass every recommendation in each of these important reports, instead the Action Plan aims to complement these reports by including a number of key recommendations relating to the implementation of these reports.

Two inter-related areas of kidney disease that have received particular input are:

→ Organ donation and transplantation, and

→ Addressing the impact of kidney disease in Aboriginal and Torres Strait Islander communities.

Organ donation and transplantation

Kidney transplantation is an important treatment option for ESKD and this Action Plan acknowledges the value and significance of organ donation and transplantation to the kidney community. The development of this Action Plan coincides with two major reviews on organ donation and transplantation.

- *The 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 (CHC).
- *The Transplantation Society of Australia and New Zealand (TSANZ) Performance Report – Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia.*

This Action Plan acknowledges the work already done in the area of organ donation and transplantation in these two major reviews and aims to complement future implementation of the recommendations of these reviews once available and in collaboration with relevant stakeholders.

The Action Plan includes a number of key recommendations that are relevant to these reviews:

- **Objective 2.1.1** – Establish nationally standardised care pathways for kidney transplant (including living donation) to ensure people receive a high standard of care, irrespective of where they live.
- **Objective 2.1.5** – Facilitating living donor transplantation.
- **Objective 2.4.2** – Implement the *TSANZ Performance Report – Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia.*

Addressing the impact of kidney disease in Aboriginal and Torres Strait Islander communities

The Action Plan includes a focus on addressing the disproportionate burden of kidney disease in Aboriginal and Torres Strait Islander people. Relevant actions draw on a number of noteworthy reviews in relation to Aboriginal and Torres Strait Islander kidney health. These include:

- *The Commonwealth Aboriginal and Torres Strait Islander Renal Health Roadmap.*
- *TSANZ Performance Report – Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia.*
- *The Review of the Australian organ donation, retrieval and transplantation system.*
- *The Kidney Health Australia Caring for Australasians with Renal Impairment (KHA-CARI) Aboriginal and Torres Strait Islander Guidelines Community Consultation.*
- Research and programs from the Menzies School of Health Research and the Lowitja Institute, including the 'Catching Some AIR – Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease' project policy document.

The Action Plan may have direct correlation to a number of key recommendations in these reviews and therefore aims to complement future actions as a result.

This Action Plan includes related recommended action which can be found in:

- **Objective 2.4** – Reducing the disproportionate burden of kidney disease in Aboriginal and Torres Strait Islander communities.

Additional actions relating to Aboriginal and Torres Strait Islander people 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 and research
- health care service delivery in the community.

The importance of cultural safety and autonomy to the wellbeing of Aboriginal and Torres Strait Islander people must be forefront in all proposed actions.

Priority Areas for Action

The Action Plan includes three priority areas with nine corresponding objectives. A range of detailed actions designed to support these objectives are outlined in the following pages.



Priority One

Prevention, Detection and Education

- 1.1** Develop a nationally coordinated approach to increase the effectiveness of the prevention of chronic conditions in Australia
- 1.2** Increase early detection and management to slow the progression of kidney disease and empower people to self-manage their conditions
- 1.3** Raise community and healthcare professional awareness and understanding of CKD and other chronic conditions to support prevention and early detection targeted at priority groups.



Priority Two

Optimal Care and Support

- 2.1** Deliver high quality, equitable kidney care across Australia
- 2.2** Reduce the financial impact of kidney disease on patients, carers and families
- 2.3** Improve support for people affected by CKD
- 2.4** Reduce the disproportionate burden of kidney disease on Aboriginal and Torres Strait Islander communities.



Priority Three

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

Outcomes

This Action Plan contains a mix of short, medium and long-term actions and associated goals. While some actions, such as increased support for people affected by kidney disease will have immediate benefits, others, such as increased preventative health efforts and developing a coordinated kidney disease research collaborative, will accrue over the coming decade.

Implementing the Action Plan will provide significant benefits to the community by preventing disease and providing the necessary medical, psychosocial and financial supports to improve quality of life for people affected by kidney disease. The benefits of the Action Plan also extend to the health system, the economy and society, reducing the burden of chronic conditions and improving the effectiveness and efficiency of the management of kidney disease.

Expected outcomes include:

- A more effective, national approach to prevention of chronic conditions targeting the primary causes of chronic conditions, ultimately resulting in reduced prevalence of CKD.
- Widespread awareness and understanding of kidney disease leading to increased early detection and effective management in primary care.
- More effective and efficient use of healthcare resources resulting in increased equity of access to and outcomes from comprehensive, culturally appropriate high quality care for all Australians with kidney disease.
- Improved quality of life and health outcomes for people affected by kidney disease.
- Reduced economic burden through reduced disease burden and prevalence.
- Continuous improvements in prevention and treatment and the search for cures resulting from a focused, targeted kidney research program.

Achieving Progress

Targeted and sustainable investment will also be required to achieve the Action Plan goals of preventing kidney disease, providing optimal care and support for those affected by the disease and maximising the outcomes of research over the next ten years. The Action Plan includes a mix of short, medium and long terms actions to transform kidney disease in Australia. Some actions will require ongoing funding commitments from the Commonwealth and State and Territory Governments, while others will require smaller and/or one off funding. A number of key actions depend on agreement between the States and Territories to improve consistency in care and support nationally for people affected by kidney disease. The detailed tables for each priority identify the key bodies responsible for each action and the expected time frame for delivering these actions. Indicative costings for a number of actions have been developed, the detail of which can be found in the compendium documents, however additional costings will be required during the implementation process.

A vital first step in realising the actions outlined in the Action Plan is establishing a steering committee to oversee the Action 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 ten years as well as monitoring the progress of the Action Plan's implementation. Ultimately success will depend on collaboration between many stakeholders across all levels of government and the health system, the research sector and patient and community organisations, with a strong commitment to realising the goals of this ambitious Action Plan.

This Action Plan is the product of several key pieces of work, details of which are provided separately. These include:

- Extensive consultation with the Australian kidney community – including people with kidney disease and their carers and family, healthcare professionals, researchers, government representatives, policy makers and NGOs.
- A thorough review of the current landscape of Australian kidney health care services and resources.
- A review of current evidence, policies and strategies to guide and support the recommended priorities and actions.

Action Plan Summary Table

Priorities, Objectives and Actions

 Priority One. Prevention, Detection and Education		
1.1 Develop a nationally coordinated approach to increase the effectiveness of prevention initiatives for chronic conditions in Australia.	1.1.1 Establish a national cohesive approach for prevention of chronic conditions in Australia. 1.1.2 Promote healthier eating, including reducing consumption of salt and sugar. 1.1.3 Address barriers and promote physical activity. 1.1.4 Build on and strengthen existing tobacco control initiatives to reduce tobacco use and exposure to tobacco smoke in the community. 1.1.5 Focus on primordial and primary prevention.	
1.2 Increase early detection and management to slow disease progression and empower people to self-manage their conditions.	1.2.1 Increase access to early chronic condition risk assessment for better identification of people at risk of kidney disease. 1.2.2 Increase uptake and effectiveness of Medicare health assessments and care planning provided in primary care. 1.2.3 Prevent the 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.	
1.3 Raise community and healthcare professional awareness and understanding of CKD and other chronic conditions to support prevention and early detection targeted at priority groups.	1.3.1 Improve kidney disease health literacy through nationwide, awareness and education programs. 1.3.2 Raise community awareness and understanding of the function of kidneys, kidney disease risk factors and consequences. 1.3.3 Provide primary care education and training to encourage best practice for CKD risk assessment detection and management.	
 Priority Two. Optimal Care and Support		
2.1 Deliver high quality, equitable kidney care across Australia.	2.1.1 Establish standardised care pathways to ensure all people receive a high standard of care, irrespective of where they live across Australia. 2.1.2 Map current and future resource needs to increase equity of access to kidney care nationally. 2.1.3 Improve kidney disease care in rural and remote Australia. 2.1.4 Increase equity of access to transplant and equity of transplant outcomes. 2.1.5 Facilitate living donor transplantation. 2.1.6 Ensure access across Australia to multi-disciplinary renal genetics clinics. 2.1.7 Increase support for paediatric to adult transition for young people with kidney disease.	



Priority Two. Optimal Care and Support

Cont.

2.2

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

- 2.2.1 Reduce the out-of-pocket costs of home dialysis by addressing the national variation in utility subsidies for home dialysis.
- 2.2.2 Reduce transport and accommodation costs for both long distance travel to specialist care and for regular travel for treatment.
- 2.2.3 Increase access to the Commonwealth funded Carer Allowance for carers of patients with ESKD.
- 2.2.4 Increase access to government support for people with ESKD.
- 2.2.5 Make it easier for people with kidney disease to remain in or enter the workforce.

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.
- 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 nationally coordinated approach to make it easier for people on dialysis to travel.

2.4

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

- 2.4.1 Implement the *Aboriginal and Torres Strait Islander Renal Health Roadmap*.
- 2.4.2 Assist the National Indigenous Kidney Transplantation Taskforce (NIKTT) where required to implement the recommendations of the TSANZ Performance Report - *Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia*.



Priority Three. 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.

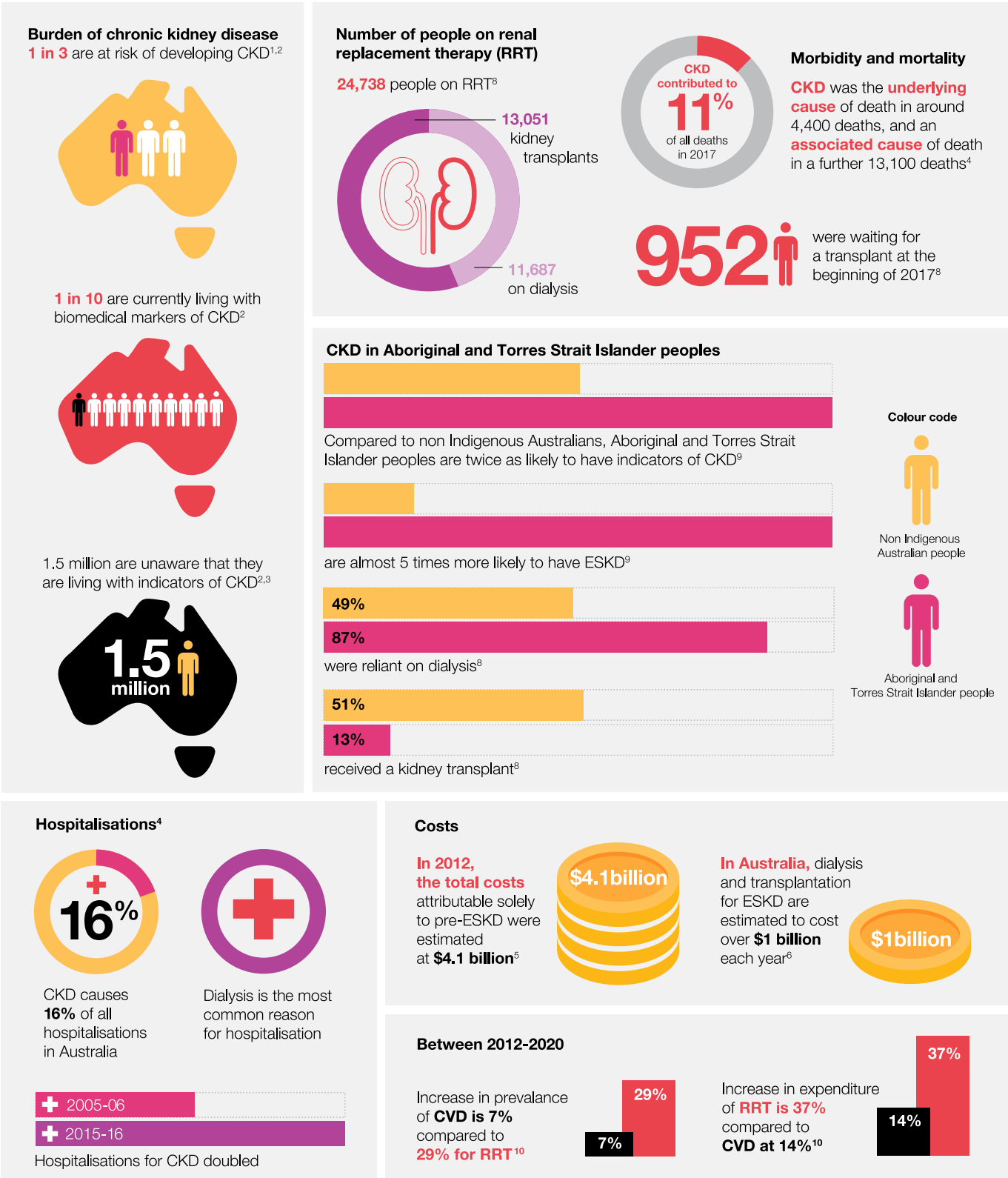
- 3.1.1 Establish a Kidney Research Collaborative to develop and implement a kidney research strategy with targeted priorities.
- 3.1.2 Invest in high quality research focused on improving kidney disease prevention and management and the search for cures.
- 3.1.3 Establish a Kidney Consumer Hub to facilitate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

3.2

Use data, evidence and research to drive improvements in 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 (ABS).
- 3.2.3 Translate research into practice through the strengthening of clinical guidelines and implementation of living guidelines.

Australian Situation



Priority 1.

Prevention, Detection and Education



What we hope to achieve

- A comprehensive long-term nationally coordinated approach to the prevention of chronic conditions in general with a focus on kidney disease, with more effective prevention programs resulting in reduced prevalence of CKD and other chronic conditions.
- Improved community and healthcare professional awareness of CKD and other chronic conditions with an increased understanding of risk factors, resulting in prevention and improved management of chronic conditions.
- Earlier detection and improved management of CKD, slowing disease progression and empowering people to self-manage their conditions.

Why is this important?

The burden of chronic conditions

Australia's health system is facing an overwhelming challenge to manage the growing burden of chronic conditions. Chronic conditions are the main causes of premature death and illness in Australia, responsible for two thirds of the country's burden of disease. Yet Australia invests only a fraction of the total health spending on prevention (1.34% of all health spending in 2013-14). Internationally, Australia is ranked 16th out of 31 Organisation for Economic Co-operation and Development (OECD) countries for per capita expenditure for preventative health, spending less than half the amount spent in the United States of America, United Kingdom, Canada and New Zealand.¹¹

Reducing the burden of CKD requires addressing the shared root causes of chronic conditions. More than fifty percent of Australians have at least one chronic condition and nearly a quarter live with two or more chronic conditions.⁷

The role of social determinants

Addressing the social determinants of health is vital to reducing the burden of chronic conditions. Changing the social and environmental conditions that places particular populations at higher intergenerational risk of chronic conditions is fundamental to this approach, in particular in Aboriginal and Torres Strait Islander communities.

Moving beyond disease "silos"

It is vital that Australia coordinates its efforts to increase the effectiveness of chronic condition prevention funding and approaches. Diseases such as diabetes, cardiovascular disease (CVD) 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 measures and programs that tackle the causes of disease, from social determinants onwards, underpinned by supportive government regulation, widespread targeted awareness campaigns and a focus on increasing health literacy. Consistent with this approach, a comprehensive range of measures and programs from within and outside of the health system are needed to prevent, reduce and manage the risks associated with CKD.

Early detection is key

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.

Addressing health literacy and awareness

The effectiveness of preventative health programs will depend on increasing understanding of key risk factors for chronic conditions and providing clear, accessible information to encourage follow up for people at risk.

Addressing low awareness of kidney disease is also vital. Widespread lack of knowledge about the role of the kidneys exacerbates the silence around kidney disease in the community. Preventing kidney disease and improving early detection and management depends on concerted efforts to raise the profile of kidneys and kidney disease across Australia. This includes equipping primary care physicians with the knowledge and tools to increase the rates of early detection in primary care settings.

Priority 1.

Prevention, Detection and Education



Under-diagnosis is a serious problem¹²

- The proportion of people with CKD remaining undiagnosed by primary care physicians is as high as 50%, despite the automated reporting of estimated glomerular filtration rate (eGFR), 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.

In the words of the kidney community:

"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."

"Basically (we need to) 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."

Priority 1.

Prevention, Detection and Education



Objective 1.1 Develop a nationally coordinated approach to increase the effectiveness of prevention initiatives for chronic conditions in Australia.			
Action	Implementation	Responsibility	Timeframe
1.1.1 Establish a national cohesive approach for prevention of chronic conditions in Australia.	- Establish and fund a Commonwealth body tasked with developing a comprehensive, integrated and long term approach to chronic condition prevention in Australia, overseeing the delivery and evaluation of evidenced based/ best practice programs. This new national prevention body will: - develop a coordinated multi-pronged strategy among stakeholders for preventative actions against chronic conditions at all stages of life course, - 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, - deliver coordinated 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), - determine the research agenda for preventative strategies, - identify strategies for promotion of prevention within the health workforce.	The Commonwealth Government in partnership with States and Territories, Aboriginal and Torres Strait Islander peak bodies, chronic conditions peak bodies, professional bodies, researchers, private health and the community.	Short to long term
1.1.2 Promote healthier eating, including reducing consumption of salt and sugar.	- Finalise the National Obesity Strategy - Develop and fund a new National Nutrition Policy to align with recommendations from the World Health Organisation (WHO), the United Nations Steering Committee on Nutrition and the Food and Agriculture Organisation, including: - restrict marketing of unhealthy food and beverages to children, - implement a national sugar and salt levy and use funds raised to support preventative health programs, including affordable food in remote communities, - strengthen national food reformulation, including reducing dietary sodium and sugar levels as well as portion control measures, - invest in effective education campaigns, including a focus on early years, - mandate the national Health Star Rating system with enhanced consumer education measures. - These activities will be supported by national multimedia chronic conditions awareness and school chronic conditions health literacy campaigns (Action 1.3.1).	CHC / Australian Health Ministers' Advisory Council (AHMAC).	Medium term

Priority 1.

Prevention, Detection and Education



Action	Implementation	Responsibility	Timeframe
1.1.3 Address barriers and promote physical activity.	- Develop a National Physical Activity Strategy, complementing the National Obesity Strategy, building on existing successful state-based programs, with a range of programs to encourage physical activity to be developed and rolled out nationally. - These activities will be supported by national multimedia chronic conditions awareness and school chronic conditions health literacy campaigns (Action 1.3.1).	CHC/AHMAC	Short to medium term
1.1.4 Build on and strengthen existing tobacco control initiatives to reduce tobacco use and exposure to tobacco smoke in the community.	- Strengthen Australia's implementation of the WHO Framework Convention Tobacco Control. - Align with and support implementation of a new National Tobacco Strategy to supersede the 2012-2018 Strategy. - Invest in a mass media education campaign to further reduce tobacco smoking prevalence for the life of the next National Tobacco Strategy: - employ a population level approach as well as complementary targeted approaches for populations with higher tobacco smoking rates than the general population, - investment would complement existing funding provided for the Tackling Indigenous Smoking program. - Develop and disseminate national clinical guidelines and program support to embed the treatment of tobacco dependency into health services, primary care, community and social service organisations as part of routine care, including in Aboriginal Community Controlled Health Organisations (ACCHOs), in taking a patient centred approach. - Fund a national Quitline as a referral, training and behaviour support service provider.	CHC/AHMAC in partnership with Quit Victoria and the Cancer Council.	Short to medium term
1.1.5 Focus on primordial prevention.	- Develop a range of programs focused on primordial prevention in at risk populations/communities, in line with recommendations from the <i>Aboriginal and Torres Strait Islander Renal Health Roadmap and the Best practice primary and secondary preventative interventions in chronic disease in remote Australia</i>. 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: - food security, - low breastfeeding rates, - health in pregnancy including access to antenatal care - tobacco use prevention and control (including tobacco smoking cessation), - appropriate and affordable housing, - obesity prevention. 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.	These measures would be funded, implemented and evaluated by a taskforce established to implement the Renal Roadmap for health in partnership CHC/AHMAC.	Medium to long term



Prevention, Detection and Education

Objective 1.2 Increase early detection and management to slow disease progression and empower people to self-manage their conditions.			
Action	Implementation	Responsibility	Timeframe
1.2.1 Increase access to early chronic conditions risk assessment for better identification of people at risk of kidney disease.	Develop a chronic conditions 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. Make the tool available in community settings. Those found to be high risk will have immediate access to a primary care Integrated Health Check (Action 1.2.2).	Commonwealth Government	Short term
1.2.2 Increase uptake and effectiveness of Medicare health assessments and care planning provided in primary care.	- Support improvement of the new interim Medicare Benefits Schedule (MBS) rebatable Heart Health Checks to explicitly include screening for CKD and diabetes, transforming it into an "Integrated Health Check" to maximise the effectiveness of these new items to detect chronic conditions under the requirements of the Medical Services Advisory Committee (MSAC). - Enhance existing MBS rebatable Health Assessments through standardisation and link them to professional guidelines outlining the expected content of those assessments, including incorporating Integrated Health Checks. - Provide primary care education and training to encourage best practice CKD detection and management (Action 1.3.3). - Increase the use of software tools to improve CKD risk factor identification, testing, diagnosis and management. - Improve early stage disease management through increased referral to and uptake of multidisciplinary lifestyle modifications programs (Action 1.2.3). - Set standardised patient resources for primary care chronic disease management planning to increase understanding of treatments and encourage successful self-management of early CKD. This includes developing materials in multiple formats appropriate for varying literacy levels, learning styles, languages and cultures.	Commonwealth Government, MSAC, primary care providers, peak and professional bodies.	Short term

Priority 1.

Prevention, Detection and Education



Action	Implementation	Responsibility	Timeframe
1.2.3 Prevent the onset and slow the progression of CKD through lifestyle modification programs.	- Enhance and standardise lifestyle behavior modification programs targeted at people identified as at high risk for chronic conditions and those with early stage kidney disease. Programs will be culturally appropriate and tailored for and by different population groups. Activities include: - enhance existing evidence-based lifestyle modification programs to include CKD, - develop lifestyle behavior modification programs (based on existing successful programs) in states where there are currently no such programs, - 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, - resource Aboriginal Community Controlled Health Services (ACCHS) to develop and implement chronic disease prevention programs within their communities.	The sector to implement and supported by Commonwealth and State and Territory Governments.	Medium term
1.2.4 Provide easier, nationally consistent access to genetic counselling and testing to enable earlier detection and treatment of inherited kidney disease.	- Address the disparities in access to genetic testing for inheritable kidney disease across jurisdictions. Initial activities include: - seek in principle State and Territory agreement for a national approach to counselling and testing for inheritable kidney disease, including applications such as preimplantation genetic diagnosis (where applicable), - 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.	Commonwealth and State and Territory Governments, via the CHC.	Medium term

Priority 1.

Prevention, Detection and Education



Objective 1.3 Raise community and healthcare professional awareness and understanding of CKD and other chronic diseases to support prevention and early detection.			
Action	Implementation	Responsibility	Timeframe
1.3.1 Improve kidney disease health literacy through nationwide, awareness and education programs targeted at priority groups.	- Develop a national school education campaign to increase health literacy in young people, particularly in relation to chronic conditions and healthy lifestyles. This campaign will support various State and Territory based programs aimed at teaching healthy behaviours in school, such as healthy eating/cooking programs. Options include: - integration of additional chronic conditions modules into existing State and Territory based health literacy programs, - development of a new national school chronic conditions literacy program. - Develop a multi-platform, multilingual, nationally coordinated chronic conditions awareness campaign to increase knowledge of the risk factors associated with chronic conditions. 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 Aboriginal and Torres Strait Islander communities (Action 2.4.1).	The sector to implement and supported by Commonwealth and State and Territory Governments.	Short term
1.3.2 Raise community awareness and understanding of the function of kidneys, kidney disease risk factors and consequences.	- 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. Content will include: - the essential role of kidneys, - risk factors for CKD, - the need for early detection and how to do it, - consequences of CKD and ESKD especially links to cardiovascular risk, - simple preventative measures for chronic disease and CKD.	The sector to implement and supported by Commonwealth and State and Territory Governments.	Short term
1.3.3 Provide primary care education and training to encourage best practice CKD risk assessment, detection and management.	Provision of a national CKD education and training to primary care health professionals in line with current best practice guidelines to improve early detection of CKD 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).	Kidney Health Australia in collaboration with the Royal Australian College of General Practitioners (RACGP) and Australian Primary Health Care Nurses Association (APNA).	Short term

Priority 2.

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 kidney disease on Aboriginal and Torres Strait Islander communities is reduced through a comprehensive suite of programs targeting the root causes of disease and improved access to effective, culturally appropriate care.

Why is this important?

Better, more equitable care

Overall, in Australia, people with kidney disease receive high quality care, however care standards and resources vary significantly across the country. These differences are particularly stark in rural, remote and Aboriginal and Torres Strait Islander communities. While a number of jurisdictions have developed a range of rigorous models of kidney care, more needs to be done to ensure that best practice care is available across Australia.

The disproportionate burden of kidney disease on vulnerable populations, including Aboriginal and Torres Strait Islander communities, requires targeted and tailored models of care and resource planning, underpinned by concerted efforts to address the root causes of chronic conditions.

The toll of kidney disease on patients and families

Beyond the health care system, people affected by kidney disease are 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 arduous and ongoing and comes with a range of debilitating side effects. Expenses associated with treatment, including transport, parking, utilities and medications, frequently coupled with an inability to work, can place families in financial stress.

Acknowledging the role of ESKD carers

Carers play an essential role in both home and hospital-based dialysis. Despite this, carers of people with ESKD are usually not considered eligible for the Commonwealth Carer Allowance. 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.

A 2013 Australian study¹³ found 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% increasing 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.

In the words of the kidney community:

"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**."

"(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"

"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 into 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."

Priority 2.

Optimal Care and Support



Objective 2.1 Deliver high quality, equitable kidney care across Australia.			
Action	Implementation	Responsibility	Timeframe
2.1.1 Establish standardised care pathways to ensure all people receive a high standard of care, irrespective of where they live across Australia.	- Establish standardised best practice care through the development and roll out of nationally agreed Optimal Care Pathways for Kidney Disease (OCPKD). OCPKD outline the best care for patients with kidney disease. There are individual pathways for different areas of kidney disease. The pathways are designed to promote a full understanding of the patient journey in order to foster quality care. Each pathway identifies specific points and recommended care at each stage. - The pathways will include: - people at increased risk of CKD, - early stage kidney disease (detection, diagnosis and management), - inherited kidney disease, - adolescent to adult transition of care, - ESKD care and transition to dialysis, - kidney transplants (work up, recipient eligibility, pre- and post-transplant care), - living kidney donation, - supportive care for patients with ESKD who will not have dialysis or a transplant, - Aboriginal and Torres Strait Islander specific kidney care pathways. Aboriginal and Torres Strait Islander pathways will be developed as part of the implementation of the <i>Aboriginal and Torres Strait Islander Renal Health Roadmap</i> (Action 2.2.1). The voices of people affected by kidney disease will be central to the development of each of these guidelines. It is essential that OCPKD are developed with evidence-based guidelines as the foundation (Action 3.2.3). Also crucial to the OCPKD will be ensuring the necessary workforce training and requirements to effectively implement pathways (Action 2.1.2).	Commonwealth and State and Territory Governments (with oversight by AHMAC), in partnership with healthcare organisations and societies. This will include Aboriginal and Torres Strait Islander healthcare organisations for the development of Aboriginal and Torres Strait Islander pathways.	Short to medium term
2.1.2 Map current and future resource needs to increase equity of access to kidney care nationally.	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 to aid service planning across all levels of government. The tool will draw on a range of Commonwealth and State and Territory data.	Collaboration of AIHW, ABS, Australian and New Zealand Society of Nephrology (ANZSN), State and Territory Governments, healthcare organisations.	Medium term

Priority 2.

Optimal Care and Support



Action	Implementation	Responsibility	Timeframe
2.1.3 Improve kidney disease care in rural and remote Australia.	• Improve resource/service planning (Action 2.1.2) so that integrated healthcare for CKD can be delivered closer to home where possible. • Partner with local community health organisations and NGOs to deliver care tailored to the needs of individual communities. • Develop innovative models of integrated care for more effective use of the rural and remote health workforce. • Increase support for primary and community CKD care and enhanced integration with tertiary level kidney care. • Increase the use of telemedicine to provide access to specialist services and advice where needed. These actions align with the activities outlined in the <i>Aboriginal and Torres Strait Islander Renal Health Roadmap</i> and the <i>Best practice primary and secondary preventative interventions in chronic conditions in remote Australia</i>.	Commonwealth and State and Territory Governments in partnership with community health organisations.	Medium to long term
2.1.4 Increase equity of access to transplant and equity of transplant outcomes.	This action includes: • Identify barriers to selecting, working-up, referring, assessing and waitlisting patients for kidney transplantation. • Develop clear and nationally consistent guidelines for recipient eligibility. • Develop OCPKD for pre-, peri- and post-transplantation (as per Action 2.1.1). • Support transplant specialist outreach in regional, rural and remote Australia to augment support of individuals post-kidney transplantation (as per Action 2.1.3).	Commonwealth and State and Territory Governments in partnership with TSANZ.	Medium term
2.1.5 Facilitate living donor transplantation.	• Support living donation through: - develop nationally standardised support subsidies to reduce inequities between and within States and Territories, - consider ongoing funding for the Supporting Living Organ Donors program beyond 30 June 2021, - reduce disparities in early pre-transplant work up and planning, including rolling out clear best practice guidelines for living donation, - increase 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. • Guidelines for early transplant workup and living donation will form part of the OCPKD program (Action 2.1.1).	Commonwealth and State and Territory Governments in partnership with, TSANZ and Kidney Health Australia.	Medium term

Priority 2.

Optimal Care and Support



Action	Implementation	Responsibility	Timeframe
2.1.6 Ensure access across Australia to multi-disciplinary renal genetics clinics.	Establish national multi-disciplinary renal genetics clinics – where families are seen by teams including nephrologists, clinical geneticists and genetic counsellors and where appropriate, provided with clinical diagnostic genomics to seek a genetic diagnosis – to be made available to all Australians with inherited kidney disease.	Commonwealth and State and Territory Governments.	Short term
2.1.7 Increase support for paediatric to adult transition for young people with kidney disease.	- Increase hospital funding for young people in adult renal care to assist the transition from paediatrics and support young people newly presenting with kidney disease. - Implement a range of psychosocial supports for young people including: - telephone and online support (Action 2.3.1), - peer support programs (Action 2.3.2), - life skills and self management. Programs will be developed for different populations including Aboriginal and Torres Strait Islander populations, with these programs being developed by Aboriginal and Torres Strait Islander leaders and organisations.	State and Territory Governments in collaboration with Kidney Health Australia.	Short term

Objective 2.2 Reduce the financial impact of kidney disease on patients, carers and families and the health system.			
Action	Implementation	Responsibility	Timeframe
2.2.1 Reduce the out of pocket costs of home dialysis by addressing the national variation in utility subsidies for home dialysis.	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 and Territory Health Ministerial agreement to address this problem via the CHC.	State and Territory Governments.	Medium term

Priority 2.

Optimal Care and Support



Action	Implementation	Responsibility	Timeframe
2.2.2 Reduce transport and accommodation costs for both long distance travel to specialist care and for regular travel for treatment.	- 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: - increasing payment rates, - lowering travel thresholds, - national consistency between the schemes. In principle State and Territory Health Ministerial agreement for this program will be sought via the CHC.	State and Territory Governments.	Short to Medium term
2.2.3 Increase access to the Commonwealth funded Carer Allowance for carers of people living with ESKD.	Extend eligibility for the Commonwealth Carer Allowance to include the provision of complex medical care, to acknowledge the unique burden of caring for someone with ESKD, particularly those undergoing home dialysis.	Commonwealth Government.	Medium term
2.2.4 Increase access to government support for people with ESKD.	- Address the gaps in financial and social support for people with ESKD. Specific activities associated may include: - including patients with ESKD in existing government programs, - developing a specific ESKD allowance for under 65s to assist with out of pocket costs for care, - increasing access to a healthcare card to provide pharmaceutical support that reflect the costs of kidney disease treatment. - 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).	Commonwealth Government.	Medium term
2.2.5 Make it easier for people with kidney disease to remain in or enter the workforce.	Develop education materials for employers to increase understanding of ESKD and treatment and accommodating the needs of employees.	State and Territory Governments in collaboration with Kidney Health Australia.	Medium term

Priority 2.

Optimal Care and Support



Objective 2.3 Improve support for people affected by kidney disease.			
Action	Implementation	Responsibility	Timeframe
2.3.1 Increase the availability of health, wellbeing and psychosocial support for people with CKD, carers and families.	- Address the need for ongoing psychosocial support for patients and carers through: - 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, - developing web-based, downloadable information on relevant topics. The program would draw on the patient guides developed as part of the Optimal Care Pathways for Kidney Disease (Action 4.1).	Commonwealth, State and Territory Governments.	Short term
2.3.2 Create peer support networks (virtual and face to face) across Australia for people affected by kidney disease.	- Develop and support programs that connect 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: - young adults, - regional and remote populations, - people with PKD, - Aboriginal and Torres Strait Islander populations, with these programs being developed by Aboriginal and Torres Strait Islander leaders and organisations, - carers.	Commonwealth, State and Territory Governments.	Short term
2.3.3 Introduce a nationally coordinated approach to make it easier for people on dialysis to travel.	- Implement a national dialysis travel program to make it easier for patients to travel. Possible approaches include: - making spare private renal unit capacity available nationally (based on the 'Enable NSW Away From Home Dialysis Program'), - a dialysis swap program, with State agreement for all hospitals to participate and supported by the appropriate technology. The first step in this action is obtaining in principle CHC commitment to facilitating better access to dialysis away from home.	State and Territory Governments.	Short to Medium term

Priority 2.

Optimal Care and Support



Objective 2.4 Reduce the disproportionate burden of kidney disease on Aboriginal and Torres Strait Islander populations.			
Action	Implementation	Responsibility	Timeframe
2.4.1 Implement the Aboriginal and Torres Strait Islander Renal Health Roadmap.	- Implement the <i>Aboriginal and Torres Strait Islander Renal Health Roadmap</i> including the development and rollout of key actions across the five domains of the <i>Renal Roadmap</i>. The implementation will be governed by the principle that Aboriginal and Torres Strait Islander peoples must be key players and involved in: - setting and formulating policies affecting their communities, - developing and implementing locally relevant programs, - health care service delivery in the community.	Commonwealth Government (Minister for Indigenous Australians portfolio) with State and Territory Governments and Aboriginal and Torres Strait Islander healthcare organisations.	Short to long term
2.4.2 Assist the National Indigenous Kidney Transplantation Taskforce (NIKTT) where required to implement the recommendations of the TSANZ Performance Report - Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia.	- Implement the key priorities identified in the <i>TSANZ Performance Report - Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia</i>. These are: - establish a National Aboriginal and Torres Strait Islander Transplant Taskforce to drive policies and programs related to improving transplant access and outcomes, - implement programs to improve access to wait listing, including piloting a patient navigator program and the establishment of multidisciplinary pre- and post-transplant clinics, - create a framework for testing post-transplantation changes through enhanced data collection and reporting.	Commonwealth Government (Minister for Indigenous Australians portfolio) with State and Territory Governments and Aboriginal and Torres Strait Islander healthcare organisations.	Short to medium term

Priority 3.

Research and Data



What we hope to achieve

- A well-funded and coordinated kidney research program, 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 driving improvements in the effectiveness and efficiency of kidney disease prevention, treatment and support.

Why is this important?

An effective kidney research community

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 significant and consistent investment in cancer research, accompanied by public health interventions, over the recent decades, have resulted in improvements in survival rates across a number of cancers, including breast and prostate cancers. 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 Australian Medical Research and Innovation Priorities 2018-2020.

Listening to patient voices

Consumer driven research is a key Australian Medical Research and Innovation priority and there is 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 provides a deeper understanding of key issues around kidney disease and facilitates translation of research into real interventions with the potential to transform the lives of those living with kidney disease.

Priority 3.

Research and Data



The importance of high quality data

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 for ESKD. The Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA) and the Australian and New Zealand Organ Donation Registry (ANZOD) databases collect a range of information about dialysis and transplantation that inform improvements in ESKD treatment and renal service planning.

However, little data is routinely captured at diagnosis and early treatment of early and mid-stage CKD, which affects the capacity to effectively manage, plan and evaluate the efficacy of early interventions.

Linking primary care data with ANZDATA and ANZOD 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.

In the words of the kidney community:

"We need **research** into finding a **long term cure / treatment** that doesn't include transplant or regular ongoing dialysis. We need to search for a **better answer** and give people their lives back instead of just surviving."

"I would **most** like to see a **national strategic approach** with increased research funding into **prevention, care and cures** like stem cells. I'd like to be out of a job in the **next 20 years.**"

"Please ensure the research is **qualitative and quantifiable**. The problem is **REAL** and it's here. People are **dying everyday.**"

Priority 3.

Research and Data



Objective 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.			
Action	Implementation	Responsibility	Timeframe
3.1.1 Establish a Kidney Research Collaborative to develop and implement a kidney research strategy with targeted priorities.	The Kidney Research Collaborative would develop and implement an integrated kidney research strategy with targeted priorities, focused on prevention, early detection, 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. This action will depend on developing strong partnerships between researchers, medical professionals and nurses, policymakers, research funders and community members.	Commonwealth Government, kidney research community and peak and professional bodies.	Short to medium term
3.1.2 Invest in high quality research focused on improving kidney disease prevention and management and the search for cures.	- Manage targeted funding opportunities for identified priority areas from the Medical Research Future Fund (MRFF) and NHMRC. - Coordinate collaborative funding bids.	Kidney Research Collaborative (Action 3.1.1).	Short to medium term
3.1.3 Establish a Kidney Consumer Hub to facilitate joint research priority setting and enable consumer driven, targeted research.	Establish a National Kidney Consumer Research Hub, in line with Australian Medical Research and Innovation Priorities 2018-2020. The Hub will be a key component of the national strategy for kidney disease, including research priority setting (Action 3.1.1).	Kidney Research Collaborative (Action 3.1.1).	Short term

Priority 3.

Research and Data



Objective 3.2 Use data, evidence and research to drive improvements in kidney disease prevention, treatment and outcomes.			
Action	Implementation	Responsibility	Timeframe
3.2.1 Implement nationally consistent data collection at all points of care to support ongoing improvements in kidney disease prevention, detection and management.	• Increase CKD data collection in primary care (Actions 1.2.1, 1.2.2). • Increase linkages between the breadth of CKD data collected, including biospecimens and genomic, phenomic and multiomic data where available. • Ensure consistency in data through the development of data standards. • Ensure the long-term viability and currency of ANDATA /ANZOD through: - secure and ongoing funding for medical director and staff for ANZDATA/ANZOD, - investment in information technology (IT) infrastructure and platforms, - expanding consumer engagement – including ready access through IT portals (Action 3.1.3), - developing expanded patient reported outcome measures (PROMs) collections, - driving the quality and safety/key performance indicator (KPI) agenda.	State and Territory Governments, ANZDATA and ANZOD.	Short to medium term
3.2.2 Roll out an improved AHS in conjunction with ABS.	Fund and roll out a follow-up of the AHS which was last done in 2011-13. This supports a large number of actions in this Action Plan. The AHS should include the relevant kidney disease questions and biomarkers of CKD.	ABS funded by Commonwealth Government.	Short term
3.3.3 Translate research into practice through the strengthening of clinical guidelines and implementation of living guidelines.	This action includes: • Ongoing sustainable funding for the KHA-CARI clinical guidelines. • Investment in digital transformation and for technological innovation. • 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. • Development and funding of a living guideline Frontier project (pilot project) as the first step in transforming KHA-CARI guidelines into living guidelines. • Research to inform optimal approaches to translating guidelines into clinical practice.	KHA-CARI in partnership with the Cochrane Consortium.	Short term

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Appendices

1: Advisory Group Members

Karen Booth	Primary Care Nurse; President, Australian Primary Health Care Nurses Association (APNA)
Fiona Donnelly	Renal Nurse; President, Renal Society Australasia (RSA)
Chris Forbes	Chief Executive Officer, Kidney Health Australia
Prof Kirsten Howard	Professor of Health Economics, Sub Dean Research The University of Sydney School of Public Health; Menzies Centre for Health Policy Faculty of Medicine and Health
A/Prof Shilpa Jesudason	Clinical Director, Kidney Health Australia; Nephrologist, Royal Adelaide Hospital.
Prof David Johnson	Director of Metro South and Ipswich Nephrology and Transplant Services (MINTS); Medical Director, Queensland Renal Transplant Services; Professor of Medicine (University of Queensland); Professor of Population Health (University of Queensland); Co- Director of Centre for Kidney Disease Research, Translational Research Institute; Chair, PEAK.
Prof Peter Kerr	Professor and Director of Nephrology Monash Health and Monash University.
A/Prof Duncan Mortimer	Associate Professor of Health Economics (Research); Head of Teaching Centre for Health Economics, Monash Business School.
David Parker	Consumer; Director, Kidney Health Australia Board; Chief Executive Officer & Chair, Clean Energy Regulator; Treasurer, Gift of Life ACT Board.
Prof Carol Pollock	Nephrologist; Professorial Chair of Medicine, University of Sydney, Royal North Shore Hospital; Chair, Northern Sydney Local Health District Board; Director, NSW Clinical Excellence Commission Board; Director, NSW Agency for Clinical Innovation Board; Chair, Kidney Health Australia Board.
Prof Tim Usherwood	Professor of General Practice and Head, Westmead Clinical School, Faculty of Medicine and Health, The University of Sydney; Member, PEAK.

2: Expert Organisations

Australian Genomics Health Alliance (AGHA)
Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)
Australia and New Zealand Society of Nephrology (ANZSN)
Australian Primary Health Care Nurses Association (APHNA)
The Better Evidence and Translation – Chronic Kidney Disease (BEAT-CKD)
Deloitte Access Economics Australia
Diabetes Australia
The George Institute for Global Health
The Heart Foundation
KidGen
Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group (KHA-CARI)
Kidney Health Australia National Consumer Council
Menzies School of Health Research
National Aboriginal Community Controlled Health Organisation (NACCHO)
PKD Foundation of Australia
Primary Care Education Advisory Committee for Kidney Health Australia (PEAK)
Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation)
Royal Australian College of General Practitioners (RACGP)
Renal Society of Australasia (RSA)
State Primary Health Networks
The Stroke Foundation
The Organ and Tissue Authority (OTA)
Top End Renal Services Northern Territory Department of Health
Transplantation Society of Australia and New Zealand (TSANZ)

3: Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
ANZOD	Australia and New Zealand Organ Donor Registry
ANZSN	Australian and New Zealand Society of Nephrology
APNA	Australian Primary Health Care Nurses Association
CHC	Council of Australian Governments Health Council
CKD	chronic kidney disease
CVD	cardiovascular disease
ESKD	end-stage kidney disease
KHA-CARI	Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group
MBS	Medicare Benefits Schedule
MRFF	Medical Research Future Fund
MSAC	Medical Services Advisory Committee
NHMRC	National Health and Medical Research Council
NIKTT	National Indigenous Kidney Transplantation Taskforce
OCPKD	Optimal Care Pathways for Kidney Disease
OECD	Organisation for Economic Co-operation and Development
OTA	Organ and Tissue Authority
PKD	polycystic kidney disease
PROMs	Patient Reported Outcome Measures
RACGP	Royal Australian College of General Practitioners
RRT	renal replacement therapy
TSANZ	Transplantation Society of Australia and New Zealand
WHO	World Health Organisation

