

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:

01/01/2020 to 31/12/2020

4. Contact person:

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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.

Despite the impact of the COVID pandemic across Australia and New Zealand, Registry operations, including data management and reporting, have continued with minimal interruption to regular process.

A Senior Project Officer was recruited for additional projects in conjunction with those of this agreement, that cover the EDR data collection expansion and reporting as well as scoping a renewed Cardiothoracic Transplant Registry. The incumbent for this position is also tasked with providing additional senior support to the Registry Manager on human resource and operational matters.

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 |
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| 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. Working on improving the quality and completeness of all datasets; Supporting centres who are migrating from paper collection to electronic data entry and more sophisticated 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 and developing streamline data collection and process 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; |
| 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 and sectors, as well as requirements for expanding dialysis and transplant suite of data collection; current Version: 2021.1.7.0. (Releases x3 in 12month period) |
| Ensure consistency of data provided by contributing hospitals/units through the use of agreed and documented data definitions | Ongoing; Rolled out a focused electronic communication and teaching strategy for consistent and complete data capture across all contributing units. |
| 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 a 'Special Report' on the results of the centre survey; Plan to continue to undertake the survey in conjunction with patient survey annually, on specific questions relevant to clinical practice, research and service planning. |
| 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 to align reporting outputs for standardised and comparable output on organ waiting list and transplant outcomes. 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; Updated data request policies and data sharing agreements to ensure data relating to ethnicity has relevance to the concepts raised on those diverse key groups, is in consultation with the ethnically diverse group and provides for how the results or outcomes of the research is shared back with the relevant community. |

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| 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, DonateLife Network and OTA on streamline data collection and reporting outputs; Monthly and Annual Reports published in a timely manner for each collection period. A review of the ANZOD annual report was conducted in collaboration with OTA and the formation of a working group for future reporting will meet current and future requirements. |
| 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 2020, 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 a downloadable on data to the end of 2020; Published accompanying infographic summarising the key aspects of the annual activity for 2020. |

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| 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; Positive SARS-CoV-19 (COVID-19) data collection in the Dialysis and Transplant patient cohort continues and with the suite collected variables extended to include vaccination status in case. Reporting weekly to TSANZ and key stakeholders |
| 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; Updated ongoing agreement continues the collaboration and data exchange arrangements 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; The provision of analysis supports researchers Number of requests responded to by the Registry averages 22/month; continues and assistance statistical |
| 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 |
| Collect de-identified unit record transplant outcome data from renal units and other outcome registries for inclusion in ANZOD and ANZDATA reporting | Ongoing; Relationship management and communications maintained in the absence of formal meeting in the reporting period. Liaising with Cardiothoracic units directly for ongoing activity in the absence of ANZCOTR in the aim to continue future reporting |
| 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 used to facilitate aggregated transplant activity reporting by OTA within the DonateLife Network. | Ongoing; Quarterly reports delivered to OTA via secure datafile transfer |
| 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 virtually in the absence of face-to-face meeting due to COVID-19 border restriction; |

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| 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; |
| 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; |
| 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). |

OTA Strategic Plan objectives:

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| 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 support 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)

Date

EXECUTIVE OFFICER - ANZDATA REGISTRY
Position (block letters)