

The Twenty Fifth Report

# Australia and New Zealand Dialysis and Transplant Registry

2002



**Edited by**  
**Stephen P McDonald and Graeme R Russ**

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## **APPENDIX II AUSTRALIA**

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## **APPENDIX III NEW ZEALAND**

See Website ([www.anzdata.org.au](http://www.anzdata.org.au))

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**Suggested Citation**

An example of suggested citation for this report is as follows:

Collins J  
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Adelaide, South Australia.

Editors: Stephen P McDonald and Graeme R Russ

Publications based upon ANZDATA Registry information reported here or supplied upon request, must include the citation as noted above and the following notice:

The data reported here have been supplied by the Australia and New Zealand Dialysis and Transplant Registry. The interpretation and reporting of these data are the responsibility of the Editors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.



This is the 25th Report from ANZDATA Registry.

It is in line with our recent approach where chapters are multi-authored. In the last two years the Registry Database has formed the basis for an increasing number of analyses by members of the nephrological community and others. A number of contributions in this Report arise from those analyses. In addition, there have been publications arising from these which have been published in the national and international scientific literature.

The Annual Report is again a comprehensive and detailed account of the delivery of dialysis and transplantation services in Australia and New Zealand. We are proud of the fact that 100% of Australia and New Zealand Units contribute to the Registry and we are confident that there is 100% reporting of patients.

This year has seen a greater emphasis on privacy issues and the Registry. The recently enacted Federal Privacy Legislation has meant that we have had to put in place processes which conform with the Legislation. Patients whose personal information is contributed are now informed about the Registry and have the right to access their data. The processes which we have put in place have been the subject of extensive debate in the nephrological community.

In addition further progress has been made with the development of an Internet Based Data Exchange Scheme. Progress has been slower than we would have hoped but we are now at the stage of having a new system available for testing. In 2003 the system will be tested by four pilot sites before being offered for roll out to other units. This has only been made possible through generous grants from Novartis, Janssen Cilag and Wyeth.

This year has also seen the first full year of the appointment of Dr Stephen McDonald as Fellow in Epidemiology. This appointment has been made possible by a generous grant from Amgen. Dr McDonald's appointment has been an outstanding success with his single minded approach to relevant analysis of the data. This has led to a number of publications being accepted in the international literature. In addition a grant from Novartis has enabled the appointment of a Fellow in Cancer. Dr Angela Webster of Wesmead Hospital, has taken up this role.

In addition, funds have been made available by Fresenius for the establishment of a Haemodialysis Vascular Access Registry (HAR). Data collection commenced on 1 August 2002 and after the first six months an analysis will be made. This project has involved a number of units and is under the direction of Dr Mark Siddins.

Once again the major funding for the Registry has been made available from the Commonwealth Department of

Health and Ageing. The allocation of funds for the financial year 2001/2002 was considerably more than previously and has enabled us to pursue further projects including the planned appointment of further analytical staff. It is hoped that this will streamline the production of reports for contributors and those requesting analysis of data. Funds from the Australian Kidney Foundation and The New Zealand Ministry of Health are acknowledged.

The staff of the Registry have been stable for a number of years now. Lee Excell continues in her lead role as Manager with responsibility for maintaining the database and overview of analysis. Brian Livingston continues as our main computer programmer and analyst and Lis Steinmetz provides administrative support.

The ANZDATA Registry Executive and the ANZDATA Registry Advisory Committee are sub-committees of the Dialysis, Nephrology and Transplant Committee of the Australia and New Zealand Society of Nephrology and the Australian Kidney Foundation. The ANZDATA Registry Advisory Committee which meets face to face annually currently consists of

A/Prof R Walker (Chair)  
A/Prof G Russ (Chair of ANZDATA Executive)  
Dr S P McDonald (AMGEN Fellow in  
Epidemiology)  
Mrs L Excell (Registry Manager)  
A/Prof T Mathew (AKF Representative)  
Dr Steven Chadban (Manager/Transplantation)  
Dr Jeremy Chapman (Manager/Cancer)  
Dr Angela Webster (NOVARTIS Cancer Fellow)  
Dr Jonathan Craig (Manager/Paediatrics)  
A/Prof Peter Kerr (Manager/Haemodialysis)  
Dr John Collins (Manager/CAPD)  
Dr N Hay (NZ Representative)  
Dr D Johnson  
Dr H Moody  
Dr J Agar  
Dr M Marshall

In addition small working groups have been established in each of the specialty areas and this has streamlined the production of multi-author reports and analyses of data.

For the second year, this Report will also be on CD and will be provided together with a printed copy.

*Graeme Russ*  
*Chair ANZDATA Executive*



In December 2001 changes to the Commonwealth Privacy Act were introduced which have led to changes to the collection of personal information. Essentially these extend to the private sector a number of changes based around 10 “National Privacy Principles” (NPP’s). A detailed exposition of these can be found at the Privacy Commissioners Website ([www.privacy.gov.au](http://www.privacy.gov.au)). Briefly however, health information is treated as “sensitive” information, which must usually be collected and handled with consent of the person, unless certain conditions are met.

### **COLLECTION OF DATA**

ANZDATA spent some time during 2002 formulating an appropriate response to these issues including seeking advice from a variety of sources. The approach taken has been that of a “opt-out” consent, whereby patients are distributed information outlining the nature and purpose of the information collected, offered an opportunity to view that data and ask questions, and the opportunity to request withdrawal of part or all of their data. This approach is explicitly suggested for Registries by the Privacy Commissioner in his “Guidelines for the Health Sector”. To this end ANZDATA has circulated to all participating hospitals a patient information sheet, for each hospital to use (or a locally modified version if appropriate) to inform patients.

### **USE OF DATA**

ANZDATA does not release data identifiable by patient name. Results are published/released in tabular or graphic format. On occasion, when data identifying particular hospitals is involved, consent from the Director of the relevant renal unit is sought prior to the release of information.





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(04 09 02)

## Important Privacy Information

As part of routine medical care of people receiving treatment with dialysis or kidney transplantation, your kidney specialist collects certain information about the patients they treat. All kidney specialists throughout Australia and New Zealand report this information every 6 months to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). ANZDATA collects the information for the purpose of monitoring treatments and performing analyses to improve quality of care for people with kidney failure.

### 1. What is ANZDATA ?

ANZDATA is an organization set up by the Australian Kidney Foundation and the Australia and New Zealand Society of Nephrology to monitor dialysis and transplant treatments. ANZDATA is funded by the Australian and New Zealand Governments and the Australian Kidney Foundation.

### 2. What information is collected about you ?

This information includes your name, age, gender, racial origin, hospital of treatment, some aspects of your medical condition (such as whether you have diabetes) and details about the type of kidney treatment you are receiving (dialysis or transplant).

We **DO NOT** collect details about your address, telephone number, medical insurance, or non-medical matters such as occupation, income, etc

### 3. Is personal data ever released ?

The identity of people in the database **IS NOT released publicly nor in any reports**. Measures have been put into place to ensure the security of all collected information.

### 4. What is this information used for ?

The information is used primarily for quality assurance, investigating patterns of kidney disease, and planning appropriate health services. We release reports on a variety of topics, including an Annual Report examining the rates and treatment of kidney failure in Australia and New Zealand. We also have a major role in ensuring the quality of patient care by sending to each kidney unit each year a report outlining their activity. These reports also compare the outcome of the treatment they provide with that of other units throughout the two countries. Reports are also produced at a state and national level, and from time to time analyses are also produced for renal units, government health departments and industry concentrating on particular aspects of renal failure management eg peritoneal dialysis, transplantation, haemodialysis.

### 5. Can you see what personal information ANZDATA collects and the reports that it produces ?

Individuals are able to view their own information on request. You can request alterations if you believe it is inaccurate. You may also opt not to have your treatment included in this database, and you should let your kidney specialist know if this is the case. You can also choose not to have some information (e.g. racial origin) recorded. However, if your information is not included in the Registry, the ability to compare results in Australia and New Zealand or to analyse the results of different treatment methods and for different patient types (eg diabetics) will be compromised.

The national reports and much other material produced by ANZDATA are available free on the Internet at [www.anzdata.org.au](http://www.anzdata.org.au), or they can be sent to you on request to the address above. Your kidney specialist will also have copies of many of the reports.

If you wish to discuss any of the issues raised here, please let your doctor know or telephone the ANZDATA Registry direct on 08 8222 6704. You may also write to us (ANZDATA Registry, C/- The Queen Elizabeth Hospital, 28 Woodville Road SA 5011) or send us an e-mail ([anzdata@anzdata.org.au](mailto:anzdata@anzdata.org.au)).



## **GUIDELINES FOR DATA RELEASE**

The policy for release of data to investigators, renal units and others has been revised during 2002 and is summarised on the Website. ANZDATA encourages the analysis, use and citation of its data, and receives many data requests annually which vary in size and complexity. At times these overwhelm the limited resources within the Registry, and must be prioritised. Generally, formal requests for data are preceded by a period of consultation with a member of the Registry staff. Requests are welcome from Renal Physicians, other staff members of Renal Units, Charitable Bodies, Academic Institutions, Government Departments and Industry. Requests dealing with identifiable Hospital data will only be fulfilled with the explicit consent of the Heads of the relevant Hospital Units.

## **ATTRIBUTION OF PUBLICATIONS**

The policy on attribution of publications which incorporate ANZDATA sourced data has been revised during 2002, following a period of consultation with participating physicians.

Where a member of a participating unit has analysed data provided by ANZDATA and subsequently prepared a manuscript, then “ANZDATA Registry” should be acknowledged as a secondary institution in addition to the author’s Hospital or University. This applies whether the primary data analysis is performed by the author or by ANZDATA staff. Where the author is an ANZDATA office holder or staff member then the primary attribution should be “ANZDATA Registry”.

Where ANZDATA data is only a minor portion of the work, then it may be more appropriate to acknowledge the source explicitly in the “Acknowledgements” section.

In both cases the disclaimer on page iv should be included.

In all cases the source and treatment of the data should be made clear in the “Methods” section. Preferably the abstract (and keywords if applicable) should also include “ANZDATA” which would allow for searching Registry publications.

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