

South Australia Health and Medical Research Institute Limited (T/A SAHMRI), the host agency for the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) and the Australian and New Zealand Organ Donation Registry (ANZOD)

Legal Entity Number:

961428

Contract Period:

1 July 2020 to 30 June 2022

Contract Number:

360263 / 01

Reporting Period:

01/07/2021 to 30/06/2022

Invoice Due Date:

1/07/2022

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ADDITIONAL INFORMATION

Compliance Statement:

The organisation remains under the business name ANZDATA (Australia and New Zealand Dialysis and Transplant Registry) and ANZOD (Australia and New Zealand Organ Donation Registry) trading under the auspices of the SAHMRI (South Australian Health and Medical Research Institute) ABN 54 141 228 346.

Project materials remain in use in accordance with the current funding agreement and service provision continues to occur as per agreed timeframes.

A table with date of receipt of annual data output and proportion of data submitted electronically by each DHB contributing unit:

Table 1 ANZDATA survey data submissions for the period ending 31 December 2021

Centre Code	Hospital/Centre Name	Notification	Method for 2021 Data Submissions
STAR	Starship Children's	20/01/2022	Online Data Entry
CHCH	Christchurch	14/03/2022	Online Data Entry
DUDN	Dunedin	04/04/2022	Online Data Entry
WELN	Wellington	11/05/2022	Online Data Entry
WHAN	Whangarei	16/05/2022	Online Data Entry
MIDM	Middlemore	19/05/2022	File Import
HAWK	Hawkes Bay	27/05/2022	Online Data Entry
WKTO	Waikato	10/06/2022	Paper
TARA	Taranaki	20/06/2022	Online Data Entry
PALM	Palmerston North	21/06/2022	Online Data Entry
WMAT	Waitemata	21/06/2022	Online Data Entry
AUCK	Auckland City	24/06/2022	Online Data Entry

Status of real time reporting to DHBs

- Reports are as listed in Appendix A

Update on activity during the reporting period related to:

- **Data collection and processing** continues to be streamlined. Highlights in the reporting period include:
 - ANZDATA is finalising data collection on Survey 72 (Data to 31-Dec-2021) from all units across Australia and Aotearoa New Zealand. Table 1 identifies the timeliness of NZ data submissions and the method of collection per renal unit. Units are notified weekly of the survey submission progress to encourage timely and complete data collection <https://www.anzdata.org.au/wp-content/uploads/2022/06/2021-Survey72-Progress.pdf>
 - Data from the 44th Annual ANZDATA Report (2021) includes analyses of data to 31-Dec-2020. For the survey period ending 31-December-2020, all renal units across Australia and New Zealand contributed data to the Registry. The report produces a wide range of statistics relating to incidence, prevalence, and outcomes of

treatment, of those with end stage kidney failure. This report is available for the Registry website <https://www.anzdata.org.au/anzdata/publications/reports/>

- Extended data collection in areas of parenthood and centre characteristics were analysed in the reporting period and the first of a series of special reports were produced. These reports aim to complement existing output (such as the Annual Report) and provide an opportunity to release material that is of relevance to contributors but does not fit readily within an annual reporting structure, or suitable for publication in a peer-reviewed research journal. These reports are prepared and reviewed internally.
 - Abridged versions of the dialysis and transplant hospital reports were prepared for general distribution and published to the Registry website. The individual hospital reports were also created, which contain more detailed information about the characteristics and outcomes within each hospital. Distribution of these reports were at the discretion of the Head of Unit. However, ANZDATA also sent a copy of the reports to hospital's Chief Executive Officer, District Health Boards and the National Renal Advisory Board in New Zealand with a covering letter providing some context and recommendation for bringing the reports to the attention of the relevant quality and safety committee.
 - The ANZDATA Quality Indicators Annual Report 2020 summarises quality indicators over the 12-month period ending 31-DEC-2020. This Report was produced in response to recommendations by the Australia and New Zealand Society of Nephrology (ANZSN) Key Performance Indicator Workgroup and feedback from consultation with contributors.
 - The collaboration with New Zealand Peritoneal Dialysis Registry (NZPDR) continues to improve the implementation of webservice technology (application programming interface – API) with ANZDATA allowing real-time data capture and submission between the registries
 - The collaboration with Australasian Clinical Trials Network (AKTN) in Registry-based trials continues to support investigator-initiated clinical trials which aim to improve the life for people living with chronic kidney disease. The BEST-Fluids trial data collection was completed and is now for analysis reporting and publication; TEACH-PD trial continues its recruitment phase, and its data collection in New Zealand is strongly supported by API technologies ANZDATA and NZPDR to reduce data capture burden to participating units.
 - Living kidney and deceased organ donation data collection continues and monthly reporting of activity of organ donation is available for general distribution <https://www.anzdata.org.au/anzlkd/reports/annual-summary/>
 - Development of a New Zealand specific infographic representation of data collected was finalised and produced for general distribution <https://www.anzdata.org.au/anzdata/resources/nz-info-resources/>
 - Registry research projects continue with the registry team exploring innovative ways to inform development of practice, policy and health services. Our team includes
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practicing clinicians, epidemiologists, biostatisticians, researchers, project managers, clinical trialists, academics and consumers. A number of current research programs are listed on our website and are at varying stages of analyses and preparation for peer reviewed publication <https://www.anzdata.org.au/anzdata/research/registry-projects/>

- COVID-19 reporting continued in the reporting period to inform on the number of the dialysis and transplant patients affected by the virus across Australia and New Zealand. Extended data collection on the patients' clinical course and outcome was impacted by the increased burden of the pandemic on health services and alternative reporting methods were implemented. Expressions of interest were sought for a Clinical Working Group was distributed with the group to convene and analyse data collected thus far.
 - **Collaboration with Aotearoa New Zealand Working Group** continues.
 - <https://www.anzdata.org.au/anzdata/about/working-groups/aotearoa-new-zealand-working-group/>
 - The Aotearoa New Zealand Working Group convened twice in the reporting period.
 - There was a changeover of convenor from Dr Michael Collins to Dr Tina Sun.
 - New members joined including advanced trainees supported by collaboration with University of Otago resulted in a specific ANZDATA Quantitative Research Project
 - The group has expanded the generation of research ideas and provided ongoing assistance on Aotearoa NZ specific data requests and promoting ANZDATA across the sector
 - A guidance document was developed to provide ANZDATA advice for data requests specifically involving New Zealand patients. This guidance takes into consideration patient ethnicity, disadvantaged groups such as children or minority populations and Māori participants to ensure that data requestors are aware of the context in which New Zealand patients share their information and that these data are managed and disseminated in a way that is used to benefit New Zealand patients
 - Development of additional policies for child protection are under way that further support the child and adolescent patient information sheets and ascent documentation.
 - **Analytical support for New Zealand reporting**
 - Responding to requests for assistance with projects and enquiries for additional or new information continues. Projects including New Zealand data are circulated to the Registry's New Zealand Working Group and, in some cases, the New Zealand Renal Advisory Board when required for their input.
 - ANZDATA compiled tables and graphs for the Aotearoa Nephrology annual performance report for presentation to the National Renal advisory board of NZ and NZ Health
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Figure 1 - Requests by Month for Projects including NZ Data (Jan 2020-Dec 2021)

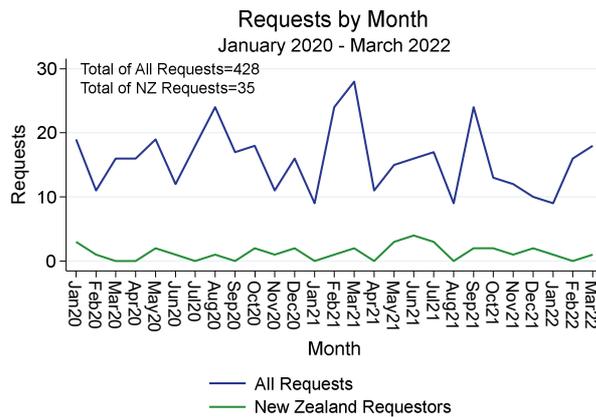


Figure 2 - Requests by Month for Projects from NZ Requestors (Jan 2020-Dec 2021)

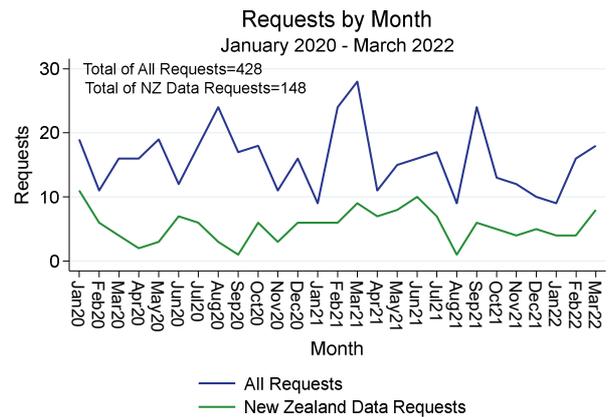
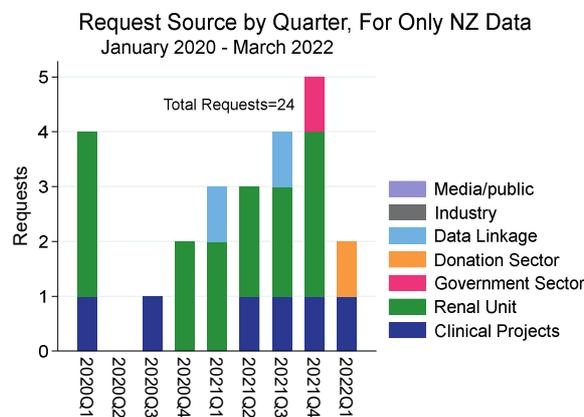


Figure 3 - Requests by Quarter for Projects for only NZ Data (Jan 2020-Dec 2021)



• **Achievement and Risks**

- The ANZDATA - NZ Blood and Organ Service (NZBS) data exchange was disrupted in 2021. Ongoing discussions have continued to during the reporting period to enable streamlined and comprehensive organ wait list, donation and transplant activity reporting and analysis, however it is recommended that a data exchange agreement (DEA) be signed off before data can flow seamlessly. Such a DEA would be separate to the current funding agreement between SAHMRI-ANZDATA and Health NZ. In preparation for a data exchange, NZBS and ANZDATA have undertaken a privacy impact assessment to reassure compliance with recent changes to the NZ Privacy Act.
- ANZDATA’s past and present leadership continues to contribute to high quality of care New Zealanders with renal disease. Data from the registry has also contributed to the high international reputation of the New Zealand researchers in Nephrology with a high percentage of publications, abstracts, presentations, and posters at annual scientific meetings.
- Despite this these achievements, the registry still faces significant challenges such as:
 - Increasing demands for real time NZ data
 - An expanding population of patients

- Decreasing time available for data collection within some participating NZ units
 - Delays in production of data from some NZ units holding up the provision of key reports
 - Increasing demands on the registry leadership as registry science and governance issues becomes more complex
 - A lack of funds to remunerate the in-kind effort of the Registry's Executive Officer
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APPENDIX A

Realtime Output

<https://secure.anzdata.org.au/>

- ANZDATA Quality Indicators Reports (2021, 2022)
- Individual Dialysis Hospital Report 2015-2020 (AUCK, CHCH, DUND, HAWK, MIDM, PALM, STAR, TARA, WELN, WHAN, WKTO, WMAT)
- Individual Transplant Caring Hospital Report 2015-2020 (AUCK, CHCH, DUND, HAWK, MIDM, PALM, STAR, TARA, WELN, WHAN, WKTO, WMAT)
- Individual Transplanting Hospital Report 2015-2020 (AUCK, CHCH, STAR, WELN)
- Interim Summary of Incidence Monthly Report (Jun 2021 to July 2022)

<https://services.anzdata.org.au/>

^ UNIT SUMMARY		
TX PERFORMED	NEW STARTS	SURVEY COMPLETENESS
SURVEY COMPLETENESS DATA - DETAIL	DECEASED PATIENTS - IDENTIFIED	SURVEY COMPLETENESS BY CENTRE
PENDING CANCER SURVEY DATA	TX PERFORMED - LIVING DONOR	PREVELANT PATIENTS DEMOGRAPHICS
REJECTION EPISODES - DETAILED	PATIENT LIST - SURVEY	PATIENT LIST BY SURVEY
PERITONITIS EPISODES - DETAILED	PATIENT CENTRE TRANSFERS	MODALITY CHANGES
PATIENT TREATMENT CHANGES	TRANSPLANT FUNCTION	TRANSPLANT ANNIVERSARY FOR FOLLOWUP - CURRENT SURVEY
RENAL UNIT SERVICE PROVISION	TRANSPLANT ANNIVERSARY FOR FOLLOWUP - REALTIME	PARENTHOOD OUTCOME REPORT
PENDING SURVEY CHECKS - CALCIPHYLAXIS	CALCIPHYLAXIS EPISODES - DETAILED	TRANSPLANT ANNIVERSARY BY YEAR
TRANSPLANT SURGICAL DATA REPORT BY TX CENTRE	SURGICAL DATA - DETAILED	PREVALENT DIALYSIS PATIENT CURRENT SURVEY DATA
PARENTHOOD OUTCOME – DETAILED	FUNCTIONING TRANSPLANT SURVIVAL	DIALYSIS ONLY - PATIENT SURVIVAL
LONGEST SURVIVAL ON ANY RENAL REPLACEMENT	PREVALENT DIALYSIS PATIENTS BY YEAR	CENTRE TREATMENTS
MISSING TRANSPLANT INDUCTION THERAPIES	ANZDATA SYSTEM USER LIST FOR A PARENT CENTRE	

Publications

<https://www.anzdata.org.au/anzdata/publications/scientific-articles/>