



Maximising Organ Donor offer Utility System-wide (the MODUS study)

TECHNICAL REPORT

Centre for
Organ 
Donation
Evidence

Acknowledgements and Disclaimers

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

Corresponding author:

Professor Angela Webster
Professor of Clinical Epidemiology
The University of Sydney
Room 129A, Edward Ford Building (A27)
Camperdown NSW 2006 Australia
Phone:
Email: angela.webster@sydney.edu.au

This research was led by Professor Angela Webster.

The projects within MODUS were undertaken by (in alphabetical order): Heather Baldwin, Nicholas Chan, Rachel B Cutting, Nicole L De La Mata, James A Hedley, Patrick J Kelly, Danielle M Muscat, Brenda M Rosales, Karan K Shah, Imogen K Thomson, Karen MJ Waller, Sarah White.

Collaborators on projects within MODUS were (in alphabetical order): Elena Cavazzoni, Philip Clayton, Nicholas Cross, George Doukas, Catherine Francis, Rhonda Holdsworth, Georgina Irish, Shilpa Jesudason, Sarah Khanlari, Isis Maitland-Scott, Kirsten McCaffery, Rachael L. Morton, Michael O'Leary, Henry Pleass, Vidiya Ramachandran William Rawlinson, Sacha StelzerBraid, Lee Taylor, Claire Vajdic Narelle Watson, Jennie Webster, Kate Wyburn, Melanie Wyld.

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

Maximising Organ Donor offer Utility System-wide (the MODUS study)

Ethics approval for this project was granted by the University of Sydney Human Research Ethics Committee. HRC reference number: 2020/828. Date received: 09 November 2020

Study Details: MODUS developed evidence to support policy and complex clinical decisions in the organ donor referral process in Australia. Using the NSW Ministry of Health Biovigilance Public Health Register (SAFEOD) as the study platform, we used advanced statistical methods to better understand retrospective donor referral risk profiles, the impact of accepting or declining potential donors forgone for biovigilance concerns on patient and transplant outcomes and determine any potential donor gains through varying the acceptable biovigilance risk thresholds for accepting donors. Using economic modelling with microsimulation, we investigated the impact of variable donor referral decisions on quality, safety and value of kidney transplant outcomes (transplant and recipient survival).

Aims:

1. Describe the patient journey on the kidney transplant waitlist, including episodes of suspension and reactivation, time waiting and whether transplanted.
 - [Published work](#)
2. Describe the characteristics of patients on the kidney transplant waitlist who decline a deceased donor organ offer and patient outcomes after their first decline.
 - [Continuing work](#)
3. Determine potential gains made through increased donor acceptance and profile potential donors forgone for medical suitability.
 - [Published work](#)
 - [Continuing work](#)
4. Use economic modelling to investigate the benefits and costs of increasing donor acceptance.
 - [Published work](#)

Consumer engagement

MODUS was designed with input from peak consumer organisations and key stakeholders in delivery of Australia's organ donation and transplantation service. The NSW Ministry of Health supported the development of the Biovigilance Public Health Register (SAFEOD) and contributed to outcome development. The NSW Organ and Tissue Donation Service contributed expertise and helped fidelity through close relationship with medical suitability advisors and transplanting hospitals. Kidney Health Australia provided ongoing consumer liaison.



Members of the MODUS team at the final investigators' meeting, November 2024

Funding

The CI Professor Angela Webster received \$369,182 (#1171364) NHMRC Partnership Grant in the 2019 round, in partnership with Kidney Health Australia, the NSW Ministry of Health and the NSW Organ and Tissue Donation Service. Kidney Health Australia committed \$40,000 in-kind support over the grant's duration. The NSW Ministry of Health committed \$120,000 cash and \$40,000 in-kind support over the same period.

Output Synopsis *as of 3 November 2025*

Output	Number
Manuscripts	23
Published	16
In press	2
In preparation	5
Decision tools	3
Completed	3
Conferences	50
National (including NZ)	35
International	18
Students	11
HDR	7
Brenda Rosales	
James Hedley	
Rachel Cutting	
Victor Khou	
Karan Shah	
Imogen Thomson	
Karen Waller	
HDC	2
Nick Chan	
Jack Marsden	
Other	2
Fred Lee	
Claire Johnson	

Timelines

Planned timeline																				
Year	2020				2021				2022				2023							
Quarter	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4				
Profiling																				
Modelling (economic)																				
Supporting (decision-support)																				
Dissemination																				
Policy translation																				
Actual timeline																				
Year	2020				2021				2022				2023				2024			
Quarter	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Profiling																				
Modelling (economic)																				
Supporting (decision-support)																				
Dissemination																				
Policy translation																				

*Profiling took longer than anticipated due to covid/staffing – with flow on effects

Continuing work timeline

Year	2025			
Quarter	1	2	3	4
Cancer transmission in deceased donor organ transplantation (BR)				
Environmental scan: decision support tools (SW)				
Understanding factors influencing decision-making during the organ donor referral process (DM)				
Consequences of declining a donor offer: outcomes for individuals after first decline (HB)				
Donor type versus recipient health resource use (NC)				
Maximum gains from potential donors forgone for deceased organ donation and transplant (BR)				
Infection transmission risk from kidney donors with active HBV: a systematic review and meta-analysis of observational data (KW)				
Infection transmission risk from kidney donors with past HCV: a systematic review and meta-analysis of observational data (KW)				
Study protocol: decision support tool development and testing (MODUS 2.0)				

Journey to kidney transplantation: patient dynamics, suspensions, transplantation and deaths in the Australian kidney transplant waitlist

Investigators: Nicole De La Mata, Victor Khou, James Hedley, Patrick Kelly, Rachael Morton, Kate Wyburn, Angela Webster.

Summary: We described the patient journey on the Australian kidney waitlist, focusing on transitions between active waitlisting and suspensions, and identified factors contributing to inequities. Using data from the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), we examined all individuals waitlisted for their first kidney transplant from 2006-2019. We found suspensions occurred in one-third of patients. Prior suspensions made likelihood of returning to the waitlist 50% and future suspensions increase 4.2-fold. Prior suspensions also reduced the likelihood of transplantation by 30% and led to a 1-year longer wait over a five-year period. When suspended death risk increased 12-fold. Non-Indigenous males were 13% and Asian males were 23% more likely to return to the waitlist after suspension than females of the same ethnicity. Aboriginal and Torres Strait Islanders were 31% less likely to return to the waitlist after suspension compared with non-Indigenous Australian and New Zealanders. This study identifies where health service delivery is best placed to effectively support returning to the waitlist sooner.

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

1. 2021 Australian and New Zealand Society of Nephrology, by Nicole De La Mata
N De La Mata, V Khou, J Byrnes, P Kelly, J Hedley, R Morton, A Webster. Patient experience of the kidney transplant waitlist: an Australian cohort study
<https://anzsnasm.com/12900>
2. 2021 Transplantation Society of Australia and New Zealand, by Nicole De La Mata
Khou V, De La Mata N, Kelly P, Hedley J, Webster, Patient dynamics across a lifespan of kidney waitlisting and transplantation: an Australian cohort study <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8109145/>
3. 2022 Women in Transplantation, International symposium on sex and gender in transplantation: The female perspective, by Nicole De La Mata
Sex differences in the kidney transplant waitlist: An Australian cohort study, 2006-2019. Best abstract award (1 of 3 internationally)
4. 2022 International Congress of the Transplantation Society, by Nicole De La Mata
5. 2023 European Renal Association, poster by Nicole De La Mata

Publication: Nicole L De La Mata, Victor Khou, James A Hedley, Patrick J Kelly, Rachael L Morton, Kate Wyburn, Angela C Webster, Journey to kidney transplantation: patient dynamics, suspensions, transplantation and deaths in the Australian kidney transplant waitlist, Nephrology Dialysis Transplantation, 2023;, gfad253, <https://doi.org/10.1093/ndt/gfad253>

Link/access: <https://doi.org/10.1093/ndt/gfad253>

Values, preferences and risk tolerance for people waitlisted for kidney transplant: a systematic review (in press)

Investigators: Rachel Cutting, Danielle Muscat, Pinika Patel, Nicole De La Mata, Georgina Irish, Melanie Wyld, Sarah White, Angela Webster.

Summary: This systematic review aimed to explore the values, preferences, and risk tolerance of patients on the kidney transplant waitlist, regarding extended criteria donors or donors with increased risk of transmitting blood-borne virus or cancer. A systematic review of 25 studies involving 2630 participants revealed several key findings. Firstly, waitlist patients desired freedom from dialysis, and were willing to accept shorter graft function to reduce wait-time. Conversely, those satisfied with dialysis were hesitant to accept riskier transplants, fearing negative health impacts. Patients' understanding of their prognosis influenced their urgency for a transplant, with older individuals more inclined to accept increased risk kidneys due to perceived limited time. Knowledge gaps were evident, with many patients underestimating the risks of dialysis and transplant outcomes. Despite desiring shared decision-making, patients often felt powerless in the process, emphasising the need for improved communication and evidence-based decision tools. The study highlights the importance of shared decision-making, personalised information, and evidence-based tools to support patient-centered decisions at the time of donor kidney offer. Further research is needed, particularly on patients' preferences of increased cancer risk donors and incorporating diverse populations.

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

1. 2023 Australian and New Zealand Society of Nephrology, by Rachel Cutting
Rachel Cutting, Pinika Patel, Nicole De La Mata, Georgina Irish, Melanie Wyld, Angela Webster Values, preferences, and risk tolerance of people waitlisted for kidney transplant: a systematic review, 2023, Mini Oral,
<https://anzsnasm.com/18639>

Patient journey on the transplant waiting list: the waitlist navigator decision support tool

Investigators: James Hedley, Nicole De La Mata, Angela Webster.

Summary: This tool calculates expected outcomes after being waitlisted for a kidney transplant, based on patient characteristics: age, sex, country/state/territory, ethnicity, blood group, prior suspensions, cause of kidney failure, comorbidities, time on dialysis prior to waitlisting. This work is based on Nicole L De La Mata, Victor Khou, James A Hedley, Patrick J Kelly, Rachael L Morton, Kate Wyburn, Angela C Webster, Journey to kidney transplantation: patient dynamics, suspensions, transplantation and deaths in the Australian kidney transplant waitlist, Nephrology Dialysis Transplantation, 2023,, gfa253, <https://doi.org/10.1093/ndt/gfa253>

Link/access: https://organ-donation-evidence.shinyapps.io/WaitList_Navigator/

New blood-borne virus infections among organ transplant recipients: an Australian data-linked cohort study examining donor transmissions and other HIV, hepatitis C and hepatitis B notifications, 2000-2015

Investigators: Karen Waller, Nicole De La Mata, James Hedley, Brenda Rosales, Michael O’Leary, Elena Cavazzoni, Vidiya Ramachandran, William Rawlinson, Patrick Kelly, Kate Wyburn, Angela Webster.

Summary: We aimed to estimate the rates of known and unknown viral transmission events between organ donors and recipients and to establish the rates of new blood-borne virus notifications among transplant recipients in NSW, Australia. Using SAFEBOD, we included donor (deceased and living)-recipient pairs transplanted between 2000-2015. We identified diagnoses of hepatitis B (HBV), C (HCV), or human immunodeficiency virus (HIV) in both donors and recipients. Among 2,120 donors 72 had a viral infection (9/72 active, 63/72 past) and donated to 173 recipients of whom 24/173 already had the same infection as the donors, and 149/173 did not, so were at risk of transmission. Among those at risk, 3/149 recipients had proven/probable viral transmissions (1 HCV, 2 HBV). There were no deaths from transmissions. There were no donor transmissions from donors without known blood-borne viruses. An additional 68 recipients had new virus notifications, of whom 2/68 died, due to HBV infection. This study shows the low rate of viral transmission and supports targeted increases in donation from donors with viral infections (when known). This study also supports the use of linked health data for better surveillance and outcomes, especially regarding the number of new viral infections among organ recipients.

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

1. 2020 International Society for Organ Donation Procurement (ISODP) Organ Donation Congress, by Karen Waller
2. 2020 International Population Data-Linkage Network, by Karen Waller
Karen MJ Waller, Nicole L De La Mata, James A Hedley, Brenda M Rosales, Michael J O’Leary, Elena Cavazzoni, Vidiya Ramachandran, William D Rawlinson, Patrick J Kelly, Kate R Wyburn, Angela C Webster, New Blood Borne Virus Infections Among Organ Transplant Recipients: A Data-Linked Cohort Study Examining Transmissions and De Novo Infections, 2020, <https://doi.org/10.23889/ijpds.v5i5.1642>
3. 2020 Transplantation Society of Australia and New Zealand, by Karen Waller

Publication: Waller KMJ, De La Mata NL, Hedley JA, Rosales BM, O'Leary MJ, Cavazzoni E, Ramachandran V, Rawlinson WD, Kelly PJ, Wyburn KR, Webster AC. New blood-borne virus infections among organ transplant recipients: An Australian data-linked cohort study examining donor transmissions and other HIV, hepatitis C and hepatitis B notifications, 2000-2015. *Transpl Infect Dis.* 2020 Dec;22(6):e13437. doi: 10.1111/tid.13437. Epub 2020 Aug 27. PMID: 32767859.

Link/access: [10.1111/tid.13437](https://doi.org/10.1111/tid.13437)

Characteristics and donation outcomes of potential organ donors perceived to be at increased risk for blood-borne virus transmission: an Australian cohort study

Investigators: Karen Waller, Nicole De La Mata, Brenda Rosales, James Hedley, Patrick Kelly, Imogen Thomson, Michael O'Leary, Elena Cavazzoni, Vidiya Ramachandran, William Rawlinson, Kate Wyburn, Angela Webster.

Summary: We aimed to describe potential organ donors in NSW, Australia, who were perceived to have an increased risk of blood-borne virus (BBV) transmission and to examine whether they proceeded to donation. We conducted a cohort study of all people referred for organ donation from 2010-2018. Of 5749 potential donors, 624 (10.9%) were perceived to have increased BBV transmission risk and 239 (4.2%) with increased risk behaviors (no known BBV). We found many potential donors with hepatitis C (HCV) and increased risk behaviors had favorable characteristics, such as younger age and fewer comorbidities, compared to baseline risk potential donors. Despite this, many potential donors (82 with HCV, 38 with high-risk behaviors) were declined for donation because of perceived BBV transmission risk. Most were excluded before BBV testing. Even after the availability of direct-acting antivirals for HCV in 2016, potential donors with HCV were still frequently excluded. When potential donors with HCV did donate, they donated fewer organs than baseline risk donors (median 1 versus 3), especially kidneys and lungs. There is scope to increase donation rates by improving testing and reconsidering the acceptance of donors with perceived increased BBV transmission risk.

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

1. 2020 Australian Gastroenterology Week, by Karen Waller
2. 2020 International Society for Organ Donation Procurement (ISODP) Organ Donation Congress, by Karen Waller (combined with manuscript above)
3. 2020 International Population Data-Linkage Network, by Karen Waller (combined with manuscript above)

Karen MJ Waller, Nicole L De La Mata, James A Hedley, Brenda M Rosales, Michael J O'Leary, Elena Cavazzoni, Vidiya Ramachandran, William D Rawlinson, Patrick J Kelly, Kate R Wyburn, Angela C Webster, New Blood Borne Virus Infections Among Organ Transplant Recipients: A Data-Linked Cohort Study Examining Transmissions and De Novo Infections, 2020, <https://doi.org/10.23889/ijpds.v5i5.1642>

Publication: Waller KMJ, De La Mata NL, Rosales BM, Hedley JA, Kelly PJ, Thomson IK, O'Leary MJ, Cavazzoni E, Ramachandran V, Rawlinson WD, Wyburn

KR, Webster AC. Characteristics and Donation Outcomes of Potential Organ Donors Perceived to Be at Increased Risk for Blood-borne Virus Transmission: An Australian Cohort Study 2010-2018. Transplantation. 2022 Feb 1;106(2):348-357. doi: 10.1097/TP.0000000000003715. PMID: 33988336.

Link/access: [10.1097/TP.0000000000003715](https://doi.org/10.1097/TP.0000000000003715)

Notifiable infectious diseases among organ transplant recipients: a data-linked cohort study, 2000–2015

Investigators: Karen Waller, Nicole De La Mata, Kate Wyburn, James Hedley, Brenda Rosales, Patrick Kelly, Vidiya Ramachandran, Karan Shah, Rachael Morton, William Rawlinson, Angela Webster.

Summary: We assessed the burden of notifiable infectious diseases among solid organ transplant recipients in NSW, Australia, compared to the general population, from 2000-2015 using SAFEBOOD. Of 4858 recipients followed for 39,183 person-years, there were 792 notifiable infectious diseases reported (some recipients had >1 infection notified). Most notifications were vaccine-preventable diseases, predominantly influenza, followed by gastrointestinal diseases. The most prevalent infections were influenza (1358 per 100 000 person-years, highest within 3 months post-transplant), followed by pertussis (97 cases per 100,000 person-years) and invasive pneumococcal disease (79 cases per 100,000 person-years). Salmonellosis was the most common gastrointestinal disease, with an incidence of 117 cases per 100,000 person-years. These infections often led to hospitalisation and ICU admissions, particularly influenza and invasive pneumococcal disease, indicating a significant impact on health services. This highlights the importance of vaccination, health education interventions and screening to mitigate the burden of infectious diseases among transplant recipients.

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

1. 2020 Australian Gastroenterology Week, by Karen Waller
2. 2020 International Population Data-Linkage Network, by Karen Waller
Waller, K. M., De La Mata, N. L., Wyburn, K. R., Kelly, P. J., Ramachandran, V., Shah, K., Morton, R., Rawlinson, W. D. and Webster, A. C. (2020) "Vaccine-Preventable Infections Among Solid Organ Transplant Recipients: A Data-Linked Cohort Study, Australia, 2000-2015", International Journal of Population Data Science, 5(5). doi: 10.23889/ijpds.v5i5.1643. <https://ijpds.org/article/view/1643>
3. 2020 Australian and New Zealand Society of Nephrology, by Nicole De La Mata
Notifiable infections among kidney transplant recipients: a data-linkage cohort study, New South Wales, 2000-2015 K Waller, N De La Mata, K Wyburn, P Kelly, V Ramachandran, K Shah, R Morton, W Rawlinson, A Webster <https://anzsnasm.com/11313>
4. 2020 The Transplantation Society, by Karen Waller
Waller, Karen; De La Mata, Nicole; Wyburn, Kate; Kelly, Patrick; Ramachandran, Vidiya; Shah, Karan; Morton, Rachael; Rawlinson, William; Webster, Angela. Vaccine-preventable infections among solid

organ transplant recipients: a data-linked cohort study, Australia, 2000-2015. Transplantation 104(S3):p S313, September 2020.10.1097/01.tp.0000700100.35245.4a

https://journals.lww.com/transplantjournal/fulltext/2020/09003/vaccine_preventable_infections_among_solid_organ.464.aspx

5. 2021 Transplantation Society of Australia and New Zealand, by Karen Waller
Waller K, De La Mata N, Wyburn K, Hedley J, Rosales B, Kelly P, Ramachandran V, Shah K, Morton R, Rawlinson W, Webster A, Notifiable infections among organ transplant recipients: an Australian data-linked cohort study, 2000-2015
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8109145/>
Early Career Researcher Award, Transplantation Society of Australia and New Zealand

Publication: Karen M J Waller, Nicole L De La Mata, Kate R Wyburn, James A Hedley, Brenda M Rosales, Patrick J Kelly, Vidiya Ramachandran, Karan K Shah, Rachael L Morton, William D Rawlinson, Angela C Webster, Notifiable Infectious Diseases Among Organ Transplant Recipients: A Data-Linked Cohort Study, 2000–2015, Open Forum Infectious Diseases, Volume 9, Issue 8, August 2022, ofac337, <https://doi.org/10.1093/ofid/ofac337>

Link/access: <https://doi.org/10.1093/ofid/ofac337>

Cancer transmissions and non-transmissions from solid organ transplantation in an Australian cohort of deceased and living organ donors

Investigators: James Hedley, Claire Vajdic, Melanie Wyld, Karen Waller, Patrick Kelly, Nicole De La Mata, Brenda Rosales, Kate Wyburn, Angela Webster.

Summary: Utilising data from SAFEBOD, we investigated cancer transmissions and non-transmissions in organ donors and recipients over a 13-year period in NSW, Australia. We included solid organ transplants from deceased donors between 2000-2012 and living donors between 2004-2012. Cancer diagnoses were identified through the NSW Central Cancer Registry and provided at least one-year post-transplant follow up. Among 1431 donors and 2502 recipients, 38 donors (3%) had past or current cancer and donated to 68 recipients (median 6.7-year follow-up). The most common cancers in donors were kidney (37%), brain (18%), prostate (16%), melanoma (11%), breast (8%), and thyroid (8%). Among 68 transplant procedures from 38 donors with past or current cancers, there were 64 (94%) non-transmissions and 4 (6%) transmissions from two living and two deceased donors (all kidney cancers discovered during organ recovery). Overall, cancer transmissions were rare (0.16% of transplant procedures), with non-transmission being much more common (94%) than transmissions (6%). Considering the variability in recipient outcomes following cancer transmission, this study highlights the importance of incorporating patient preferences into decisions regarding accepting or declining an offered organ to ensure the risks of accepting a transplant from a donor with cancer are balanced against the risks of remaining on an organ waiting list. Further research could investigate the economic implications of expanding organ donation from such donors.

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

1. 2021 Transplantation Society of Australia and New Zealand, by James Hedley
Hedley J, Waller K, Thomson I, De La Mata N, Rosales B, Wyburn K, Kelly P, Webster A, Cancer transmissions and non-transmissions from solid organ transplantation: a NSW cohort study
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8109145/>
2. 2021 European Society for Organ Transplantation (ESOT) The International Transplant Congress, by James Hedley

Publication: Hedley JA, Vajdic CM, Wyld M, Waller KMJ, Kelly PJ, De La Mata NL, Rosales BM, Wyburn K, Webster AC. Cancer transmissions and non-

transmissions from solid organ transplantation in an Australian cohort of deceased and living organ donors. *Transpl Int.* 2021 Sep;34(9):1667-1679. doi: 10.1111/tri.13989. PMID: 34448264

Link/access: [10.1111/tri.13989](https://doi.org/10.1111/tri.13989)

Perceived versus verified cancer history and missed opportunities for donation in an Australian cohort of potential deceased solid organ donors

Investigators: James Hedley, Patrick Kelly, Karen Waller, Imogen Thomson, Nicole De La Mata, Brenda Rosales, Kate Wyburn, Angela Webster.

Summary: We examined the accuracy of cancer history in donor records, identified missed donor opportunities, and evaluated strategies to improve donor utilisation. Using data from SAFEBOD, we compared perceived cancer diagnoses at the time of referral with verified diagnoses from linked health records in NSW, Australia from 2010-2013. Transmission risks were based on clinical guidelines. Among 472 potentially suitable donor referrals, 132 (28%) were declined due to perceived transmission risk and 340 (72%) donated. Out of the 132 declined (and assuming a low-risk threshold) 38 (29%) were considered missed opportunities and five (1%) were excess-risk donors. Decision support tools and real-time data linkage could reduce these missed opportunities and excess-risk donors. Decision support alone would result in five (13%) more suitable donors being accepted. Although, this would also result in two (40%) more excess-risk donors being accepted. Combining decision support with real-time data linkage would reduce missed opportunities by 6 (16%) and reduce excess-risk donors by 2 (40%). With increased risk tolerance there would be six (16%) fewer missed opportunities and 11 (220%) more excess-risk donors. Decision support and real-time data linkage to existing health data sets, would reduce both missed opportunities and excess-risk donors. Implementing these strategies could marginally increase the number of available donors without significantly compromising recipient safety.

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

1. 2020 Transplantation Society of Australia and New Zealand, by James Hedley
2. 2020 International Population Data Linkage Conference, by James Hedley
Hedley, J. A., De La Mata, N., Rosales, B. M., Waller, K. M. J., Thomson, I. K., Kelly, P. J., O'Leary, M., Cavazzoni, E., Wyburn, K. and Webster, A. C. (2020) "Perceived vs. Verified Cancer Transmission Risk from Deceased Organ Donors in New South Wales (NSW), Australia, 2010-2015", International Journal of Population Data Science, 5(5). doi: 10.23889/ijpds.v5i5.1495.
3. 2021 European Society for Organ Transplantation (ESOT), by James Hedley

Publication: Hedley JA, Kelly PJ, Waller KMJ, Thomson IK, De La Mata NL, Rosales BM, Wyburn K, Webster AC. Perceived Versus Verified Cancer History and Missed Opportunities for Donation in an Australian Cohort of Potential Deceased Solid Organ Donors. Transplant Direct. 2022 Jan 13;8(2):e1252. doi: 10.1097/TXD.0000000000001252. PMID: 35047659; PMCID: PMC8759621.

Link/access: [10.1097/TXD.0000000000001252](https://doi.org/10.1097/TXD.0000000000001252)

Potential organ donors with primary brain tumours: missed opportunities for donation and transplantation identified in Australian cohort study 2010–2015

Investigators: Imogen Thomson, James Hedley, Brenda Rosales, Kate Wyburn, Michael O'Leary, Angela Webster.

Summary: We examined the agreement of primary brain tumour (PBT) biovigilance risk classification during donor procurement with other medical records, characterised PBT referrals and donation outcomes, identified any tumour transmission events, and quantified potential missed donation opportunities. The research was conducted in NSW, Australia from 2010-2015, utilising data from the Organ and Tissue Donation Services (OTDS) and SAFEBOOD. Among 2957 potential donors, 76 (3%) had PBT. Of these, 18 (24%) were declined because of perceived PBT transmission risk and 10 (13%) proceeded to donation with no transmission events observed. PBT potential donors had fewer comorbidities (1.6 vs. 2.1, $P = 0.006$) than non-PBT potential donors. We found that many perceived high-risk PBT at the time of donation decisions were actually lower risk upon further review. Specifically, five out of 76 potential donors had their tumour grades overestimated, and discrepancies between OTDS logs and SAFEBOOD led to overestimations of transmission risk. Missed opportunities were identified, with potential donors having risk profiles comparable to those who donated successfully. Real-time data linkage and improved decision support could enhance donor utilisation and accuracy in risk assessment.

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

1. 2020 The Transplantation Society, by Imogen Thomson
Thomson, Imogen Kate; Hedley, James; Rosales, Brenda; Kelly, Patrick; Wyburn, Kate; Webster, Angela. Missed opportunities for organ donation from potential donors with primary brain tumours in australia; cohort study 2010-2015. Transplantation 104(S3):p S220, September 2020. | DOI: 10.1097/01.tp.0000699520.63932.16
2. 2020 Australian and New Zealand Society of Nephrology, by Imogen Thomson
I K Thomson, J Hedley, B Rosales, A Webster. Missed opportunities for organ donation among donors with primary brain tumours (PBT): New South Wales (NSW) cohort study 2010-2015. <https://anzsnasm.com/11003>

Publication: Thomson, I.K., Hedley, J., Rosales, B.M., Wyburn, K., O'Leary, M.J. and Webster, A.C. (2022), Potential organ donors with primary brain tumours: missed opportunities for donation and transplantation identified in Australian cohort

study 2010–2015. ANZ Journal of Surgery. <https://doi.org/10.1111/ans.18037>

Link/access: <https://doi.org/10.1111/ans.18037>

Transmission and non-transmission of melanoma from deceased solid organ donors to transplant recipients: risks and missed opportunities

Investigators: Brenda Rosales, James Hedley, Nicole De La Mata, Elena Cavazzoni, Claire Vajdic, John Thompson, Patrick Kelly, Kate Wyburn, Angela Webster.

Summary: We aimed to estimate the transmission risk of melanoma from deceased organ donors to recipients and identify missed donation opportunities in NSW Australia, (where melanoma prevalence is high) from 2010-2018. Using SAFEBOD we found, among 5667 potential donors, 993 donated organs, including 9 donors with melanoma (four in situ low-risk and five invasive high-to-unacceptable risk, four were unrecognised prior to donation), none of whom transmitted melanoma to their 16 transplant recipients. Among 35 of 3588 potential donors forgone for melanoma risk alone, 17 were otherwise suitable for donation (six had no melanoma, 2 had in situ melanomas and 9 had thin invasive melanomas (localized, ≤ 0.8 mm thickness). Improved access to real-time cancer registry data could enhance the accuracy of melanoma risk assessment during donor evaluation. This could increase the donor pool without compromising recipient safety. Our evidence supports more consistent decisions for donors with low-risk melanomas, potentially increasing the donor pool and access to transplantation.

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

1. 2020 Clinical Research Prize, NSW Has (Scientific) Talent Competition, Sydney Health Partners Renal Stream & Amgen Australia, Sydney Local Health District, awarded to Brenda Rosales.
2. 2021 Australian and New Zealand Society of Nephrology, by Brenda Rosales
B Rosales, N De La Mata, C Vadjic, J Thomson, P Kelly, K Wyburn, A Webster. Melanoma in solid organ donors and transplant recipients: transmission risk and missed opportunities. 2021. <https://anzsnasm.com/12637>
3. 2023 Transplantation Society of Australia and New Zealand, by Brenda Rosales
Rosales B, Hedley J, De La Mata N, Cavazzoni E, Vajdic C, Kelly P, Wyburn K, Webster A. Transmission and non-transmission of melanoma from deceased organ donors to transplant recipients: an update using re-linked data <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10750682/>
4. 2023 Donation & Transplantation Conference – Back to the future, by James Hedley

Publication: Rosales BM, Hedley J, De La Mata N, Cavazzoni E, Vajdic CM, Thompson JF, Kelly PJ, Wyburn K, Webster AC. Transmission and Non-transmission of Melanoma

From Deceased Solid Organ Donors to Transplant Recipients: Risks and Missed Opportunities. Transplantation. 2024 Feb 29. doi: 10.1097/TP.0000000000004961. Epub ahead of print. PMID: 38419163.

Link/access: [10.1097/TP.0000000000004961](https://doi.org/10.1097/TP.0000000000004961)

Non-retrieval and non-utilisation of deceased donor kidneys for transplantation: an Australian cohort study

Investigators: Rachel Cutting, Nicole De La Mata, Animesh Singla, James Hedley, Helen Opdam, Philip Clayton, Kate Wyburn, Elena Cavazzoni, Paul Robertson, Henry Pleass, Angela Webster

Summary: This study examined the rates, donor and system factors, and reasons for non-retrieval and non-utilisation of kidneys from deceased donors in Australia between 2014-2021. Using data from the Australia and New Zealand Organ Donation Register (ANZOD), we found 9% of kidneys were not retrieved and 7% of retrieved kidneys were not utilised. The non-retrieval rate doubled from 5% in 2014 to 10% in 2021, while the non-utilisation rate remained relatively stable. Kidney Donor Profile Index (KDPI) $\geq 75\%$ was strongly associated with non-retrieval, and donor factors such as diabetes and history of cancer were also significant. Donation after circulatory determination of death (DCDD) kidneys were more likely to be non-utilised. Perfusion issues accounted for 17% of non-utilisation, however most reasons lacked transparency. The findings highlight the need for targeted efforts to maximize the utilisation of high KDPI kidneys and support the implementation of enhanced perfusion techniques. Improved data collection is crucial for further insights to optimise kidney utilisation through better systems and processes.

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

1. 2024 OTDS Clinical Network Meeting, by Rachel Cutting
2. 2024 NSW Deceased Donor Organ Procurement Service (DDOPS), by Rachel Cutting
3. 2024 Transplant Program Webinar, Transplant Surgery Section, by Rachel Cutting
4. 2024 Australian and New Zealand Society of Nephrology, by Rachel Cutting
Rachel Cutting, Nicole De La Mata, Animesh Singla, James Hedley, Helen Opdam, Philip Clayton, Kate Wyburn, Elena Cavazzoni, Paul Robertson, Henry Pleass, Angela Webster. Non-retrieval and non-utilisation of deceased donor kidneys for transplantation: and Australian cohort study.
<https://anzsnasm.com/23000/>
5. 2025 The European Society of Organ Transplantation, by Rachel Cutting, presented by Angela Webster
Rachel Cutting, Nicole De La Mata, Animesh Singla, James Hedley, Helen Opdam, Philip Clayton, Kate Wyburn, Elena Cavazzoni, Paul Robertson, Henry Pleass, Angela Webster. Non-retrieval and non-utilisation of deceased donor kidneys for transplantation: and Australian cohort study (brief oral).

6. 2025 Transplantation Society of Australia and New Zealand (TSANZ), by Rachel Cutting. Rachel also received the TSANZ Early Career Researcher Award.
Rachel Cutting, Nicole De La Mata, Animesh Singla, James Hedley, Helen Opdam, Philip Clayton, Kate Wyburn, Elena Cavazzoni, Paul Robertson, Henry Pleass, Angela Webster. Non-retrieval and non-utilisation of deceased donor kidneys for transplantation: and Australian cohort study (oral).
7. 2025 The International Society of Organ Donation Professionals, Organ Donation Congress, by Rachel Cutting
Rachel Cutting, Nicole De La Mata, Animesh Singla, James Hedley, Helen Opdam, Philip Clayton, Kate Wyburn, Elena Cavazzoni, Paul Robertson, Henry Pleass, Angela Webster. Non-retrieval and non-utilisation of deceased donor kidneys for transplantation: and Australian cohort study (brief oral).

Publication: Cutting RB, De La Mata NL, Singla A, Hedley JA, Opdam H, Clayton P, Wyburn K, Cavazzoni E, Robertson P, Pleass H, Webster AC. Non-Retrieval and Non-Utilisation of Deceased Donor Kidneys for Transplantation: An Australian Cohort Study. ANZ J Surg. 2025 Jul-Aug;95(7-8):1584-1596. doi: 10.1111/ans.70208. Epub 2025 Jun 5. PMID: 40470609.

Link/access: [10.1111/ans.70208](https://doi.org/10.1111/ans.70208)

Decision Support Tools in Deceased Donor Kidney Transplantation: An Environmental Scan and Appraisal of Online Resources

Investigators: Sarah White, Danielle Muscat, Pinika Patel, Rachel Cutting, Matilda McLean, Angela Webster.

Summary: We conducted an environmental scan and reviewed 17 freely available online decision aids and risk tools (6 patient-directed decision aids, 1 clinician-directed decision aid, and 10 risk calculator) designed to assist patients and clinicians once the decision has been made to proceed with kidney transplantation. We appraised their quality relative to validated usability scales and health literacy guidelines and thus their usefulness to both clinicians and patients in making healthcare decisions regarding kidney donation and transplantation. We found 3 out of 6 patient-directed decision aids did not fully describe available treatment options or what it is like to experience the consequences of the options. Four were understandable, only 1 was actionable. The usability of the 10 risk calculators ranged from 50% ‘major usability concerns’ to 85% ‘indicating good usability’ with a mean score of 71%. Overall, the common communication and usability concerns were information overload, key points not reinforced, poor design and low interpretability, lack of visual aids, no actionable direction the user can take, and no contextual information or data sources.

Publication: White, Sarah L. PhD1; Cutting, Rachel B. MPH1; McLean, Matilda BA (Psych)2,3; Muscat, Danielle M. PhD1,2; Patel, Pinika PhD1; Webster, Angela C. PhD1,4,5. Decision Support Tools in Deceased Donor Kidney Transplantation: An Environmental Scan and Appraisal of Online Resources. Transplantation
()10.1097/TP.0000000000005473, July 14, 2025. | DOI:
10.1097/TP.0000000000005473

Link/access: [10.1097/TP.0000000000005473](https://doi.org/10.1097/TP.0000000000005473)

Assessing absolute risk from deceased kidney donors' decision support tool

Investigators: James Hedley, Sarah White, Pinika Patel, Angela Webster.

Link: https://organ-donation-evidence.shinyapps.io/donor_risk/

Summary: This study aimed to develop a decision support tool to assist specialists in deciding whether to accept kidneys from deceased donors with a history of cancer. Using ANZDATA-linked data, the tool models absolute rates of kidney graft survival based on donor characteristics, excluding recipient data. The tool, created using the R package 'shiny', allows users to input donor and cancer details, presenting absolute risk of graft survival after 1 or 5 years for potential and comparison donors. Findings suggest evidence-based risk assessment could promote greater utilisation of kidneys from donors with cancer history, aligning with clinical guidelines and enhancing specialists' confidence in donation decisions.

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

1. 2023 Donation and Transplantation Conference, by James Hedley
2. 2023 Australian and New Zealand Society of Nephrology, by James Hedley
James Hedley, Pinika Paten, Angela Webster. 2023. Decision support tool for assessing absolute risk of cancer transmission from deceased kidney donors
<https://anzsnasm.com/18660>
3. 2023 Transplantation Society of Australia and New Zealand, by James Hedley
Hedley J, Patel P, Webster A. Decision support tool for assessing absolute risk of cancer transmission from deceased kidney donors (mini oral)
https://tsanz.com.au/storage/ASM_2023/2023-Abstract-Book-FINAL.pdf

Donor and recipient pair: paired offer decision support tool (prototype)

Investigators: James Hedley, Sarah White, Angela Webster.

Link: https://organ-donation-evidence.shinyapps.io/patient_decision_support/

Summary: We developed a decision-support tool for patients and clinicians to help compare consequences of accepting versus declining a kidney offer from a deceased donor with risk of cancer or BBV virus. Outcomes include transmission risk and probability of waitlist suspension, cancer, death or better offer in next 5 years.

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

1. 2024 Transplantation Society of Australia and New Zealand, by James Hedley
Hedley J, White S, Muscat D, Wyburn K, Webster A. Decision support tool to aid risk Assessment of accepting versus declining a kidney offer from a donor with a history of Cancer. (Poster)
https://tsanz.com.au/storage/ASM_2024/FINAL-2024-Program-Book.pdf
2. 2024 Australian and New Zealand Australian and New Zealand Society of Nephrology, by James Hedley. James also received the TSANZ Early Career Researcher Award.
James Hedley, Sarah White, Danielle Muscat, Kate Wyburn, Angela Webster. Decision support tool to aid risk assessment of accepting versus declining a kidney offer from a donor with a risk of disease transmission.
<https://anzsnasm.com/23002/>
3. 2025 The European Society for Organ Transplantation (ESOT), by James Hedley presented by Angela Webster.
James Hedley, Sarah White, Danielle Muscat, Kate Wyburn, Angela Webster. Decision support tool to aid risk assessment of accepting versus declining a kidney offer from a donor with a risk of disease transmission (poster)

Kidney donor risk decision support tool: user testing final report

Investigators: Sarah White, James Hedley, Angela Webster.

Summary: This is a mixed-methods study, based on interview-led surveys with open-ended feedback and response to structured survey questions from clinicians involved in determining medical suitability for organ transplantation. The aim was to evaluate the impact of the [*'absolute risk from deceased kidney donors decision support tool'*](#) on decisional conflict in decisions related to the medical suitability of kidneys from potential deceased donors and assess the useability of the decision support tool. Feedback of the tool included additional information about how the tool creates its risk scores and key information such as proteinuria results. Interaction with the user interface was positive overall. Responders believed this tool would be most useful for clinicians who are new to advising on donor medical suitability and for donor coordinators to rapidly synthesise information and calculate risk estimates. They also saw potential value in improving the degree of consistency in decision-making.

Link/access: <https://organdonationevidence.org.au/wp-content/uploads/2024/11/Kidney-Donor-Risk-Decision-Support-Tool-FInal-Report.pdf>

AIM 4 PUBLISHED MANUSCRIPTS

Cost-effectiveness of kidney transplantation from donors at increased risk of blood-borne virus infection transmission

Investigators: Karan Shah, Melanie Wyld, James Hedley, Karen Waller, Nicole De La Mata, Angela Webster, Rachael Morton.

Summary: We evaluated the cost-effectiveness of accepting kidneys from donors with an increased risk of blood-borne virus (BBV) transmission compared to the current practice of rejecting such kidneys. We used a Markov model to assess costs and quality-adjusted life years (QALYs) associated with the new strategy. Model simulations were run over a 20-y time horizon. In the new strategy there were 7% more kidney transplants per year (2% from donors with increased risk behaviors and 5% from donors with hepatitis C (HCV) infection). In the first 2 y of the new strategy, individuals incurred a higher probability (0.3%–2% per cycle) of receiving a kidney transplant, lower probability (0.1%–0.5% per cycle) of being suspended from the waitlist, and a lower probability (0.001%–0.02% per cycle) of death on the waitlist than with current practice, with slightly higher probabilities of post-transplant HCV and hepatitis B (HBV) infections. However, the new strategy incurred lower costs and led to higher QALY gains (8.53 QALYs). Sensitivity analyses confirmed the robustness of these findings, with the new strategy remaining cost-effective across various scenarios. Accepting kidneys from donors with an increased risk of BBV transmission could lead to substantial health system cost-savings and improved quality-adjusted survival, thus advocating for policy revisions to support this practice.

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

1. 2022 Transplantation Society of Australia and New Zealand, by Karan Shah
Shah KK, Hedley JA, Wyld M, De La Mata N, Rosales BM, Waller KMJ, Webster A, Morton RL. Cost-effectiveness of accepting kidneys from deceased donors with increased risk of blood borne virus transmission
https://journals.lww.com/transplantationdirect/fulltext/2022/12001/abstracts_from_the_2022_transplantation_society_of.2.aspx
2. 2023 Health Economics Association (iHEA), by Karan Shah
Karan Ketan Shah, James A Hedley, Melanie Wyld, Angela Webster, Kristy Robledo, Rachael Lisa Morton. Cost-Effectiveness of Kidney Transplantation from Donors at Increased Risk of Blood-Borne Virus Infection Transmission: A Tale of Two Decision-Models – Markov Versus Microsimulation
<https://healtheconomics.org/wp-content/uploads/2023/10/2023-World->

Publication: Shah, K. K., Wyld, M., Hedley, J. A., Waller, K. M. J., De La Mata, N., Webster, A. C., & Morton, R. L. (2023). Cost-effectiveness of Kidney Transplantation From Donors at Increased Risk of Blood-borne Virus Infection Transmission. *Transplantation*, 10.1097/TP.0000000000004632. Advance online publication. <https://doi.org/10.1097/TP.0000000000004632>

Link/access: <https://doi.org/10.1097/TP.0000000000004632>

Cost-effectiveness of interventions to increase utilisation of kidneys from deceased donors with primary brain malignancy in an Australian setting

Investigators: James Hedley, Patrick Kelly, Melanie Wyld, Karan Shah, Rachael Morton, Juliet Byrnes, Brenda Rosales, Nicole De La Mata, Kate Wyburn, Angela Webster.

Summary: We assessed the cost-effectiveness of increasing the utilisation of kidneys from deceased donors with primary brain malignancies (PBM) in Australia. Using a Markov patient-level simulation model, we evaluated costs and quality-adjusted life-years (QALYs) for three interventions: decision support for clinicians, improved clinical information through data linkage, and increased risk tolerance for using donors with intermediate-risk PBM. On average, all proposed interventions resulted in increased QALYs and cost-savings compared to current practice. Decision support with increased risk tolerance was the most likely to be cost-effective, leading to improvement in health outcomes (+18.8 QALYs) and a reduction in healthcare expenditure (\$2.2 million). Increasing utilisation of kidneys from donors with PBM would benefit patients waiting for kidney transplants, with a potential increase in donation by 2.1% and substantial cost-savings. These findings suggest that policymakers should consider implementing strategies to increase the acceptance of kidneys from deceased donors with PBM to enhance transplantation rates and reduce healthcare costs.

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

1. 2022 Health Services Research Association Australia and New Zealand, by James Hedley
2022 Transplantation Society of Australia and New Zealand, by James Hedley
Hedley J, Shah K, Wyld M, Morton R, Byrnes J, Rosales B, De La Mata N, Kelly P, Wyburn K, Webster A. Cost-effectiveness of increasing utilisation of kidneys from deceased donors with primary brain malignancy
https://journals.lww.com/transplantationdirect/fulltext/2022/12001/abstracts_from_the_2022_transplantation_society_of.2.aspx
2. 2022 The Transplantation Society, by James Hedley
Hedley, James; Shah, Karan; Wyld, Melanie; Morton, Rachael; Byrnes, Juliet; Rosales, Brenda; De La Mata, Nicole; Kelly, Patrick; Wyburn, Kate; Webster, Angela: Cost-Effectiveness of Interventions to Increase Utilization of Kidneys From Deceased Donors With Primary Brain Malignancy in an Australian Setting. Transplantation 106(9S):p S220, September 2022. | DOI: 10.1097/01.tp.0000886496.17327.60
https://journals.lww.com/transplantjournal/fulltext/2022/09001/313_15_cost_effectiveness_of_interventions_to.328.aspx

3. 2022 Australian and New Zealand Society of Nephrology, by James Hedley
Mr James Hedley, Karan Shah, Melanie Wyld, Rachael Morton, Juliet Byrnes, Brenda Rosales, Nicole De La Mata, Patrick Kelly, Kate Wyburn, Angela Webster. Cost-effectiveness of interventions to increase utilization of kidneys from deceased donors with primary brain malignancy. 2022
<https://anzsnasm.com/15672>

Publication: Hedley JA, Kelly PJ, Wyld M, Shah K, Morton RL, Byrnes J, Rosales BM, De La Mata NL, Wyburn K, Webster AC. Cost-effectiveness of Interventions to Increase Utilization of Kidneys From Deceased Donors With Primary Brain Malignancy in an Australian Setting. *Transplant Direct*. 2023 Apr 19;9(5):e1474. doi: 10.1097/TXD.0000000000001474. PMID: 37090124; PMCID: PMC10118354.

Link/access: [10.1097/TXD.0000000000001474](https://doi.org/10.1097/TXD.0000000000001474)

Cost-effectiveness of accepting kidneys from deceased donors with common cancers – a modelling study

Investigators: Karan Shah, James Hedley, Kristy Robledo, Melanie Wyld, Angela Webster, Rachael Morton.

Summary: The aim of the study was to evaluate the cost-effectiveness of accepting kidneys from donors with common cancers, such as breast, prostate, and colorectal cancers, within acceptable transmission risk limits. Results indicated that accepting kidneys from donors with minimal or low-risk cancer profiles led to substantial gains in Quality-Adjusted Life Years (QALYs) and cost savings compared to conservative practice. Specifically, accepting kidneys from minimal-risk breast cancer donors resulted in an average of 20.12 QALYs and cost savings of \$2.3 million. Similarly, accepting kidneys from donors with minimal and low-risk breast, prostate, and colorectal cancers generated significant QALY gains ranging from 7.32 to 20.12 QALYs and statistically significant cost savings ranging from \$1.06 million to \$5.78 million. These findings highlight the potential benefits of utilising kidneys from donors with minimal or low cancer risk within acceptable transmission risk limits.

Publication: Shah KK, Hedley JA, Robledo KP, Wyld M, Webster AC, Morton RL. Cost-effectiveness of Accepting Kidneys From Deceased Donors With Common Cancers-A Modeling Study. Transplantation. 2024 Mar 19. doi: 10.1097/TP.0000000000004984. Epub ahead of print. PMID: 38499509.

Link/access: [10.1097/TP.0000000000004984](https://doi.org/10.1097/TP.0000000000004984)

Using Linked Health Service Data in Multimodal Modeling of Kidney Transplant Waitlist Outcomes: Protocol for the Maximizing Organ Donor Utility Systemwide (MODUS) Study

Investigators: Brenda Rosales, Karan Shah, Nicole De La Mata, Heather Baldwin, James Hedley, Philip Clayton, Melanie Wyld, Kate Wyburn, Patrick Kelly, Kate Wyburn, Rachael Morton, Angela Webster, MODUS Study Group: Prof Kirsten McCaffery, Dr Danielle Muscat, Prof Claire Vajdic, Dr Elena Cavazzoni, Prof Henry Pleass, Prof Nicholas Cross, Ms Rhonda Holdsworth, Prof Shilpanjali Jesudason, and Prof William Rawlinson.

Summary: This is a protocol for the overarching aim of MODUS, which seeks to determine if increasing the acceptance of donor kidneys can help more people with kidney failure get transplants. The protocol outlines the expected projects including examining the journey of patients on the kidney transplant waitlist, measuring the impact of declined donor offers on waiting times and assessing medical suitability and missed opportunities of potential donors. Consumer organisations and key stakeholders are involved in the study design to ensure it addresses the needs of people with kidney disease. Our analyses will provide evidence on the health and economic benefits of accepting more donor kidneys. Findings will have potential global applications and support better organ donor referral processes.

Publication: Rosales BM, Shah K, De La Mata N, Baldwin H, Hedley J, Clayton P, Wyld M, Kelly P, Wyburn K, Morton R, Webster A; MODUS Study Group. Using Linked Health Service Data in Multimodal Modeling of Kidney Transplant Waitlist Outcomes: Protocol for the Maximizing Organ Donor Utility Systemwide (MODUS) Study. *JMIR Res Protoc*. 2025 Jul 29;14:e67588. doi: 10.2196/67588. PMID: 40462280; PMCID: PMC12344388.

Link/access: [10.2196/67588](https://doi.org/10.2196/67588)

AIM 2 CONTINUING WORK

We anticipate the following studies will be in press by the beginning of 2026.

Consequences of declining a donor offer: outcomes for individuals after first decline

Investigators: Heather Baldwin, Brenda Rosales, James Hedley, Narelle Watson
Melanie Wyld, Angela Webster.

Summary: We will use data from SAFEBOD to understand the time it takes for patients on the kidney transplant waitlist to receive a deceased donor transplant after a declined offer in NSW from 2010-2020. By analysing records of ranked offers for actual donors and potential recipients, we will identify which donor-recipient pairs were declined by transplant teams. We will estimate the decline rates of the first donor-recipient offer based on recipient characteristics like blood group, sex, age, ethnicity, immunological sensitisation (PRA), and comorbidities. We will examine outcomes after the first offer is declined, such as the time to the next offer, the time to a better offer (with an improved KDPI), the number of offers received until transplant, the rate and duration of time spent suspended from the list, receiving a transplant (from a deceased or living donor), and death.

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

1. 2024 Transplantation Society of Australia and New Zealand, by Heather Baldwin
Baldwin H, Rosales B, Hedley J, De La Mata N, Au E, Wyburn K, Webster A.
Kidney transplant waitlist outcomes after decline of first deceased donor kidney offer: a data linkage study 2006-2019
https://tsanz.com.au/storage/ASM_2024/FINAL-2024-Program-Book.pdf

AIM 3 CONTINUING WORK

Understanding factors influencing decision-making during the organ donor referral process: a qualitative study of clinicians assessing medical suitability of donor kidneys (in press)

Investigators: Danielle Muscat, Pinika Patel, Rachel Davies, Rachel Cutting, Brenda Rosales, Kirsten McCaffery, Kate Wyburn, Angela Webster.

Summary: This qualitative study investigated the decision-making process of donation specialists during the organ donor referral process in NSW, Australia. The study aimed to understand the factors influencing clinicians' decisions and to identify key themes in their approach. Thirteen participants, including donor coordinators, transplant recipient coordinators, medical doctors, and surgeons, were interviewed. Important findings include the reliance on individual judgment and clinical guidelines, the prioritisation of transplantation over dialysis, concerns about missing or incomplete medical information, and the importance of considering recipient needs and family involvement in decision-making. The study highlights the need for standardised approaches to assess referrals and suggests the use of decision support tools to enhance risk evaluation. Ultimately, the findings show the importance of a holistic approach to organ suitability assessments, considering both medical risks and the quality of life for recipients.

Infection transmission risk from kidney donors with active HBV: a systematic review and meta-analysis of observational data (in press)

Investigators: Karen Waller, James Hedley, Nicole De La Mata, Rachel Davies, Emma Garrett, William Rawlinson, Sacha Stelzer-Braid. Kate Wyburn Angela Webster

Summary: Currently in press.

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

1. 2024 Transplantation Society of Australia and New Zealand, Clinical Network Meeting, by Karen Waller
2. 2024 The Transplantation Society, Virtual Conference, by Karen Waller

Maximum gains from potential donors forgone for deceased organ donation and transplant: a population-based data-linkage study, 2010-2022

Investigators: Brenda Rosales, Rachel Davies, James Hedley, Nicole De La Mata, Melanie Wyld, Elena Cavazzoni, Kate Wyburn, Patrick Kelly Angela Webster

Summary: Manuscript drafting currently underway.

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

1. 2025 Transplantation Society of Australia and New Zealand (TSANZ), by Brenda Rosales, presented by James Hedley. Brenda also received the TSANZ Early Career Researcher Award.
Brenda Rosales, Rachel Davies, James Hedley, Nicole De La Mata, Melanie Wyld, Elena Cavazzoni, Kate Wyburn, Patrick Kelly Angela Webster. Clinical risk aversion and potential gains from donors forgone for deceased kidney donation: a data-linkage study (oral).
2. 2025 Australasian Epidemiology Association, by Brenda Rosales.
Brenda Rosales, Rachel Davies, James Hedley, Nicole De La Mata, Melanie Wyld, Elena Cavazzoni, Kate Wyburn, Patrick Kelly Angela Webster. Maximum gains from potential donors forgone for deceased kidney donation: a data-linkage study.
3. 2025 The International Society of Organ Donation Professionals, Organ Donation Congress, by Brenda Rosales, presented by Rachel Cutting.
Brenda Rosales, Rachel Davies, James Hedley, Nicole De La Mata, Melanie Wyld, Elena Cavazzoni, Kate Wyburn, Patrick Kelly Angela Webster. Maximum gains from potential donors forgone for deceased kidney donation: a data-linkage study.

Cancer transmission in deceased donor organ transplantation: an Australian population-based linkage study of donor referral data

Investigators: Brenda Rosales, Claire Johnston, James Hedley, Nicole De La Mata, Elena Cavazzoni, Claire Vajdic, Sarah White, Patrick Kelly, Kate Wyburn, Angela Webster

Summary: Manuscript drafting currently underway.

Dissemination/Awards: This a presented at the following conferences:

1. 2024 Transplantation Society of Australia and New Zealand, by Brenda Rosales
Rosales BM, Johnston C, Hedley J, De La Mata N, Cavazzoni E, Vajdic CM, White S, Kelly P, Wyburn K, Webster AC. Common Cancer transmission and non-transmission in deceased organ donors and transplant recipients: NSW data-linkage study 2010-2018.
https://tsanz.com.au/storage/ASM_2024/FINAL-2024-Program-Book.pdf
2. 2025 The European Society of Organ Transplantation (ESOT), by Brenda Rosales, presented by Angela
Rosales BM, Johnston C, Hedley J, De La Mata N, Cavazzoni E, Vajdic CM, White S, Kelly P, Wyburn K, Webster AC. Common Cancer transmission and non-transmission in deceased organ donors and transplant recipients: NSW data-linkage study 2010-2018 (poster).

Effect of deceased donor type on kidney recipient post-transplant health service utilisation

Investigators: Nicholas Chan, Heather Baldwin, Nicole De La Mata, James Hedley, Brenda Rosales, Michael O’Leary, Elena Cavazzoni, Patrick Kelly, Kate Wyburn, Melanie Wyld, Angela Webster.

Summary: Manuscript drafting currently underway.

Dissemination/Awards: This a presented at the following conferences:

1. 2024 Australian and New Zealand Society of Nephrology, by Nicholas Chan

Nicholas Chan, Heather Baldwin, Nicole De La Mata, James Hedley, Brenda Rosales, Kate Wyburn, Melanie Wyld, Angela Webster. Effect of deceased donor type on kidney recipient post-transplant health service utilisation.

<https://anzsnasm.com/22558/>

Infection transmission risk from kidney donors with past HCV: a systematic review and meta-analysis of observational data

Investigators: Pin Han (Fred) Lee, Karen Waller, James Hedley, Rachel Davies, Emma Garrett, William Rawlinson, Sacha Stelzer-Braid, Kate Wyburn, Angela Webster

Summary: Analysis underway.

OTHER MODUS DISSEMINATION/AWARDS

1. 2021 Dialysis, Nephrology and Transplantation workshop (DNT), *Equity and transplant waiting list dynamics in Australia*, by Angela Webster
2. 2022 Transplantation Society of Australia and New Zealand, *Donor-derived infections and malignancies*, by Angela Webster
3. 2023 Transplantation Society of Australia and New Zealand, *Supporting evidence-based decisions for using donors with a prior history of cancer*, by Angela Webster
4. 2023 Donation and transplant conference, Organ and Tissue Authority, *Decision clinical aids, translating clinical knowledge and evidence into practice*, by Angela Webster
5. 2023 Australian and New Zealand Society of Nephrology, *Data for equity in transplant access and outcomes*, by Angela Webster
6. 2023 UK Kidney Week, UK Kidney Association, *Data integration and synthesis for equitable kidney care*, by Angela Webster