

1. Participant:

South Australian Health and Medical Research Institute (SAHMRI) in relation to Australia and New Zealand Organ and Donation (ANZOD) and Australia and New Zealand Dialysis and Transplant (ANZDATA) Registries

2. ABN:

54 141 228 346

3. Reporting Period:

01/07/2021 to 30/06/2022

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Organisation details

8. Have there been any changes to the organisation's details during the period of reporting? (For example, to the organisation's name, address, trust arrangements, etc). If yes, provide details. Provide an organisational structure chart/staff chart.

Registry operations, including data management and reporting, have continued with minimal interruption to regular process.

A Business Support Officer, Eliza Partridge, was recruited to provide administrative support to the Registry's executive operational secretariat activities and in conjunction with the ongoing appointment of Kelly Marshall as Deputy Registry Manager, these roles have provided the necessary additional senior support to the Registry General Manager.

The Executive Officer, Professor Stephen McDonald and Executive Deputy Officer, Associate Professor Phil Clayton, continue to provide in-kind support for Registry strategic direction and executive management.

Achieving the project outcomes

9. Describe the organisation's progress or achievements that were made in meeting the project outcomes specified in Item A of the Schedule and other activities related to the OTA Strategic Plan objectives:

Activity	Narrative
Data collection, management and development:	
Develop and maintain a database for the collection of de-identified data on deceased solid organ donation and transplantation outcomes and deceased and living tissue donation and transplantation outcomes	Ongoing; continue to align activities for timely and accurate data collection on organ and eye donation and transplantation outcomes; improving the quality and completeness of all datasets; supporting centres who are migrating with electronic data submissions and datafile transfers
Continue to develop processes, in collaboration with the eye and tissue sector, around data collection to enable reliable and accurate six-monthly reporting of eye and tissue donation and transplantation outcomes	Ongoing; the Registry continues reporting on sector activity and outcomes; continues representation on ETAC developing streamline data collection and reporting processes in collaboration with the sector
Continue to develop processes, in collaboration with the Australian Red Cross Lifeblood (as host of OrganMatch) and OTA, to identify the most appropriate data sources for wait listing and transplantation data, and optimise data collection through the use of agreed and documented data definitions	Ongoing; the Registry continues to work collaboratively with OM and OTA; supporting developments; providing guidance and clinical understanding on wait listing and transplantation data; scoping different approaches to non-kidney organ data collection for inclusion in OM; improving the quality and completeness of datasets
Develop and maintain a database for the efficient collection and storage of data on dialysis patients and renal transplants	Ongoing; developed, tested, and deployed database and system application changes and improvements relevant to the EDR, PKE and living kidney donation sectors, as well as requirements for expanding dialysis and transplant suite of data collection; current Version: 2021.2.9.6. (Releases x2 in the 12month reporting period)
Ensure consistency of data provided by contributing hospitals/units through the use of agreed and documented data definitions	Ongoing; continues with weekly communication strategy for consistent and complete data capture across all contributing hospitals/units/backs and DonateLife sector.
Collaborate with the OTA to develop and conduct a survey of participating units/hospitals to assess data provision, reporting and analysis. This survey will take place in the 2019-2020 financial year	Completed; Published initial Special Report – Unit Survey on the results of the centre survey; Roll out a of a subsequent survey in conjunction with the annual patient survey 2021 with different questions, including the number of dialysis chairs
Collaborate with the sector including other outcome registries to review and standardise data definitions and algorithms to measure transplant outcomes	Ongoing; Continuing work with other outcome registries and heart and lung units across the country in scoping a pilot registry, defining minimum data sets and incorporating organ waiting list and long term transplant outcomes. Continued active collaboration with OrganMatch.

Data governance	
Comply with the Strategic & Operating Principles for Australian Clinical Quality Registries, developed by Australian Commission on Safety and Quality in Health Care, and endorsed by the then Australian Health Ministers Conference (AHMC) in November 2010 (where applicable)	Ongoing; review of all policies and data sharing agreements to ensure relevance and compliance with Registry's visions and mission, taking in to consideration operating principles and continued development of registry science in clinical quality registries
Collaborate with OTA and other stakeholders to develop and promote data governance and privacy principles to expand appropriate analysis of data across the donation and transplantation sector	Ongoing; Participating in regular meetings providing consultation and support in collaboration with OTA and other stakeholders
Continue to develop facilities for users to perform limited analyses on the database ensuring protection of confidentiality of database elements	Ongoing; Active and responsive amendments and additions developed across the suite of reports allowing users to more interact reports and access to data, within strict privacy and security requirements.
Analysis and reporting	
Collect, analyse, and report data on all Australian and New Zealand solid deceased organ donations and transplant outcomes; and all Australian deceased and living tissue (including eye) donations and transplant outcomes to assist in improving patient care and outcomes through greater understanding of events, treatments, and outcomes in the areas of organ and tissue donation and retrieval	Ongoing; Analysis and reporting outputs continues; Working closely with Eye and Tissue banks, EBAANZ, NZ Blood and Organ Service, OrganMatch, DonateLife Network and OTA on streamline data collection and reporting outputs; Monthly and Annual Reports published in a timely manner for each collection period. EOI sought for sector engagement in an ANZOD working group in collaboration with OTA to develop future reporting requirements to meet current and future data output and research
Provide an annual report of solid organ donation in Australia and New Zealand to all relevant stakeholders, including the Authority; providing analyses of trends of organ donation and utilisation, and provide the annual report as a downloadable file available freely on the Internet for any interested person	Completed; Annual Report published by section on data to the end of 2021; Eye and tissue donation data continues to develop along a data collection and reporting plan with ETAC, monthly organ donation and transplantation activity reporting continues
Jointly with the Authority, prepare the annual Australian Donation and Transplantation Activity Report for release in early January of each year	Completed; Key deliverables provided in a timely manner to meet OTA, media, and important stakeholder expectations; output released successfully during the period
Collect, analyse, and report data on renal replacement therapy (dialysis and transplantation) in Australia and New Zealand to assist in improving patient care and outcomes through greater understanding of events, treatments, and outcomes in the areas of renal transplantation and dialysis	Ongoing; data collection continues, and a range of reports prepared, circulated, and published (Including: publicly released material, hospital specific reports, bespoke analyses for stakeholders); Communicating these reports with renal centres, their chief executive, and the broader community. Additionally, in collaboration with ANZSN, the Registry has developed a

	new quality indicator report to assist ANZSN with outlier management;
Provide an annual report of dialysis and renal transplantation in Australia and New Zealand to all relevant stakeholders, including the Authority; and provide the annual report as a downloadable file available freely on the Internet for any interested person	Completed; Annual Report published and available from the Registry website as downloadable files in *.pdf, *.xls, and *.ppt on data to the end of 2020; published accompanying infographics summarising the key aspects of the annual activity for 2020. Preparation for next annual reporting period drafted
Provide data and analysis to dialysis and transplant units, the Authority, relevant donation and transplantation forums and the general community in a regular and reliable manner to assist understanding of the benefits of dialysis and transplantation	Ongoing; continued development and production of reporting outputs, website publishing and consumer friendly material; Developed and produced consumer-friendly infographics with complementary videos, describing the ANZDATA organization and the information in the infographic material
Work with the OTA to analyse data to assist understanding the potential demand for kidney transplantation and demographics of dialysis patients and waiting lists	Ongoing; collaboration with OTA staff
Report the outcomes of ANZDATA data analysis to the Transplantation Society of Australia and New Zealand Renal Transplant Advisory Committee, as required	Ongoing; continued reporting of Positive COVID-19 on the dialysis and transplant patient cohort weekly to TSANZ and key stakeholders; Presentation at various organ advisory committee meetings on registry developments and data analysis
Continue to collaborate with the Australian Institute of Health and Welfare in the area of reporting of end-stage kidney disease trends and incidence	Ongoing; collaboration continues with an ongoing data exchange arrangement with AIHW, as well as the provision of expert clinical consultation on trends and incidence of kidney disease treatment
Respond to queries and requests for data and/or analysis from the OTA within timeframes to be agreed at the time of request	Ongoing; statistical assistance continues in the provision of data extracts, analysis and data linkage supporting researchers and OTA as requested; implementation of formal data request tracking to encourage output translates to better patient and consumer outcomes
Collate waiting list and transplant outcome data to allow for timely production of the ANZOD annual report	Ongoing; Focused efforts and collaboration with OrganMatch and OTA, facilitating streamlined monthly and annual reporting and analyses, improving quality and timely reporting
Collect de-identified unit record transplant outcome data from renal units and other outcome registries for inclusion in ANZOD and ANZDATA reporting	Ongoing;
Collect living non-renal donation data from transplant registries to facilitate consolidated reporting of living donation.	Ongoing; Reported on in the annual joint media release and for the OTA to meet the annual international reporting requirements
Provide quarterly de-identified kidney wait listing and transplant data to OTA. These data will be	Ongoing; Quarterly reports delivered to OTA via secure datafile transfer

used to facilitate aggregated transplant activity reporting by OTA within the DonateLife Network.	
Committees	
Ensure the Registry Head and or Registry Manager attend relevant Data Governance Committee and Working Group meetings and participate in the work of the Committee to ensure the future use, collation and reporting of data meets the requirements of clinicians, government, and the community	Completed; Relevant meetings attended
Ensure the Registry Head and or Registry Manager attend relevant OrganMatch Strategic Governance Committee and OrganMatch Operational Committee meetings and participate in the work of the committees to help provide an interface and foster ongoing collaboration between the donation and transplantation sector	Ongoing; Relevant meetings attended virtually by delegates progressing the OrganMatch Strategic Governance and Operation deliverables and tasks
Participate in Clinical Quality Registry Framework Review Advisory Group hosted by the Australian Commission of Quality and Safety in Health Care undertaking development of the National Arrangements for Clinical Quality Registries and provide feedback to OTA and other Transplant Outcome Registries	Ongoing; the CQR Group has had few and irregular meetings as efforts within the Safety and Quality Commission have been diverted related to COVID. We have liaised with the Commission regarding this; we understand it is their intention to increase activity in this space in the second part of 2022; within SA we have established a Centre of Excellence for Clinical Registries and Registry Science at SAHMRI; consultation in a National One Stop Shop and Front Door initiative for health-related human research approvals; contributed to presented at annual Clinical Quality Registry workshops and professional development meetings; successful application for a Communication/Collaboration hub
Assist OTA, by providing subject matter expertise, leadership and administrative support, to host a forum of Registry Heads for regular discussion of issues relating to the collection and reporting of data relating to donation and transplantation and promotion of best practice of clinical quality registry management	Ongoing; discussions continue with OTA staff and organ transplant outcome registries in the absence of formal meetings
Coordinate a stakeholder forum for discussion of dialysis and renal transplantation clinical activity and registry data collecting, analysis and report formats; and attend various sector forums, conferences, and meetings	Ongoing; Representation at various scientific meetings, conferences, and invited meetings enabled the Registry to maintain open discussions with the sector on key developments and outcomes of operations and data collection
Manage meetings of the ANZDATA Advisory Committee	Ongoing; all relevant meetings conducted and meeting minutes available
Other	
Maintain and further develop the ANZDATA/ANZOD website	Ongoing; Focused effort on interactivity and consumer friendly accessibility; content updated regularly.

Undertake other projects as mutually agreed by both Parties	Ongoing; Collaboration with AKTN, KHA-CARI Guidelines, Cochrane Renal Centre in initiatives to strengthen Registry based clinical trials and consumer engagement, (Funded by NHMRC Program Grant and other external research funding).
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OTA Strategic Plan objectives:

Objective 1: Further increase donation opportunities for transplantation	Objective 1: Further increase donation opportunities for transplantation
1.3 Increase opportunities for living kidney donation through the Australian and New Zealand Paired Kidney Exchange (ANZKX) Program	ANZDATA supports this by continuing to refine and develop reporting of donation and transplantation activity and outcomes to inform and promote living donor transplantation
Objective 4: Enhance systems to support donation and transplantation	Outcome Registry Activity
4.1 Enhance collection and analysis of data to inform clinical best practice for donation and transplantation	ANZDATA continues to collect, analyse, and distribute activity and outcome data for organ donation and kidney transplantation that allows evaluation of clinical practice.
4.2 Work with the clinical sector to improve the equity and efficiency of the organ offer process	ANZDATA has ongoing collaborations with a variety of groups (in particular, the RTAC committees) examining various elements of the kidney allocation process. Within ANZDATA we also host the National Indigenous Kidney Transplant Taskforce which has as a focus improving access to kidney transplantation for Aboriginal and Torres Strait Islander Australians.
4.5 Collaborate with states and territories to determine the requirements of the health system to support future growth in donation and transplantation	ANZDATA provides data on dialysis and kidney transplantation for jurisdictions to facilitate health service planning.

Additional information

10. Provide any additional information relevant to the project

Nil



Signature

PROFESSOR STEPHEN MCDONALD
Name (block letters)

2/7/2022
Date

EXECUTIVE OFFICER - ANZDATA REGISTRY
Position (block letters)