Stocktake Document

A compendium to the National Strategic Action Plan for Kidney Disease

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*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***.**

**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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# Executive Summary

This Stocktake Document was developed to support the National Strategic Action Plan for Kidney Disease (the Action Plan). Two other compendium documents – a Consultation Summary and an Evidence Document – provide additional context to the Action Plan.

The stocktake outlines current activities, policies and programs, collated under the three priority areas outlined in the Action Plan.

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| 1. **Prevention, Detection and Education**
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| 1. **Optimal Care and Support**
 |
| 1. **Research and Data**
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Relevant activities for inclusion in the stocktake were identified through:

* individual consultation with State and Territory governments
* a survey of main stakeholders including governments, health networks and research organisations
* a web based search by Kidney Health Australia.

The stocktake is not an exhaustive list of every activity related to the kidney disease in Australia given the time and resource constraints to deliver the document. Nonetheless it provides a clear picture of policies, programs and activities delivered by different parts of the health care sector, governments and other service providers - relating to prevention, management and treatment of kidney disease, relevant support programs and current research activities. These activities offer opportunities for building on and/or improving existing programs to deliver the outcomes outlined in the Action Plan. The stocktake also reveals a number of gaps in services and programs that the actions within the Action Plan are designed to address. The priorities and associated objectives are shown in *Table A – Action Plan priorities and objectives* on page 6. A brief summary of findings is below, with the full stocktake of existing initiatives in the following pages.

## Priority 1. Prevention, Detection and Education

The stocktake identified a range of diverse, sometimes overlapping chronic condition prevention activities in nutrition, physical activity and tobacco control across the state and territory governments. However the stocktake identified few nationally coordinated programs with the exception of tobacco control. The comprehensive and coordinated approach to reducing smoking rates across Commonwealth and State and Territory Governments is a useful model for chronic condition prevention overall.

There are also numerous local early detection and management programs, including risk assessment and detection within primary care and lifestyle modification. Evaluation of at least one program – the Improved Management in Primary Care Project (Chronic Disease IMPACT) - has demonstrated the effectiveness of such approaches. However broader rollout of evidenced based programs is needed to increase the unacceptably low rate of chronic kidney disease (CKD) detection and early management in primary care settings. Several programs demonstrate the benefits of developing targeted programs in consultation with Aboriginal and Torres Strait Islander communities.

In addition the stocktake reveals a significant gap in CKD awareness programs. Beyond awareness raising activities undertaken by Kidney Health Australia, there are few, if any, public campaigns designed to address the low awareness of kidney disease in the community. Lack of awareness of kidney disease risk is a significant barrier to early diagnosis and treatment, compromising patient outcomes and increasing healthcare costs. Raising the profile of kidney disease is therefore an urgent priority.

### Priority 2. Optimal Care and Support

The use of evidence-based models of care differs between states and territories and individual health services. Such models largely focus on treating end stage kidney disease (ESKD) through renal replacement therapy (RRT) and conservative care, with less focus on optimal management of early stage disease. Given the vast number of people with CKD who are at pre-RRT stage, developing evidence based care pathways to slow disease progression and help patients prepare for RRT is essential.

There is also a significant gap in the support available to people with CKD (particularly ESKD) and carers, demonstrated by the limited access to financial and psychosocial support programs across Australia and a lack of easy access to dialysis while traveling. In particular the time consuming, often debilitating and ongoing nature of kidney disease treatment, which frequently requires the support of a carer, does not appear to be accounted for in the eligibility requirements for Commonwealth support and state and territory community care programs.

A range of Aboriginal and Torres Strait Islander programs such as mobile dialysis and culturally safe care highlight the potential for locally developed programs to improve quality of care for Indigenous patients and families. These programs need to be supported by resourcing and a workforce reflective of the needs of the communities.

### Priority 3. Research and Data

The stocktake does not include the large number of individual research projects related to kidney disease but identifies significant research programs, including several focused on increasing consumer engagement in research. However there is a lack of clearly identified national priorities in kidney disease research.

While the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) provides high quality data about ESKD to support research and evidenced based care, there is a dearth of pre-dialysis stage data, reflected in the lack of consistent approach to detection and early management of CKD. Implementing end-to-end data collection will be essential to future kidney research, including driving improvements in care.

 Overall the stocktake highlights a need for:

* An increased focus on kidney disease awareness and prevention
* An increased focus on early detection and management, including improved data collection
* Nationally consistent evidenced-based models of care supported by the resources required to deliver best practice care to all communities across Australia.
* A target approach to kidney research supported by high quality, end-to-end data.

**Table A – Action Plan priorities and objectives**

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| Priority 1. 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 |

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| Priority 2. 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 and the health system |
| 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 |

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

## Stocktake of Existing InitiativesNational Strategic Action Plan for Kidney Disease

**Priority 1. Prevention, Detection and Education**

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

**1.1.1 Establish a national cohesive approach for prevention of chronic conditions in Australia.**

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| --- | --- | --- |
| Name of activity | Description  | Who |
| Australia: the healthiest country by 2020. National Preventative Health Strategy (2009) | Key recommendations:* Reshape industry supply and consumer demand towards healthier products by increasing availability and access to healthier food and activity choices and through the development of comprehensive national food policy.
* Protect children and others from inappropriate marketing of unhealthy foods and beverages, and improve public education and information.
* Embed physical activity and healthy eating in everyday life through school, community and workplace programs.
* Reshape urban environments towards healthy options through consistent town planning and building design that encourage greater levels of physical activity and through appropriate infrastructure investments.
* Strengthen, skill and support primary health care and the public health workforce to support people in making healthy choices, especially through the delivery of community education and advice about nutrition, physical activity and the management of overweight and obesity.
* Close the gap for disadvantaged communities through the development of targeted approaches to overweight and obesity for disadvantaged groups, particularly Indigenous and low-income Australians, pregnant women and young children.
* Build the evidence base, monitor and evaluate the effectiveness of actions.
 | Commonwealth Government Preventative Health Taskforce |

**1.1.2 Promote healthier eating, including reducing consumption of salt and sugar.**

|  |  |  |
| --- | --- | --- |
| Name of activity | Description  | Who |
| SA Healthy Kids Menu | Supporting venues to provide healthier kids menu options. | South Australian (SA) Government |
| SA Community Foodies | SA Community Foodies is a South Australian nutrition program that aims to build the capacity of individuals and communities to make healthier food choices by training and supporting volunteer community members ('Foodies') to act as agents for change.  | SA Government |
| SA Healthy Living website and nutrition resources | Healthy eating information is available and updated regularly on the SA Health website. SA Health also funds the development of nutrition resources for pre- school children and families. | SA Government |
| SA Healthy Towns Challenge | The SA Healthy Towns Challenge is a grants program for regional and rural towns to develop preventive health programs within their community. Successful projects aim to increase access or opportunity for the community to make healthier choices or participate in activities with a prevention focus. | SA Government |
| SA Healthy Workers -Healthy Futures initiative | The Healthy Workers – Healthy Futures (HWHF) initiative contributes to the prevention of lifestyle related chronic conditions in South Australian workers. The initiative involved partnering with four peak industry bodies to build the capacity and capability of South Australian industry, businesses and workers to implement health and wellbeing strategies in the workplace. | SA Government |
| SA Public Health nutritionists | SA Health funds a number of public health nutritionist roles who undertake policy work with a range of partners to promote healthy eating. | SA Government |
| Healthy Tasmania  | Tasmanian Government and community partnership, with 24 initial actions which focus on reducing health risk factors for chronic conditions including smoking, obesity, poor nutrition, low physical activity and risk alcohol consumption.  | Tasmanian (TAS) Government |
| Move Well Eat Well | Settings-based program promoting healthy eating and physical activity in early childhood centres and primary schools. | TAS Government |
| Healthy Tasmania Portal | An online resource for Tasmanians to support healthy eating, physical activity and being smoke free. | TAS Government |
| Healthy Kids Toolkit  | An online resource to support healthy eating in children and families. | TAS Government |
| Start them Right | A resource to support healthy eating. | TAS Government |
| Tasmanian School Canteen Association | Service to promote and facilitate the provision of nutritious and healthy food in school canteens. | TAS Government |
| Eat Well Tasmania | Statewide: Get Fruity and Veg it up campaigns. | TAS Government |
| Family food patch  | Peer education program that promotes healthy eating and participation in physical activity for Tasmanian children and families.  | TAS Government |
| Western Australia (WA) Healthy Weight Action Plan (initiative in development) | WA Healthy Weight Action Plan provides a five year plan for immediate action on early intervention and management of overweight and obesity in WA. Implementation as yet unfunded. | Department of Health (DoH) WA, Primary Health Alliance, Health Consumers Council  |
| Make Healthy Normal | A range of free initiatives to help make healthy normal and tackle overweight and obesity issues and a website providing information. | New South Wales (NSW) Health  |
| Healthy Together Victoria  | A prevention platform delivering multiple strategies, policies and initiatives at both the state and local levels to target all Victorians at schools, early childhood services and medium to large workplaces.  | Victorian (VIC) Government |
| Healthy Tasmania  | Tasmanian Government and community partnership, with 24 initial actions which focus on reducing health risk factors for chronic conditions including smoking, obesity, poor nutrition, low physical activity and risk alcohol consumption. | TAS Government |
| Tipping the Scales report | Includes a number of key actions designed to encourage healthy eating and reduce the impact of obesity, supported by extensive evidence. The action include:* restricting children’s exposure to unhealthy food advertising
* reformulating food to reduce salt, sugar and fat content of processed foods
* making the health star ratings system mandatory
* funding sustained education campaigns around healthy eating and physical activity
* implementing a levy on sugary drinks
* promoting physical activity through a national active travel strategy
* establishing obesity prevention as a national priority with a national taskforce, sustained funding, regular and ongoing monitoring and evaluation of key measures and regular reporting around targets.
* developing, support, update and monitor comprehensive and consistent diet, physical activity and weight management national guidelines.
 | The Obesity Coalition |

**1.1.3 Address barriers and promote physical activity.**

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| Name of activity | Description  | Who |
| SA Strength for Life  | Promotes health and well-being amongst people over 50, and over 40 for Aboriginal or Torres Strait Islanders, through strength training programs run by accredited fitness providers. | SA Government |
| Get Active Program | Promotes involvement in physical activity. 10-week series of 2-hour workshops. Seeks to engage people of all ages who are not currently physically active, and who may have experienced barriers to physical activity such as lack of confidence or motivation.  | DoH TAS, Women sport and Recreation Tasmania |
| Make Healthy Normal | Includes a range of free initiatives to encourage physical activity. | NSW Government |
| Walk Wise Program | Tasmanian program combines individual, social and environmental factors. A three-pronged approach to encourage older Australians to walk more often including built environment, education and transition to brisk walking model. | Heart Foundation – funded by Move it Australia - Better Ageing Grant |
| Active Living Coalition | The purpose of the Coalition is to translate evidence into policy and practice, build on existing partnerships and develop new partnerships as required, raise the profile of active living and support advice and advocate for improvements in the built and natural urban environments including improved access to our parks and open spaces. | State and non-government organisation (NGO)  |
| Being Active Matters  | Resource to improve fundamental movement skills in children. | TAS Government |
| Blueprint for an Active Australia | Includes 13 action areas to increase physical activity in Australia. | Heart Foundation |
| Australia's Physical Activity and Sedentary Behaviour Guidelines | Physical Activity Guidelines through different life stages. Guidelines include:* Australian 24-Hour Movement Guidelines for the Early Years (Birth to 5 years)
* Australia’s Physical Activity and Sedentary Behaviour Guidelines for Children (5-12 years)
* Australia’s Physical Activity and Sedentary Behaviour Guidelines for Young People (13-17 years)
* Australia’s Physical Activity and Sedentary Behaviour Guidelines for Adults (18-64 years)
* Choose Health: Be Active – A physical activity guide for older Australians
* Make Your Move – Sit Less – Be active for life! - A resource for families.
 | Commonwealth Government |
| Triple P – Group Lifestyle | A multi-component intervention for families with overweight or obese children. The aim of the program is to help parents develop effective strategies for managing their child’s weight by introducing gradual permanent changes to their family’s lifestyle. Group Lifestyle Triple P consists of ten 90-minute group sessions and four telephone support calls. | South Western Sydney Primary Health Network (SWSPHN) |

**1.1.4 Build on and strengthen existing tobacco control initiatives to reduce tobacco use and exposure to tobacco smoke in the community**

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| Name of activity | Description  | Who |
| [The South Australian Tobacco Control Strategy 2017-2020](https://www.sahealth.sa.gov.au/wps/wcm/connect/b40d38804cf2224a9768f717a0dc4741/SA%2BTobacco%2BControl%2BStrategy%2B2017-2020%2BFinal%2BPrint.pdf?MOD=AJPERES&CACHEID=b40d38804cf2224a9768f717a0dc4741&CACHE=NONE) | The strategy has a specific focus on reducing smoking rates in the South Australian community, including delivering evidence-based smoking cessation campaigns and services to encourage and support people to quit smoking, legislative measures such as regulating how tobacco products are sold and prohibiting smoking in certain areas. | SA Government  |
| Smokefree workplaces | Smoke Free Environments Project 2019-2020 aims to increase smoke free areas around the Launceston General and Royal Hobart Hospital sites and the surrounds; extending to all education and health facilities with possible legislation. This includes supporting priority populations, such as mental health patients, as well as health services staff to quit smoking. | TAS Government |
| Tobacco Free Communities George Town | Voucher based incentives and cessation support. Healthy Tasmania Community Innovation grant project. | TAS Government |
| Have Grit & Quit | Smoking cessation and health promotion program led by “grit champions”. Healthy Tasmania Community Innovation grant project. | TAS Government |
| No One Left Behind: An action plan to achieve a smoke free Tasmania 2018 – 2021 | Action plan to support people who smoke from priority populations. Includes four key focus areas - smoking cessation, effective messaging, supportive environments and tobacco control. | TAS Government |
| Free nicotine replacement therapy trial | A trial of the provision of free nicotine replacement therapy for priority populations identified via the Quitline. The trial is being managed by Quit Tasmania (part of Cancer Council Tasmania) in collaboration with the University of Tasmania and partner organisations. | Cancer Council, University of Tasmania, TAS DoH and partners |
| The NSW Tobacco Strategy 2012-2017 | Strategy for tobacco and smoking control in NSW. Includes a comprehensive set of policies, programs and regulatory initiatives to achieve the ambitious tobacco control targets in the Government’s NSW 2021 Plan. Focus areas of the Strategy broadly include:* addressing smoking in populations with high smoking rates, particularly [Aboriginal communities](https://www.health.nsw.gov.au/tobacco/Pages/aboriginal-communities-smoking.aspx), women smoking in pregnancy, mental health consumers and people in correctional facilities
* enhancing programs to help smokers quit
* taking measures to protect people from harmful second-hand smoke in outdoor areas.
 | NSW Government |
| National Tobacco Campaign[www.quitnow.info](http://www.quitnow.info)- the Quit Book- ‘Want to quit?’ brochure | The campaign aims to deliver personally relevant information about the health impacts of smoking and importantly, to show smokers the health benefits that quitting has for themselves and their community.A range of tools are available that provide further support for smokers including the Quitline 13 7848 and the My QuitBuddy (An app personalised to help a person quit smoking on their own terms) and Quit for You Quit for Two apps.QuitCoach, QuitMail, QuiteTxt. Quit.org.au State-based centres are run through the relevant state and territory health departments: Quit Victoria, Quit South Australia, Quit Tasmania, Quit Western Australia, Quit Tasmania, iCanQuit website (NSW), NSW Quitline (13 QUIT) | Australian Government DoH |
| Tobacco Action Plan 2016-2018 | The Tobacco Action Plan for the Northern Territory (NT) s a commitment to the prevention and reduction of tobacco related harm and commits to the National Partnership Agreement on Preventive Health (NPAPH) benchmarks. | NT Government |
| Smoke Free Young People Strategy  | New strategy currently being developed by the Smoke Free Young People working group.  | TAS Government |
| Tackling Indigenous Smoking (TIS) | Funded by the Australian Government under the Indigenous Australian's Health Programme to reduce smoking rates among Aboriginal and Torres Strait Islander people. The programme includes grant funding for regional tobacco control activities. | Australian Government DoH |

**1.1.5 Focus on primordial and primary prevention.**

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| Name of activity | Description  | Who |
| National Partnership Agreement on Closing the Gap (CTG) in Indigenous Health Outcomes (2009-2013) | This agreement sets out specific action to be taken by the Australian Government and complementary action by state and territory governments to address the gap in health outcomes experienced by Aboriginal and Torres Strait Islander people. Includes five priority areas: * tackling smoking
* providing a healthy transition to adulthood
* making Indigenous health everyone’s business
* delivering effective primary health care services
* better coordinating the patient journey through the health system.
 | Council of Australian Governments (COAG) |
| Investing in the Early Years – A National Early Childhood Development Strategy 2009 | A collaborative effort between the Commonwealth and the state and territory governments to ensure that by 2020 all children have the best start in life to create a better future for themselves and for the nation. Programs: New Directions, Mothers and Babies Services, Australian Nurse Family Partnership, Strong Fathers Strong Families and Healthy for Life. | An initiative of the COAG |
| Regional Services Reform: Resilient Families, Strong Communities | Aims to improve the lives of Aboriginal people in regional and remote WA, and to bring about long-term systemic change. A roadmap for major reforms to the delivery of housing, education, employment and human services was released in July 2016. The three priority areas are:* improving living conditions to enable families to prosper
* supporting families to build skills and overcome barriers to do so, through improved service redesign and delivery
* education, employment and housing opportunities, and supporting families to take them up.

Regional Services Reform had an initial focus on the Pilbara and Kimberley and in 2017 expanded in to the Goldfields. Change will be implemented at the local level by district leadership groups, made up of representatives from State and Commonwealth governments, local government, the community services sector, Aboriginal Community-Controlled Organisations and industry. | Government of WA Regional Services Reform program |
| Indigenous Advancement Strategy | Aims to improve the lives of Indigenous Australians with a particular focus on:* getting Aboriginal and Torres Strait Islander Australians into work, fostering Aboriginal and Torres Strait Islander business and ensuring Indigenous people receive economic and social benefits from the effective management of their land and native title rights
* ensuring children go to school, improving literacy and numeracy and supporting families to give children a good start in life
* increasing Year 12 attainment and pathways to further training and education
* making communities safer so that Indigenous people enjoy similar levels of physical, emotional and social wellbeing as that enjoyed by other Australians
* increasing participation and acceptance of Indigenous Australians in the economic and social life of the nation
* addressing the disproportionate disadvantage in remote Australia.

The strategy began on 1 July 2014 and replaced more than 150 individual programmes and activities with five flexible, broad-based programmes. The new streams are:* jobs, land and economy
* children and schooling
* safety and well-being
* culture and capability
* remote Australia strategies.
 | Commonwealth Government |
| Aboriginal Family Wellbeing Project | Aims to address social and emotional health risks in Aboriginal and Torres Strait Islander communities across the Kimberley, Pilbara and Goldfields regions, in WA.The project includes an accredited six-month Certificate II training program, which will be delivered jointly by the WA Mental Health Commission, Aboriginal Health Council of WA (ACHWA) and ACHWA’s 22 Aboriginal Medical Service members. | WA Mental Health Commission, ACHWA  |
| Connected Beginnings | Funding program that aims to help Aboriginal and Torres Strait Islander children in areas of high need be well prepared for school by supporting Aboriginal and Torres Strait Islander pregnant women, and Aboriginal and Torres Strait Islander children from birth to school age. Over time it is anticipated the program will contribute to reducing the difference in school readiness and education outcomes between Indigenous and non-Indigenous children. The Connected Beginnings program includes initiatives that will:* provide outreach and support so more Aboriginal and Torres Strait Islander families get involved in early childhood services
* bring early childhood and health services together so Aboriginal and Torres Strait Islander families have a place in their community for these services
* improve sharing of information, so families only have to tell their story once.
 | Department of Education |
| Footprints to Stronger Familie*s*  | Aims to improve the social and emotional wellbeing of Aboriginal and Torres Strait Islander people in the Esperance, Gibson and Norseman regions of Western Australia. The program offers cultural healing, support and guidance to individuals and their families who may be experiencing issues with family violence, alcohol and other drugs, homelessness, and other social problems. The program uses an early intervention and intensive family support method, with short, medium and long term interventions for Aboriginal and Torres Strait Islander children, adolescents and their families to improve their emotional and physical wellbeing. Program activities include: home visitation, school visits, community engagement, workshops, men's groups, women's groups, camps and activities for young people. | Esperance office of Centrecare, funded through the Indigenous Advancement Strategy, Department of Prime Minister and Cabinet |
| The Aboriginal Connection Program | Alcohol and other drug treatment service for Aboriginal people living within or frequenting the inner city area of Adelaide, in SA. The program uses an assessment, case planning and case work approach in transitioning clients through the relevant alcohol and other drug use interventions and treatment stages (including assessment, detoxification, and rehabilitation). The program is based on an outreach model of care and works collaboratively with existing inner city services.Aboriginal Connection Program can also assist Aboriginal people who are vulnerable, homeless, or at risk of homelessness with:* substance misuse assessment regarding alcohol, tobacco and other drugs
* referrals to services for homelessness and mental health issues
* assistance in connecting clients with relevant support services.
 | Drug and Alcohol Services SA |
| Blue Mountains Aboriginal [Healthy For Life](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=4) Program | The Aboriginal Healthy For Life Program aims to:* enhance the quality of life for Aboriginal and Torres Strait Islander people with chronic and complex illness
* improve the health of Aboriginal and Torres Strait Islander mothers, babies and children
* improve the health of Aboriginal and Torres Strait Islander men and boys
* reduce the incidence of adult chronic illness over time
* improve the long term health outcomes for Aboriginal and Torres Strait Islander Australians.

Includes clinical staff and support staff who:* meet in the family home or other preferred location place to chat about health issues
* provide a link to health professionals, doctors or specialists
* arrange regular health checks
* arrange transport to health appointments.
 | Commonwealth Government |
| The Aboriginal Medical Services Alliance Northern Territory (AMSANT) Alcohol and Other Drug (AOD) and mental health program supports | AMSANT understands that social determinants are critical to improving health outcomes for Aboriginal Communities and recognises the role that these determinants play in the development of mental health and harmful substance use issues within communities. AMSANT works with Community Controlled Health Services, specific AOD services and other relevant community and government organisations to develop a strategic approach to the challenges of dangerous alcohol use in Aboriginal communities. This includes:* Advocating and lobbying to government for the improvement of the social determinants of health and mental health for Aboriginal people.
* Developing a Model for Integrating AOD - an integrated approach to the provision of Social and Emotional Well-being services in Aboriginal Primary Health care and sets out a clear case for increased resourcing for the sector. The model emphasises the importance of community driven, community development and preventative approaches as well as clinical/therapeutic approaches.
* Developing a policy on alcohol control, which argues for the necessity of introducing a floor price for alcohol throughout Australia as an effective, evidence-based means of reducing alcohol consumption and the associated harms.
* Employment of a Mental Health Professional to provide support to AOD and mental health programs and workers throughout the sector. AMSANT works to support the provision of AOD and mental health services as part of comprehensive Primary Health Care throughout the Northern Territory with the aim of enhancing the detection and management of mental health and AOD problems within our communities.
 | AMSANT |

Objective 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.**

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| Name of activity | Description  | Who |
| Integrated care for patients with chronic conditions | Program focusing on the identification of people with one or more chronic conditions who are at risk of rehospitalisation in the next 15 months and who are more likely to benefit from one or more of the integrated care interventions. The program supported by an evidenced based clinical risk assessment tool for selecting patients to the right support intervention. NSW has defined three integrated care interventions:1. Health coaching
2. Care navigation
3. Care coordination.
 | NSW Government |
| The Australian Type 2 Diabetes Risk Assessment Tool (AUSDRISK)  | Developed by Baker Heart and Diabetes Institute using data from the 5-year follow-up of the Australian Diabetes, Obesity and Lifestyle study (AusDiab). Predicts incident diabetes based on demographic, lifestyle and simple anthropometric information. Available as:* [Interactive diabetes risk assessment tool](http://www.health.gov.au/internet/main/publishing.nsf/Content/diabetesRiskAssessmentTool) - online risk level calculator
* [Non-interactive diabetes risk assessment tool](http://www.health.gov.au/internet/main/publishing.nsf/Content/diabetesRiskAssessmentToolStatic).
 | Diabetes Australia |
| This Australian Absolute Cardiovascular Disease Risk Calculator | Combines several risk factors to calculate a risk score (expressed as a percentage), which is a person’s chance of having a cardiovascular event such as a heart attack or stroke in the next five years. | National Vascular Disease Prevention Alliance (NVDPA) |
| Kidney Risk Test | Online risk assessment tool developed by Kidney Health Australia’s Primary Care Education Advisory Committee. Includes 10 questions. | Kidney Health Australia |
| QKidney® risk calculator | The QKidney® algorithms are based on routinely collected data from many thousands of general practices across the United Kingdom who have contributed data to the QResearch database for medical research. The calculator requires height, weight and systolic blood pressure measures as well as responses to a few questions that relate to risk factors for CKD. It is a great educational tool as people will learn what factors increase their risk of developing CKD. | ClinRisk |
| The Aboriginal Chronic Care Program (ACCP): Murr-roo-ma Dhun-Barn | Aims to close the gap in chronic conditions for Aboriginal and Torres Strait Islander people who come into contact with the criminal justice system in NSW. The program is operational in 16 correctional facilities (including 15 adult facilities and one juvenile facility). ACCP aims to address chronic conditions and their risk factors among Aboriginal prisoners, including kidney disease.Services provided include:* systematic screening and follow up
* referral to the Care Navigation Support Program for follow up (while in custody)
* health education and promotion
* strategies for chronic condition self management.
 | NSW DoHACCP |
| Well Person’s Health Check Days | Aims to educate and increase awareness of health issues affecting the community by encouraging community members to have a general and sexual health check and follow up with their General Practitioner (GP) for a full adult health check. Local Aboriginal and Torres Strait Islander and non-Indigenous organisations are encouraged to hold an information stall to promote their services and to link in and liaise with the Aboriginal and Torres Strait Islander community. Available on the day, are:* general health checks
* sexual health checks
* diabetes education
* information on reducing risk factors for chronic conditions
* influenza and pneumococcal vaccinations
* free healthy food
* entertainment for adults and children
* healthy cooking demonstrations.
 | North Coast Aboriginal Corporation for Community Health (NCACCH)  |
| Mootang Tarimi (Living Longer) Outreach Screening Program | Part of the NSW Nepean-Blue Mountains Local Health District's Aboriginal Chronic Disease Management Program. The program, run by a Registered Nurse and an Aboriginal Health Worker, aims to make medical services more accessible through the provision of a mobile bus service which visits clients at a community event or organisation and provides:* education on smoking, exercise, diet, weight loss, diabetes management and dental care
* screening programs to test renal function, blood glucose levels, blood pressure and cholesterol levels
* referrals to GPs and allied health appointments.

The program also provides links for clients to other non-government organisations and community services to improve wellbeing and provide a more holistic approach to healthcare. | NSW Nepean-Blue Mountains Local Health District |

**1.2.2** **Increase uptake and effectiveness of Medicare health assessments and care planning provided in primary care.**

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| Name of activity | Description  | Who |
| eMap:CKD and Chronic Disease early detection and Improved Management in Primary Care Project (Chronic Disease IMPACT)  | These programs aim to simplify the process for GPs to earlier identify patients who may be at risk of developing some of the most common chronic conditions which include CKD, cardiovascular diseases (CVD), and type 2 diabetes mellitus (T2DM). In addition, IMPACT will facilitate efficient management of individuals already diagnosed with multiple diseases (i.e. those at most risk of being admitted to hospital). eMap:CKD was the first program focused on CKD according to the Kidney Health Australia CKD Management in General Practice handbook recommendations. IMPACT is a follow on from eMap:CKD which encompasses some of the most of the common chronic conditions.The IMPACT program includes provision of a newly designed, tested and implemented chronic conditions e-technology which acts as a-one stop shop for the detection and management of CKD, CVD and T2DM and associated risk factors; education and clinical audit planning support for GPs on CKD, CVD and T2DM detection and management. IMPACT is currently being implemented into a total of 16 Victorian General Practices located across metropolitan and regional Victoria with a total patient population of approximately 120,000.The e-technology and program design is based on input from a team of disease specialists, a population health expert and GPs in collaboration with Kidney Health Australia, Heart Foundation, Stroke Foundation and Diabetes (Vic) and is informed by the latest national chronic conditions management and prevention guidelines. | Western Health Chronic Disease Alliance, Victorian General Practices |
| [Quality Improvement in Primary Care (QIPC)](https://www.swsphn.com.au/qipc) | General practice clinical audit tools identify patients indicated with kidney disease or with a coded kidney condition and if they have received health assessments or chronic conditions management planning within appropriate time frames. SWSPHN Team facilitates QI activities with general practices to increase uptake and quality of assessments /Care Plans. | South western Sydney PHN (SWSPHN) |
| Community Health South Australia (CHSA) Diabetes Service ‘Diabetes and Endocrine Service Plan and Model of Care | The CHSA Diabetes Service ‘Diabetes and Endocrine Service Plan and Model of Care’ for Acute and Community acknowledges kidney disease as a microvascular complication of diabetes and supports screening, investigation, staging and management (including action plans and referral to specialist renal service or nephrologist). | SA Government |
| 1 Deadly Step | Promotes screening, early detection and follow up of chronic conditions in Aboriginal communities in NSW. The unique component of 1 Deadly Step is the involvement of sport and its ability to engage Aboriginal people that would not normally be screened for chronic conditions. Pilot in 2012 followed by a rollout in sine communities in 2015-16.* Deadly Step works best when it’s part of a bigger community event where the focus is on getting together and having fun.
* The event consists of screening stages for albumin creatinine ratio, HbA1c, cholesterol, blood pressure, blood glucose, body mass, waist circumference, drinking and smoking.
* A local organising committee is formed between staff from the local ACCHS, Local Health District and Primary Health Networks which will plan an event for their community to be screened for chronic conditions.
* Any participant with concerning results will be identified for follow up with their GP or another health professional.
* 1 Deadly Step has a partnership with NSW Country Rugby League who are able to support events with current and past NRL players and providing games and activities for kids.
* Data is collected using an iPad app which produces a summary of participant’s chronic condition risk status. GP’s are able to download reports for their patients via the 1 Deadly Step web portal to support efficient and targeted follow up.
 | Chronic Care for Aboriginal People Program (CCAP).NSW Government |
| Deadly Choices | Deadly Choices encourages people to access their local health service and complete a 715 Health Check - item 715 on the Medicare Benefits Schedule (MBS) - every 9-12 months. This normalises the idea of seeing a doctor not just when sick, but to remain healthy, access support, and prevent or better manage chronic conditions. | Institute for Urban Indigenous Health (IUIH) |
| Integrate Team Care (ITC) program.  | Program for Aboriginal and/or Torres Strait Islander people with diagnosed chronic conditions including CKD. Care Coordinator and Aboriginal Health Worker support for consumers in navigating through the healthcare system, enable access to Specialist services and treatment plans that have been issued by the GP and specialist. Funded until 2021. | South Western Sydney Local Health District (SWSLHD) Aboriginal Chronic Care team.  |
| Northern Territory Point-of-care testing (POCT) | This field program manages point-of-care testing (POCT) on the Abbott i-STAT device for the care of patients with both acute and chronic conditions across a network of almost 80 remote health centres in the Northern Territory.  The Abbot i-STAT device measures multiple pathology test profiles including: blood electrodes, urea, creatinine, glucose, blood gases and lactate, cardiac troponin l and international normalised ratio (INR). | Partnership between the NT Department of Health and Flinders International Centre for Point-of-Care Testing. |
| The Practice Incentives Program (PIP) - Indigenous Health Incentive (PIP IHI)  | Aims to support general practices and Aboriginal and Torres Strait Islander health services to provide better healthcare for Aboriginal and Torres Strait Islander Australian patients including best practice management of chronic conditions. PIP consists of 11 individual incentives.The incentive has three components:* sign on payment: a one-off payment to practices that agree to undertake specified activities that improve the provision of care to Indigenous patients with a chronic condition
* patient registration payment: a payment to practices for each Aboriginal and Torres Strait Islander patient over the age of 15 years who is registered for chronic condition management
* outcomes payment: a payment to practices for:
* each registered patient who receives a target level of care in a calendar year
* providing the majority of care for a registered patient within a calendar year.

The Department of Health is currently undertaking a review of the PIP IHI. This review aims to improve the efficiency and effectiveness of the PIP IHI to support general practices to provide culturally appropriate health care to Aboriginal and Torres Strait Islander people with chronic conditions. | DoH, COAG, National Partnership Agreement*Closing the Gap: tackling Indigenous chronic disease*. |
| CKD Ambassador Program | * This innovative Quality Improvement program was developed by Kidney Health Australia under guidance of Primary Care Education Advisory Committee for Kidney Health Australia PEAK in 2018 and is currently in a pilot phase with 15 clinics having complete the inaugural round in April 2019.
* The program is focussed on driving behavioural change in practice, increased detection of CKD, improved management, slowing disease progression, and implementation of guideline recommendations regarding therapy.
* Throughout the activity participating practices receive dedicated support from Kidney Health Australia project officer.
* Practices completing the Quality Improvement activity will be eligible to become endorsed “CKD Ambassadors” and will continue to receive ongoing education, support, and engagement with the Kidney Health Australia Education team.
 | Kidney Health Australia |

**1.2.3 Prevent the onset and slow the progression of CKD through better access to lifestyle modification programs.**

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| Name of activity | Description  | Who |
| Life! Diabetes and Cardiovascular Disease Prevention Program | Targeted to Victorians 50 years and over who are at high risk of developing type 2 diabetes. Program aims to give participants the awareness, skills and motivation to adopt a healthier lifestyle through simple and effective changes. The program is provided by Diabetes Victoria. Program tools include locally delivered group courses, telephone health coaching, and social marketing and education campaigns. | VIC Government, provided by Diabetes Victoria |
| My Health for Life | Offers eligible participants a structured six-month lifestyle modification program. Flexible support options will include over-the-phone health coaching, group programs and online support. The program is designed to support positive lifestyle changes in order to reduce an individual’s risk of developing type 2 diabetes, CVD and lifestyle related cancers. Griffith University is undertaking a large scale longitudinal evaluation of the program, which runs for three years. | QLD Government |
| Get Healthy Information and Coaching Service | Adult chronic condition and obesity prevention program. Includes confidential phone coaching service which supports participants to reach personalised lifestyle goals relating to; healthy eating, increasing physical activity, alcohol reduction, reaching and achieving a healthy weight or achieving a healthy weight gain in pregnancy. Includes: Includes general programs and specific programs for type2 diabetes prevention, alcohol reduction, pregnancy health and Indigenous health. | NSW government |
| Aunty Jean's Good Health Team Program | Aboriginal and Torres Strait Islander health program developed and piloted in the Illawara district of NSW, with the strong and supportive relationship between local Elders and Aboriginal Health Workers. The primary aim for the pilot project was to develop a combined model of health promotion, education and self-management that could support and sustain the development of good health behaviours and strategies for Aboriginal and Torres Strait Islander people with chronic and complex care needs. The program's community capacity-building objectives included:* improved self-management by Aboriginal and Torres Strait Islander people with chronic and complex care health problems
* appropriate and effective partnership arrangements
* culturally appropriate information-sharing, activity and self-management strategies
* the co-creation of an environment supportive of good health.

Evaluation of the program indicates improved wellbeing of Aboriginal and Torres Strait Islander people as well as improved health measures such as blood pressure and blood glucose levels. | Southern and Murrumbidgee Local Health Districts of NSW |
| Healthy Kidneys Project | Pilot program implemented by the North Coast Primary Health Network (NCPHN) in collaboration with various Aboriginal Medical Services in the north coastal region of NSW. Aimed to develop an increased focus on early identification and interventions to achieve better kidney health and ultimately, prevent the onset of CKD. Objectives included;* A population wide campaign about kidney health utilising health literacy principles and considering cultural appropriateness.
* Development and documentation of resources to support early identification and interventions to achieve better kidney health in primary care settings and to build the capacity of primary health workers to increase the education and awareness of early warning signs of CKD. This included the development of a ‘measuring for improvement’ guide to support continuous quality improvement.
 | NCPHN  |
| Work it Out! | Chronic condition self-management program that aims to close the life expectancy gap between Aboriginal and Torres Strait Islander and non-Indigenous Australians. The program adopts a holistic view of Aboriginal and Torres Strait Islander health and utilises an inter-professional health partnership approach to aid in chronic condition self-management in south-eastern Queensland. It aims to increase each participant's quality of life, confidence and ability to cope, fitness and understanding of how to live a healthy and active life. The 12 week program includes two to four sessions each week, which usually involve an hour of exercise and a 45 minute education session. The program has a research component which monitors both qualitative and quantitative health indicators including blood pressure, blood glucose and social and emotional wellbeing. Since its inception in 2011, the program has shown statistically significant improvements for these indicators. The program was evaluated in 2014 by researchers at the Queensland University of Technology. Funding for the program is from the Heart Foundation. | Urban Indigenous Health (IUIH) |
| Healthy, Black and Deadly | Aims to close the gap in health outcomes and reduce the impact of chronic conditions in the local Aboriginal and Torres Strait Islander population. Focuses on healthy lifestyles, early intervention, knowledge exchange and behavioural change and includes five programs:* [Shake a Leg](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=1580) - 10-week school-based program teaching students the benefits of physical education, personal development and welfare through health education, games and activities.
* I-Fitit Program - designed to educate and motivate Aboriginal and Torres Strait Islander people to increase their physical activity level and improve their overall health to reduce the impact of chronic conditions.
* Making Tracks - a program addressing Aboriginal and Torres Strait Islander family health issues, by providing free basic adult health checks and linking Aboriginal and Torres Strait Islander people with specialist health workers to improve their health knowledge and improve access to health services and referrals.
* Let’s Talk Tucker – aiming to support Aboriginal and Torres Strait Islander health education officers to deliver preventative nutrition information to communities as part of their existing work.
* Chronic Disease Healthy Lifestyle Program – providing low-impact rehabilitation services to low risk Aboriginal and Torres Strait Islander people who have suffered cardiac arrest, have respiratory disease, renal failure or diabetes.
 | NSW Government being implemented by the Hunter New England Local Health District |
| The Get Healthy Information and Coaching Service® | A free telephone service staffed by qualified health coaches aimed at supporting adults to make lifestyle changes regarding healthy eating, physical activity and how to reach and maintain a healthy weight.It provides information and ongoing and personalised support designed to help adults make lasting behaviour change in these areas. | SA Government |
| Ritualize  | Healthy lifestyle app supporting Tasmanian adults (particularly workers) to make dietary changes and become more physically active. Pilot funding until 30 June 2020. | TAS Government |
| Living Improvements for Everyone (LIFE)  | Aboriginal and Torres Strait Islander chronic conditions self-management program delivered by two facilitators to a group of community members once a week for six weeks. Attendees are provided with the tools and techniques to better self-manage their condition. The workshop covers topic such as: symptom management, fitness and exercise, healthy eating, relaxation, effective communication, dealing with difficult emotions, dealing with grief and loss, working with health care professionals.The program was developed under licence from Stanford University in California. It was culturally adapted by the University of South Australia, Spencer Gulf Rural Health School and Pika Wiya Health Service with the assistance of Port Augusta Elders, as part of the Sharing Health Care SA Project in 2001. It also incorporates aspects of the 'Flinders Model' of chronic condition self-management support, developed at Flinders University, SA. | SA DoH, University of South Australia, Spencer Gulf Rural Health School and Pika Wiya Health Service, Flinders University |
| Deadly choices | A health promotion initiative that aims to empower Aboriginal and Torres Strait Islander peoples to make healthy choices for themselves and their families, such as quitting smoking, eating good food, and exercising daily. Deadly Choices, has expanded to more than 35 primary health clinics. Deadly Choices is a social marketing campaign that is made up of:* tobacco cessation programs
* community events
* sport and recreation
* education programs
* cooking programs
* leadership camps
* social media.
 |  Urban Institute of Indigenous Health (IUIH) |

**1.2.4 Provide easier, nationally consistent access to genetic counselling and testing to enable earlier detection and treatment of inherited kidney disease.**

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| Name of activity | Description  | Who |
| Adult and Children Genetics Unit | Adult Genetics Unit provides a specialist clinical genetics consultation service focusing on genetic diagnosis and testing for rare disorders.  Clinics are held at metropolitan hospitals including the Royal Adelaide Hospital (RAH), The Queen Elizabeth Hospital (TQEH), Flinders Medical Unit (FMU) and the Lyell McEwen Hospital (LMH) and country hospitals. There is a component of outreach work in rural and remote Australia requiring the use of telemedicine. The Paediatric and Reproductive Genetics Unit and Paediatric Metabolic Units are based at the Women’s and Children Hospitals. | SA Government |
| KidGen Collaborative | Working with the [Australian Genomic Health Alliance](https://www.australiangenomics.org.au/) (AGHA), [Melbourne Genomic Health Alliance](http://www.melbournegenomics.org.au/) (MGHA) and the [Queensland Genomic Health Alliance](http://www.qgha.org/) (QGHA) to undertake research which looks at the implementation of diagnostic genomics across Australia. The program is developing national standards for diagnostic genomics and coordinating the development of a national network to deliver state-of-the-art clinical diagnosis. The KidGen consortium includes multi-disciplinary renal genetics clinics established within both adult and children’s hospitals in Queensland, New South Wales, Victoria, South Australia and Western Australia. At these clinics, families are seen by teams including nephrologists, clinical geneticists and genetic counsellors. When appropriate, clinical diagnostic genomics is made available to seek a genetic diagnosis in a presenting patient via National Association of Testing Authorities (NATA)-accredited diagnostic genomics services in VIC and NSW. The family will be provided counselling with respect to any identified mutation. | KidGen, AGHA, MGHA, QGHA |
| Clinical genetics services (specialty clinics)  | Victorian publicly-funded clinical genetics services provide access to genetic counselling and testing for inherited kidney disease at selected Victorian metropolitan, regional and rural health services. In 2018-19 the Victorian Department of Health and Human Services provided $28 million recurrently, for the provision of public clinical genetic services and diagnostic testing. | VIC Government |
| Melbourne Genomic Health Alliance | The Melbourne Genomic Health Alliance translational research program includes a clinical flagship examining the outcomes of genomic sequencing (n= 204 patients) to: * Determine the impact of whole exome sequencing on diagnosis and subsequent management of patients with suspected genetic kidney disease
* Decrease number of invasive tests and detrimental treatments
* Personalised surveillance and education regarding extra-renal manifestations.

Victorian Government committed $25 million over four years (2015-19) to fund the Alliance to enable the development of genomic sequencing capability across Victoria. | VIC Government |

Objective 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, targeted awareness and education programs.**

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| Name of activity | Description  | Who |

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| National Statement on Health Literacy | 2014 statement proposing a coordinated approach to improve the health literacy of Australians across three areas: 1. Incorporate health literacy into health care systems; for example, through legislation, policies, plans, standards, funding mechanisms and educational curriculums.
2. Improve communication of health information between providers and users, including interpersonal communication, written information and health promotion campaigns.
3. Include health literacy in the education of adults, children and healthcare providers.
 | Developed by the Australian Commission on Safety and Quality in Health Care  |
| Health Resource Directory.org.au  | Aims to improve the health literacy of residents of south western Sydney and support patients to take control of their health issues. | SWSPHN |
| Your Health Your Time Your Way | Portal to health information and resources for residents of South Western Sydney. | SWSPHN |
| Kidney Health Australia | Kidney Health Australia provides health literate information and resources on a wide range of kidney health topics. There are also resources specifically for Aboriginal and Torres Strait Islander people and key fact sheets have been translated into several languages: Arabic, Burmese, Chinese (Cantonese and Mandarin), French, German, Greek, Hindi, Italian, Kirundi, Japanese, Korean, Macedonian, Maltese, Spanish, Tongan and Vietnamese. | Kidney Health Australia |

**1.3.2. Raise community awareness and understanding of the function of kidneys, kidney disease risk factors and consequences.**

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| Name of activity | Description  | Who |

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| Big Red Kidney Walk | The Big Red Kidney Walk is an annual series of walks around Australia that bring the kidney community together to raise critical awareness of CKD. | Kidney Health Australia |
| Kidney Health Week | National awareness event to raise awareness about kidney disease and its impact including targeted media campaigns. | Kidney Health Australia |
| Kidney Health Australia website | Provides a range of free information and resources related to kidney health and kidney disease prevention, detection and management. An online Kidney Risk Test allows people to calculate their risk of developing kidney disease and links to relevant resources on the website to maintain healthy kidneys. There is a section for healthcare professional resources and information as well as information on research and current clinical trials.  | Kidney Health Australia |
| CKD Nurses | Provides ad-hoc community education sessions in central and northern Adelaide on risk factors for CKD and prevention. Provision of education to communities, school groups etc. when the Mobile Dialysis Unit (MDU) visits remote communities. This is not a coordinated program however MDU staff will do this when requested. Indigenous specific resources are used. | SA Government |

**1.3.3 Provide primary care education and training to encourage best practice for CKD risk assessment detection and management.**

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| Name of activity | Description  | Who |

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| Primary Care Education Advisory Committee for Kidney Health Australia (PEAK) | The Kidney Health Australia Primary Care Education program is overseen by the multidisciplinary Primary Care Education Advisory Committee for Kidney Health Australia (PEAK). Membership representatives from the Royal Australasian College of General Practitioners, the Australian Practice Nurses Association, and the Australian Institute of Health and Welfare among others. | Kidney Health Australia |
| Chronic Kidney Disease (CKD) Management in General Practice Handbook | The National reference guide for detection and management of CKD in primary care. The content of the Handbook is determined by the PEAK Committee and endorsed by the Australian and New Zealand Society of Nephrology and RACGP.The content is derived from the evidence-based recommendations from the Kidney Health Australia Caring for Australasians with Renal Impairment (KHA-CARI) Guideline on “Early chronic kidney disease: Detection, Prevention and Management”, as well as current literature and expert opinion. The Handbook provides summarised advice on detection and management of early CKD (to stage 3a/b) with clear, colour coded action plans for each CKD stage to facilitate rapid implementation of evidence-based recommendations directly into clinical practice.Kidney Health Australia has surveyed users of the Handbook who indicated the resource is well utilised within general practice including nurses. It is the highest downloaded resource from the Kidney Health Australia website.Available in hard copy and electronically. The hard copy is currently in its 4th edition. The App version of the Handbook (the CKD-Go! App) contains interactive hyperlinks to relevant tools and is one of the most utilised medical Apps in Australia. Rated ‘must have’ app my Medical Observer. | Kidney Health Australia |
| The Australian Primary Care Collaboratives Program  | Program supporting general practices to improve clinical outcomes, help maintain good health for those with chronic and complex conditions, and improve access to Australian general practice by promoting a culture of quality improvement in primary health care. Includes a CKD topic with resources for primary care practitioners to improve identification and better management of the population of patients with CKD to minimise disease progression and reduce the associated risks of CVD in those patients. | The Australian Primary Care Collaboratives |
| Kidney Health Australia National Healthcare Professional CKD Education Program | Accredited education to primary care health professionals, running since 2001. Aims to increase awareness and implementation of best practice detection, and management of CKD by primary healthcare professionals. * Free, accessible education widely distributed and promoted
* Develops and implements education modules for Australian primary care health professionals
* Education activities are accredited by peak bodies e.g. RACGP, Australian Practice Nurses Association (APNA), ANZSN
* Develops and distributes clinical tools, resources and quality improvement activities
* Contributes to research projects, peer-reviewed articles and position statements
* Addresses a range of kidney related topics from core CKD management, through extended interest topics and complex cases
* Education on CKD comorbidities, particularly focussing on the interaction between CKD, diabetes and CVD.

Targeted at: GPs, primary care nurses, Aboriginal and Torres Strait Islander Health Workers/Practitioners, pharmacist, other healthcare professionals.Includes:* interactive face-to-face workshops (usually 1 hour or 2 hour sessions)
* active learning modules – run as full day workshops or split over multiple dates
* online learning and videos
* conference sessions
* interactive web-based sessions.
 | Kidney Health Australia |
| SA CHSA Diabetes Service, Country PHN and SA Postgraduate Medical Education Association General Practice Nurse Workshops | Workshops to raise awareness and understanding of diabetes and other chronic conditions (including CKD) to support prevention and early detection (e.g. Diabetes Screening in Adult Health Checks and Annual Diabetes Cycle of Care activities). An 11th Workshop in Ceduna is planned for the 13th June 2019. | Country Health SA Local Health Network (CHSALHN)  |

**Priority 2. Optimal Care and Support**

Objective 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.**

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| Name of activity | Description  | Who |
| HealthPathways | Online clinical and referral information portal used by clinicians at the point of care. HealthPathways provide GPs access to management and treatment options on a range of clinical presentations and information about local clinical services and their referral processes. HealthPathways, including CKD pathways, are operating in numerous jurisdictions across Australia. Pathways include:* CKD (adults)
* pyelonephritis
* acute Kidney Disease
* dialysis
* care after transplant
* ESKD symptom management.
 | Local Health Networks (LHNs), Medicare, Local hospitals |
| The Advancing Kidney Care 2026 (AKC2026) Clinical Workstream | The Clinical Workstream is coordinating the development of patient pathways, resources profiles, quality statements and quality measures. These will describe the level of care that all adult kidney patients in Queensland should receive. Incudes work to look at how Queensland Health can most accurately collect and report standardised information on kidney patients, and the provision of kidney services across the state. This will be to:* measure patient outcomes
* measure service effectiveness
* measure which services are used and how
* support service planning
* inform funding decisions.

The information solution will include capture of data from information systems including the integrated Electronic Medical Record (iEMR) and other existing clinical information systems, data storage and reporting functionality. It is expected that creation of the information solution will commence in 2019.$40 million of funding (over 4 years) announced in June 2019. | QLD DoHLocal renal health services |
| Advancing Kidney Care Collaborative | QLD Advancing Kidney Care Collaborative 2026 Clinical workstream coordinates the development of evidence-based service guidelines and quality outcomes measures in:* peritoneal dialysis
* haemodialysis
* transplant
* conservative—end-of-life care.
* CKD/primary care
* acute kidney injury/inpatient
* vascular access/interventional radiology/interventional nephrology.
 | QLD Health |
| Chronic Kidney Disease Model of Care | The [Chronic Kidney Disease Model of Care](https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Renal/Chronic-Kidney-Disease-Model-of-Care.pdf) was developed by the Renal Health Network and provides a framework for comprehensive, accessible and efficient provision of prevention and treatment of CKD and its complications for all Western Australians. | Health Networks (WA Department of Health)  |
| The Northern Territory Renal Strategy 2017-2022. | Priorities include effective prevention, improved management and early intervention in kidney disease, ongoing coordination, stronger consumer participation, care closer to home, a skilled and culturally competent workforce and a sustainable service system.  | NT Government |
| The Statewide Renal Clinical Network (SReCN) | Focuses on clinical practice improvement and quality and safety enhancements, and provides expertise, direction, and advice on evidence based best practice to Queensland Health clinicians caring for renal patients. | QLD Health |
| NSW Renal supportive care program | NSW Renal supportive care program involves an interdisciplinary approach that integrates the skills of renal medicine and palliative care to help patients with CKD and ESKD to live as well as possible by better managing their symptoms and supporting them in living with advanced disease. It is a program that is embedded in usual renal care. It also encompasses advance care planning and end-of-life care. In 2015/16 NSW Health provided recurrent funding for the statewide roll out the Renal Supportive Care Model in a networked approach. | NSW Government |
| The Renal Integrated Care Pathway (RICP) | Intended to assist and guide renal service providers to deliver CKD services in a consistent, safe and evidenced-based manner that is coordinated, responsive, accessible and sustainable. The RICP is designed to improve patient decision making and coordination of high-quality care to support consistent management of the disease, and will ensure: * improved patient outcomes
* enhanced health-related quality of life
* improved patient independence
* reduced inappropriate variation in care
* improved utilisation of services.
 | Victorian Renal Clinical Network |
| Renal Supportive Care Pathway Pilot | The aim of this project is to evaluate a new supportive approach to managing patients with significant kidney disease. The project will offer renal patients with ESKD, and their families and carers, the opportunity to integrate palliative and end-of-life care planning with their ongoing care at earlier stages of their treatment and management.  Patients who agree to participate in the pilot and who meet specific criteria are invited to attend the Renal Supportive Care Pathway Clinic, Armadale Hospital. This may include people in the following situations:* people who have opted not to have dialysis or are considering withdrawing from dialysis
* people who have exhausted all options for on-going dialysis
* people who have comorbidities (additional illnesses) that have resulted in decreased mobility and ability to complete daily activities.
 | Collaboration between the Renal Health Network and the WA Cancer and Palliative Care Network.  |
| Home First Dialysis Model of Care | Prioritises empowering patients to self-manage their condition and their treatment, with support; they prioritise patient and carer education, and preparing the patient’s home. Based on the SWSLHD Renal Care Pathway aimed to improve the uptake of home dialysis therapies and ‘do more with the same’ resources. Outcomes of the SWSLHD Renal Care Pathway include introduction and use of a structured multidisciplinary predialysis pathway, introduction of a valid psychological assessment tool to support timely and appropriate referrals to a renal psychologist, and increased rates of home dialysis. Patients have also reported greater satisfaction with care, care coordination and preparation for dialysis.  | NSW Agency for Clinical Innovation (ACI) Program |
| Renal Health Network guidelines | A collaborative group of stakeholders from across the health industry related to renal care including healthcare professionals, government representatives, non-government organisations, and consumers. The purpose of the Network is to identify and deliver on state-wide strategic priorities for renal health including opportunities for research and research translation. The Network has developed strategies and guidelines such as the [Guidelines for vein preservation in CKD](https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Renal/171010_PAP_VeinPreservationGuideline_V04_FINAL.pdf), [CKD Model of Care](https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Renal/Chronic-Kidney-Disease-Model-of-Care.pdf), [Framework to improve home dialysis therapy in WA](https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Renal/Framework-to-Improve-Home-Dialysis-Therapy-in-Western-Australia.pdf), [Pathway for renal palliative care services in WA](https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Renal/Pathway-for-Renal-Palliative-Care-Services-in-Western-Australia.pdf), and [Quality improvement indicators for RRT in WA](https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Renal/Quality-improvement-Indicators-for-Renal-Replacement-therapy-in-Western-Australia.pdf). | WA Department of Health Renal Health Network |
| Improving Care for People With Advanced Chronic Kidney Disease: The I'm OK Project | The goal of this project is to enhance communications between medical staff and patients, and enable close-to-home access specialist health care in regional Aboriginal Community Controlled Health Services (ACCHS) in the Northern Territory. This initiative contributes to the creation of strong links between the many different health services for a coordinated approach, and helps reduce the mental wellbeing and financial cost often experienced by patients needing to travel from remote areas for treatment.This project allocates patients experiencing advanced CKD with a care coordinator. This coordinator acts as the key contact for that person and makes sure the person has access to all the services they need, as well as liaising with different healthcare professionals that the person is seeing. | Preventable Chronic Disease Program, the Remote Health Branch and NT Renal Services in partnerships with ACCHS |
| South Australian Palliative Care Strategy | The SA Government has committed to investing $16 million over 4 years in extending community outreach palliative care to a 24 hour, seven days a week service to more effectively support people in the final stages of life. SA Health is working on this commitment and has two Palliative Care projects in progress:1. Reviewing and updating the Specialist Palliative Model of Care as well as agreeing the distribution of the $16 million funding over 2018-2022.
2. SA End of Life Care Strategic Plan.
 | SA Government |
| Australian and New Zealand Society of Interventional Nephrology (ANZSIN)  | The ANZSN is currently developing guidelines for renal biopsy to standardize the qualifications and experience required of practicing clinicians for the benefit of patients.  | ANZSN |
| Australian and New Zealand Society of Nephrology (ANZSN) | The ANZSN via its Key Performance Indicator (KPI) Working Group is currently developing a set of KPIs that may complement care pathways and will provide a mechanism to support quality renal care. | ANZSN |
| Kimberley Renal Support Services | Set up to deliver a support service to patients who are in the early stages of kidney disease prior needing RRT such as dialysis. Multidisciplinary care focused on disease prevention slowing down the progression of renal disease. Care team includes: Aboriginal Care Coordinators; CKD Educators; Pre Dialysis Coordinators and Renal GPs. | Kimberley Aboriginal Medical Services |

**2.1.2 Map current and future resource needs to increase equity of access to kidney care nationally.**

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| Name of activity | Description  | Who |
| Clinical Services Capability Framework (CSCF). | The CSCF outlines the minimum service requirements, workforce requirements and support services for health services to deliver safe and appropriately supported clinical service delivery. The CSCF’s purpose is to:* describe a set of capability criteria that identifies minimum requirements by service level
* provide a consistent language for healthcare providers and planners to use when describing and planning health services
* assist health services to identify and manage risk
* guide health service planning
* provide a component of the clinical governance system, credentialing and scope of practice of health services
* instill confidence in clinicians and consumers that services meet minimum requirements for patient safety and guide health service planning.

Services are delineate into six levels to assist LHNs to develop localised clinical service plans. The CSCF complements existing frameworks, policies and models of care, but in doing so does not replace safety and quality standards from relevant legislation, regulations and guidelines.  | SA Government |
| Renal Dialysis Strategic Plan (under development) | SA Health is working with renal clinicians to develop a Statewide Renal Dialysis Strategic Plan – expected completion 30 June 2019. | South Australian Statewide Clinical Renal Group |
| Renal Demand Modelling Project | Aims to achieve a more accurate, valid and reliable data set for renal service planning across Western WA to reduce the risk of over- or under-spend on services, and inaccuracies in satellite locations and levels of service. This will be achieved through combined analysis of data from (1) the major WA pathology laboratories; (2) ANZDATA and (3) the mortality register. The combined analysis of this data will help track the progression of kidney disease to determine not just current rates of those receiving RRT, but filling the gap in predicting geographical future need for RRT based on current progression. The project is planned to run from 2017 to 2027 with checkpoints every 3 years to reassess funding requirements. | Renal Health Network. Funding provided through Health Networks (WA Department of Health) |
| Development of a Renal Care Capability Framework in Victoria (draft) | Development of a renal care capability framework that will delineate the role of each service in Victoria and describe the services, infrastructure and workforce required at each level of capability to deliver safe and effective patient care. For implementation in 2019-20. | VIC Government |
| State Plan for Renal Services 2010-2020 | Strategy for delivering renal care in Tasmania. | George Institute/TAS Government |
| Central Australia Renal Study | 2011 study undertaken to inform the governments in the cross‐jurisdictional region to make evidence- based policy decisions, in order to better meet the health and service needs of Aboriginal dialysis patients in the region, in affordable and sustainable ways. | George Institute on behalf of Commonwealth Department of Health and Ageing |
| ANZSN Annual workforce survey | The ANZSN conducts an annual workforce survey of its members and in 2017 developed a Workforce Report, with the results providing data to inform workforce and service planning. | ANZSN |

**2.1.3 Improve kidney disease care in rural and remote Australia.**

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| Name of activity | Description  | Who |
| Improving access to renal medicine services MBS item. | MBS item introduced in November 20-18 to provide funding for the delivery of dialysis by nurses, Aboriginal and Torres Strait Islander health practitioners and Aboriginal healthcare workers in a primary care setting in remote areas.  | Commonwealth Government |
| Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation) | Indigenous-owned and run health service operating from its base in Alice Springs with 16 remote clinics and a mobile dialysis unit called the Purple Truck. | Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation) |
| South Australian Mobile Dialysis Unit | The Mobile Dialysis Unit is a specially designed truck that has been fitted with three dialysis chairs and visits remote Aboriginal communities across South Australia. This allows Aboriginal dialysis patients living in regional or metropolitan centres to visit their home communities. | SA Government |
| The SA Digital Telehealth Network | Delivers renal services to regional and remote areas | SA Government |
| South Australian outreach specialists | Nephrologist outreach services to remote areas | SA Government |
| VIC Outreach programs | Aim to improve the range of health services available to rural and regional areas and Aboriginal and Torres Strait Islander communities in Victoria. The programs enable access to health professionals in areas that cannot attract, or cannot viably sustain, a local service provider.Rural Workforce Agency Victoria (RWAV) administer six outreach programs including the [Rural Health Outreach Fund](https://www.rwav.com.au/vicoutreach/rural-health/) and the [Medical Outreach Indigenous Chronic Disease Program](https://www.rwav.com.au/vicoutreach/medical-outreach-indigenous-chronic-disease-program/). | VIC Government |
| Reduce Miles – Spread Smiles telehealth | Darling Downs Hospital and Health Service (DDHHS) telehealth program used by a quarter of the service’s CKD patients | DDHHS |
| The Queensland Rural and Remote Health Service Framework | Developed to support Hospital and Health Services in their planning for and delivery of sustainable services. | QLD Government |
| Toowoomba Hospital renal outreach clinics | Outreach clinics staffed by Towoomba hospital’s specialist renal team via telehealth from Cherbourg, and combining the service with CKD nurse practitioner clinics on the ground. | Towoomba Hospital |
| Service Level Agreements and arrangements for linked rural and metropolitan care | The Health Service Providers and the Department of Health have Service Level Agreements. As part of this all metropolitan tertiary hospitals have formal links with dedicated regional areas of WA to allow for the quick and efficient transfer of patients from regional and remote areas to the Perth metropolitan area for critical care. | WA Government |
| The Rural Health Outreach Fund (RHOF) | The RHOF aims to improve health outcomes for people living in regional, rural, and remote areas by supporting the delivery of outreach health activities. The fund is the consolidation of five existing rural health outreach programs including the Medical Specialist Outreach Program and includes support for chronic condition management. | Funded by the Commonwealth Department of Health and administered by state-based organisations |
| The WA Country Health Service (WACHS) renal dialysis plan 2010-21 | Provides agreed strategies for both meeting the need for dialysis services across WACHS for the next ten years, and for enabling dialysis clients to live as close to home as possible.  | WA Country Health Service |
| WA Country Health Service agreements with Kimberley Aboriginal Medical Services Council | WA Country Health Service contracts the Kimberley Aboriginal Medical Services Council to provide renal dialysis and support services to communities across the Kimberly region. | WA Country Health Service |
| Kimberley Renal Services Mobile Dialysis Unit | Operational since June 2014. Provides mobile dialysis services to allow people to have treatment closer to home. | Kimberley Aboriginal Medical Services |
| Renal outpatients telehealth service | Royal Melbourne Hospital delivers renal outpatient services via telehealth established through Victorian Government Telehealth Specialist Clinic Initiative. | Royal Melbourne Hospital |
| Telehealth Tasmania | Telehealth available in all renal clinics. | Tasmanian Government |

**2.1.4 Increase equity of access to transplant and equity of transplant outcomes.**

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| Name of activity | Description  | Who |
| Progressing Australian organ and tissue donation and transplantation to 2022. The 2018–19 to 2021–22 strategy | The plan identifies the objectives, strategies and actions for the four years 2018–19 to 2021–22 and the key performance measures against which progress will be reported. Includes four objectives:* Optimise donation opportunities
* Provide specialist support for families involved in the donation process
* Increase registration and family discussion contributing to higher consent rates
* Enhance systems to support donation and transplantation
 | Organ and Tissue Authority |
| The Review of Organ Donation, Retrieval and Transplantation System | This review is yet to be released but takes into consideration current systems, practices and processes in the retrieval and transplant sector including equity of access for all Australians, wait listing criteria, organ offer, allocation and acceptance processes;* Consider where there may be jurisdictional variations in existing donation, retrieval and transplantation arrangements;
* Analyse cross-jurisdictional retrieval and transplantation processes including resourcing for tissue typing, retrieval and transplant services; and
* Consider existing models and arrangements to identify the optimal systems, resourcing and workforce requirements to support future donation activity.
 | Department of Health for all governments through Council of Australian Governments Health Council (CHC)Organ and Tissue Authority (OTA) |
| Transplantation Society of Australia and New Zealand (TSANZ) Performance Report - Improving Aboriginal and Torres Strait Islander Transplantation Outcomes. | Identifies three key immediate priorities1. Establishing a resourced National Indigenous Kidney Transplantation Taskforce, with representations from DoH, TSANZ, ANZDATA, ANZSN, OTA and invited subject experts, to drive the implementation of the report’s recommendations, consult the Indigenous and healthcare communities, and advocate for equitable access to transplantation for Indigenous patients.
2. Enhancing data collection and reporting processes on pre- and post-transplant outcomes by:
* Implementing a 12-month pilot project to capture additional pre- and post-kidney transplant data points in an expanded ANZDATA data collection protocol;
* Incorporating a specific chapter in the ANZDATA annual report on kidney transplantation among Aboriginal and Torres Strait Islander people; and
* Undertaking additional data linkage and research projects that target Indigenous patients’ post-transplant outcomes, enabling identification of best practice immunosuppression, infective prophylaxis and vascular complication protocols.
1. Improving the equity and accessibility of transplantation for Indigenous patients by:
* Establishing an Indigenous reference group in every transplant unit to help design pathways and models of care that are culturally appropriate;
* Trialling the adoption of patient navigators as part of pre-transplant care protocols;
* Evaluating and leveraging existing initiatives that target cultural bias in health services to facilitate the rollout of best practice pre-transplant care and support interventions for Indigenous transplant candidates; and
* Trialling a multidisciplinary pre- and post-transplant clinic in one major regional centre for 12 months, prioritising the availability of dental and cardiac services, as well as travel and accommodation support for rural and remote patients.
 | TSANZ |
| Increasing Organ Donation in NSW: Government Plan 2012 | Includes five outcomes:1. Enabling people’s intentions regarding organ donation to be known by their family or significant others, and preferably documented and accessible
2. Addressing information gaps about organ donation, including addressing myths and misperceptions
3. Identifying all opportunities for organ donation in NSW hospitals
4. Supporting clinicians in having conversations with donor families that enable fully informed decisions about proceeding with organ donation
5. Supporting living donor programs
 | NSW Government |
| National Health and Medical Research Council (NHMRC) Ethical Guidelines for Organ Transplantation from Deceased Donors | Informs ethical practice for health professionals in relation to eligibility criteria for entry onto organ transplant waiting lists, donor suitability criteria for organ allocation for transplantation, and the organ allocation protocols for determining transplant recipients. | NHMRC |
| The Transplant Society of Australia and New Zealand (TSANZ) Clinical Guidelines for Organ Transplantation from Deceased Donors – | Informs the eligibility and assessment criteria for organ transplantation, and protocols for the allocation of deceased donor organs to wait-listed patients. As part of the implementation of the National Reform Agenda, TSANZ received funding from the Australian Organ and Tissue Authority to develop nationally uniform eligibility criteria to ensure equitable and transparent processes for listing patients for transplantation of organs obtained from deceased donors; and develop nationally uniform allocation protocols to ensure consistency across Australia in the criteria used to determine allocation of donated organs and tissues. The funding support received from OTA in 2015, patient eligibility and allocation criteria were comprehensively revised to reflect current international best practice and advances in technology and published as version 1.0 in April 2016. The Clinical Guidelines for Organ Transplantation from Deceased Donors (Clinical Guidelines), version 1.1 May 2017 incorporates changes in clinical practice in respect to the utilisation of Hepatitis C Virus (HCV)+ve donor livers in HCV-+ve recipients. It is understood that the TSANZ will be reviewing the access issue, possibly in conjunction with the Australian Medical Association in the near future. | TSANZ |
| Increased Transplant clinics in NT | 4X year consultant clinics in Darwin and Alice Springs. | Northern Territory Government |
| Tasmanian CKD Linkage Study  | CKD linkage study – examining gender and geographic equity in access to kidney care and RRT in Tasmania from 2004 until present. This study will map people’s residential address against health services.  | Tasmanian Community Fund grant |
| Nationally Funded Centres (NFC) Program – Kidney Pancreas Transplantation | The Nationally Funded Centres (NFC) Program was established in 1990 to provide equitable access to certain high cost, low demand, new and emerging medical technologies and procedures.NFCs are approved by the Australian Health Ministers' Advisory Council (AHMAC) and funded by states and territories. Includes national access and reimbursement to combined kidney-pancreas transplantation at selected sites (three across Australia, including Monash Medical Centre, Royal Adelaide Hospital and Westmead Hospital). | SA, VIC and NSW Governments |
| ANZSN Kidney Transplant Working Group | The ANZSN has established a Kidney Transplant Working Group (KTWG) to advise on practical strategies to promote and support best practice in kidney transplantation. The KTWG’s remit includes consideration of barriers and opportunities to improve waitlisting for transplantation, which will consider issues affecting access for patients in rural and remote Australia. (also refer 2.1.2). | ANZSN |

**2.1.5 Facilitate living donor transplantation.**

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| Name of activity | Description  | Who |
| Supporting Living Organ Donors Program | Aims to reduce barriers to living organ donors by providing a financial contribution to employers to either replenish an employee’s leave or contribute towards reimbursing an employer who has made a payment to their employee in place of income lost due to organ donation. Also allows donors to claim reimbursement for some out of pocket expenses, enabling donors who are not employed to participate. The Program provides a payment of up to nine weeks, based on a 38 hour week (a maximum of 342 hours), at up to the National Minimum Wage. | Commonwealth Government |
| The Australian Paired Kidney Exchange (AKX) Program | Paired kidney exchange program to increase living donor kidney transplants by identifying matches for patients who are eligible for a kidney transplant, and have a living donor who is willing but unable to donate because of an incompatible blood type or tissue type. | Organ and Tissue Authority |
| Organ Donation and Transplant Foundation of WA | Organ Donation and Transplant Foundation of WA: Provides community education, promotion, support and advocacy on all aspects of organ and tissue donation in WA. | Organ Donation & Transplant Foundation |

**2.1.6 Ensure access across Australia to multi-disciplinary renal genetics clinics.**

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| Name of activity | Description  | Who |
| KidGen consortium | Includes multi-disciplinary renal genetics clinics established within both adult and children’s hospitals in Queensland, New South Wales, Victoria, South Australia and Western Australia. At these clinics families are seen by teams including nephrologists, clinical geneticists and genetic counsellors. ​When appropriate, clinical diagnostic genomics is made available to seek a genetic diagnosis in a presenting patient via NATA-accredited diagnostic genomics services in Victoria and NSW. The family will be provided counselling with respect to any identified mutation. | KidGen, Australian Genomics Health Alliance |

**2.17 Increase support for paediatric to adult transition for young people with kidney disease.**

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| Name of activity | Description  | Who |
| Royal Adelaide Hospital Young Adult Clinic | The transferring paediatric hospital to the Royal Adelaide Hospital is the Women’s and Children’s Hospital. The hospital also has its own transition/transfer program linked in with the Royal Adelaide Hospital and the Young Adult Clinic. | Royal Adelaide Hospital |
| Mater Hospital Young Adult Clinic | The transferring paediatric hospital is the Queensland Children’s Hospital. The hospital has its own transition /transfer programs linked in with the Mater and Princess Alexandra Hospitals and the Young Adult Clinic. | Mater Hospital Young Adult Clinic |
| Tasmanian Young Adult Kidney & Transplant clinic | Runs every second month and evaluation has just been performed and to be submitted for on-going funding.  | Royal Hobart Hospital |
| Paediatric to adult service transition program  | The WA Department of Health’s [Child and Youth Health Network](https://ww2.health.wa.gov.au/Articles/A_E/Child-and-Youth-Health-Network) manage a program of work related to improving transition from paediatric to adult health services for people with chronic conditions, under which kidney disease would fall. This program of work contains a suite of projects at various stages of development targeting different areas of the complex issue of transition. | WA Department of Health. |
| Royal Melbourne Young Adult Clinic | Established in 2019. The transferring paediatric hospital is the Royal Children’s Hospital. The hospital has its own Transition/Transfer Program and this is now linked in with the Royal Melbourne (Young Adult Clinic), Austin Hospital and the Royal Hobart Young Adult Clinic.Another transferring paediatric hospital is the Monash Children’s Hospital – which has a Transition/Transfer Program which is informally linked with the Monash Hospital. | Royal Melbourne Hospital |
| NSW Paediatric transition services | Available at Westmead Children’s Hospital and Sydney Children’s Hospital.  | Westmead and Sydney Children’s Hospitals |
| Western Australia paediatric transition services | The transferring paediatric hospital is the Perth Children’s Hospital, creating links with the Fiona Stanley and Sir Charlie Gairdner Hospitals.  | WA Government |
| Kidney Health Australia Young Adult Program | The Young Adult Program will support improved health outcomes for younger patients through the development of peer support networks around the country, outside of the typical clinical settings. The program will facilitate face to face activities as well as online support groups, with telephone support through Kidney Health Australia’s national Kidney Helpline service. | Kidney Health Australia, funded by the Commonwealth Government |

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

**2.21 Reduce the out-of-pocket costs of home dialysis by addressing the national variation in utility subsidies for home dialysis.**

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| Name of activity | Description  | Who |
| SA subsidies  | Includes: * SA Water concession - 180 kilolitres of water provided free of charge.
* SA Essential medical equipment payment - $152 annually provided for concession card holders.
* SA Utility concessions for concession card holders $259 for water, $110 for sewerage. $215 per annum for energy concessions.
* $165 annually for all patients on home dialysis program.
 | SA Water, Department of Human Services,Department of Communities Social Inclusion, SA Health and utilities |
| WA subsidies | Includes:* Life Support Equipment Electricity Subsidy (Machine Assisted Peritoneal Dialysis Equipment) - offered by the WA Government to support families and households with the costs associated with operating life support equipment at home.
* WA Government Energy Assistance Program - This rebate supports eligible concession card holders by paying $300 of their energy bill each year.
 | WA Government and utilities |
| NSW subsidies  | Includes:* Low income household rebate - $200 per year to help various concession card holders with their energy costs.
* Water concession - Water suppliers in NSW offer a special dispensation for home haemodialysis patients, providing between 80 and 400 kilolitres of water per year without charge in some areas. Rates differ between providers
* Household Assistance -Essential medical equipment. Subsidises the cost of increased electricity requirements for home dialysis patients with a credit of $0.69 per day ($251.85 per year), which is deducted from personal electricity bills by energy retailers.
 | NSW Government and utilities |
| Northern Territory Pensioner and Carer Concession Scheme  | Provides general concessions on some utility costs for holders of various concession cards. * Energy costs - the fixed daily concession is $1.18 per day ($430.34 per year) with an additional concession for energy consumption charges.
* Water - fixed daily concession for water is 72.5 cents per day ($264.63 per year), with an additional concession available for water consumption charges.
* Sewerage - the concession for sewerage services is 75.4 cents per day ($275.21 per year).
 | NT Government and utilities |
| TAS Subsidies  | Provides general concessions on some utility costs for concession card holders. * Energy concession - $111.70 cents per day ($407.71 per year).
* Some water suppliers in Tasmania offer a special dispensation for home haemodialysis patients, providing up to 200 kilolitres of water per year without charge.
* Electricity – Life Support Machine Rebate, increased electricity requirements for home dialysis patients subsidized with a credit of 31.30 cents per day ($114.23 per year), which is deducted from personal electricity bills by energy retailers.
 | TAS Government and utilities |
| QLD subsidies  | Includes* Energy Life Support Concession - credit of $26.19 per month ($314.31 per year), which is paid quarterly. To be eligible for this concessional payment, patients must have received their dialysis equipment free of charge through a Queensland Health Hospital.
* General concessions on some utility costs for concession card holders. Eligible concession card holders can receive a rebate of $230 per year on energy costs. Those residing in the South East Queensland water grid can receive up to $120 to assist with their water costs.
* Water suppliers in Queensland offer a special dispensation for home haemodialysis patients, providing between 50 and 400 kilolitres of water per year without charge in some areas.
 | QLD Government and utilities |
| ACT | Concession card holders may be eligible to receive ACT Government funded rebates on their utility costs. * Energy - the maximum rebate of $346.20 per year.
* Sewerage and water - rebate of up to 68% on their water and sewerage costs.
* Home Haemodialysis Water rebate - up to $3.29 per day on water costs ($1,200 per year).
* Life support electricity rebate – credit of $121.87 per year, which is deducted from personal electricity bills by energy retailers.
 | ACT Government, utilities  |
| VIC Subsidies  | * Home Haemodialysis patients receive $1,327 per year and peritoneal dialysis patients receive $503 per year.
* Concession card holders can access:
* Energy - discount equal to the cost of 1,880 kilowatts per year, which is deducted from personal electricity bills by energy retailers.
* Water – rebate of 168 kilolitres of water per year and $270.20 rebate on their water usage and sewerage charges. Some water suppliers offer a further discount on remaining water charges.
 | VIC Government, utilities |
| Commonwealth Essential Medical Equipment Payment | $157 annually for each piece of qualifying essential medical equipment and medically required heating or cooling. | Commonwealth Government |

**2.2.2 Reduce transport and accommodation costs for both long distance travel to specialist care and for regular travel for treatment.**

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| Name of activity | Description  | Who |
| SA Patient Assistance Transport Scheme (PATS) | For patients travelling greater than 100km to place of treatment**Travel*** private transport by car - 16 cents per kilometre travelled
* public transport - subsidy calculated based on a standard priced ticket.
* air travel - patients must have a valid medical reason for air travel for each leg of the journey, otherwise the subsidy will be the price of the equivalent journey by most economic mode of travel.

**Accommodation*** Subsidy is flat rate of up to $80 per night per patient (plus GST).

**Others*** Potential donors are not eligible for PATS for medical specialist services involving initial screening or tissue/blood matching.
* Closing The Gap covered Aboriginal patient transport costs up until Oct 2018 however funding withdrawn and became local health network responsibility.
 | SA Government |
| TAS PATS | For patients who need to travel more than 50 km (one way) to the nearest dialysis treatment centre or more than 75 km (one way) to the nearest appropriate specialist medical service.**Travel*** Health Care or Pensioner Concession cardholders are required to contribute $16.50 towards the cost of each return journey. Non-cardholders are required to contribute $82.50 towards the cost of each return journey.

**Accommodation*** Subsidised accommodation is available at some Tasmanian medical facilities. When this is not available or not appropriate, PTAS may fund a maximum of $66 per night.

In any one financial year, the maximum contribution for cardholders is $132, and for a non-cardholder is $330. If these limits are reached, no further contributions will be required for that year. | TAS Government |
| WA Country Health Service [PATS](http://www.wacountry.health.wa.gov.au/index.php?id=pats) | Financial assistance for patients travelling more than 100kms to access the nearest eligible medical specialist service (including telehealth). **Travel*** Country patients needing to travel more than 70kms to access specialist medical treatment for cancer or dialysis, where the health service is unable to provide a transport service, are also eligible for some assistance.
* Private vehicle fuel subsidy of 16 cents per kilometre.
* When two or more patients are travelling in a minibus or similar group transport vehicle owned by a community organisation, the fuel subsidy is 25 cents per kilometre payable to the relevant organisation. Only one subsidy per vehicle is provided.
* Public transport - costs are reimbursed according to the relevant economy or discounted fare.
* Patients living between 70 and 100kms from the treatment centre and qualifying for PATS for cancer or dialysis treatment receive a flat subsidy of $20 per return trip, irrespective of mode of travel or the need for an escort. This travel subsidy is only available when the health service is unable to provide alternative transport options.

**Accommodation**Subsidies for people who live 100kms away and are required to stay overnight for medical reasons, distance or transport schedules. * Private home accommodation $20 per night or $40 per night for a patient travelling with an approved escort.
* Commercial accommodation up to $60 per night for single accommodation or up to $75 per night if travelling with an approved escort.
 | WA Country Health Service |
| NSW Isolated PATS | Financial assistance for patients travelling least 100km one way or 200km on multiple trips.**Travel*** 22 cents per kilometre for private car travel
* full reimbursement for public transport (minus GST)
* full reimbursement for approved air travel (minus GST)
* taxi reimbursement at the following maximum rate:
* 1 day appointment: maximum $202 - 7 day appointment: maximum $408 - 14 day appointment: maximum $8015 or more days appointment: maximum $160.

**Accommodation**Private accommodation:$20 per night regardless of the number of nights or $40 per night with escortDifferent rates for not for profit and for profit accommodation not-for-profit: * $43 per night for single occupancy (or $60 per night if with escort) up to seven nights
* additional nights during the same financial year at $65 per night for single occupancy (or $85 per night if with escort)

For-profit accommodation (per financial year): * one to seven nights: $43 per night for single occupancy (or $60 per night if with escort)
* eight to fourteen nights: $80 per night for single occupancy (or $105 per night if with escort)
* fifteen nights plus: $105 per night for single occupancy (or $120 per night if with escort).
 | NSW Enable/State Government |
| Queensland Patient Travel Subsidy Scheme (PTSS) | Patients approved for PTSS receive a subsidy to attend the closest public hospital or health facility where the specialist medical treatment is available. **Transport*** Public transport - fully subsidised payment equal to the lowest available discount fare (including economy/government discount rates).
* Private road travel – fuel subsidy pf $0.30 per km, calculated using the fastest, toll free route in Google Maps or Whereis. The distance is calculated from the patient's closest public hospital or health facility to the nearest available public medical specialist service.

**Accommodation** * commercial up to $60 per night
* private up to $10.

Eligible patients are required to pay for the first four nights of accommodation each financial year, unless they are a minor (under 18 years of age) or a concession card holder. | Queensland Government |
| NT PATS | Financial assistance for patients who live more than 200km away from the nearest approved specialist or have to travel more than 400km in one week for renal treatment.**Travel*** ground transport costs - such as for taxis and buses - a maximum of $50 each trip
* Private car travel – fuel subsidy of 20 cents per kilometre for trips of over 200km to an appointment.

**Accommodation** * costs of up to $60 each night
 | NT Government |
| VIC PATS  | Financial assistance for patients who need to travel more than 100 kilometres one way or an average of 500 kilometres a week for one or more weeks.**Travel*** Private vehicle costs - fuel subsidy of 20 cents per kilometre.
* Public transport for patients and an approved escort(s) – reimbursement based on the cost of an economy fare or the relevant concession fare if travelling by rail, bus, coach or ferry.
* For patients and an approved escort(s) air travel for the cost of an economy fare or relevant discounted fare is provided if the journey exceeds 350 kilometres one way and a commercial flight is used to travel to the most appropriate approved medical specialist
* Patients who are not a primary card holder of an approved pensioner concession card or health care card and are of 18 years of age or older will pay the first $100 each treatment year.

**Accommodation**A patient and an approved escort(s) staying in commercial accommodation are each eligible for a maximum of $41.00 per night excluding GST, or a maximum of $45.10 per night including GST. This accommodation subsidy is only available if the patient and an approved escort(s) are eligible for travel assistance.  | VIC Government |
| Interstate Patient Transport Assistance Scheme (IPTAS) | ACT IPTAS is available to permanent residents of the ACT where the access to inpatient or outpatient medical treatment and/or specialist oral health surgical treatment is not available in the ACT.Under ACT IPTAS reimbursement of fares is at economy surface level using rail or coach services, unless the referring medical practitioner or treating specialist certifies that the patient has a specific medical condition that requires them to travel by air. | ACT Government |
| Kidney Health Australia Transplant Housing Program | * Transplant Houses Program is currently available in three states, WA, VIC and SA
* Suitable for transplant donors, recipients, home dialysis training from regional or remote areas
* Free accommodation for those who travel from rural/regional areas who need to travel more than 100km to a capital city.
* Kidney Health Australia bulk bills the relevant state PTAS for an accommodation rebate provided for the patient’s stay. Thus, the accommodation is provided at no charge to the patient. Administrative and other costs are funded by Kidney Health Australia.
* The program has been running in WA since 2013, in VIC since 2014 and in SA since 2018. In 2018, the Transplant Housing Program provided over 1000 nights of home away from home accommodation.
 | Kidney Health Australia |

**2.2.3 Increase access to the Commonwealth funded Carer Allowance for carers of patients with ESKD.**

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| Name of activity | Description  | Who |
| Commonwealth Carer Payment, Carer Allowance and Carer Supplement | [Carer Payment](https://www.humanservices.gov.au/individuals/services/centrelink/carer-payment) provides financial help to people who are unable to work in substantial paid employment. This must be because they provide full time daily care for either someone with severe disability or medical condition or who is frail aged.[Carer Allowance](https://www.humanservices.gov.au/individuals/services/centrelink/carer-allowance) is an income supplement for parents or carers providing extra daily care for either:* an adult or dependent child with disability or a medical condition, or
* someone who is frail aged.

Carer Allowance is a fortnightly payment. There is an annual [income test](https://www.humanservices.gov.au/individuals/topics/what-adjusted-taxable-income/29571), but no assets test.[Carer Supplement](https://www.humanservices.gov.au/individuals/services/centrelink/carer-supplement) is an annual lump sum payment. It helps with the costs of caring for a person with disability or a medical condition. Carer Supplement is available if receive Carer Payment or Carer Allowance. | Commonwealth Government |

**2.2.4 Increase access to government support for people with ESKD.**

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| Name of activity | Description  | Who |
| Commonwealth Home Support Programme | National Home Assistance Program for people who are:* having trouble doing everyday activities without help, and
* need support to live independently in the community.

Available to people:* 65 years or older (50 years or older and identify as an Aboriginal or Torres Strait Islander person), or
* 50 years or older (45 years or older for Aboriginal and Torres Strait Islander people) and on a low income, homeless or at risk of being homeless.

Requires an initial phone based eligibility assessment and a home support assessment to establish care needs. Support available includes:* in home services
* community Services
* allied health support services
* respite care.
 | Commonwealth Government |
| VIC Home and Community Care Program for Younger People | Provides services for people aged under 65 and aged under 50 for Aboriginal people with disabilities and their carers. Includes basic support and maintenance services to help people with disabilities remain living at home as independently as possible. Some people with CKD may be eligible for this program however eligibility criteria largely excludes people with CKD. | VIC Government and VIC local councils |
| WA Home and Community Care Program (HACC) | WA HACC support is designed to assist people with the greatest need and aims to maximise people’s independence by providing a low level support of a few services. Eligibility criteria includes:* being under 65 or an Aboriginal or Torres Strait Islander person aged under 50
* having a disability that impacts on their ability to undertake everyday tasks, including accessing their local community
* being the carer of a person who is eligible for WA HACC support
* not receiving support through the National Disability Insurance Scheme (NDIS).

Program includes providing basic support for people:* to participate in social activity in a group or one-on-one
* with everyday household tasks
* to enhance nutrition, function, strength, independence and safety
* to support independence in personal care activities such as showering and dressing
* to keep up with essential activities such as shopping, banking and maintaining social contacts.

Some people with CKD may be eligible for this program however eligibility criteria largely excludes people with CKD. | WA Government |
| TAS HACC | The Tasmanian HACC Program provides funding for basic community care services that support people who are under 65 years or Aboriginal and Torres Strait Islander people aged less than 50 years of age living with disabling conditions and their carers. Services are targeted towards people who live in the community and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long term residential care. Some people with CKD may be eligible for this program however eligibility criteria largely excludes people with CKD. | TAS Government |
| Queensland Community Care Services | Eligibility:* under 65, or under 50 for Aboriginal and Torres Strait Islander people, and
* moderate, severe or profound disability, or a condition which restricts the ability to carry out activities of daily living, and
* living in the community, and
* having difficulty performing the core activities of daily living due to functional limitations, and
* at risk of losing independence without assistance from Community Care.

Provides basic support (usually one to five hours per week) to people with a disability or condition that restricts their day-to-day living.Types of services available:* in home services
* community-based services and support
* clinical services
* respite care

Some people with CKD may be eligible for this program however eligibility criteria largely excludes people with CKD. | QLD Government |

**2.2.5 Make it easier for people with kidney disease to remain in or enter the workforce.**

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| Name of activity | Description  | Who |
| Wage Subsidy Scheme | The Commonwealth Government through the Wage Subsidy Scheme, may pay an employer up to $1,500 (excluding GST) as an incentive to employ a person with disability who is registered with a Disability Employment Services provider.Other conditions apply, refer to Department of Jobs and Small Business. | Commonwealth Government |

Objective 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.**

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| Name of activity | Description  | Who |
| Kidney Health Australia Helpline  | * Free, national support service (email and telephone support) for people living with and/or affected by kidney and urinary disease.
* Provides information, support and referral information for patients, carers, family member and friends; and healthcare professionals.
* Accessed by over 2,000 people per year including from kidney patients, carers, and healthcare professionals every year.
* Staffed by 6 staff members including a clinical nurse
 | Kidney Health Australia |
| South Australia Better Care in the Community  | Programs are available for people in the community with a range of chronic conditions including CKD or dialysis patients. CHSA’s Better Care in the Community program provide support to people with Kidney Disease, usually not as a condition on its own but as a comorbidity of other chronic conditions. The Better Care in the Community Program aims to reduce the number of potentially avoidable admissions for patients with diabetes, cardiac or respiratory conditions, or reduce their length of stay if admitted to hospital.  | CHSA |
| Social Support 'Malpas' | Program to support people who have had to move to Alice Springs for dialysis treatment. Malpa means friend/helper in the Pintupi language. The program acts as friends for people from the Western Desert and Tanami regions of the Northern Territory and Western Australia, to support them with the challenges of kidney failure and absence from family and country.The program aims to help with:* looking at accommodation options
* sorting out Centrelink/carers benefits
* accessing emergency relief
* advocating on patients' behalf
* assistance with transport to attend appointments
* social activities such as:
* bush medicine making
* bush picnics and outings
* art activities
* hospital visiting.
 | Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation |
| Royal Hobart Hospital Multidisciplinary Renal Clinic | This multidisciplinary clinic provides holistic care for all people with kidney disease in Southern Tasmania. It incorporates a clinical psychologist, social worker, dietitian, clinical pharmacist, kidney educator, transplant nurse, vascular access nurse and kidney specialist. | TAS Government |
| Wellbeing Project | Helps Aboriginal and Torres Strait Islanders who travel away from their community to undergo dialysis for CKD, to maintain a connection to their country, culture, family and traditional healing practices. Patients are able to embrace their culture and reduce the sense of dislocation through social enterprise projects such as making traditional bush balms and soaps, or providing a catering service that uses traditional ingredients. The program engages the expertise of patients, and utilises the knowledge of elders to train younger people in traditional medicines so that cultural knowledge and skills are kept alive and passed on to future generations. The younger trainees also learn skills in business management and promotion.  | Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku), Making all our families well Aboriginal Corporation, Caritas Australia |
| Launceston General Hospital (LGH) Renal Supportive Care Clinic | Multidisciplinary clinic incorporating kidney specialist, kidney educator and social worker; targeting those with advanced CKD in Northern Tasmania choosing non-dialysis conservative management. Also available via telehealth for remotely located patients. | State and LGH renal unit funding |
| Carer Australia advisory service | The Carer Advisory Service provides information and advice to carers and their families about carer supports and services. | Carer Australia |
| Kidney Health Australia Website | Provides a range of patient and carer information about prevention and detection, treatment and care options and support services available. | Kidney Health Australia |
| Kidney Kids Camp | Kids Camp running since 1995. Held nationally on an annual basis. Children living with CKD and their siblings invited to attend camp at no cost to the family. | Kidney Health Australia |
| Improving renal patient provider communication and support | This initiative includes:* developing a statewide minimum dataset for informed consent and re-consent that would incorporate shared decision-making
* exploring if the SURE test/decision support tool (or equivalent) is appropriate for renal patients to
* measuring education effectiveness
* piloting a KPI to measure the effectiveness of education
* enabling scaling up and replicating of successful telemedicine practices in renal services
* developing staff training resources.
 | Victorian Renal Clinical Network |
| Integrated Subspecialty Clinic | This is a general practice based service providing wrap around co-ordinated for people with severe and persistent mental illness. Following referral from their GP, a consumer is provided a mental health assessment and chronic condition assessment and linked to a Care Coordinator based in the practice and seconded from the local health district. Through the program patients gain access to other mental health services, physical health services and social supports which are coordinated by the care coordinator. The PHN has also funded additional gap-free chronic condition management sessions above the five they currently receive through a billed Medicare CDM plan. Currently there is a proof of concept funded at Tahmoor Medical Centre. It is funded through the PHN, and both Tahmoor Medical Centre and SWSLHD are funded to deliver the service. | SWSPHN |
| Carers Australia and state based carers organisations. | Carers Australia is the national peak body representing Australia’s unpaid carers. It works collaboratively with partners and its member organisations, the Network of state and territory Carers Associations, to deliver carer services. Services differ between states and services however key services include:* information and support including carer advisory line
* links to NDIS services
* education and training
* carer counselling
* mental health counselling
* carer respite care.
 | Carers Australia |

**2.3.2 Create peer support networks (virtual and face to face) across Australia for people affected by kidney disease.**

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| Name of activity | Description  | Who |
| Kidney Health Australia Kidney Clubs | Organised with local hospitals, volunteers and members of the kidney community to support people at any stage of kidney disease and their families. Currently 30 clubs across seven states and territories. | Kidney Health Australia |
| Tasmanian Kidney Network | This Network has been established by kidney care consumers. It consists of a Facebook page and occasional social events. | Tasmanian Kidney Network |
| Get the most out of life | Group-based 6-week program. Peer education program that provides knowledge and skills to support self-management. Targets people with ongoing health conditions including kidney disease.  | TAS Government |
| Canberra Region Kidney Support Group (CRKSG) | CRKSG is a patient self-help group made up of people with kidney failure and their families, carers and friends.  | CRKSG |

**2.3.3 Introduce a nationally coordinated approach to make it easier for people on dialysis to travel.**

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| Name of activity | Description  | Who |
| The Away from Home Haemodialysis (AFHH) Program | Service offered to increase flexibility for haemodialysis patients living in NSW. Under the new NSW statewide program run by EnableNSW, patients have better access to haemodialysis services when travelling away from home for purposes such as education, work and holidays. Eligible patients may access up to three sessions per year at one of the participating private renal units located away from their usual place of residence at no cost, subject to availability and program funding. | EnableNSW |
| Big Red Kidney Bus | Kidney Health Australia's award-winning Big Red Kidney Bus program provides a mobile haemodialysis service, allowing those who require haemodialysis the chance to have a holiday whilst still receiving treatment. The Big Red Kidney Buses are open to all Australians on hospital, satellite or home haemodialysis. The buses travel to popular holiday destinations across VIC and NSW, where they are located for up to six weeks at a time, staffed by experienced dialysis nurses and renal technicians. | Kidney Health Australia |
| South Australian Mobile Dialysis Unit | The truck provides respite dialysis services to Indigenous dialysis patients in the Anangu Pitjantjatjara Yankunytjatjara (APY) land and country. The truck services have also been expanded to provide holiday dialysis intrastate. | SA Government |
| Kimberley Renal Services Mobile Dialysis Unit | Operational since June 2014. Provides mobile dialysis services to allow Kimberley haemodialysis patients to have extended visits home to be with family and maintain ties with their communities. | Kimberley Aboriginal Medical Services |
| Purple Truck | The Purple Truck is a self-contained dialysis unit on wheels that gives patients with ESRF the chance to return home for family, cultural or sorry business. With two dialysis chairs, the Purple Truck travels to remote communities, letting patients visit home, confident they’ll survive the trip. | Purple (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation) |

Objective 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.***

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| Name of activity | Description  | Who |
| Catching Some AIR: Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease | In Darwin, Thursday Island and Alice Springs, the C-AIR project invited community members with lived-experiences of diabetes and CKD to recommend best practice for kidney health in relation to 1) clinical care and 2) the collection and use of kidney health data.The key policy recommendations are referenced to Aboriginal and Torres Strait Islander community-informed and expressed priorities for best practice for health, in particular for diabetes and kidney health. The issue, impact, proposed solution and potential funding requirements are discussed for each item.* coordinated and economically sustainable strategies to address renal health across all levels of government
* meaningful knowledge sharing for the Aboriginal and Torre Strait Renal Patient Community
* preventative health care
* sustainable workforce.
 | Menzies School of Health Research, Lowitja Institute Aboriginal and Torres Strait Islander Health CRC, a collaborative partnership funded by the Cooperative Research Centres Program |
| KHA-CARI Guidelines for Management of for Aboriginal and Torres Strait Islander Peoples Community Consultation | In 2018, the Minister for Indigenous Health, the Hon. Ken Wyatt AM, MP, commissioned Kidney Health Australia to undertake consultations with Aboriginal and Torres Strait Islander community members around Australia, as well as health experts, service providers and peak bodies to inform the development of the inaugural KHA-CARI Guidelines for the Management of Chronic Kidney Disease among Aboriginal and Torres Strait Islander Peoples. A total of 16 consultations “Yarning Kidneys” are taking place across metropolitan, rural and remote communities of Australia. This process is imperative to ensure appropriateness, effectiveness, and integration in order to have maximum impact on quality of health outcomes. Complementing the consultation conducted by Kidney Health Australia, the “Catching Some Air” project team led by the Lowitja Institute committed to undertake these consultations in the Northern Territory, and a separate consultation process is being undertaken in Aotearoa New Zealand with respect to Maori and Pacific Islander peoples.The aim of the community consultations is to determine the appropriate methods for translating the new clinical guidelines into culturally-safe consumer information, tools and education materials. Key goals are to seek feedback and advice on the* focus and content of new clinical guidelines for the management of CKD among Aboriginal and Torres Strait Islanders; specifically the priorities for clinical care
* appropriate methods for translation of the new clinical guidelines into consumer information, tools and education materials, to facilitate implementation in clinical practice.

It is anticipated the guideline will be published in 2022. | Kidney Health Australia |
| Aboriginal Kidney Care Together: Improving Outcomes Now (aKction Study) | This collaborative action research project brings together Aboriginal kidney patients, family members, Aboriginal and non-Aboriginal healthcare professionals, health services, academics, researchers and other stakeholders to identify gaps and develop strategies to improve kidney care in SA. Aboriginal renal patients are positioned as Reference Group members and co-researchers who have unique knowledge and experiences. Healthcare professionals and managers bring understanding of health systems and how strategies might be most effectively implemented, and academics guide the research process and assist nursing, medical and allied health students to better understand how to provide culturally safe care. Funded by SA Translational Research Centre Medical Research Future Fund (MRFF) allocation. | University of Adelaide |
| SA Aboriginal Torres Strait Islander Health Practitioner | Implementation of two of the Aboriginal and Torres Strait Islander Health Practitioner (ATSIHP) candidates into renal services via CTG seed funding (ends June 2020) with expectation that roles will be converted into operating monies.CTG funding also supported 2 day cultural safety training for all. | CTG Enhancing In hospital care and continuity of care  |
| Closing the Gap in Indigenous Health Outcomes – Indigenous Chronic Disease Package (ICDP) | The *Closing the Gap in Indigenous Health Outcomes – Indigenous Chronic Disease Package (ICDP) rolled out over four years from 2009* established a range of preventative health measures and workforces positions specifically targeting the risk factors of chronic conditions – smoking, poor nutrition and lack of physical activity. The program focused on:* health promotion and prevention of ill health, in particular healthy lifestyle programs
* improved financial support for the Aboriginal community-controlled health sector in the delivery of primary health care
* addressing barriers to access to follow-up services, such as allied health and the Pharmaceutical Benefits Scheme (PBS) growing the numbers and skills of Indigenous health workers.
 | Commonwealth Government |
| Western desert kidney health project | $7 million project launched on 7 October 2010 in Kalgoorlie, Western Australia (WA) and involved a multidisciplinary team of Aboriginal health, medical and community development workers and artists, whose aim was to reduce kidney disease and diabetes by 20% over three years in 10 Aboriginal communities, representing six language groups. The research component of the project was be implemented for a period of three years as part of the measures for 'closing the gap' in Indigenous health outcomes. The project is now a partnership between the people of the Western Desert and many delivery, corporate, government and philanthropic partners. Two three-tonne 'healthy lifestyle' trucks are used for this project. One is a mobile clinic used for early detection of disease and chronic condition management, health promotion and evaluation. The other transports artists and healthy lifestyle workers who educate communities about kidney health. The project also plays a role in promoting awareness of the issues affecting each community through advocacy, publication of research findings and media publicity. | Partnership between the people of the Western Desert, health services, governments, research institutes and private organisations. |
| Closing the Gap PBS Co-payment Measure | Improves access to PBS medicines for eligible Aboriginal and Torres Strait Islanders who are living with, or at risk of, chronic conditions. CTG prescriptions attract a lower or nil patient co-payment for PBS medicines. | Commonwealth Government |
| Danila Dilba Kidney Health Program | Aims to implement a case management service to clients in the Greater Darwin Area, who have identified stage 4 or 5 CKD. The kidney health program provides education and family based consultation to help clients understand the choices that they have when their kidneys get sick. The program also works closely with an outreach team that visits renal patients living in town-based communities in Palmerston and Darwin. The program practices continuous quality improvement by using the ABCD audit tools from Menzies School of Health and Research, and works with other areas of Danila Dilba Health Service in promoting the screening for CKD through adult health checks. | Danila Dilba Health Service |
| The Flinders Closing the Gap Program  | A set of tools and processes enabling healthcare professionals to support their Aboriginal and Torres Strait Islander clients to better self-manage their chronic conditions. It is an adaptation of the generic Flinders Program™, a chronic condition management program based on cognitive behaviour therapy, problem solving and motivational interviewing techniques. Resources include:* training resources for health professionals - an educational DVD, manuals, a website and [online learning modules](https://fctgp.flinders.edu.au/)
* resources for clients - posters, brochures and the [My Health Story](https://healthinfonet.ecu.edu.au/key-resources/publications/34830/) care plan for use with Aboriginal and Torres Strait Islander clients.
 | Flinders University |
| Gudbinji Chronic Disease Program | Provides chronic and communicable disease management services to improve the overall health of Indigenous families living in the Katherine region of the Northern Territory. The clinic will treat and support adults who have been diagnosed with a chronic condition such as diabetes, heart disease, respiratory disease, renal disease and cancer.Gudbinji holds events and specialist visits such as healthy heart days, diabetes education days and renal medicine specialist visits, as well as providing regular services including:* well person's health checks
* planned screening days targeting groups that are deemed to be at higher risk
* chronic condition care plans tailored to individual requirements
* patient information recall system for follow-up treatments.
 | Wurli-Wurlinjang Health Service, funded by the Commonwealth Government through the Department of Health as part of the Healthy for Life initiative |
| Improving Care for People With Advanced Chronic Kidney Disease: The I'm OK project | The goal of this project is to enhance communications between medical staff and patients, and enable close-to-home access specialist health care in regional ACCHS in the Northern Territory. This initiative contributes to the creation of strong links between the many different health services for a coordinated approach, and helps reduce the mental wellbeing and financial cost often experienced by patients needing to travel from remote areas for treatment. This project allocates patients experiencing advanced CKD with a care coordinator. This coordinator acts as the key contact for that person and makes sure the person has access to all the services they need, as well as liaising with different health professionals that the person is seeing. | Preventable Chronic Disease Program, the Remote Health Branch and NT Renal Services and the Aboriginal community controlled health sector. |
| Indigenous Australians’ Health Programme (IAHP) | The objective of the IAHP is to provide Aboriginal and Torres Strait Islander people with access to effective high quality, comprehensive, culturally appropriate, primary health care services in urban, regional, rural and remote locations across Australia. This includes through ACCHS, wherever possible and appropriate, as well as services across the entire health system that deliver comprehensive, culturally appropriate primary health care.Funding may be provided through the following five themes:* Primary Health Care Services
* Improving Access to Primary Health Care for Aboriginal and Torres Strait Islander People
* Targeted Health Activities
* Capital Works
* Governance and System Effectiveness.
 | Commonwealth Government |
| Medical Outreach Indigenous Chronic Disease Program (MOICDP) | Provides funding to support a broad range of multi-disciplinary team-based health outreach services that focus on the prevention, detection and management of chronic conditions in Aboriginal and Torres Strait Islander people across Australia (primary and secondary care). The MOICDP supports the delivery of a wide range of medical specialist, GP and allied health outreach services.Successful fundholders of the MOICD to date include the New South Wales Rural Doctors Network, Northern Territory Primary Health Network, CheckUp Australia, Rural Doctors Workforce Agency South Australia, Tasmanian Department of Health and Human Services, Rural Workforce Agency Victoria and Rural Health West. | Commonwealth Government |
| Central Australian Renal Study | The Central Australian Renal Study, commissioned by the Federal Government in 2010, informed the NT, SA and WA Governments about the scale of health and service needs of Aboriginal dialysis patients in the cross-jurisdictional region, in order to make evidence based policy decisions that are affordable and sustainable. | Commonwealth Government |
| ANZSN position statement | In 2019-20 the ANZSN will develop a position statement on renal care for First Nations people as part of its commitment to improving kidney health for Aboriginal and Torres Strait Islander people. | ANZSN |
| Embedding Northern Territory Continuous Quality Improvement (CQI) Aboriginal Primary Health care | The program will provide capacity within primary health care by funding CQI Facilitators to work with primary health care services in each Health Service Delivery Area. The CQI Facilitators will be supported and mentored by two CQI Coordinator positions located with AMSANT (in Darwin and Alice Springs). Facilitators will assist health service staff in improving organisational processes, using tools and techniques to assist in the identification of opportunities for improvement, action planning and measuring and monitoring improvements. The CQI focus is on improvement in health service delivery to further achieve Aboriginal health outcomes.  | NT Aboriginal Health Forum, as part of Expanding Health Service Delivery Initiative (EHSDI). |
| Purple House Patient Preceptors program | Purple House employs a team of Patient Preceptors, people who have lived experience of the renal disease journey and can provide expert advice and reassurance to Aboriginal renal patients. The preceptor role strongly complements the roles of liaison officer, health worker, nurse, and nephrologist. They provide input on cultural safe care and aspects of delivering appropriate education within the context of the local community, addressing language and cultural barriers. In addition, preceptors can serve as local champions for kidney disease awareness.  | Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation) |
| The Northern Territory Aboriginal Health Forum (NTAHF) | The NTAHF is the partnership vehicle through which the [*Agreement on Northern Territory Aboriginal Health and Wellbeing 2015-2020*](http://www.amsant.org.au/wp-content/uploads/2015/10/Agreement-on-Northern-Territory-Aboriginal-Health-and-Wellbeing-reduced.pdf)is implemented. The NTAHF provides high-level guidance and decision-making aimed at ensuring that Aboriginal peoples in the Northern Territory enjoy health and wellbeing outcomes equal to that of the community as a whole. The NTAHF aims to:* increase the effectiveness of the health system, including through:
1. ensuring appropriate resource allocation
2. maximising Aboriginal community participation and control as a key element of sustainable, viable, effective and efficient health services
3. encouraging better service responsiveness to / appropriateness for Aboriginal people
4. promoting quality, evidence-based care

improving access for Aboriginal people to both mainstream and Aboriginal specific health services1. increasing engagement of health services with Aboriginal communities and organisations.
* ensure that the social determinants of health are addressed through high level collaboration and advocacy outside the health system.
* work streams include
* primary care
* hospital and specialist care
* social determinants of health
* health system strengthening and monitoring.
 | Northern Territory Aboriginal Health Forum |

**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.***

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| Name of activity | Description  | Who |
| Implement the *TSANZ Performance Report - Improving Access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander People in Australia.*  | In response to the *TSANZ Performance Report - Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia* report, the Commonwealth Government announced funding for a project to the increase Indigenous kidney transplantation (March 11 2019).The report prioritises three of its 35 recommendations:* Establishing a National Indigenous Kidney Transplantation Taskforce to consult with and advocate for Aboriginal and Torres Strait Islander patients.
* Enhanced data collection and reporting processes on pre- and post-transplant outcomes.
* Establishing an Indigenous reference group in every transplant unit, with the trialing of patient navigators and expansion of initiatives targeting cultural bias in health services.
 | Commonwealth Government, TSANZ |

**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.

**3.1.1 Establish a Kidney Research Collaborative to develop and implement a kidney research strategy with targeted priorities**

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| Name of activity | Description  | Who |
| ANZSN research strategy | The ANZSN has developed a research strategy, which it is progressively implementing through its Research Advisory Committee (RAC). The RAC includes representation from affiliated organisations with a shared interest in promoting kidney research, including Kidney Health Australia. | ANZSN |
| Kidney Health Australia Research | Kidney Health Australia has been funding research for over 50 years, distributing over $30 million towards kidney research. Current research program includes three research streams:1. Improving quality of life and duration of life for those living with CKD
2. Making kidney transplants last longer
3. Preventing the progression of CKD.

Within each stream priority is given to three areas:* Basic science
* Psychosocial
* Clinical science/population health.

In 2018 Kidney Health Australia allocated a total of $250k to five programs under Stream 1. | Kidney Health Australia |

**3.1.2 Invest in high quality research focused on improving disease prevention and management and the search for cures.**

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| Name of activity | Description  | Who |
| The Australasian Kidney Trials Network (AKTN) | Established in 2005 to address the paucity of clinical trials in Nephrology with NHMRC funding. The AKTN:* Enables clinician-investigator research by delivering the infrastructure that allows kidney care researchers access to methodological, statistical, operational and skilled database staff with expertise in all stages of clinical research design, conduct, co-ordination, trial and data management and statistical analysis.
* Provides researchers and students access to training, guidance and advice in clinical research conduct, and has an established culture of mentoring that supports Early- and Mid-Career Researchers.
* Has completed 8 randomised controlled trials and 1 observational study and, with global partners, is currently developing a number of investigator initiated trials, each with a design focus utilising novel and pragmatic methods of data collection and/or randomisation.
 | AKTN |
| Centre for Research Excellence (CRE): Intervention Research in Chronic Disease | This Centre of Research Excellence, commonly known as the 'Kanyini Vascular Collaboration', brings together Indigenous and non-Indigenous researchers, healthcare professionals, policy-makers and communities with a common goal of:* improving health outcomes for Indigenous Australians at risk of vascular diseases including heart disease, kidney disease and diabetes
* establishing the barriers to the best possible management of chronic conditions among Aboriginal and Torres Strait Islander Australians
* building capacity within local ACCHS with community needs and priorities driving the research.

Current and past research projects of the CRE include:* [Home Based Outreach Chronic Disease Management Exploratory Study (HOMES)](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=2231)
* ['Getting It Right': the Validation Study](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=2751)
* [A Wellbeing Framework for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=2752)
* [Kanyini Qualitative Study](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=2755)
* [The Kanyini Guidelines Adherence with the Polypill study - Kanyini GAP](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=1536)
* Kanyini Vascular Audit
* Communication Project
* Electronic Decision Support Tool.
 | Kanyini Vascular Collaboration CRE |
| NHMRC CKD Centre for Research Excellence | * Mission is to advance knowledge about chronic kidney disease and its management across the health care spectrum, in order to improve patient outcomes.
* Current projects:
* Chronic Kidney Disease in Queensland (CKD.QLD Registry)
* aCQuiRE (Ckd.Qld fabRy Epidemiology) Study
* CKD and Health Utilisation
* Drop CKD Study
* Audit 4
* GP CKD Referral Project
* Kidney Supportive Care Program
* Integrated Chronic Disease
* Person-centred Care in CKD: The CKD-SMS Study
* The CKD Biobank
* Treating CKD with Plant Extracts
* Safe Water
 | University of Queensland, NHMRC, AIHW, QLD DoH, Queensland University of Technology, CKD LD,Kidney Health Australia, University of Melbourne, Western Health, VIC DoH, University of NSW, University of Sydney, NSW DoH, University of Tasmania, TAS DoH, WA DoH |
| The Menzies School of Health Research | The Menzies School of Health Research (the Menzies) is an independent medical and research institute, a national leader in health, education and research training. The Menzies is Australia’s only medical research institute dedicated to improving Indigenous health and wellbeing. The team at Menzies carry out research in more than 60 Indigenous communities across Australia and in developing countries in our region. Research addresses critical issues such as mental health, nutrition, substance abuse, child health and development, as well as chronic conditions such as cancer, kidney disease and heart disease. Global research examines life-threatening illnesses in the Asia-Pacific, such as malaria and tuberculosis.Current programs include:* Catching Some Air-Asserting Indigenous Information Rights in Renal Disease
* Dialysis Models of Care Project
* Territory Kidney Care
* The PK Study
* Evaluation of Top End Health Services Renal Outreach Program
* eGFR study: accurate assessment of renal function and progression of chronic kidney disease in Indigenous Australians
* A retrospective study of the characteristics and outcomes of dialysis requiring acute kidney injury among adults in an acute dialysis unit
* The PK Study
* Kidney Yarning Circles: Pathways to My Home
* Fish and Fruit Study
 | The Menzies School of Health Research |
| Better Evidence And Translation – Chronic Kidney Disease (BEAT-CKD) | Collaborative research program that aims to improve the lives of people living with CKD in Australia and globally by generating high-quality research evidence to inform healthcare decisions made by patients, health professionals, and policy makers. BEAT-CKD addresses the entire spectrum of CKD, from early stage CKD, through to dialysis, and kidney transplantation. NHMRC-funded.The objectives are to:* identify promising interventions for existing high priority outcomes
* identify new priority outcomes that are patient-centred, and potential interventions to improve these outcomes
* provide robust evidence about these interventions
* identify which patients might achieve the most benefit from these interventions
* identify and evaluate strategies to deliver these interventions in diverse clinical settings.
 | BEAT-CKD AKTNANZDATAKHACARICochrane Renal |
| The Standardised Outcomes in Nephrology (SONG) | SONG initiative aims to establish a set of core outcomes and outcome measures across the spectrum of kidney disease for trials and other forms of research. The outcomes will be developed based on the shared priorities of patients, caregivers, clinicians, researchers, policy makers, and relevant stakeholders. This will help to ensure that research is reporting outcomes that are meaningful and relevant to patients with kidney disease, their family, and their clinicians; to support decisions about treatment.Current projects:* haemodialysis (SONG-HD)
* transplantation (SONG-Tx)
* peritoneal dialysis (SONG-PD)
* children and adolescents (SONG-Kids)
* polycystic kidney disease (SONG-PKD).
 |  |
| The George Institute for Global Health Renal and Metabolic Division | * The George Institute, the Renal and Metabolic team conducts research to address the challenges of the global impact of CKD through:
* Targeting knowledge gaps
* Building global collaborations

Recent projects include:* CREDENCE study - the study evaluated the efficacy and safety of canagliflozin compared to placebo in patients with CKD and T2DM, in addition to standard of care. Canagliflozin reduce by the risk of the progression to ESKD by 30%
* STandard versus Accelerated initiation of Renal Replacement Therapy in Acute Kidney Injury (STARRT-AKI): A Multi-Centre, Randomized, Controlled Trial
* REDUcing the burden of dialysis Catheter ComplicaTIOns: a National approach (REDUCCTION)
* Prevention of Serious Adverse Events following angiography (PRESERVE)
* Therapeutic Evaluation of STeroids in IgA Nephropathy Global study (TESTING)
* EXamining ouTcomEs in chroNic Disease in the 45 and Up Study (EXTEND45)
* OUTcomes Of Older patients with Kidney failure (OUTLOOK) and Treatment modalities for the InfirM ElderLY with ESKD (TIMELY) – The ELDERLY Program
* Aldosterone bloCkade for Health Improvement EValuation in End-stage renal disease (ACHIEVE)
* The Affordable Dialysis Project (the design and roll-out of a portable and relatively low-cost dialysis machine, seeks to challenge the existing dialysis business model by delivering cheap, transportable treatment to patients that could otherwise not access the life-saving care)
* Dialysis Outcome in India
* Study of Heart and Renal Protection Extended Review (SHARP-ER)
* ACTIVE Dialysis - A clinical trial of intensive dialysis
* Australian Kidney Trials Network (AKTN)
* Prediction of the outcome of acute renal replacement therapy (PREDICT)
* Filtration In the Neuropathy of ESKD Symptom Evolution (FINESSE)
* Randomised Evaluation of Sodium Dialysate Levels on Vascular Events (RESOLVE)
 | The George Institute for Global Health Renal and Metabolic Division, global collaborations |
| Jacquot Fellowships and Awards | Fellowships and scholarships jointly administered by The Royal Australasian College of Physicians (RACP) and the Australian and New Zealand Society of Nephrology (ANZSN). The selection committee includes representatives of RACP and ANSZN. | ANZSNRACP |

**3.2.3 Establish a Kidney Consumer Hub to facilitate joint research priority setting and enable consumer driven, targeted research.**

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| Name of activity | Description  | Who |
|  SONG | See 3.1.2 above | SONG |
| BEAT-CKD  | See 3.1.2 above | BEAT-CKD |
| Kidney Health Australia National Consumer Council | Formed in 2003 to provide a formal pathway for people living with kidney disease to gain visibility about issues and opportunities they are experiencing. The purpose of the Kidney Health Australia National Consumer Council is to:* Act as a link to the wider patient community, identifying and prioritising any unaddressed issues or changes impacting kidney patients and their carers, either negative or positive.
* Provide KHA and, where possible, the broader clinical community with an open and frank mechanism for feedback on policy, priorities, collateral and bodies of work supporting people living with kidney disease.
* Advise and support Kidney Health Australia in regard to consumer involvement in kidney research.
* Support Kidney Health Australia where requested, in advocating for change to public health policy from the kidney patient perspective.
* Work with Kidney Health Australia to educate about and raise the profile of kidney disease and the programs and services offered by Kidney Health Australia, within local communities and networks.
 | Kidney Health Australia |
| Improving Aboriginal Kidney Care Together | This collaborative action research project brings together Aboriginal kidney patients, family members, Aboriginal and non-Aboriginal healthcare professionals, health services, academics, researchers and other stakeholders to identify gaps and develop strategies to improve kidney care in SA. Community consultations and focus groups will be held in Adelaide and Port Augusta to enable Aboriginal patients, their family and community members to highlight their kidney care needs and priorities. Emerging themes will inform local and state health services, and new National Guidelines for Management of CKD for Indigenous people in Australia and New Zealand. | The University of Adelaide |

Objective 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**.

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| --- | --- | --- |
| Name of activity | Description  | Who |
| ANZDATA | Collects and reports the incidence, prevalence and outcome of dialysis treatment and kidney transplantation for patients with ESKD across Australia and New Zealand. The Registry was established in 1977 from the merger of separate dialysis and transplant registries to provide information on the patterns and outcomes of dialysis and kidney transplantation, and to support safety and quality activities and the planning of appropriate health services. The aim of ANZDATA is to improve the quality of care and outcomes for people with ESKD in Australia and New Zealand by:* collecting and analysing accurate and comprehensive data from all patients receiving long term dialysis or kidney transplantation in Australia and New Zealand
* producing and disseminating reports
* informing development of practice, policy and health services
* working with stakeholders to improve the understanding of kidney disease and outcomes of treatment.
 | ANZDATA |
| Safer Care Victoria Renal Clinical Network Victorian Renal Key Performance Indicator program | The Safer Care Victoria Renal Clinical Network Victorian Key Performance Indicators have been functioning since 2012 as a quality improvement program for Victorian renal healthcare services. The aim of the indicators is to drive service improvement through the transparent comparison of renal service performance.  | Safer Care Victoria Renal Clinical Network |
| ANZSN | The ANZSN provides in-kind support (members provide data at a unit level) to the ANZDATA registry.The ANZSN is also working closely with ANZDATA, is developing a set of KPIs to be implemented nationally to improve quality and safety in renal care.The ANZSN, through its Dialysis Advisory Committee, is also in the process of exploring the potential to establish a standardized critical incident reporting system in heamodialysis and peritoneal dialysis. | ANZSN |
| National Chronic Kidney Disease Registry | This project will establish a national registry and surveillance collaboration to develop profiles of chronic CKD patients in various primary care and renal practice settings, in several states. The profiles will include both Indigenous and non-Indigenous people. It is anticipated that the outputs of the research will result in improved detection of CKD, slowed progression, fewer cardiovascular deaths, better care pathways, and some deceleration in rising rates of RRT, with more rationalised resource utilisation. | WA Renal Health Network |

**3.2.2 Roll out an improved Australian Health Survey (AHS) in conjunction with Australian Bureau of Statistics (ABS).**

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| Name of activity | Description  | Who |
| Australian Health Survey (AHS) | The AHS, conducted by the Australian Bureau of Statistics (ABS) in 2011-12, is made up of three components: the National Health Survey 2011-12; the National Nutrition and Physical Activity Survey 2011-12; and. the National Health Measures Survey 2011-12. The AHS will provide a better understanding of the health of people living in Australia. The AHS is the largest and most comprehensive health survey conducted in Australia, and provides an understanding of the health of people living in Australia. The AHS involved about 50,000 adults and children and included both a household survey component conducted by professional interviewers and a biomedical component.The information collected was used to identify key health information gaps in nutrition and physical activity. It will provided objective data for a number of markers of nutritional status and chronic conditions such as high or low levels of blood sugar, cholesterol and kidney function. | ABS |

**3.2.3 Translate research into practice through the strengthening of clinical guidelines and implementation of living guidelines.**

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| Name of activity | Description  | Who |
| KHA–CARI guidelines | Since 1999 KHA-CARI Guidelines seeks to improve the quality of care and outcomes for patients with kidney disease in Australia and New Zealand by facilitating the development and implementation of clinical practice guidelines based on the best available evidence and effectiveness. The guidelines are funded by Kidney Health Australia along with the ANZSN.KHA-CARI is an internationally respected Guidelines group and works closely with KDIGO, Cochrane Renal and Transplant group and other kidney Guidelines organisations to deliver gold-standard evidence synthesis methodology and output.Current projects include:* Management and Screening of Infectious Diseases in Haemodialysis Units [for publication in 2017)
* Autosomal Dominant Polycystic Kidney Disease Patient and Caregiver guidelines [for publication in 2017]
* Management of CKD in Australian Indigenous and New Zealand Maori People [for publication in 2018]
* [Renal Biopsy Guideline: Draft](http://www.cari.org.au/CKD/CKD%20renal%20biopsy/KHA-CAR__renal_biopsy_DRAFT_for_comment.html) FOR COMMENT until 18 January 2019
* Frontier kidney guideline for Australian Living Evidence Consortium.
* KHA CARI Guidelines reach and impact
* On average, over 1,000 unique visitors per month to the KHA-CARI website in 2017
* Over 500 guideline pdfs downloaded from the KHA-CARI website in 2017
* Almost 6,000 guideline pdfs downloaded via the Nephrology journal website in 2017
* Multiple peer-reviewed publications published
* 65 peer-reviewed publications cited KHA-CARI guidelines in 2017
 | KHA-CARI |
| National Guide to a Preventative Health Assessment for Aboriginal and Torres Strait Islander peoples  | The Royal Australian College of General Practitioners (RACGP) together with NACCHO have developed the National Guide to a preventive health assessment for Aboriginal and Torres Strait Islander peoples, now in its third edition. This broad-ranging, practical resource for primary care management includes a brief, evidence-based chapter on key recommendations for CKD management, aligned with the RACGP Red Book (*Guidelines for preventive activities in general practice*), the Kidney Health Australia CKD in General Practice Handbook and the KHA-CARI Guidelines. The RACGP and NACCHO promote these guidelines, and in 2018-19 have undertaken a review of implementation strategies to facilitate integration into clinical practice and better care. | RACGPNACCHO |
| Cochrane Kidney and Transplant | Cochrane Kidney and Transplant (previously known as the *Cochrane Renal Group*) - one of 53 Cochrane Review Groups that are part of [Cochrane](http://www.cochrane.org/), an international, independent not-for-profit organisation dedicated to providing up-to-date, accurate information about the effects of health care. Cochrane Kidney and Transplant is concerned with the evaluation of care relevant to patients with kidney disease and with complications of diabetes and hypertension and the means of managing problems associated with interventions for kidney diseases (chronic care, prevention, treatment, rehabilitation and side effects of medication).Cochrane Kidney and Transplant's scope covers the following major areas of kidney disease:* Acute kidney failure
* CKD (pre-dialysis, haemodialysis, peritoneal dialysis)
* Diabetic kidney disease
* Glomerulonephritis (including nephrotic syndrome, IgA nephropathy, lupus nephritis, Henoch-Schonlein Purpura, and other glomerular diseases)
* Kidney transplantation
* Solid organ transplantation
* Urinary tract infections
* Effect of drugs on kidney function.

Attention focuses mainly on clinical outcomes, such as death or the need for dialysis treatment, and quality of life issues. Non-clinical outcomes such as renal function measurement and proteinuria may be acceptable as secondary outcomes. | Cochrane  |
| Australian Living Evidence Consortium  | Led by Cochrane Australia, the Australian Living Evidence Consortium is a world-first collaboration that is bringing together experts in evidence synthesis, guideline development and digital technologies to build a next generation system for delivering reliable, accessible, up-to-date evidence in health.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. Practically, this means that living systematic reviews and living guidelines:* Are underpinned by continual, active evidence surveillance and monitoring.
* Rapidly incorporate new important evidence that is identified.
* Can communicate in near real-time the current status of the review or guideline, and any new evidence being incorporated in the recommendation/s.
* In addition to continuous updating, Living Evidence aims to improve the quality, use and value of evidence synthesis activities by:
* Engaging large and diverse groups of stakeholders to be actively engaged in finding and appraising evidence.
* Broadening the range of research and health-related data that can be included, such as real-world data from clinical quality registries and individual patient-level data.
* Publishing recommendations in multi-layered digitals formats that can be integrated at the point of care into electronic medical records and decision support tools.
* Using structured (semantic) data to improve the discoverability and re-use of research and health-related data.

The program will be driven by Frontier Projects to develop living guideline recommendations for some of Australia’s most pressing health conditions including stroke, diabetes, kidney disease, musculoskeletal conditions and heart disease. | Cochrane Australia, School of Public Health and Preventative Medicine at the Monash University, Kidney Health Australia, Stroke Foundation, Australian Diabetes Society, Diabetes Australia, The Australia and New Zealand Musculoskeletal Clinical Trials Network, Heart Foundation, The Australasian Paediatric Endocrine Group, The Australian Diabetes Educators Association |
| Guideline for Vein Preservation in Chronic Kidney Disease 2017 | The Guideline for Vein Preservation in Chronic Kidney Disease was developed in 2017 by the Renal Health Network in partnership with clinical staff across WA involved in the care of patients with chronic CKD. The Guideline provides guidance and practical recommendations based on the latest research for optimal vein preservation in patients with CKD.Implementation funding is the responsibility of Health Service Providers | Health Networks (WA Department of Health) core funding, no project funding was allocated to the development.  |

# Abbreviations

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| --- | --- |
| ABS | Australian Bureau of Statistics |
| ACCP | The Aboriginal Chronic Care Program: Murr-roo-ma Dhun-Barn |
| ACCHS | Aboriginal Community Controlled Health Services |
| ACHWA | Aboriginal Health Council of Western Australia |
| ACI | Agency for Clinical Innovation |
| ACT | Australian Capital Territory |
| AGHA | Australian Genomic Health Alliance |
| AHS | Australian Health Survey |
| AIHW | Australian Institute of Health and Welfare |
| AKTN | The Australasian Kidney Trials Network |
| AKX | The Australian Paired Kidney Exchange Program |
| AMSANT | The Aboriginal Medical Services Alliance Northern Territory |
| 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 |
| AOD | Alcohol and Other Drug  |
| APNA | Australian Primary Health Care Nurses Association |
| ATSIHP | Aboriginal and Torres Strait Islander Health Practitioner |
| BEAT-CKD | Better Evidence And Translation – Chronic Kidney Disease  |
| CDU | Charles Darwin University |
| CHC | Council of Australian Governments Health Council |
| CHSA | Country Health South Australia |
| CHSALHN | Country Health South Australia Local Health Network |
| CKD | chronic kidney disease |
| COAG | Council of Australian Governments |
| CQI | Continuous Quality Improvement |
| CRE | Centre Research Excellence |
| CRKSG | Canberra Region Kidney Support Group |
| CSCF | Clinical Services Capability Framework |
| CTG | Closing The Gap |
| CVD | cardiovascular disease |
| DoH | Department of Health |
| ESKD | end-stage kidney disease |
| FMU | Flinders Medical Unit |
| HACC | Home and Community Care Program |
| IAHP | Indigenous Australians’ Health Programme |
| ICDP | Indigenous Chronic Disease Package |
| IPTAS | Interstate Patient Transport Assistance Scheme  |
| IUIH | Institute for Urban Indigenous Health |
| KHA-CARI | Kidney Health Australia Caring for Australasians with Renal Impairment Guidelines Group |
| KPI Key | Performance Indicator |
| LHN | Local Health Networks |
| LGH | Launceston General Hospital |
| LMH | Lyell McEwen Hospital |
| LIFE | Living Improvements for Everyone |
| MBS | Medicare Benefits Schedule |
| MGHA | Melbourne Genomic Health Alliance |
| MDU | Mobile Dialysis Unit |
| MOICDP | Medical Outreach Indigenous Chronic Disease Program |
| MRFF | Medical Research Future Fund |
| MSAC | Medical Services Advisory Committee |
| NDIS | National Disability Insurance Scheme |
| NATA | National Association of Testing Authorities |
| NCACCH | North Coast Aboriginal Corporation for Community Health |
| NCPHN | North Coast Primary Health Network  |
| NGO | Non-Government Agency |
| NPAPH | National Partnership Agreement on Preventive Health  |
| NHMRC | National Health and Medical Research Council |
| NSW | New South Wales |
| NT | Northern Territory  |
| NTAHF | Northern Territory Aboriginal Health Forum |
| NVDPA | National Vascular Disease Prevention Alliance  |
| OCPKD | Optimal Care Pathways for Kidney Disease |
| OECD | Organisation for Economic Co-operation and Development |
| OTA | Organ and Tissue Authority |
| PATS | Patient Assistance Transport Scheme |
| PHN | Primary Health Network |
| PIP IHI | The Practice Incentives Program Indigenous Health Incentive |
| PKD | polycystic kidney disease |
| POCT | Point-of-care testing  |
| PROMs | Patient Reported Outcome Measures |
| PTSS | Queensland Patient Travel Subsidy Scheme  |
| QIPC | Quality Improvement in Primary Care |
| QGHA | Queensland Genomic Health Alliance |
| RAC | Research Advisory Committee |
| RACGP | Royal Australian College of General Practitioners |
| RAH | Royal Adelaide Hospital |
| RICP | The Renal Integrated Care Pathway |
| RRT | renal replacement therapy |
| SA | South Australia |
| SAHMRI | South Australian Health and Medical Research Institute |
| SONG | Standardised Outcomes in Nephrology  |
| SReCN | The Statewide Renal Clinical Network |
| SWSLHD | South Western Sydney Local Health District |
| SWSPHN | South Western Sydney Primary Health Network |
| TAS | Tasmania |
| TSANZ | Transplantation Society of Australia and New Zealand |
| TQEH | The Queen Elizabeth Hospital |
| VIC | Victoria |
| WA | Western Australia |
| WACHS | Western Australia Country Health Service |