

# *Summary of kidney health among Aboriginal and Torres Strait Islander people*



## Australian Indigenous Health/InfoNet

The Australian Indigenous Health/InfoNet's mandate is to contribute to improvements in Aboriginal and Torres Strait Islander health by making relevant, high quality knowledge and information easily accessible to policy makers, health service providers, program managers, clinicians and other health professionals (including Aboriginal and Torres Strait Islander health workers) and researchers. The Health/InfoNet also provides easy-to-read and summarised material for students and the general community.

The Health/InfoNet achieves its commitment by undertaking research into various aspects of Aboriginal and Torres Strait Islander health and disseminating the results (and other relevant knowledge and information) mainly via its website ([healthinfonet.ecu.edu.au](http://healthinfonet.ecu.edu.au)). The research involves analysis and synthesis of data and other information obtained from academic, professional, government and other sources. The Health/InfoNet's work in knowledge exchange aims to facilitate the transfer of pure and applied research into policy and practice to address the needs of a wide range of users.

### Recognition statement

The Australian Indigenous Health/InfoNet recognises and acknowledges the sovereignty of Aboriginal and Torres Strait Islander people as the original custodians of the country. Aboriginal and Torres Strait Islander cultures are persistent and enduring, continuing unbroken from the past to the present, characterised by resilience and a strong sense of purpose and identity despite the undeniably negative impacts of colonisation and dispossession. Aboriginal and Torres Strait Islander people throughout the country represent a diverse range of people, communities and groups each with unique identity, cultural practices and spiritualities. We recognise that the current health status of Aboriginal and Torres Strait Islander people has been significantly impacted by past and present practices and policies.

We acknowledge and pay our deepest respects to Elders past and present throughout the country. In particular, we pay our respects to the Whadjuk Nyoongar peoples of Western Australia on whose country our offices are located.

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### Tell us what you think

We value your feedback as part of our post-publication peer review process, so please let us know if you have any suggestions for improving this summary.

ISBN Web: 978-0-6488625-6-7

ISBN Hard copy: 978-0-6488625-5-0



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# Summary of kidney health among Aboriginal and Torres Strait Islander people

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## Suggested citation

Australian Indigenous HealthInfoNet. (2020). *Summary of kidney health among Aboriginal and Torres Strait Islander people*. Perth, W.A. Australian Indigenous HealthInfoNet.

Based on: Schwartzkopff K.M., Kelly, J., Potter, C. (2020). Review of kidney health among Aboriginal and Torres Strait Islander people. *Australian Indigenous HealthBulletin* 20(4).

## Acknowledgements

Special thanks are extended to;

- Kelli Owen, National Community Engagement Coordinator, National Indigenous Kidney Transplantation Taskforce & AKtion Reference Group member, for providing her expert perspective on this topic
- Dr Uncle Mick Adams, Senior Research Fellow at the Australian Indigenous HealthInfoNet, for cultural feedback on this summary
- staff at the Australian Indigenous HealthInfoNet for their assistance and support
- the Australian Government Department of Health for their ongoing support of the work of the Australian Indigenous HealthInfoNet.

## Further information

The summary, reviews and more information about kidney health among Aboriginal and Torres Strait Islander people can be viewed at: [healthinfolnet.ecu.edu.au/kidney](http://healthinfolnet.ecu.edu.au/kidney).

## Contents

Introduction.....	6
Kidneys and kidney disease .....	6
The context of Aboriginal and Torres Strait Islander health and kidney health .....	8
How common is kidney disease among Aboriginal and Torres Strait Islander people? .....	9
Chronic kidney disease.....	9
End-stage kidney disease .....	9
Hospital admissions and treatment .....	10
Hospital admissions for chronic kidney disease .....	10
Deaths from kidney disease.....	10
Treatment and care .....	10
Types of treatment.....	10
How common are dialysis and transplantation among Aboriginal and Torres Strait Islander people? .....	11
Transplantation.....	12
Hospital admissions for dialysis.....	13
Deaths and dialysis .....	13
Survival on dialysis .....	13
Survival after transplantation .....	14
Types of care and care considerations .....	14
Palliative care .....	14
Mental health .....	15
Access for people in rural and remote areas.....	15
Helping people living in remote areas access dialysis close to home .....	15
Aboriginal and Torres Strait Islander health workforce .....	16
Cultural safety and effective communication for non-Indigenous health professionals..	16
Peer support.....	16
Developing patient informed clinical guideline .....	17
Strategies to improve kidney care in Australia for and with Aboriginal and Torres Strait Islander people.....	18
Addressing systemic racism.....	19
Concluding comments.....	19
References .....	20



### Cover artwork

Watiya-warnu Jukurra (Seed Dreaming) by Evelyn Nangala Robertson

This painting tells the story of a Jangala ‘watiya-warnu’ (*Acacia tenuissima*) ancestor who travelled south from a small hill called Ngurlupurranyangu to Yamunturrngu (Mount Liebig). As he travelled, he picked the ‘watiya-warnu’ seeds and placed them in ‘parrajas’ (food carriers), one of which he carried on his head. Watiya-warnu is a seed-bearing tree that grows in open spinifex or mulga country. When people returned to their camp after collecting the seeds, they would make large windbreaks for shelter and winnow the seed in the late afternoon. The associated ‘watiya-warnu’ ceremony involves the preparation of a large ground painting. This Jukurra belongs to Nampijinpa/Nangala women and Jampijinpa/Jangala men. In contemporary Warlpiri paintings, traditional iconography is used to represent the Jukurra, particular sites and other elements. In paintings of this Dreaming, ‘U’ shapes are often depicting women collecting the ‘watiya-warnu’ seeds. Oval shapes represent the ‘parrajas’ where they carry the seeds, and straight lines beside them frequently portray digging sticks.

### Featured icon artwork

by Frances Belle Parker

The HealthInfoNet commissioned Frances Parker, a proud Yaegl woman, mother and artist, to produce a suite of illustrated icons for use in our knowledge exchange products. Frances translates biomedical and statistically based information into culturally sensitive visual representations, to provide support to the Aboriginal and Torres Strait Islander workforce and those participating in research and working with Aboriginal and Torres Strait Islander people and their communities. Frances came to prominence winning the Blake Prize in 2000, making her the youngest winner and the first Indigenous recipient over the 65 year history of the prize.

*“Birrinda is the Yaegirr name for the mighty Clarence River (NSW). It is this river that is the life giving vein for the Yaegl people. And it is this river which inspires much of my artwork. I am deeply inspired by my Mother’s land (Yaegl land) and the Island in the Clarence River that my Mother grew up on, Ulgundahi Island. The stories which are contained within this landscape have shaped me as a person as an artist and most recently as a Mother. This is my history, my story and it will always... be my responsibility to share this knowledge with my family and my children.”*

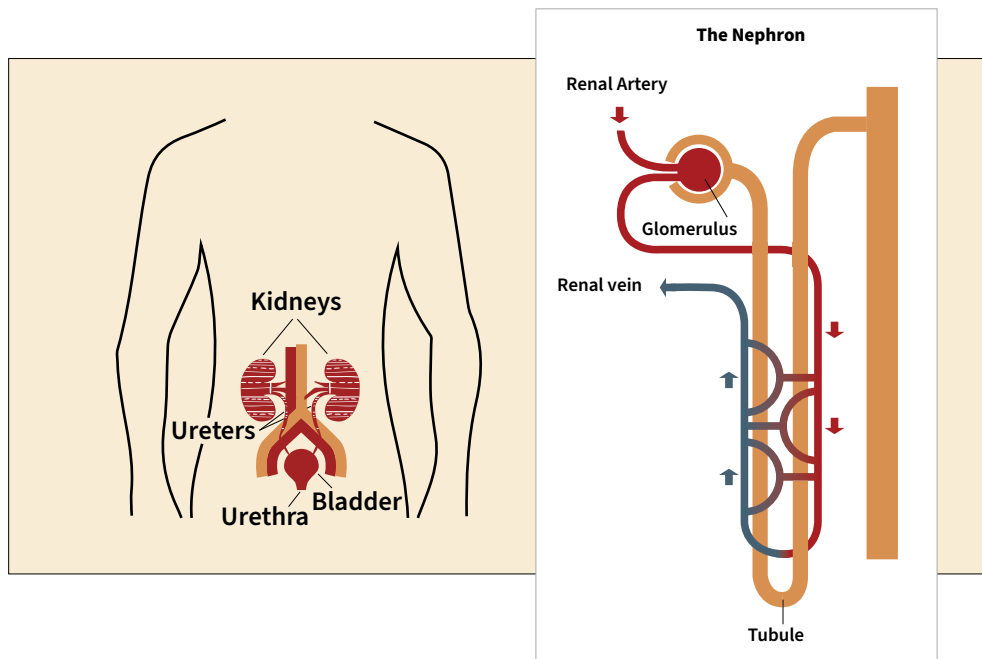


## Introduction

Kidney disease is a serious and growing health concern for Australians<sup>[1]</sup>. Aboriginal and Torres Strait Islander people in particular experience high levels of the disease, especially those people living in remote areas<sup>[2]</sup>.

## Kidneys and kidney disease

The main function of the kidneys is to filter blood to remove waste and extra fluid from the body<sup>[3]</sup>. They also help control blood pressure, produce red blood cells and keep bones strong. Each kidney has around a million 'nephrons' that filter blood<sup>[4]</sup>. Each nephron has a 'glomerulus' that filters blood and a 'tubule' that returns needed substances to the blood and removes waste<sup>[5]</sup>.

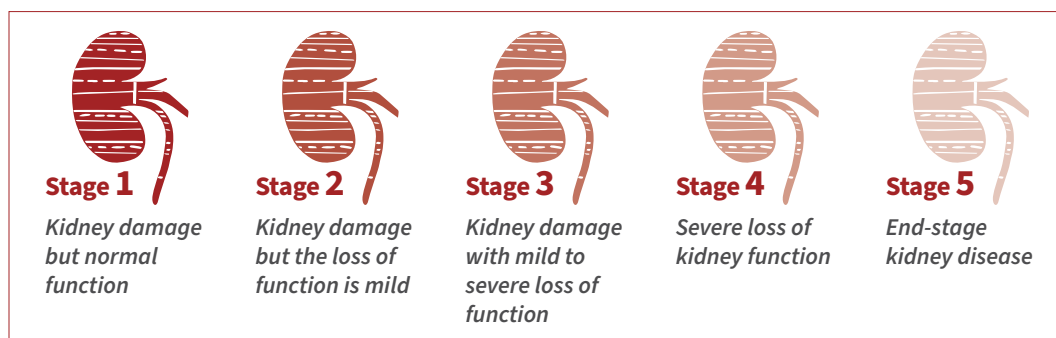


Source: Derived from U.S. Department of Health and Human Services (2018)<sup>[5]</sup>

Kidney disease is a general term for when the kidneys are damaged or do not function properly<sup>[6]</sup>. There are several treatments, but kidney disease often goes undiagnosed until serious damage has been done.

Of particular importance to Aboriginal and Torres Strait Islander people is chronic kidney disease (CKD), defined as, damage to the kidneys or reduced functioning of the kidneys that lasts for three months or longer<sup>[7,8]</sup>. CKD includes a range of conditions like diabetic nephropathy, hypertensive renal disease, glomerular disease, chronic kidney failure and end-stage kidney disease (ESKD). CKD has five stages with ESKD being the last stage<sup>[1]</sup>.

## Five stages of chronic kidney disease



Sources: Derived from Kidney Health Australia, 2020<sup>[9]</sup>, AIHW, 2015<sup>[1]</sup>

## Risk factors for kidney disease

There are many risk factors for developing kidney disease. These risk factors are related to both a person's health and social circumstances <sup>[10, 11]</sup>. Aboriginal and Torres Strait Islander people are at higher risk of developing CKD and ESKD and also of developing CKD and ESKD at younger ages than non-Indigenous Australians <sup>[12]</sup>. A holistic and comprehensive approach to health is needed to reduce the risk of CKD and ESKD among Aboriginal and Torres Strait Islander people. The risks listed have been established as correlated but not necessarily causative.



**Diabetes** can damage the kidneys, which is called 'diabetic kidney disease' or 'diabetic nephropathy' <sup>[13]</sup>. Having diabetes can damage the part of the kidneys that filters blood, making the filter 'leaky' and letting protein into urine. This is one of the most common causes of CKD in Aboriginal and Torres Strait Islander people <sup>[9]</sup>. **In 2018-19, 8% of Aboriginal and Torres Strait Islander people reported having diabetes** <sup>[14]</sup>.



**Low birth weight (LBW)** has been linked to long-term risk of CKD and ESKD <sup>[15]</sup>. It is thought that LBW makes the kidneys more vulnerable to damage through diabetes and high blood pressure. Recently, **up to 35% of adult Aboriginal people were born having LBW**, which may explain the high number of Aboriginal and Torres Strait Islander people with CKD <sup>[16]</sup>. **In 2017, 13% of Aboriginal and Torres Strait Islander babies were born with LBW** <sup>[17]</sup>.



**Post streptococcal glomerular nephritis (PSGN)** is a kidney disease that develops several weeks after a skin or throat infection <sup>[18]</sup>. PSGN is a common complication from scabies (a condition caused by mites burrowing under the skin causing itchy lesions), and scabies has been shown to increase the risk of CKD <sup>[19-21]</sup>. PSGN most commonly occurs in children and generally occurs in poorer communities with lower housing and sanitation conditions <sup>[18]</sup>. **Having multiple PSGN infections can increase the risk of developing CKD in later life** <sup>[19]</sup>. Outbreaks occasionally arise in Aboriginal and Torres Strait Islander communities, particularly those in rural or remote areas <sup>[22]</sup>.



**Smoking** is linked to kidney damage, both in healthy individuals and in people with diabetes and hypertension <sup>[23]</sup>. In 2018-19, 37% of Aboriginal and Torres Strait Islander adults smoked daily <sup>[14]</sup>. The **good news is that smoking has decreased** among young people aged 18-24 years from **50% in 2004-05 to 36% in 2018-19** <sup>[14]</sup>. In 2018-19, smoking was more common among Aboriginal and Torres Strait Islander people living in remote areas (49%) than those living in cities (35%).



**Cardiovascular disease (CVD)** is the term for all diseases and conditions that affect the heart and the blood vessels that carry the blood through the body <sup>[24]</sup>. It is a risk factor and major complication of ESKD <sup>[25-27]</sup>. **Patients with ESKD commonly have CVD and it is the most common cause of death of ESKD patients** <sup>[27]</sup>. In 2018-19, **15% of Aboriginal and Torres Strait Islander adults reported having CVD** <sup>[14]</sup>.



**Dyslipidaemia** is when there are high levels of cholesterol or fats and lipids in the blood <sup>[28]</sup>. It is both a risk factor for developing CKD and a complication from CKD. In 2018-19, **4.5% of Aboriginal and Torres Strait Islander people reported having high cholesterol** <sup>[14]</sup>. The proportion increased with age.



**High blood pressure** is a risk factor for CKD <sup>[29]</sup>. In 2018-19, 26% of Aboriginal and Torres Strait Islander adults reported having high blood pressure <sup>[14]</sup>.



**Chronic stress** is a risk factor for chronic disease generally and CKD specifically <sup>[30, 31]</sup>. Aboriginal and Torres Strait Islander people experience high rates of chronic stress <sup>[30]</sup>. In 2018-19, **31% of Aboriginal and Torres Strait Islander people reported high or very high levels** of psychological distress <sup>[14]</sup>.



**Family history of CKD:** Having a family history of CKD is a risk factor for developing CKD <sup>[32]</sup>. Because CKD is common in the Aboriginal population, many people have a family history of this condition <sup>[33]</sup>.



**Overweight or obesity:** Being overweight or obese is a risk factor for CKD <sup>[34, 35]</sup>. In 2018-19, **72% of Aboriginal and Torres Strait Islander people over the age of 15 years reported a body mass index above the healthy range** (overweight or obese) <sup>[14]</sup>.

## The context of Aboriginal and Torres Strait Islander health and kidney health

Aboriginal and Torres Strait Islander people have lived on their traditional lands across Australia, including the islands of the Torres Strait, for many thousands of years <sup>[36]</sup>. Before colonisation, Aboriginal and Torres Strait Islander people lived in family and community groups and moved across the land as the seasons changed and knowledge and culture was passed on through oral traditions <sup>[37]</sup>.

Colonisation of Australia occurred around 1788 and led to many changes in the way Aboriginal and Torres Strait Islander people lived <sup>[36, 38-40]</sup>. Colonisation caused a fast and dramatic decline in population caused by new diseases, wars and genocide, and the forced removal of people from land onto missions, all of which have had lasting negative impacts <sup>[41]</sup>. The destruction of Aboriginal and Torres Strait Islander populations and societies caused significant losses of languages, cultural practices and knowledge <sup>[37]</sup>. The continued marginalisation, separation from culture and land, food and resource insecurity, intergenerational trauma, disconnection from culture and family, racism, systemic discrimination and poverty have resulted in poorer physical and mental health for many Aboriginal and Torres Strait Islander people, and an increase in chronic conditions including CKD <sup>[42, 43]</sup>.

Aboriginal and Torres Strait Islander concepts of health and wellbeing are holistic and collective, and are centred around the importance of family, culture, Country, connectedness and relationships <sup>[38]</sup>. Unfortunately, the strengths and priorities of Aboriginal and Torres Strait Islander peoples have often been overlooked in western health care systems that have tended to focus on identifying diseases and treating only the body <sup>[44]</sup>. These two different world views have led to cultural clashes and miscommunication, which in turn has impacted on access to and quality of care <sup>[45]</sup>.

### Statistical terms

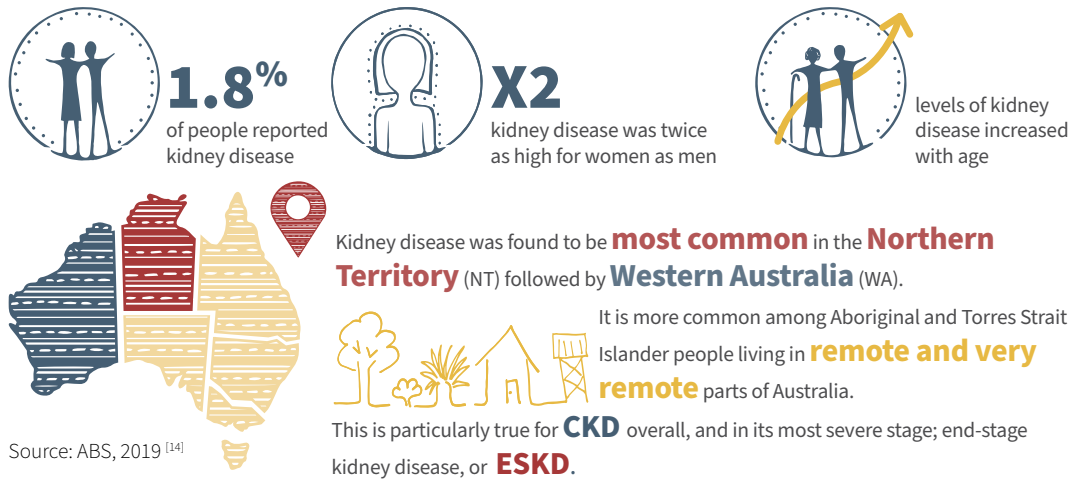
**Hospitalisation** (or a hospital admission) refers to a period of care for someone admitted to hospital for at least an overnight stay. Hospitalisation rates are calculated as the total number of periods of care for admitted patients divided by the total number of members of the population. The rate is usually written per 1,000 or per 10,000 members of the population.

**Median** is the middle value in a list of numbers.

**Prevalence** is a way of describing how common a disease or condition is. It is a proportion (%) of cases of a disease or condition in a population at a particular time.

## How common is kidney disease among Aboriginal and Torres Strait Islander people?

The most recent statistics come from the 2018-19 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) that found <sup>[14]</sup>:



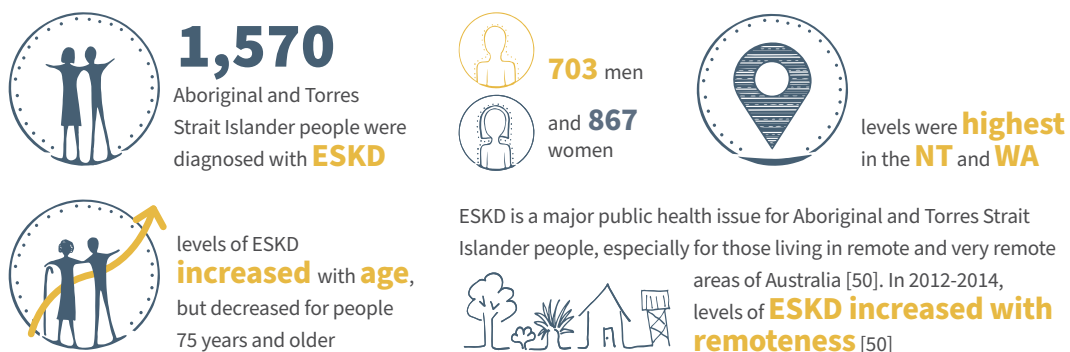
### Chronic kidney disease

The 2012-13 National Aboriginal and Torres Strait Islander Health Measure Survey (NATSIHMS) indicated that among Aboriginal and Torres Strait adults <sup>[6]</sup>:



### End-stage kidney disease

Data on ESKD are provided in yearly reports by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) <sup>[8, 46, 47]</sup>. These yearly reports show that the prevalence of ESKD among Aboriginal and Torres Strait Islander has fluctuated from year-to-year but has been increasing in recent years <sup>[8]</sup>. Between 2014 and 2018 (Derived from <sup>[48, 49]</sup>):



## Hospital admissions and treatment

Information about hospital admissions does not show how much kidney disease there is in the community, but it does provide information on the impact of the disease and who is accessing services.

Dialysis is a treatment for some stages of kidney disease, and it is the most common reason that Aboriginal and Torres Strait Islander people go to hospital <sup>[51]</sup>. Patients need to get dialysis at a hospital or satellite centre three times per week, so the same person will be admitted into hospital multiple times for treatment <sup>[52]</sup>.

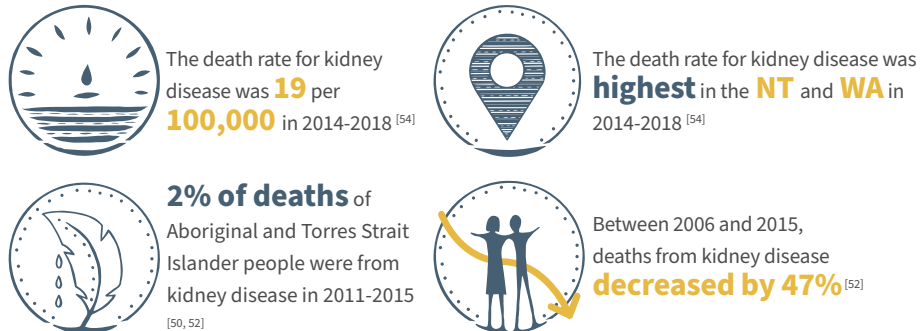
## Hospital admissions for chronic kidney disease

After excluding the hospital admission for dialysis, the latest information about hospitalisations among Aboriginal and Torres Strait Islander people for CKD showed:



## Deaths from kidney disease

The most recent information about deaths among Aboriginal and Torres Strait Islander people for kidney disease found:



## Treatment and care

### Types of treatment

Treating kidney disease is very important. In the early stages of CKD, the aim of treatment is to reduce the risk of developing CVD, slow the progress of the disease, and prevent and manage complications of the disease <sup>[55]</sup>. Treatment of early stages can include changes to lifestyle and medications <sup>[9]</sup>. If CKD is left untreated, kidney function can decrease to the point where a patient may require kidney replacement therapy (KRT) to survive <sup>[56]</sup>. There are two types of KRT:

1. Information is available for CKD hospitalisations (excluding dialysis) by Indigenous regions <sup>[53]</sup>. The Indigenous regions geographical classification (IREG) enables comparisons that reflect the distribution of the Aboriginal and Torres Strait Islander population (compared to the total Australian population).



**Dialysis:** where a machine filters the blood to remove excess water and waste products. There are two types of dialysis:

- **Peritoneal dialysis (PD):** PD happens inside the body using the ‘peritoneal membrane’ as a filter<sup>[57-59]</sup>. This membrane lines the abdominal cavity, covering organs like the stomach, liver, spleen and intestines. PD can be done at home; it is usually done four times per day and takes about 30-45 minutes.
- **Haemodialysis (HD):** HD happens outside the body using a machine that pumps blood from the bloodstream, filters out the waste and extra water, then pumps the blood back into the bloodstream<sup>[57-59]</sup>. HD usually takes 4-6 hours and needs to be done 3-5 per week. HD can be done at home, in a satellite dialysis unit or the hospital.



**Transplantation:** when a kidney from either a living or recently deceased donor is surgically implanted into the patient<sup>[57]</sup>.

KRT cannot cure kidney disease but can help people survive<sup>[60]</sup>.

The active treatment options for ESKD are dialysis or transplantation<sup>[57, 58, 60]</sup>. Kidney transplantation is the best treatment for most people<sup>[61]</sup>. However, treatments are expensive and have a marked impact on the quality of life of those who suffer from the disease as well as those who care for them<sup>[61-63]</sup>.

### Personal impact of diagnosis and starting dialysis

Getting a CKD or ESKD diagnosis can significantly impact on a person and their way of life. When they first get diagnosed, people may feel shocked and feel overwhelmed by the situation<sup>[64, 65]</sup>.

The fact that many Aboriginal and Torres Strait Islander people experience CKD and ESKD at relatively young ages adds an additional burden<sup>[66]</sup>. Many Aboriginal and Torres Strait Islander people are still completing their education, working and/or paying mortgages when they start dialysis and other kidney treatments. It is important to have a range of programs to support patients who are newly diagnosed to help them during this overwhelming and confusing time.

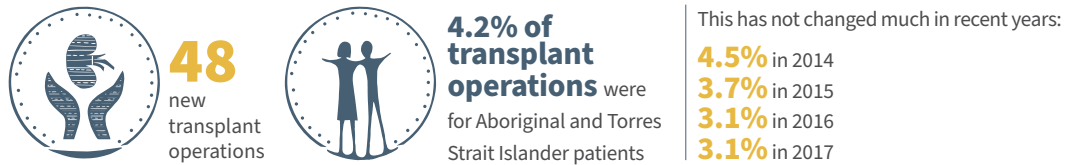
## How common are dialysis and transplantation among Aboriginal and Torres Strait Islander people?

In 2018, 355 Aboriginal and Torres Strait Islander people started KRT for ESKD<sup>[67]</sup>. Between 2014 and 2018, HD was by far the most common type of KRT for people who were just starting treatment and those who were continuing treatment.

- The number of Aboriginal and Torres Strait Islander people with treated ESKD at the end of 2018 was 2,224<sup>[67]</sup>.
- The number on KRT continued to increase over the period 2014-2018 from 1,819 in 2014 to 2,224 in 2018.
- There were clear differences in treatment modalities for Aboriginal and Torres Strait Islander people with most treated with HD (between 80-81%).
- The proportion with a transplant as a long-term treatment for ESKD was consistent over the period at 12-13%.

## Transplantation

Not very many Aboriginal and Torres Strait Islander people get a kidney transplant <sup>[67]</sup>. In 2018 <sup>[67]</sup>:

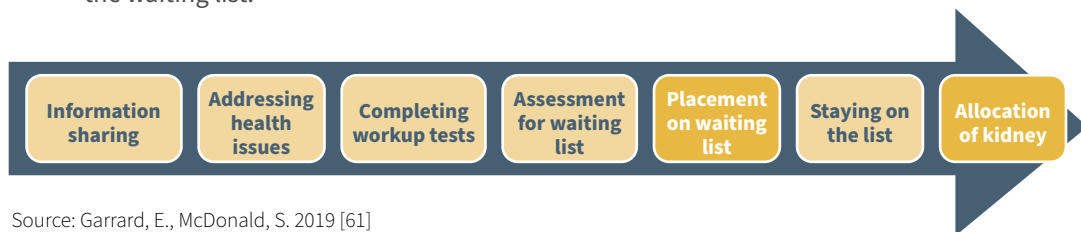


At the end of 2018, **4.5%** of the patients on the **transplantation waiting list** were Aboriginal and/or Torres Strait Islander people. This was a **39% increase** from 2017.

It is more common for Aboriginal and Torres Strait Islander people to receive a kidney from a donor who has died than from a living donor <sup>[67]</sup>. Between 2009 and 2018 there were 21 transplants from a living donor and 302 from a donor who had died.

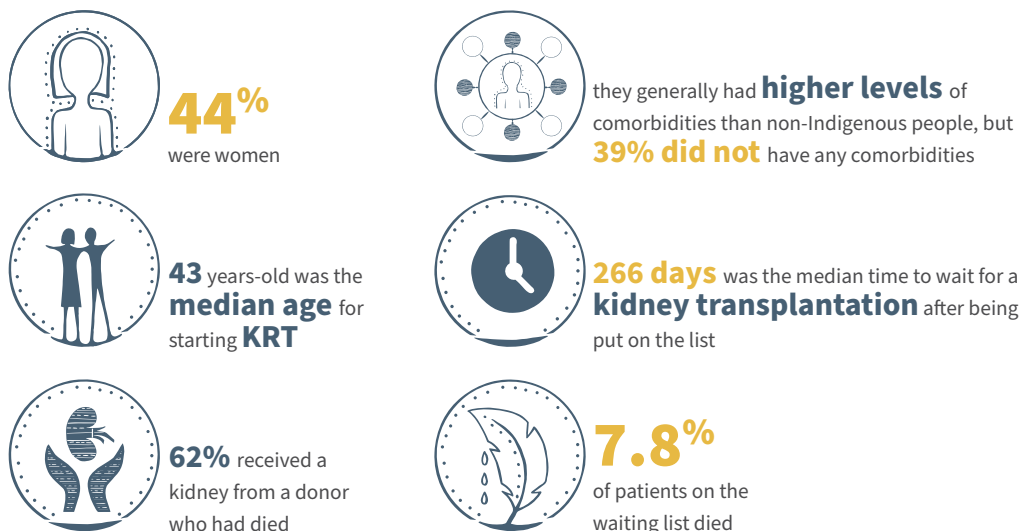
There are many possible reasons for the low numbers of transplants among Aboriginal and Torres Strait Islander people:

- relatively high levels of other health conditions (also known as ‘comorbidities’) among people starting KRT might mean they are not good candidates for transplantation <sup>[60, 61]</sup>
- these comorbidities may also explain why fewer people are assessed as suitable to donate their kidneys to relatives
- they generally have poorer outcomes after transplant than other Australians <sup>[61, 68-70]</sup>
- there is a whole series of steps involved in being put on the kidney transplant waiting list <sup>[61]</sup>. If this process is not well managed, these steps may become barriers to being put on the waiting list.



Source: Garrard, E., McDonald, S. 2019 <sup>[61]</sup>

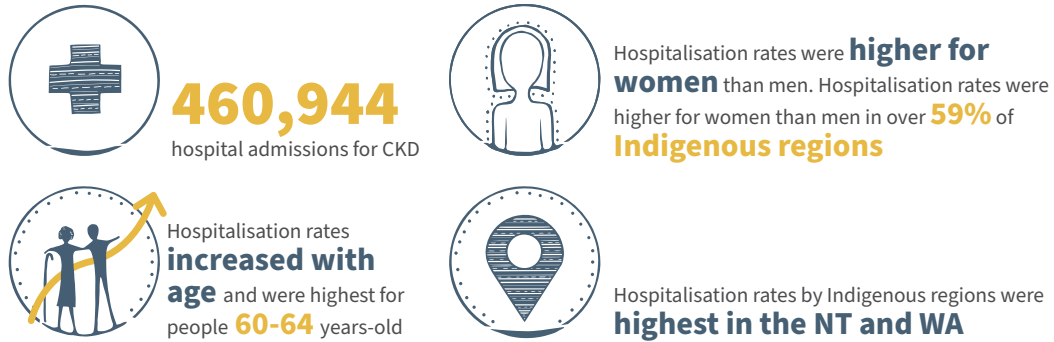
A study about Aboriginal and Torres Strait Islander people’s access to kidney transplantation found that Aboriginal and Torres Strait Islander people on dialysis were less likely than non-Indigenous people to be put on the kidney transplantation waiting list <sup>[70]</sup>. The difference was particularly large for older patients and those living in remote areas. The study (2006-2016) found that among the 217 Aboriginal and Torres Strait Islander patients on the waiting list:



## Hospital admissions for dialysis

In 2017-18, 49% of hospital admissions of Aboriginal and Torres Strait Islander people were for dialysis<sup>[51]</sup>. A 2019 report showed that regular dialysis for CKD was the most common type of hospital admission in 2014-16 for people over 50 years of age<sup>[46]</sup>.

Including the hospital admissions for dialysis, information about hospitalisations among Aboriginal and Torres Strait Islander people for **CKD** in 2015-17 showed<sup>[53]</sup>:

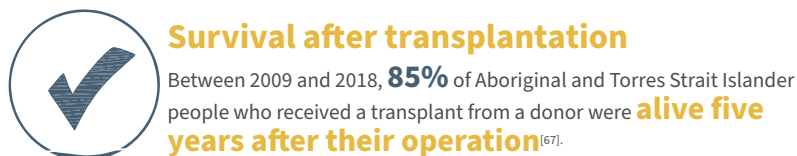
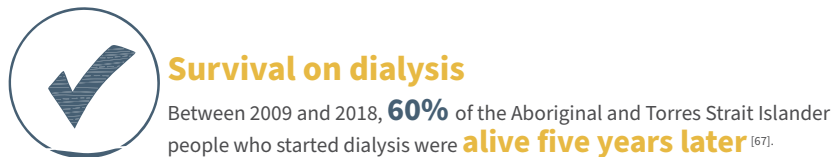


Information about hospitalisations in 2014-15 among Aboriginal and Torres Strait Islander people for **ESKD** showed<sup>[71]</sup>:



## Deaths and dialysis

In 2018, 215 Aboriginal and Torres Strait Islander people who were receiving dialysis died<sup>[67]</sup>. The most common causes of death for dialysis patients were CVD and patients making the decision to stop treatment. A recent report found that the most common reason for patients stopping treatment was for 'psychosocial' reasons (reasons relating to a person's mental health and social situation).



However, Aboriginal and Torres Strait Islander people are also more likely to die in the first five years after transplant compared to non-Indigenous people, and researchers and clinicians are seeking to understand why and change this. In the five years after a transplant, some transplanted kidneys may be lost because the transplant failed or because the patient died<sup>[67]</sup>. Between 2009-2018, 72% of Aboriginal and Torres Strait Islander people who had received a transplant had a functioning kidney five years after the operation.

## Types of care and care considerations

### Palliative care



Palliative care is care providing physical, mental and spiritual support to people and their loved ones who are facing problems from a terminal or life-threatening illness, like ESKD <sup>[72]</sup>. These services can improve the quality of life for patients by managing the symptoms that cause suffering.

Palliative care is a human right and appropriate care needs to be available for Aboriginal and Torres Strait Islander people <sup>[72]</sup>. This care needs to be of good quality, culturally appropriate and accessible to all patients regardless of where they live. Conservative, supportive and end-of-life care are different but related forms of palliative care for CKD and ESKD patients <sup>[73]</sup>. Patients should have the right to choose the type of care they receive, and care should be holistic.

Palliative care is not always well-known or well understood by Aboriginal and Torres Strait Islander renal patients <sup>[74]</sup>. Health services need to provide clear information about palliative care options and discuss these options with patients in a respectful way and at regular intervals.

Some patients may decide to stop dialysis due to the social isolation and cultural loss they experience during their treatment <sup>[75]</sup>. Most ESKD patients will not live long after the dialysis stops. This will lead to the start of end-of-life care and renal and palliative care teams working together to help the patient.

**Program of Experience in the Palliative Approach (PEPA)** is a project that has developed guidelines that outline the cultural considerations when providing end-of-life care for Aboriginal and Torres Strait Islander people <sup>[76]</sup>. The guidelines outline several factors to be aware of when caring for Aboriginal and Torres Strait Islander people in the end-stage of their life:

- most Aboriginal and Torres Strait Islander people live in collective societies and patients and/or their families may nominate a spokesperson or decision-maker who is not the patient or next of kin
- returning to Country before the end of life: many Aboriginal and Torres Strait Islander people believe that a person's spirit stays in the location where they have passed on. This makes it very important that people can return to Country before their passing. If this is not possible and they die away from Country, smoking ceremonies or other cultural ceremonies can be conducted to allow the release of the spirit to go back home.

**Managing Two Worlds Together Study** is a study that developed a tool to look at the patients' journey through the health care system as well as the priorities, concerns and commitments of the patient, the priorities of the family or carer, and the priorities of the health service <sup>[77]</sup>. The tool identified where the priorities and concerns of the patient and their family were mismatched with those of various health service providers. This allowed health care providers and patients and their families to discuss strategies and avoid issues <sup>[78]</sup>.

(For more information about palliative and end-of-life care see <https://healthinonet.ecu.edu.au/learn/health-system/palliative-care>.)

## Mental health



Evidence suggests that CKD and ESKD can harm people's emotional wellbeing [64]. Depression has been linked to poorer quality of life and health outcomes for CKD and ESKD patients, so it is important that treatment of mental health is incorporated into CKD and ESKD treatment plans [79]. There is currently not a lot of information on mental health programs for Aboriginal and Torres Strait Islander CKD patients, but the Wellbeing Intervention for Chronic Kidney Disease (WICKD) study aims to use a wellbeing app for keeping Aboriginal and Torres Strait Islander kidney patients mentally strong throughout their illness; the results of this study will be published in the future [80].

## Access for people in rural and remote areas



Most Aboriginal and Torres Strait Islander people get HD as a treatment for kidney disease [81, 82]. Because these patients need to get HD three times a week, many patients need to leave their homes in rural and remote areas and move to regional areas or cities for treatment. This often causes kidney patients to experience isolation, grief and disconnection from Country because they are away from their family and communities and not able to participate in cultural events. Many Aboriginal and Torres Strait Islander people in remote communities want to be able to get care on Country and be cared for by their own family and community or mob [83].



A number of mobile dialysis units have been developed to support remote kidney patients to return to their homelands for significant events, funerals and to reconnect with family and country. These include the SA Health Mobile Dialysis Bus, the Kimberley Renal Services Mobile Dialysis Unit (MDU) and the Purple House Dialysis Truck [84-86]. An evaluation of the SA Health service found that it provided much needed respite for patients who needed to attend events and/or had been disconnected from country [86].



In addition to mobile dialysis units, there are calls for more options for Aboriginal and Torres Strait Islander people to receive care 'on Country'. Studies show that this is supported by patients and staff [64, 83]. Home HD, and PD could provide another option for Aboriginal and Torres Strait Islander patients, but there are currently barriers like the quality and availability of housing, technology for this treatment, health literacy and access to local medical support [82]. Additionally, while a number of patients have expressed interest in home dialysis, some also worry that without nurses to assist it would place a burden on family members.

## Helping people living in remote areas access dialysis close to home



In November 2018, the Federal Government introduced a new Medicare Benefits Schedule (MBS) item to help fund the delivery of dialysis by nurses, Aboriginal and Torres Strait Islander Health Practitioners and Aboriginal Health Workers in remote primary care settings [87]. 'Item 13105' pays for the supervision of dialysis in very remote areas of Australia.

## Aboriginal and Torres Strait Islander health workforce



The benefits of an Aboriginal and Torres Strait Islander health workforce in improving Indigenous kidney care are increasingly being recognised. Aboriginal and Torres Strait Islander kidney patients and patient-experts have made repeated calls for the Aboriginal and Torres Strait Islander workforce to be strengthened and for the non-Indigenous workforce to be more culturally appropriate <sup>[88, 89]</sup>. An important part of improving care is ensuring there is an Aboriginal and Torres Strait Islander workforce, including Aboriginal Health Workers and Aboriginal Liaison Officers <sup>[90, 91]</sup>. Aboriginal and Torres Strait Islander staff can help create a feeling of belonging and acceptance, increase comfort and improve outcomes of care for Aboriginal and Torres Strait Islander patients <sup>[88]</sup>. In 2009, the Federal Government recognised the importance of this workforce as part of the Closing the Gap initiative <sup>[92]</sup>.

## Cultural safety and effective communication for non-Indigenous health professionals



Over the past 20 years, there has been a focus on improving communication and relationships between Aboriginal and Torres Strait Islander patients and non-Indigenous staff <sup>[63]</sup>. Some healthcare staff, particularly non-Indigenous staff, struggle to communicate effectively with their patients <sup>[64, 93]</sup>.

Studies have found that patients describe having poor communication: reporting that they were not well informed about their treatment options <sup>[93]</sup>. This impacted on ‘compliance’ with care and the patients’ abilities to make decisions. Nurses and health service staff are often busy and not able to take the time needed to build strong relationships; cultural training is often not required, targeted appropriately or prioritised because of a lack of resources. Sometimes when basic cultural awareness or competency training has been provided it has left some staff unsure and confused about the specifics of how best to care for Aboriginal and Torres Strait Islander patients, leading to further misunderstanding <sup>[86]</sup>. The complex history of colonisation and racism in Australia has created barriers and a lack of trust between Aboriginal and Torres Strait Islander patients and their healthcare workers and services <sup>[94]</sup>. Cultural safety and similar approaches that take into account history, power and ongoing colonisation and racism impacts are more effective <sup>[95]</sup>.



What is needed is a shift in focus from the cultural awareness of individual practitioners to ‘incorporating cultural values into the design, delivery and evaluation of services’ <sup>[96]</sup>. In 2011, the National Health Ministers endorsed ten National Safety and Quality Health Service (NSQHS) standards <sup>[97]</sup>. One of these standards aimed to increase patients’ involvement in the design, delivery and evaluation of health care services and systems, as well as patients increasingly being partners in their own care. In 2017, six specific actions for improving care for Aboriginal and Torres Strait Islander people were added <sup>[98]</sup>, the first of which was working in partnership and building effective and ongoing relationships with Aboriginal and Torres Strait Islander people, communities, organisations and groups.

## Peer support



Peer support can play an important and unique role for Aboriginal and Torres Strait Islander people who have experienced kidney disease, dialysis care and transplantation. **One example is the NT’s Purple House Patient Preceptors** who provide expert advice and reassurance to patients <sup>[99]</sup>.

In 2017, there was the Indigenous Patient Voices: Gathering Perspectives Finding Solutions for Chronic and End Stage Kidney Disease Symposium which outlined the priorities and opinions of health care users, expert-patients, carers and non-patient-carer delegates for health care reforms [63]. Key solutions included:

- increasing local and Indigenous workforce, including patient-expert navigators
- improving access to culturally safe kidney care that is close to home
- creating meaningful health information, promotion and education about chronic diseases, kidney care, transplantation and how the health system operates
- strengthening partnerships with primary health care and Indigenous organisations
- using new models of care that are responsive to Aboriginal and Torres Strait Islander people's needs (for example, separate gender spaces in dialysis)
- training a culturally competent and clinically safe, skilled and knowledgeable inter-professional workforce that can communicate clearly and respectfully
- increasing Aboriginal and Torres Strait Islander leadership, governance and self-determination.

Similar findings arose from studies conducted in the NT and nationally over the previous 20 years [100, 101].

## Developing patient informed clinical guideline



Currently there are no national clinical guidelines about kidney care specifically for Aboriginal and Torres Strait Islander Australians. In 2018, Kidney Health Australia-Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines aimed to develop the first clinical guideline for the “Management of Chronic Kidney Disease (CKD) among Aboriginal and Torres Strait Islander Peoples and Maori” [102]. Three strategies were drawn up to make sure the guideline was supported by recommendations suggested from within the Aboriginal and Torres Strait Islander community, and that reflected and supported the needs of clinicians. The three strategies included:

1. the engagement of a panel of Aboriginal and Torres Strait Islander health clinicians
2. targeted consultations with locally based Aboriginal and Torres Strait Islander consumers and services
3. consultation and feedback from the Australian national peak organisations.

A plan for national community consultations was developed, and consultations have taken place in cities, regional and remote areas with more consultations currently being planned. Priorities identified by community members so far include [103]:

- kidney disease prevention and early detection
- rural and remote education involving family, storytelling, and face-to-face workshops to improve access to care
- stabilising local workforces
- encouraging availability of expert Aboriginal and Torres Strait Islander patients to provide peer education and support
- improved access to interpreters and language resources
- reliable transportation to care.

## Strategies to improve kidney care in Australia for and with Aboriginal and Torres Strait Islander people

There are number of things that can be done to improve Aboriginal and Torres Strait Islander kidney care in Australia:

- establish and support partnerships between Aboriginal and Torres Strait Islander patients, doctors, health professionals, peer support and governance in delivering health care, developing policy and research. More specifically:

- develop new quality and safety standards that promote partnership and improve cultural safety in health care <sup>[98]</sup>
- invite, welcome and sponsor Aboriginal and Torres Strait Islander patients to attend and present at conferences about kidney health and transplantation <sup>[104]</sup>
- have Indigenous reference groups and advisory groups involved in decision making in research, data collection, developing clinical guidelines and care <sup>[102]</sup>
- provide peer support for Aboriginal and Torres Strait Islander in volunteer, research and paid roles <sup>[99]</sup>
- have community consultations with Aboriginal and Torres Strait Islander patients, carers, family members and communities <sup>[103]</sup>

- address, fund and respond to the gaps in care that are identified in studies, policy briefs and consultations by:

- increasing funding for HD so patients in remote areas can access treatment closer to home through changes to MBS items <sup>[87]</sup>
- improving information, access and support for Aboriginal and Torres Strait Islander Australians who need kidney transplantation through the National Indigenous Kidney Transplantation Taskforce (NIKTT), and increasing outreach services, coordination and support roles <sup>[105]</sup>
- increasing support and survival after people have had a kidney transplant <sup>[105]</sup>
- identifying ways to improve cultural awareness and cultural safety of health professionals and services, and address systemic racism and bias <sup>[98, 106]</sup>
- increasing the responsiveness of health professionals and kidney care services to the needs of Aboriginal and Torres Strait Islander patients with new models of practice and care and increasing the use of telehealth <sup>[107]</sup>

- recognise the importance and needs of the Aboriginal and Torres Strait Islander workforce in kidney care, and the unique role that Aboriginal health professionals, peer navigators, preceptors and coordinators play in delivering care <sup>[108]</sup>
- work with Aboriginal and Torres Strait Islander communities and organisations to identify ways to prevent or slow the progression of kidney disease <sup>[103, 107]</sup>.

## Addressing systemic racism

It is vital that racism in the health system is addressed so that Aboriginal and Torres Strait Islander people have access to health services that are effective, of high quality, that meet their needs and that they can afford <sup>[109]</sup>. Work in the past on racism has focused on the individual level <sup>[110]</sup>, however this is changing, for example, a framework has been developed in Australia to measure institutional racism in Australia's health care system using publicly available data <sup>[111]</sup>.

The Transplantation Society of Australia and New Zealand performance report <sup>[61]</sup> outlines the barriers faced by Aboriginal and Torres Strait Islander patients who want a kidney transplant together with actions for moving forward.

A framework has also been developed to guide organisations and health professionals to provide better health care outcomes for Aboriginal and Torres Strait Islander people <sup>[106]</sup>. The key items that should be looked at to reduce racism in the health care system for Aboriginal and Torres Strait Islander people are:

- Indigenous governance
- Indigenous workforce and Indigenous workforce development
- cultural awareness and safety training of non-Indigenous workforce
- improved access and support for Aboriginal patients at all stages of CKD (i.e. prevention, early detection, dialysis, transplantation and palliative care)
- decolonising models of practice that include improved communication, power sharing and shared decision making
- adherence to the six specific actions within the National Safety and Quality Standards
- creating and implementing institutional policies to reduce racism, for example a reconciliation action plan and Aboriginal and Torres Strait Islander health policy.

## Concluding comments

Kidney disease is a serious concern for Aboriginal and Torres Strait Islander people, particularly for people living in remote areas of Australia<sup>2]</sup>. There is increasing recognition of the need for primordial prevention, so people do not become ill with CKD <sup>[112]</sup>. This is very important for Aboriginal and Torres Strait Islander people due to the socioeconomic challenges they face. The prevention needs to address the social determinants of health and risk factors for CKD.

There are a number of things that can be done to ensure effective treatment and care is provided to Aboriginal and Torres Strait Islander Australians:

- providing holistic care that addresses social and cultural wellbeing needs is effective in reducing or preventing chronic disease <sup>[113]</sup>. This holistic care needs to understand the historical and social context of Aboriginal and Torres Strait Islander people
- ensuring programs led by, or work in collaboration with, Aboriginal and Torres Strait Islander families, communities, health professionals and services <sup>[114]</sup>.

Aboriginal Community Controlled Health Organisations (ACCHOs) have been working to address the social determinants of health for, and with their communities, and are in a good place to continue and expand this work <sup>[115]</sup>. Health programs and services such as those provided by, and in collaboration with ACCHOs effectively address the impact of intergenerational marginalisation, poverty, grief and loss and racism <sup>[116,117]</sup>. There is recognition that additional support and resources are often required in order to achieve equal health and wellbeing outcomes between Aboriginal and Torres Strait Islander and other Australians <sup>[117]</sup>.

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Core funding  
is provided by the  
Australian Government  
Department of Health