What's New in Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)

As group across Australia and New Zealand, ANZDATA acknowledges the traditional custodians of the lands throughout Australia and Aotearoa New Zealand, their culture and heritage. We pass our respects to elders past, present and emerging. We also acknowledge Māori as tangata whenua and the Treaty of Waitangi in Aotearoa.

ANZSN ASM - ANZDATA Session 31st August 2021 - Kylie Hurst

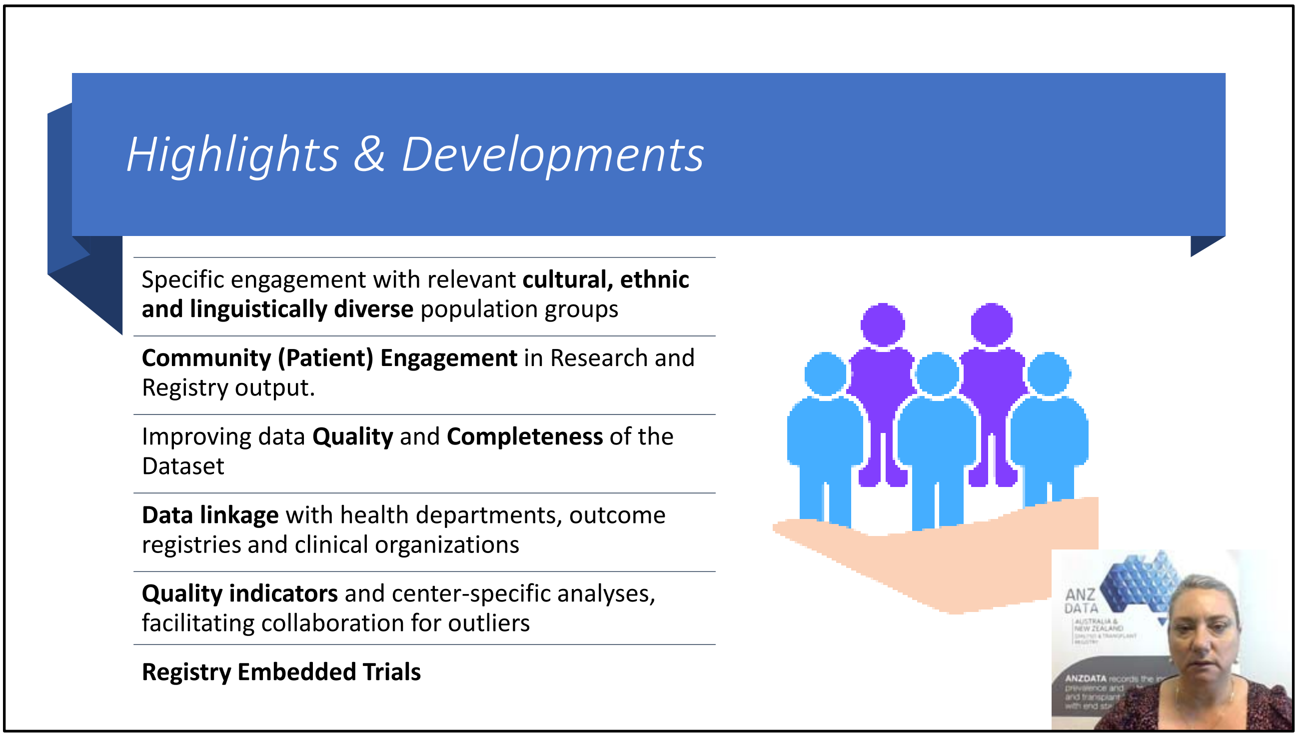
Na Marni, Kia Ora, Greetings and thank you for the opportunity to present what's new at the Australia and New Zealand Dialysis and Transplant Registry.

Acknowledgment

I'd like to start by recognising the dedicated team who support contributors in order to provide accurate, timely reporting and research output. We certainly have grown and now have 25 personnel across all the Registry themes.

Since our move to the South Australian Health and Medical Research Institute, 5 years ago, we have strengthened our position as leaders in Registry science and in collaboration with other clinically relevant registries and organizations.

Although acknowledging here our funding support, the real success of the Registry and its outputs, is the culmination of the valuable in-kind support from all Renal Centres across the two countries; as well as members of the Advisory Committee and Clinical Working Groups.



Highlights & Developments

- Specific engagement with relevant **cultural, ethnic and linguistically diverse** population groups
- **Community (Patient) Engagement** in Research and Registry output.
- Improving data **Quality** and **Completeness** of the Dataset
- **Data linkage** with health departments, outcome registries and clinical organizations
- **Quality indicators** and center-specific analyses, facilitating collaboration for outliers
- **Registry Embedded Trials**

The Registry, continues working towards and changing how we engage with contributors, researchers and the community; with the aim to improve the interpretation of and access to the data we collect.

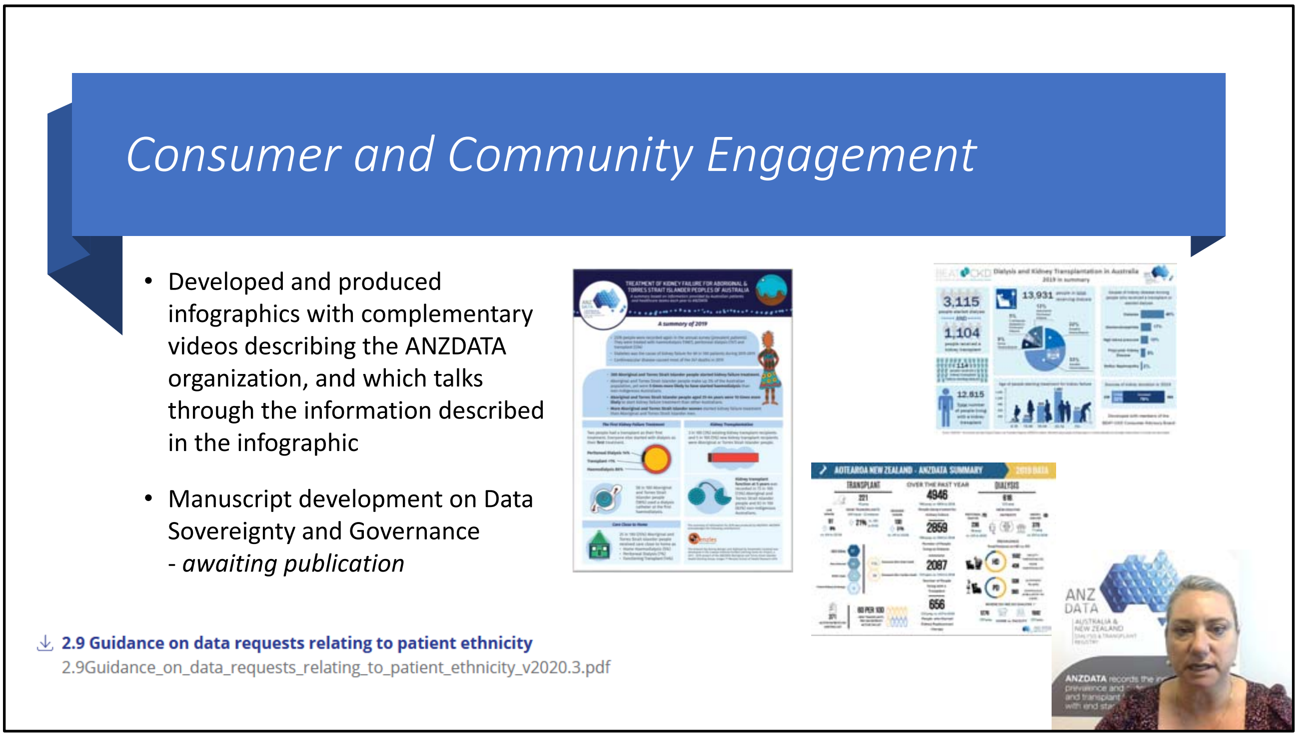
It has particularly been a directional drive, with great support from the Aboriginal and Torres Strait Islander Health Working Group and the Aotearoa New Zealand Working Group, and this is changing key Registry processes in the use of data.

Additionally, we are working on improving the quality and completeness of the dataset. In continuing to support centres who are migrating from paper collection to electronic data entry and more IT sophisticated file transfers, the completeness and quality of data items will essentially produce reliable analyses and comparisons.

Equally, we are expanding the data set, preferably without adding to the suite of collected variables, and increasing the use of data linkage and registry embedded trials, providing clinicians with better evidence for transforming clinical practice without the burden of additional data collection.

For a number of years now, the Registry has published centre-specific analyses on the survival of KRT patients. Communicating this with renal centres, their chief executive, and the broader community. More recently this has progressed to an ongoing collaboration between ANZSN and ANZDATA welcoming the development of new quality indicators and the implementation of such.

I will just briefly expand on a few of these.



Consumer and Community Engagement

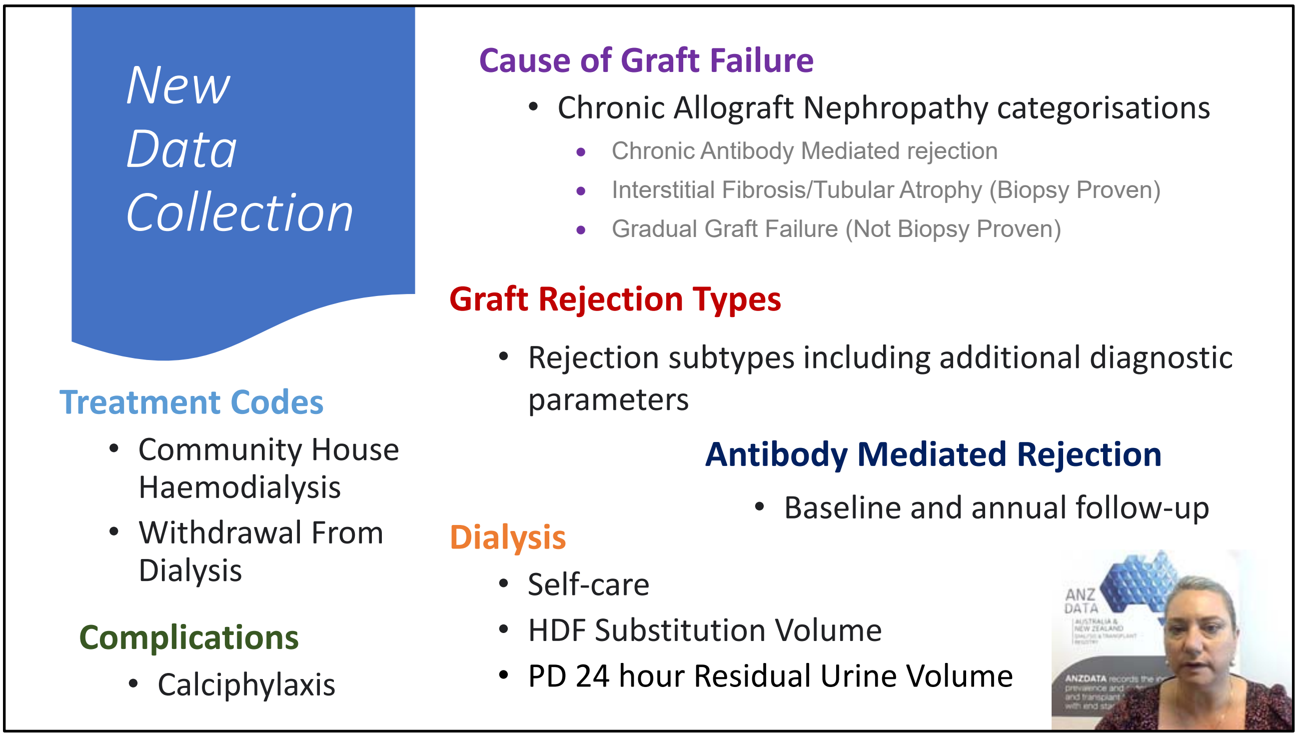
- Developed and produced infographics with complementary videos describing the ANZDATA organization, and which talks through the information described in the infographic
- Manuscript development on Data Sovereignty and Governance
  - *awaiting publication*

2.9 Guidance on data requests relating to patient ethnicity
2.9Guidance_on_data_requests_relating_to_patient_ethnicity_v2020.3.pdf

Our commitment to Indigenous Data Sovereignty is a key aspect of ANZDATA and these infographics and accompanying descriptive videos have been a significant achievement. We are now able to be reproduced these with a "push of a button", following annual data lock, to easily present the updated data of interest.

Essential to consumer engagement though, has also been the modification of our data request policy and data sharing agreements. Available from our website, these policies ensure data relating to ethnicity has relevance to the concepts raise on key groups, whether they are Aboriginal or Torres Strait Islanders, Maori, Pacifika, or any other ethnically diverse group.

We now encourage researchers to consider and demonstrate this relevance and engage in consultation with members of the ethnic groups, as well as provide how the results or outcomes of their research will shared back with relevant community.



New Data Collection

Treatment Codes

- Community House Haemodialysis
- Withdrawal From Dialysis

Complications

- Calciphylaxis

Cause of Graft Failure

- Chronic Allograft Nephropathy categorisations
  - Chronic Antibody Mediated rejection
  - Interstitial Fibrosis/Tubular Atrophy (Biopsy Proven)
  - Gradual Graft Failure (Not Biopsy Proven)

Graft Rejection Types

- Rejection subtypes including additional diagnostic parameters

Antibody Mediated Rejection

- Baseline and annual follow-up

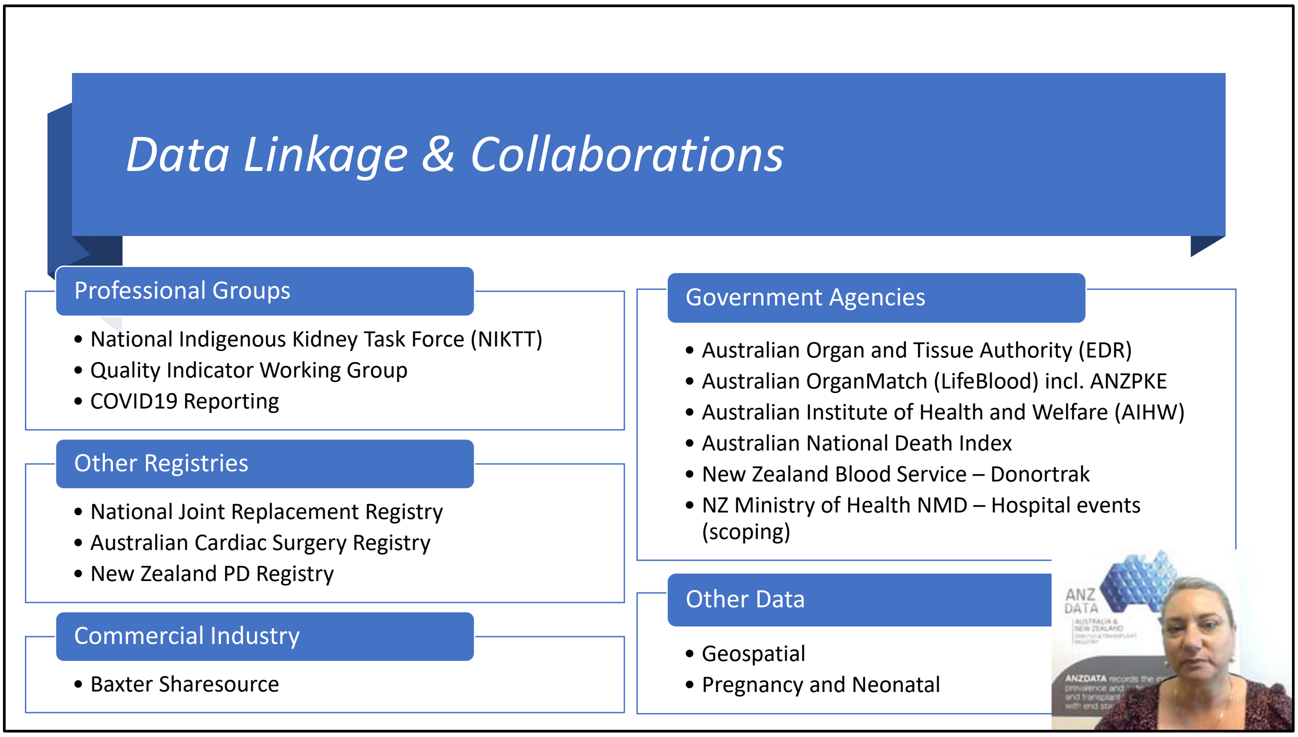
Dialysis

- Self-care
- HDF Substitution Volume
- PD 24 hour Residual Urine Volume

A challenge for any Registry is to be clear about which data are essential to produce reliable evaluations and interpretations. In recent years we have made adjustments and additions to better reflect the changes in practice.

Here are a number of data elements added and will be reported on in the forthcoming report. The expansion of antibody mediated graft rejection data collection is the next entity for implementation an we will be circulating information on this data collection in the coming month.

Additionally, the new ANZDATA Epi Fellow, Georgina Irish, is tasked with reviewing data collection on Primary Renal Disease, Patient Commodities and Biochemical Indicators that cross the Registry clinical groups. What you will see therefore in the coming surveys, is the gradual evolution of some data elements. So watch this space.



Data Linkage & Collaborations

Professional Groups

- National Indigenous Kidney Task Force (NIKTT)
- Quality Indicator Working Group
- COVID19 Reporting

Other Registries

- National Joint Replacement Registry
- Australian Cardiac Surgery Registry
- New Zealand PD Registry

Commercial Industry

- Baxter Sharesource

Government Agencies

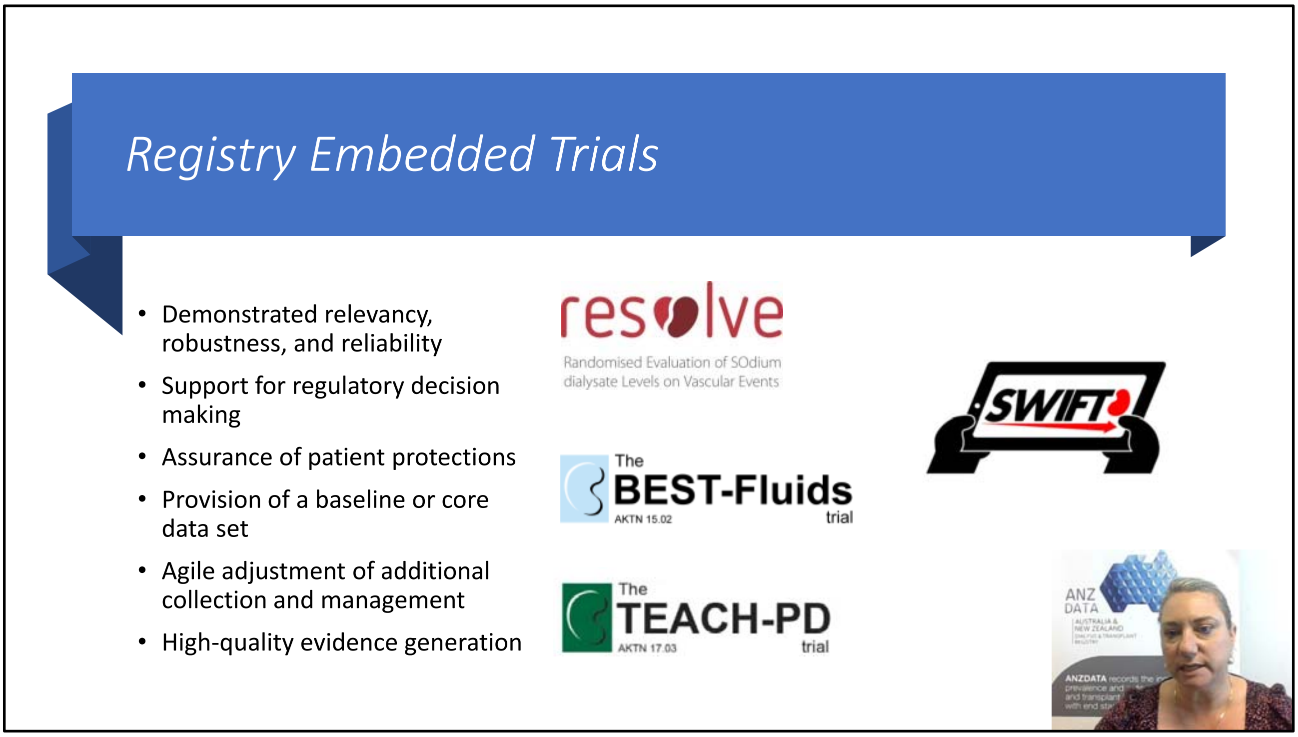
- Australian Organ and Tissue Authority (EDR)
- Australian OrganMatch (LifeBlood) incl. ANZPKE
- Australian Institute of Health and Welfare (AIHW)
- Australian National Death Index
- New Zealand Blood Service – Donortrak
- NZ Ministry of Health NMD – Hospital events (scoping)

Other Data

- Geospatial
- Pregnancy and Neonatal

Listed here are a few of the linkage projects and collaborations that ANZDATA have currently underway. These projects and other ongoing developments in data linkage, aim to better understand patient treatment outcomes broader than the clinical audit and service planning.

For more information on these projects or to pursue a linkage project of your own, please visit our website or get in contact with us.



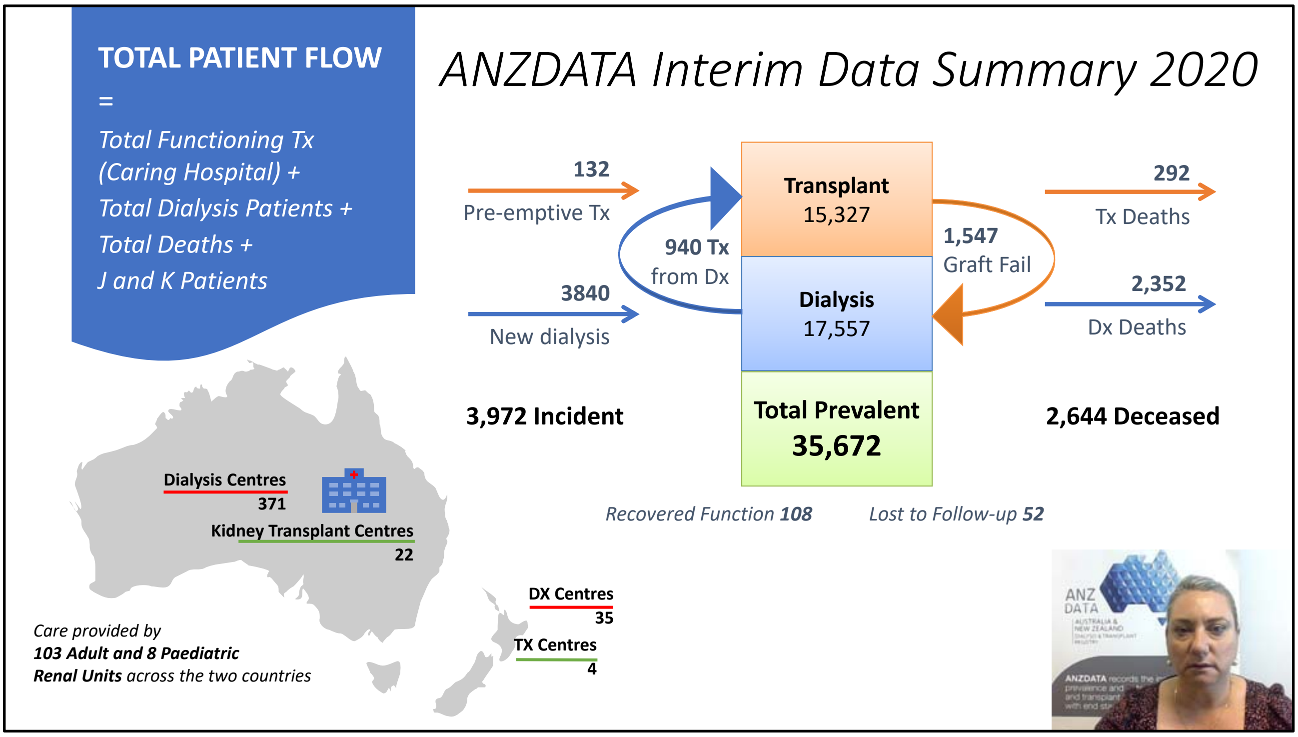
Registry Embedded Trials

- Demonstrated relevancy, robustness, and reliability
- Support for regulatory decision making
- Assurance of patient protections
- Provision of a baseline or core data set
- Agile adjustment of additional collection and management
- High-quality evidence generation

The success and increasing interest of Registry based trials has demonstrated this past few years the benefit of a sustainable and reusable infrastructure and we anticipate clinical trial stakeholders continue to want to collaborate and increase utilisation of our new RET module.

To name just a few advantages, the registry embedded trials modules enables registry infrastructures to identifying potential sites, reduce site workload, identify and recruit patients rapidly, provide easier patient follow-up and act as a platform to investigate agile adjustments in data collection and management,.

We have seen a significant shift in culture of participating centres of Registry trials., noting the improved uptake of electronic data capture, timely new patient registration and rereporting of patient movement as well as better data integrity.



TOTAL PATIENT FLOW
=
Total Functioning Tx (Caring Hospital) +
Total Dialysis Patients +
Total Deaths +
J and K Patients

ANZDATA Interim Data Summary 2020

Care provided by
***103 Adult and 8 Paediatric Renal Units** across the two countries*

The the Registry has assisted units these past few years in transitioning to electronic data capture and with that I am pleased to inform that again this year, we have met the challenge to bring current data and relevant to this Annual Scientific Meeting.

We presently have **103 adult and 8 paediatric Renal Units** across the two countries, with over 400 dialysis facilities and 26 kidney transplanting hospitals; and despite the current circumstance of the pandemic, contributors have enabled the Registry to again bring timely reporting closer to the end of the survey period. Here is the interim summary for 2020 and with the Data Lock occurring this week, we will commence publishing annual report chapters, individual hospital reports, infographics and more, before the end of September.

Again I'd like thank contributions, committee members, sponsors and consumers for their ongoing support and for more information on Registry Developments and what's new please visit our website or get in contact with us directly.

Thank you