Australia and New Zealand Dialysis and Transplant Registry

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The ANZDATA Registry includes all patients treated with renal replacement therapy (RRT) throughout Australia and New Zealand. Funding is predominantly from government sources, together with the non-government organization Kidney Health Australia. Registry operations are overseen by an Executive committee, and a Steering Committee with wide representation. Data is collected from renal units throughout Australia and New Zealand on a regular basis, and forwarded to the Registry. Areas covered include demographic details, primary renal disease, type of renal replacement therapy, process measures, and a variety of outcomes. From this data collection a number of themes of work are produced. These include production of Registry reports with an extensive range of national and regional data, a suite of quality assurance reports, key process indicator (KPI) reports, and data sets for a variety of audit and research purposes. The various types of information from the ANZDATA Registry are used in a wide variety of areas, including health services planning, safety and quality programs, and clinical research projects.

Registries have a long history in the area of kidney disease; the uptake and outcome of therapies (in particular dialysis and transplantation) has been documented far better than that of many other diseases or therapies.

There have, however, been important changes in the role of registries in renal disease. From an initial role in collecting the incidence and outcomes of rare diseases and exotic treatments, increases in incidence rates and availability of dialysis treatment has driven a steady progression toward a role incorporating provision of information to support health service development and quality activities.

The Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry is a registry based in Adelaide, Australia, which covers renal dialysis and kidney transplantation. It includes all patients treated with renal replacement therapy (RRT) throughout Australia and New Zealand. Formed in 1975 by the merger of separate dialysis and transplant registries in Australia, it has national coverage across both countries of all people treated with these therapies since 1963. In this article, the operations and breadth of output of the Registry are described and discussed.

MATERIALS AND METHODS
Data collection and analysis
Data is collected by the registry from renal units throughout Australia and New Zealand, on all patients receiving chronic dialysis or kidney transplantation. The key inclusion criterion is that RRT is commenced with the intention of chronic RRT; unlike some Registries ANZDATA does not impose a criterion based on the time of dialysis but uses an intent-based definition of 'chronic RRT'.

There are two basic streams of data collection: the registry asks to be notified in 'real-time' (in actuality, within 30 days) of key events (dialysis, transplantation, death, and loss of transplant function). In addition, a cross-sectional survey is conducted of all patients at 31 December each year. The survey includes substantial amounts of process information, depending on the treatment modality. For those receiving haemodialysis, this includes dialyser type, dialysis prescription, dry weight, and type of dialysis access; for peritoneal dialysis patients, episodes of peritonitis are collected as are PET results and fluids used. Basic biochemistry (haemoglobin, calcium, and phosphate) are collected for all dialysis patients. For transplant recipients graft function, rejection episodes and immunosuppressive drug use and dosage are recorded.

Details of the data collection items are available at anzdata.org.au. 'Real-time' data is submitted via a secure web-based portal or

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on paper. The year-end survey is currently paper based, with pre-printed forms distributed from the office at the end of each year. Trials of electronic data entry from some units with computerized patient management systems are underway. Within individual renal units, approaches vary to the actual collection of data. In some cases, nephrologists fill out the bulk of the information. In other units, substantial amounts are performed by administrative staff, with clinical staff adding key components (e.g., comorbidity prevalence).

Like all health information, privacy and confidentiality of data collection and storage are important. This is now governed by clear principles and guidelines agreed at a national level.[1,2]

Funding and governance

Funding for ANZDATA is provided by the Australia Organ and Tissue Donation and Transplantation Authority, the New Zealand Ministry of Health and Kidney Health Australia. This funding covers the expenses of the core office staff. The costs of data collection are borne by the individual renal units from within their own budgets.

The central office is conducted at the Royal Adelaide Hospital, co-located with the Australia and New Zealand Organ Donation Registry. Day-to-day operations are overseen by an Executive Group, and strategic directions are overseen by a Steering Committee. This committee is responsible both to the Australia and New Zealand Society of Nephrology and to Kidney Health Australia, and has wide representation from the nephrology community in Australia and New Zealand, and nursing and consumer representation.

RESULTS
Data utilization

From this data collection a number of themes of work are produced. Annual Reports (with an extensive range of national and regional data) are produced and distributed via the website as well as print. A variety of other reports are produced for various groups on a regular basis, including various quality assurance reports, key process indicator (KPI) reports and interim data summaries.

Registry reports

Each year the Registry produces a report with an extensive range of data on incidence and management of end-stage kidney disease in Australia and New Zealand.

Rates of incident dialysis have stabilized over the last 5 years or so, in both Australia and New Zealand (Table 1). However, the changes in incidence rates have not affected all age groups equally, with differing trends over time seen among younger versus older people (Figure 1). The most common diagnosis for primary renal disease is now diabetic nephropathy, which overtook glomerulonephritis some years ago.

Aboriginal and Torres Strait Islander people (the indigenous people of Australia) and Maori (the indigenous people of New Zealand) both suffer from substantially increased rates of kidney disease, as do 'Pacific Peoples' in New Zealand. There is considerable literature describing the origins and background to this, with high rates of albuminuria at all ages attributed to multiple causes.[3] Risk of end-stage kidney disease varies with age, with a particular increase among those aged 30–60 years (Figure 2).

Table 1 | Rates of new renal replacement therapy (dialysis and transplantation) per million population per year for Australia and New Zealand

Year	Australia	New Zealand
2012	112	116
2011	112	110
2010	106	18
2009	112	135
2008	119	116

Health service planning

One of the key roles of a registry is to provide information to assist appropriate planning of health services. Data from the ANZDATA registry has been provided to a variety of jurisdictions over time, to support work analyzing and projecting demand for various types of RRT. Although incidence rates have stabilized, the number of prevalent patients has progressively increased over time, with an increasing proportion of dialysis patients Figure 3. Within the dialysis population, the overall proportion of peritoneal dialysis patients is falling in both Australia and New Zealand with a progressive increase in the proportion of satellite and hospital haemodialysis-treated patients Figure 4.

Projecting the likely direction of these trends into the future is important both to understanding the demands for service provision, and also to inform policy developments. At a national level, major work has recently been undertaken by the Australian Institute of Health and Welfare[4] with ongoing increase in dialysis numbers expected. At a state and territory, more detailed work has been undertaken examining the current and projected demand for various dialysis modalities. Examples of recent policies in Australia to encourage greater uptake of home-based modalities include the introduction of a national scheme to reimburse costs of living kidney donors, and a number of state-based schemes to encourage uptake of home-based dialysis modalities by providing compensation for patients' water and electricity charges, and aligning hospital funding incentives with the proportion of home dialysis haemodialysis (HD) and peritoneal dialysis (PD) patients.

Individual hospital reports and KPIs

For many years, ANZDATA has produced yearly individual hospital reports describing the outcomes at an individual hospital level. From origins with simple unadjusted analyses, these have evolved into more complex documents with comparisons of observed outcomes with those expected on the basis of an individual centre's patient mix.

An example of one such analysis is shown in Figure 5. This is a funnel plot; it illustrates the ratio between observed and expected numbers of deaths within 1 year of transplantation together with the statistical confidence limits assuming the actual (true) performance of a centre is at the national average (i.e., underlying ratio of observed/expected events = 1.0). The graph illustrates some important issues surrounding these types of graphs related to the calculation of expected numbers from multivariate analysis. This particular illustration uses