End stage kidney disease (ESKD) is the final stage of chronic kidney disease (CKD), where the kidneys fail and cannot recover. ESKD rates are 15 times greater among Aboriginal and Torres Strait Islander peoples than they are in non-Indigenous Australians.

Treatment options for ESKD are dialysis and transplantation. Kidneys can be used for transplantation that have been taken from a living donor or deceased donor.

In non-Indigenous Australians, transplantation has high success rates and improves patient survival and quality of life. Success rates are best with living related donors, and both donors and recipients usually do well.

Aboriginal and Torres Strait Islander people with ESKD, on the other hand, are much less likely to receive a transplant, and when they do, their outcomes are overall poorer. Unlike non-Indigenous Australian living kidney donors, Indigenous people who donate their kidneys often don’t do well.

Action is needed to ensure access to transplantation for Indigenous people with kidney disease who are likely to benefit from it, and to support them through the process.

The Royal Australasian College of Surgeons Foundation for Surgery funded the Monash University National Trauma Research Institute (NTRI) to develop evidence-based action plans (EBAPs) within the surgical areas of road injury prevention, transplantation, ophthalmology and ear, nose and throat (ENT), to improve the delivery of surgical services to Indigenous communities.

Evidence-based action plans are action-oriented overviews aimed at helping solve real problems. They are generated by engagement of stakeholders and reviews of existing research evidence.

This EBAP, specifically looking at kidney disease and transplantation in Aboriginal and Torres Strait Islander populations, is one of a series of four EBAPs for Indigenous health in Australia.

**Research Implications...**

Research, evaluation and implementation challenges:

- Commission an analysis of the Australians and New Zealand Dialysis and Transplant Registry (ANZDATA) that directly compares adjusted outcomes for Aboriginal and Torres Strait Islander patients post-transplant with long-term dialysis
- Assess previous clinical strategies to reduce acute rejection and infection following transplantation, and develop and evaluate novel strategies to reduce these risks in Aboriginal and Torres Strait Islander patients
- Develop and evaluate clinical models of patient selection for deceased donor wait-listing that predict better patient and kidney survival, and reduce hospitalisation for Indigenous ESKD patients
- Develop and evaluate new clinical models that select lower-risk Indigenous live kidney donors and provide them long-term support after donation
- Support national data collection that outlines the journey to accessing specialist renal services, experienced by Indigenous patients with CKD and ESKD
- Evaluate state and hospital-based programs working to understand and increase rates of Indigenous deceased donation
- Evaluate existing tailored communication to Indigenous patients with kidney disease regarding transplantation
- Investigate which government and non-government initiatives improve access to, and delivery of, renal and transplant services to Aboriginal and Torres Strait Islander people.

**Policy and Practice Implications...**

Make a commitment

- Transplantation is likely to enable some Aboriginal and Torres Strait Islander patients to achieve the best possible survival and quality of life – policies should aim to identify who the most suitable are and support them in their transplant journey.
- Addressing issues of access to waiting lists and improved donation rates may expand the group of potential recipients, and steps should be taken to overcome barriers to transplantation.

**Overview**

End stage kidney disease is the final stage of chronic kidney disease, where the kidneys fail and cannot recover. ESKD rates are 15 times greater among Aboriginal and Torres Strait Islander peoples than they are in non-Indigenous Australians.

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Aboriginal and Torres Strait Islander people with ESKD, on the other hand, are much less likely to receive a transplant, and when they do, their outcomes are overall poorer. Unlike non-Indigenous Australian living kidney donors, Indigenous people who donate their kidneys often don’t do well.

Action is needed to ensure access to transplantation for Indigenous people with kidney disease who are likely to benefit from it, and to support them through the process.
Outcomes among non-Indigenous Australians

- Renal transplantation is the most effective treatment to improve patient quality of life and survival for ESKD at all ages, and lowers the long-term mortality risk of ESKD patients by 80%.
- After five years, 90% of patients are alive and 80% of kidneys are functioning following deceased donor kidney transplantation, and 95% of patients are alive and 85% of kidneys are functioning after live donor kidney transplantation.
- Renal transplantation costs less than long-term dialysis treatment.
- Pre-emptive transplantation is now the preferred first-line therapy for ESKD patients, as it reduces health care costs, loss of employment and dialysis-related illness.
- Thirty-nine percent of transplant recipients receive kidneys from live donors, and live donors do not usually have any adverse outcomes.

Outcomes among Aboriginal and Torres Strait Islander peoples

- Aboriginal and Torres Strait Islander people with ESKD undergo renal transplantation at less than one-quarter of the rate of non-Indigenous Australians.
- Indigenous transplant recipients die at 3.6 times the rate of non-Indigenous Australian transplant recipients, and only 80% are alive at three years.
- Aboriginal and Torres Strait Islander peoples are much more likely to die from infections after transplantation, due both to a much higher risk of infection post-transplant and an increased severity of infection.
- Transplanted kidneys fail three times faster in Indigenous than non-Indigenous Australians, and more than half of all kidney transplants to Indigenous people have failed by five years. This is due to increased rate of acute rejection, more human leukocyte antigen (HLA) mismatching, more sensitisation and a longer time waiting from the start of dialysis treatment.
- Only 22% of Indigenous transplant recipients receive kidneys from live donors (Indigenous or non-Indigenous).
- Live Indigenous donors have much higher risk of death, progressive kidney disease leading to ESKD, and cardiovascular disease than non-Indigenous Australians who do not donate.

Organ donation rates and availability

**General population** - The demand for kidneys for transplantation heavily outweighs the supply of kidneys from living or deceased donors, increasing the number of registered potential organ donors, and the donation rate in Australia is a current priority. However, the annual number of kidney transplant operations has risen, due to a more than six-fold increase in the number of live donor transplants performed each year.

**Aboriginal and Torres Strait Islander populations** - There have been almost no deceased Indigenous organ donors in Australia in the last ten years. In the Northern Territory, cultural complexities are thought by health professionals to be an important barrier to deceased donation, but this has not been studied systematically. There are few live donations to Indigenous people. Compared to Indigenous populations in New Zealand, Canada and the USA, Aboriginal and Torres Strait Islander peoples had the lowest rate of live donor transplant. Little knowledge or guidance exists to improve the rate of live or deceased kidney donation from Indigenous people, and the Australian Organ and Tissue Authority does not have a targeted strategy for Indigenous peoples. However, with the current and proposed criteria for organ allocation in Australia, increasing Indigenous deceased donation rates may not lead to more transplants or improved outcomes for Aboriginal and Torres Strait Islander ESKD patients.

Implementation Considerations...

**Barriers to kidney transplantation**

**Geography** - There is no acute transplantation service operating in Northern Australia, where most Aboriginal and Torres Strait Islander people with ESKD live. Geographic location alone may contribute to poorer transplant outcomes observed in Indigenous patients, due to the increased time the kidney is out of the body before it is transplanted.

**Waiting lists** – In Australia the waiting time to receive a kidney from a deceased donor is often three to five years. Longer times spent on dialysis prior to transplantation increase risk of death before transplantation (i.e. dying whilst waiting), and decreases donor kidney survival rates. Fewer Indigenous patients receiving dialysis are put on transplantation waiting lists.

**Late referrals to specialist services for ESKD treatment** – Indigenous people with ESKD are more likely to be referred for treatment at a later stage of their kidney disease, which makes them less likely to undergo a renal transplant, and have a significantly greater risk of dying.

**Human leukocyte antigen (HLA) mismatch and sensitisation** - HLA matching, which aims to “match” deceased donor kidneys to recipients on the waiting list with a similar immunologic “fingerprint”, reduces acute rejection and improves transplant survival. Aboriginal and Torres Strait Islander ESKD patients are more likely to receive a kidney transplant with more mismatches than non-Indigenous Australian patients. Indigenous ESKD patients on the waiting list are also more likely to have pre-formed antibodies to elements of potential donor kidneys (“sensitisation”), leading either to a longer wait for a kidney to which they do not have a pre-formed antibody or an increased risk of acute rejection if this is over-ridden.

**Clinicians’ attitudes and decisions regarding renal transplantation** - There is no evidence that cultural or ethnicity factors alone affect clinical decisions to proceed to transplant. Also, 95% of nephrologists say they would recommend donation to a potential donor if suitable.

What don’t we know?

- It is not clear that Aboriginal and Torres Strait Islander people live longer or have a better quality of life after kidney transplantation compared to continuing long-term dialysis.
- Despite a voluntary live donor registry being established in 2005, the national experience of live donation has not been reported. What are the outcomes experienced by Aboriginal and Torres Strait Islander live kidney donors?
- There is no published data on the cost effectiveness or quality of life of kidney transplantation compared to dialysis for Indigenous people.