AcceSS and Equity in Transplantation New South Wales (ASSET NSW)

TECHNICAL REPORT

Centre for
Organ
Donation
Evidence

Acknowledgements and Disclaimers

The analysis presented in this report was undertaken by the ASSET NSW team. The interpretation is theirs alone.

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This research was led by Professor Angela Webster.

The projects within ASSET NSW were undertaken by (in alphabetical order): Heather Baldwin, James A Hedley, Melanie Wyld, Nicole L De La Mata, and Trishala Sharma.

Student & trainee contributors (in alphabetical order): Andrea Huang *University of Sydney*, Andrew Brodzeli *University of Sydney*, Nicolas Chan *University of Sydney*, Ricki Ng *University of Sydney.*

Collaborators (in alphabetical order): Fred Wu, Grant Sara and Nicholas Glozier.

This report was written by Angela C Webster and Rachel B Cutting.

AcceSS and Equity in Transplantation New South Wales (the ASSET NSW study)

Ethics approval for this project was granted by the NSW Population and Health Services Research Ethics Committee (2019/ETH01620).

Study Details: In partnership with the Mental Health Living Longer (MHLL) programme, based at NSW Health, (MHLL protocol) we developed a program of work investigating the intersection of mental illness and kidney disease. Using a population-wide linked dataset established through the MHLL programme, we applied a systems-based approach to examine how people with severe and persistent mental illness experience kidney transplant services compared to those without mental illness. We aimed to quantify disparities in healthcare delivery, access to transplantation and post-transplant outcomes. This work addresses a major evidence gap for a highly disadvantaged population with known comorbidities and reduced life expectancy. By identifying inequities and unmet needs, the study aims to inform service reform and support data-driven improvements in kidney care for people living with mental illness.

Aims:

- 1. Describe the patient journey on the kidney transplant waitlist, for those with and without mental illness, including episodes of suspension and reactivation, time waiting and whether transplanted.
    - Published work
        - 1.1 Closing the gap in kidney disease: validating the reporting of Aboriginal and/or Torres Strait Islander identification in a clinical quality registry using linked data
    - Continuing work
        - 1.2 Access to kidney transplantation waitlisting for people with mental illness, an Australian cohort study 2006-2020
        - 1.3 Landscape of mental illness in kidney failure: a three-nation comparison between Australia, New Zealand and Scotland
        - 1.4 Kidney waitlist dynamics in people with both kidney failure and severe mental illness: An Australian data linkage study
- Describe post-transplant outcomes for people with kidney failure and mental illness, including the healthcare needs and burden of care following transplantation
    - Published work
    - Continuing work
        - 2.1 The effect of mental illness on mortality, graft failure, and acute rejection post-kidney transplant
        - 2.2 Burden of care for psychiatric illness in the early post-transplant years

Other ongoing questions include prevalence and severity of disease, barriers and critical points for health services.

Consumer and community engagement

The MHLL project governance committee includes representatives from NSW peak bodies for general health consumers, mental health consumers, mental health carers, and an Aboriginal community representative. This committee plays a central role in setting analytical priorities and guiding the interpretation and dissemination of findings. The MHLL Aboriginal Sovereign Steering Committee ensures the inclusion of Aboriginal perspectives in all aspects of the program.

Funding

CI Professor Angela Webster received $25,000 from the 2021 External Research Collaboration Seed Funding on 31 January 2022. This was supplemented by $26,833 of in-kind personnel support from the University of Sydney and $36,806 from the NSW Ministry of Health covering both in-kind personnel support and data linkage costs.

Output Synopsis ***as of 31 July 2025***

Output	**Number**
Manuscripts	**6**
Published	1
In press	0
In preparation	5
Conferences	**9**
National (including NZ)	7
International	2
Students	**4**
HDR	2
Andrea Huang: *PhD*	
HDC	3
Ricki Ng: *Master of Clinical Epidemiology* Trishala Sharma: *Master of Biostatistics* Andrew Brodzeli: *Medical student*	

AIM 1 PUBLISHED MANUSCRIPTS

1.1 Closing the gap in kidney disease: validating the reporting of Aboriginal and/or Torres Strait Islander identification in a clinical quality registry using linked data

Investigators: Heather J Baldwin, Nicole De La Mata, Grant Sara, Faye McMillan, Brett Biles, Jianyun Wu, Paul Lawton, Stephen McDonald and Angela C Webster

Summary: This population-based study assessed the accuracy of the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) in identifying Aboriginal and/or Torres Strait Islander people with kidney failure in New South Wales (2006–2020). Compared with Enhanced Reporting of Aboriginality (ERA) using linked health data, ANZDATA identified only two-thirds of Aboriginal and/or Torres Strait Islander patients (sensitivity 67.0%; specificity 99.8%). Sensitivity was lower among males, younger and older age groups, those in more advantaged areas, urban settings, and without comorbidities. Patients identified in ANZDATA had lower rates of waitlisting and transplantation, and higher mortality, than those not identified. These findings reveal under-identification and systematic differences, highlighting the need for improved data collection and routine data linkage to better capture and address health inequities.

Dissemination/Awards: This study was disseminated via:

1. Koori radio Blackchat, by Angela Webster, 2025
2. The Limbic https://thelimbic.com/nephrology/effort-required-to-improve-reporting-of-indigenous-status/
3. The Benchmark, Australia Clinical Trials Alliance, Clinical Quality Registries Special Interest Group (CQR SIG) newsletter May 25 https://clinicaltrialsalliance.org.au/wp-content/uploads/2025/06/Benchmark-Newsletter-Q2-Edition-May-2025.pdf
4. Mental Health Living Longer, NSW Health, https://www.health.nsw.gov.au/mentalhealth/professionals/Pages/mental-health-living-longer.aspx
5. "Research Highlights Across The Ditch", Research Advisory Committee and the young ANZSN Committee June 2025

Publication: Baldwin, H.J., De La Mata, N., Sara, G., McMillan, F., Biles, B., Wu, J., Lawton, P., McDonald, S. and Webster, A.C. (2025), Closing the gap in kidney disease: validating the reporting of Aboriginal and/or Torres Strait Islander identification in a clinical quality registry using linked data. Med J Aust, 222: 240-248. https://doi.org/10.5694/mja2.52613

Link/access: https://doi.org/10.5694/mja2.52613

AIM 1 CONTINUING WORK

1.2 Access to kidney transplantation waitlisting for people with mental illness, an Australian cohort study 2006-2020

Investigators: Andrew Brodzeli, James Hedley, Heather Baldwin, Nicole De La Mata, Nicholas Glozier, Grant Sara, Angela Webster.

Summary: This cohort study in New South Wales, Australia, investigated whether people with pre-existing mental illness experienced delays in access to kidney transplant waitlisting. We included 5,252 individuals aged 2-64 initiating dialysis without prior transplant between 2008 and 2020. Mental illness was classified as severe or persistent (SPMI), other mental illness (OMI), or none. The study found that within six months of starting kidney failure treatment, those with SPMI were about half as likely to be waitlisted or receive a living donor transplant compared to those without mental health service use, while those with OMI had higher rates of waitlisting. Over the first year and subsequent years on dialysis, people with SPMI consistently had lower likelihoods of waitlisting, with both SPMI and OMI groups less likely to be waitlisted in later years compared to those without mental illness. These findings highlight delayed access to transplant waitlisting among people with severe mental illness and suggest that better coordination between mental health and kidney services could help reduce inequities in kidney care access.

Dissemination/Awards: This study was presented at the following conferences:

1. 2025 The European Society for Organ Transplantation (ESOT), poster, by Andrew Brodzeli (presented by Angela Webster).
2. 2025 The Transplantation Society of Australia and New Zealand (TSANZ), by Andrew Brodzeli invited speaker.
   Access to KTx with major psychiatric disorder
3. 2024 Australia and New Zealand Society of Nephrology (ANZSN), by Andrew Brodzeli
   Mr Andrew Brodzeli, Dr Heather Baldwin, Dr Nicole De La Mata, Professor Angela Webster, Professor Grant Sara. Access to kidney transplant waitlisting for people with mental illness; a cohort study in NSW. 2024
   https://anzsnevents.com/22998/
4. 2024 The Transplantation Society of Australia and New Zealand (TSANZ), by Andrew Brodzeli
5. 2023 Psychosis Australia Conference, by Nicole De La Mata

1.3 Landscape of mental illness in kidney failure: a three-nation comparison between Australia, New Zealand and Scotland

Investigators: James Hedley, Grant Sara, Angela Webster.

Summary: Upcoming. Our hypothesis: people with mental illness have lower rates of transplantation. We will compare prevalence of mental illness in people with kidney failure and time to transplantation by mental illness using similar definitions across three countries: New South Wales Australia, New Zealand, and Scotland.

Dissemination/Awards: This study was presented at the following conferences:

1. 2025 The Transplantation Society of Australia and New Zealand (TSANZ), by James Hedley

1.4 Kidney waitlist dynamics in people with both kidney failure and severe mental illness: An Australian data linkage study

Investigators: Andrea Huang, Nicole De La Mata, James Hedley, Nicholas Glozier, Grant Sara, Angela Webster.

Summary: Upcoming

AIM 2 CONTINUING WORK

2.1 The effect of mental illness on mortality, graft failure, and acute rejection post-kidney transplant

Investigators: Trishala Sharma, James Hedley, Nicole De La Mata, Nicholas Glozier, Grant Sara, Fred Wu, Angela Webster.

Summary: This population-based study examined the impact of pre-transplant mental illness on outcomes in 2,716 kidney transplant recipients in New South Wales between 2008 and 2020. Mental illness, identified through specialist service use, was present in 9% of recipients and categorised as severe/persistent (SPMI) or moderate (MMI). It was more common among younger recipients, women, and Aboriginal and/or Torres Strait Islander people. Mental illness was not associated with higher risks of acute rejection, graft failure, or death. However, recipients with SPMI and MMI had significantly higher hospitalisation rates. The results show that mental illness does not compromise transplant success, supporting fair access to transplantation and the need for ongoing support after transplant.

Dissemination/Awards: This study was presented at the following conferences:

1. 2025 The European Society for Organ Transplantation (ESOT), poster, by Trishala Sharma (presented by Angela Webster).
2. 2025 The Transplantation Society of Australia and New Zealand (TSANZ), by Trishala Sharma.

2.2 Burden of care for psychiatric illness in the early post-transplant years

Investigators: Ricki Ng, James Hedley, Trishala Sharma, Nicole De La Mata, Nicholas Glozier, Grant Sara, Fred Wu, Angela Webster.

Summary: This retrospective cohort study examined mental health service use over time among adults in New South Wales with pre-existing mental illness who received a first kidney transplant between 2008 and 2020. Individuals with pre-existing mental illness including those with severe or persistent mental illness (SPMI) were identified based on diagnostic codes and prior service use. The study tracked hospital admissions and community mental health contacts post-transplant, calculating incidence rate ratios to assess changes over time. The expected outcomes include detailed insights into how mental health service use evolves following transplantation for those with pre-existing mental illness, informing strategies to support this group and improve integrated care post-transplant.

Dissemination/Awards: Upcoming