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Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)

38th Annual Report

Data to 31 December 2014

Acknowledgments

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Introduction

The ANZDATA Registry has great pleasure in presenting the 2015 Annual Report. This is the 38th Annual Report from the Registry and covers data collected to 31st December 2014.

The Report is a result of the involvement of renal units throughout Australia and New Zealand, and reflects enormous time and effort from staff of these units. Participation of all renal units in Australia and New Zealand continues.

There have been progressive changes in the report format, largely to make more detailed information available in a timely fashion. To this end substantial tabular data is placed online in the Appendices. All the tables and figures are also available from our website in PowerPoint and Excel formats.

Dr Philip Clayton continues as the Editor of the Annual Report.

Dr Namrata Khanal has now completed her period as the Epidemiology Fellow, and has commenced a PhD. We are greatly indebted to Amgen who continue to make the commitment through the funding of this position. For 13 years now this position has proven to be a major stimulus for the academic output of the Registry.

Mrs Kylie Hurst enters her fifth year as Manager of the ANZDATA Registry and we acknowledge the pivotal role that she has played in generating new ideas and innovations in the way the Registry functions. Brooke Martin continues to provide administrative support. After a number of years of committed service as biostatistician Dr Nancy Briggs relocated to Sydney in late 2015. We welcome Dr Shahid Ullah who joins Mr Chris Davies in provision of bio statistical support.

Within the Registry, there are two major changes in 2016. The first is the relocation to the SA Health and Medical Research Institute in May 2016, driven by the pending move of the Royal Adelaide Hospital where the Registry has previously been located. Other than changes in postal and telephone contacts, this has no effect on Registry operations. However, the opportunity presented to relocate to SAHMRI in an environment with a number of other Registries. In the longer term this is anticipated to provide benefits in collaboration particularly around methodological issues. Physically SAHMRI is adjacent to the new Royal Adelaide Hospital so the close clinical links of the Registry will be maintained.

The second major change is the expansion of research staff, funded by an NHMRC Program Grant awarded to the Beat -CKD consortium. This group links the Registry, the Australasian Clinical Trials Network, the Renal Cochrane Centre and the CARI (Australasian Renal Guidelines) Centre. Over the next 5 years this will fund a number of collaborative projects to enhance the value of the Registry output and provide a clear and direct link to driving and monitoring change in clinical practice.

Professor Matthew Jose continues in his role as the Chair of the ANZDATA Registry Steering Committee. His enthusiasm and ongoing interest in the Registry and its operations and output are acknowledged.

Through 2016 the Registry Steering Committee will be considering a number of areas including reviewing policies and procedures relating to data access and utilisation, the mechanism of consultation with consumers and the outcomes measures collected.

The members of the ANZDATA Registry Committees and Working Groups are listed on page vii and viii of this report. The Executive gratefully acknowledges the involvement and contribution of these many individuals.

Major funding for the Registry has been provided from the Australian Commonwealth Department of Ageing through the Australian Organ and Tissue Donation and Transplant Authority, Kidney Health Australia and the New Zealand Ministry of Health.

We also gratefully acknowledge industry support which in 2015 consisted of non-tied grants from AMGEN Australia, Alexion Pharmaceuticals, Novartis Pharmaceuticals, Pfizer and Roche Products.

Stephen McDonald

Executive Officer August 2016

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Paediatric Working Group

Dr Sean Kennedy (Project Manager)

Dr Ann Durkan

Dr Lily Johnstone

Dr Tonya Kara

Dr Amelia Le Page

A/Professor Stephen McDonald

Dr Peter Trnka

Dr Amanda Walker

Peritoneal Dialysis Working Group

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Guidelines for Data Release

The policy for release of data to investigators, renal units and others was revised during 2013 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 (i.e. data which identifies outcomes of an individual hospital) will only be fulfilled with the explicit consent of the Heads of the relevant Hospital Units. Individual patient identified data (names) is not released.

Attribution of Publications

The policy on attribution of publications which incorporate ANZDATA sourced data was 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 ii of this report 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.

Suggested Citation

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

.. [Author’s name] ..

Peritoneal Dialysis .. [page numbers] ..

ANZDATA Registry Report 2016

Australia and New Zealand Dialysis and Transplant Registry

Adelaide, South Australia.

Editors: Philip Clayton, Kylie Hurst

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 authors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.*

Privacy Aspects of Data Collection

In December 2001 changes to the Commonwealth Privacy Act were introduced 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 Commissioner’s website (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. Patients are entitled to view the information the Registry holds about them, and request alterations if the data is thought to be inaccurate.

Each Australian State has also enacted similar provisions which cover practice and patients in public hospitals.

ANZDATA does not release data identifiable by patient name. Results are published/released in tabular or graphic format only. Requests for data are met using deidentified data only. 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.

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 that endorsed by the Safety and Quality Commission for Clinical Registries (http://www.safetyandquality.gov.au/our-work/information-strategy/clinical-quality-registries/strategic-operating-principles-for-clinical-quality-registries/). To this end ANZDATA has circulated to all participating hospitals a patient information sheet (see opposite), for each hospital to use to inform patients if they wish. Many hospitals have developed their own sheets to meet local needs.

At the time of data collection each unit is asked to certify that they have complied with measures under the relevant privacy measures.

In Australia, tissue typing data and transplant waiting list data are collected in each Tissue Typing Laboratory and entered into the National Organ Matching System (NOMS) database. These data are transmitted to ANZDATA for inclusion in the ANZDATA database and for this Report. In addition to the ANZDATA policies, requests for analyses of waiting list data also require approval by NOMS. New Zealand tissue typing and waiting list data comes from the New Zealand Blood Service (NZBS).

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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 twelve 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 Kidney Health Australia 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 Kidney Health Australia.

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 e.g. 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 (eg 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, 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 0949. You may also write to us (ANZDATA Registry, C/- Royal Adelaide Hospital, DX800, Mail Point 117, North Terrace, Adelaide, SA. 5000) or send us an e-mail (anzdata@anzdata.org.au).

Definitions and Methods

A number of definitions given below are used throughout this report unless otherwise stated.

1. Wording

Throughout this report 'treatment' refers to renal replacement therapy, including haemodialysis, peritoneal dialysis and transplantation. In places the word "graft" (or "allograft") is used for kidney transplant.

HD = haemodialysis
CAPD = continuous ambulatory peritoneal dialysis
APD = automated peritoneal dialysis
ESKD = end stage kidney disease

2. Data collection

ANZDATA collects information from all renal units in Australia and New Zealand. Data collection occurs at two time points. Key events (new patients, deaths, transplants) are notified as they occur, with units requested to send this at least monthly. This can occur either via a web-based interface or paper submission. An extensive cross-sectional survey is then performed annually (for data to 31st December). Currently this is by a paper-based system, with manual completion of the form and manual data entry. No formal audit mechanism is in place at this stage.

For kidney transplants, HLA matching and panel reactive antibodies are obtained direct from the National Organ Matching System. Monthly summaries are distributed to the contributing units. Results contained in this report are based on a final database locked and prepared after the end of year survey returns are received.

3. Inclusion criteria

Included in the Registry are all patients resident in Australia or New Zealand receiving renal replacement therapy where the intention to treat is long-term, i.e. medical opinion is that renal function will not recover. Cases of acute renal failure are excluded. People who move overseas permanently are censored at date of last treatment (or departure in the case of transplant recipients).

4. Modality attribution

For survival analysis the initial mode of dialysis is generally determined at 90 days after first treatment, to allow for early changes and maturation of access. Other transfers (between modalities, or from satellite to hospital haemodialysis etc.) are not analysed if less than 30 days, except for transfers between dialysis centres to which a 60 day rule is applied to allow for holiday movements.

5. Underlying renal disease

This is recorded by the treating hospital according to a modified EDTA coding system (details on back of survey form).

6. Deaths

Death rate is predominantly reported as number of patients died/total number of years of treatment of all patients treated at any time during the year. It is expressed as deaths per 100 patient years (pt yrs) at risk.

7. Comorbid conditions

These are recorded by the treating hospital. No formal definitions are supplied; the treating clinician is asked to record whether the patient has coronary artery disease, chronic lung disease, cerebrovascular disease, peripheral vascular disease or diabetes according to their clinical opinion on a yes / suspected / no basis.

8. Transplant Waiting List

The active transplant waiting list is based on data from the National Organ Matching System (Australia) linked probabilistically with ANZDATA.

9. Derived measures

9.1 Haemoglobin

Haemoglobin is recorded as the last available measurement before the end of the survey period.

9.2 Erythropoietic agents

Erythropoietin agent use is recorded as "yes" if these agents were used at any time during the survey period.

9.3 Iron studies

Iron studies are requested within the last three months of the survey period.

9.4 Estimated glomerular filtration rate

Where glomerular filtration rate is estimated from serum creatinine at entry or post transplantation, the CKD-EPI formula is used: [1]

Females with Cr<=62 micromol/L: $eGFR = (144 + 22 \text{ if black}) \times (Cr/0.7)^{-0.329} \times 0.993^{age}$

Females with Cr>62 micromol/L: $eGFR = (144 + 22 \text{ if black}) \times (Cr/0.7)^{-1.209} \times 0.993^{age}$

Males with Cr<=80 micromol/L: $eGFR = (141 + 22 \text{ if black}) \times (Cr/0.9)^{-0.411} \times 0.993^{age}$

Males with Cr<=80 micromol/L: $eGFR = (141 + 22 \text{ if black}) \times (Cr/0.9)^{-1.209} \times 0.993^{age}$

Where Cr is creatinine in micromol/L and age is age in years. The correction for "black" race, based on US data, is not applied to any patients.

9.5 Urea reduction ratio / Kt/V

Results are requested in one of these formats, using the stop flow method on a mid-week dialysis. Single pool Kt/V is collected, along with the method used. For conversion of URR to Kt/V urea the formula used [3] is Kt/V = 0.023*PRU - 0.284 (note that PRU = percent reduction in urea and not URR).

9.6 Body mass index

Body mass index (BMI) is calculated as $\frac{\text{weight (kg)}}{(\text{height (m)})^2}$ The categories used are : underweight <20 kg/m^2, normal 20-24.9 kg/m^2, overweight 25-29.9 kg/m^2, obese >=30 kg/m^2

9.7 Peritoneal dialysis measures

These are the standard measures, often calculated by computerised patient management programs.

9.7.1 Residual renal function

The measure used is the arithmetic mean of urea and creatinine clearance from a 24-hour urine collection and serum creatinine and urea.

9.7.2 Peritoneal equilibration test

The ratio of dialysate to plasma glucose is used, following a 4 hour dwell of a 2 litre 2.5% bag of dialysate, performed within 6 months after initiation of peritoneal dialysis.

10. Rates and Measures

10.1 Incidence rates

Except where otherwise stated, quoted incidence rates are per calendar year, and are expressed per million population.

10.2 Prevalence rates

Except where otherwise specified, prevalence rates are point prevalence rates at 31st December 2011.

10.3 Population denominator

All populations used in this report were stratified by age and sex.

Australian populations were taken from the Australian Bureau of Statistics (ABS) and New Zealand populations were taken from Statistics New Zealand (SNZ).

All estimated and projected populations used for Australia and New Zealand were for 30 June of each year , and all websites were accessed 23 September 2014 for analysis of the annual 2013 locked dataset..

Estimated population data for each Australian state and territory came from ABS 3101.0 series [4]

Projected population data for each Australian state and territory came from ABS 3222.0 series [5]

Population data for Indigenous Australians were taken from ABS 3238.0[6], using series A (the most conservative estimates) for populations after 1996.

Populations serviced by the Greater Southern Area Health Service were estimated by the South Eastern Region of NSW. These estimates were taken from ABS 3235.0[7]

All New Zealand population estimates were taken from Statistics NZ Infoshare [8] and projected population were taken from NZ Stats (9). Maori populations were taken from NZ Infoshare Maori population estimates [10].

Estimates of resident Pacific People populations after were taken from NZ Stats [11] for years 2006 onwards. Prior to this, populations of Pacific people before 2006 were only available for years 1996, 2001 (and 2006), and we used loglinear interpolation to estimate populations for each age and sex group for the years 1997-2001 and 2002-2005.

10.4 Death Population Data:

All Australian death data were taken from ABS 3302.0 series [12]. Death data is not available for publications by age and sex on ABS website for some states. Overall data by states and territory is used. New Zealand death data were taken from NZ Infoshare [13]

10.5 Survival rates

For transplant recipients, survival rates exclude those who were transplanted overseas or were recipients of multiple organ grafts.

Graft survival (unless otherwise qualified) includes both cessation of graft function (ie return to dialysis) and patient death.

Rates for patient survival for fixed periods for transplantation are calculated according to the life-table method and thus include an adjustment to the risk-set of ½ of those censored without failure over the interval to create an “average” risk set.

10.7 Graft survival

For outcomes of kidney transplants, graft failure includes both loss of graft function (i.e. return to dialysis) and death of patients

(with graft function). Calculations of patient survival for transplant recipients includes all subsequent modalities (i.e. deaths after graft failure are included). Patients transplanted overseas are excluded from calculations.

10.8 Dialysis Survival
Patient and technique survivals for haemodialysis and peritoneal dialysis are based on the dialysis modality at 90 days after first treatment for patients not transplanted during that period. Patients are followed up until they are either transplanted (at which point they are censored) or until they have a 'permanent' change of dialysis modality or until death or most recent follow up date. A 'permanent' change of dialysis is defined as any change in excess of 30 days.

Peritonitis survivals are calculated from first peritoneal dialysis (ignoring all earlier treatments) to date of first peritonitis episode. If there were no episodes of peritonitis then calculation is censored at change of treatment from peritoneal dialysis to haemodialysis or transplantation. Peritoneal dialysis includes automated peritoneal and continuous ambulatory peritoneal dialysis. Excluded are patients who had peritonitis before commencing peritoneal dialysis.

10.9 Death and other event rates
Rates are expressed per 100 person years at risk (unless otherwise stated). Some analyses include survival of all patients, others exclude the first 90 days of follow up. This is stated in the individual analyses.

10.10 Age standardisation
All rates are crude, not age-standardised. The age distribution of the populations for Australia and New Zealand can be obtained by contacting the Registry.

10.11 Peritonitis rates
Peritonitis rates are present using episodes of peritonitis reported during periods of peritoneal dialysis - episodes reported prior to commencement of peritoneal dialysis (for example between Tenckhoff catheter insertion and commencement of peritoneal dialysis) are not included in these calculations.

11. Database

Data is stored on a relational database using Oracle version 9I.

12. Statistics

Statistical analyses were performed using Stata version 14.

13. References

1) Levey AS, Stevens LA, Schmid CH, Zhang YL, Castro AF, Feldman HI, et al. A new equation to estimate glomerular filtration rate. Ann Intern Med. 2009 May 5;150(9):604-612.

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3) Basile C, Casino F, Lopez T: Percent reduction in blood urea concentration during dialysis estimates Kt/V in a simple and accurate way. Am J Kidney Dis 1990: 15;40-45.

4) http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3101.0Mar%202014?OpenDocument

5) http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3222.02012%20(base)%20to%202101?OpenDocument

6) http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3238.02001%20to%202026?OpenDocument

7) http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3235.02014?OpenDocument

8) http://www.stats.govt.nz/infoshare/SelectVariables.aspx?pxID=3e317ac0-5674-4037-99a5-45121873f289

9) http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3218.02012-13?OpenDocument

10) http://www.stats.govt.nz/browse_for_stats/population/estimates_and_projections/MaoriPopulationEstimatesHOTPAtJun14.aspx

11) http://nzdotstat.stats.govt.nz/wbos/Index.aspx#

12) http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.02014?OpenDocument

13) http://www.stats.govt.nz/infoshare/SelectVariables.aspx?pxID=67222c3f-668c-46c6-a129-127ed988184b

Contributing Units

Parent hospitals, transplanting unit and satellite dialysis units together with their state and unit codes are listed below. In some cases, these have combined as part of a regional network and this is also indicated. The definition of a 'parent hospital' is a pragmatic one, and refers to units which offer a full range of dialysis services (i.e. can commence patients on dialysis, have on-site nephrologist presence and can deal with patients of all degrees of complexity). In contrast, satellite units provide haemodialysis treatments to selected patients, usually with lower staff ratios and no on-site nephrologist.

NOTE: The states listed below are in no particular order.

Queensland (State code 4)

PARENT HOSPITALS	Unit Code
Allamanda Private Hospital (Fresenius)	ALLA
Bundaberg Base Hospital	BUND
Cairns Base Hospital	CAIR
Chermside Dialysis Unit (Fresenius)	CHER
Child and Adolescent Renal Service	CARS
Gold Coast Hospital	GOLD
Greenslopes Private Hospital (Baxter)	GREN
Hervey Bay Hospital	HERV
John Flynn Hospital	FLYN
Mackay Base Hospital	MACK
Princess Alexandra Hospital	PSAH
Queensland Renal Transplant Service	QRTS
Rockhampton Base Hospital	ROCK
Royal Brisbane Hospital	RBSH
St Andrew's Dialysis Clinic (Diaverum)	GSTA
Sunshine Coast Health District	
Caloundra Private Hospital	CALO
Nambour General Hospital	NAMB
Nambour Selangor Private Hospital	NPRV
The Townsville Hospital	TOWN
Toowoomba Hospital	TWMB
Wesley Private Hospital	WSLY

TRANSPLANTING UNIT	Unit Code
Queensland Renal Transplantation Service	QRTS

Princess Alexandra Hospital (Adult and Paediatric)
Ipswich Road
Woolloongabba 4102

SATELLITE DIALYSIS UNITS	Unit Code
Atherton Private Hospital	ATHR
Cairns Home Training Unit	CHTR
Cairns Private Hospital Satellite	CPRV
Caloundra Public Hospital	CAPU
Cooktown Satellite	COOK
East Street Self Care Dialysis Unit	EAST
Gympie Satellite	GYMP
Home Hill Satellite	HILL
Innisfail Hospital	INNI
Ipswich Satellite	IPSW
Kingaroy Satellite	KROY
Logan Satellite	LOGN
Maryborough Hospital	MARY
Mossman Satellite	MOSS
Mt. Isa Satellite	MTIS
Noosa Satellite	NOOS
North Lakes Dialysis Unit	NLAK
North Ward Satellite	NWAR
Palm Island Satellite	PISL
Redcliffe Satellite	REDC
Redlands Satellite	REDL
St Vincent's Robina Satellite	STVR

Australian Capital Territory (ACT) (State code 9)

PARENT HOSPITALS	Unit Code
The Canberra Hospital	CANB

SATELLITE DIALYSIS UNITS	Unit Code
Access Nephrology	ACCE
Canberra Community Satellite	CSAT
Northside Dialysis Clinic (Fresenius)	NSID

Tasmania (State code 7)

PARENT HOSPITALS	Unit Code
Launceston General Hospital	LAUN
Royal Hobart Hospital	RHBT

SATELLITE DIALYSIS UNITS	Unit Code
Launceston Community Centre Satellite	LCCS
North West Renal Unit, Burnie	NWRU

South Australia (State code 5)

PARENT HOSPITALS	Unit Code
Flinders Medical Centre	FMDC
Central Northern Adelaide Transplant Service	CNAR
The Queen Elizabeth Hospital	QEZB
Royal Adelaide Hospital	RADL
Women's and Children's Hospital	WCHL

TRANSPLANTING UNIT	Unit Code
Central Northern Adelaide Transplant Service Royal Adelaide Hospital North Terrace Adelaide 5000	CNAR
Women's and Children's Hospital 72 King William Road North Adelaide 5006	WCHL

SATELLITE DIALYSIS UNITS	Unit Code
Berri Satellite	BERI
Ceduna Hospital	CEDU
Clare Satellite	CLAR
Hampstead Rehabilitation Satellite	HAMP
Hartley Private Hospital (Fresenius)	HART
Port Lincoln Satellite Centre	LINC
Lyell McEwin Satellite	LMCK
Millicent Hospital	MILL
Maitland Hospital	MLAN
Modbury Satellite (Fresenius)	MSAT
Mount Gambier Satellite	MTGA
Murray Bridge Hospital	MURR
Noarlunga Satellite	NOAR
Payneham Satellite (Fresenius)	PAYN
Port Augusta Hospital	PTAG
Port Piri Satellite	PIRI
Victor Harbour Satellite	VHAR
Wayville Satellite Centre	WAYV
Whyalla Satellite Centre	WHYA

Northern Territory (State code 1)

PARENT HOSPITALS	Unit Code
Alice Springs Hospital	ALIC
Royal Darwin Hospital	DARW

SATELLITE DIALYSIS UNITS	Unit Code
Flynn Drive Satellite	FDVE
Katherine Dialysis Unit	KATH
Nightcliff Community Centre	NTCL
Palmerston Satellite	PTON
Tennant Creek Hospital	TENN
Tiwi Dialysis Centre	TIWI

Western Australia (State code 6)

PARENT HOSPITALS	**Unit Code**
Fiona Stanley Hospital	FSTH
Princess Margaret Hospital for Children	PMHC
Royal Perth Hospital	RLPT
Sir Charles Gairdner Hospital	SCGH

TRANSPLANTING UNIT	**Unit Code**
Princess Margaret Hospital for Children Roberts Road Subiaco 6008	PMHC
Fiona Stanley Hospital 102-118 Murdoch Drive Murdoch 6150	FSTH
Sir Charles Gairdner Hospital Verdun Street Nedlands 6009	SCGH

SATELLITE DIALYSIS UNITS	**Unit Code**
Albany	ALBA
Armadale Satellite	ARMA
Bunbury Satellite	BUNB
Busselton Satellite	BUSS
Cannington Dialysis Clinic (Diaverum)	CANN
Derby Satellite	DERB
Geraldton Hospital	GRLD
Joondalup Satellite	JOON
Hollywood Private Hospital	HPRH
Kalgoorlie Dialysis Unit	KALG
Kimberley Dialysis Centre	KIMB
Melville Satellite	MELV
Midland Private Dialysis Centre (Baxter)	MIDL
Murdoch	STJM
Peel Health Campus	MAND
Port Hedland Dialysis Unit (Pilbara)	PTHD
Rockingham Satellite	RHAM
Spearwood Satellite	SPEA
Stirling Dialysis Clinic (Diaverum)	STIR
St. John of God Private Hospital Subiaco	SJOG

Victoria (State code 3)

PARENT HOSPITALS	Unit Code
Alfred Hospital	ALFD
Austin Health	AUST
Bendigo Hospital	BEND
Diamond Valley Dialysis Clinic (Diaverum)	GDIA
Eastern Health Integrated Renal Services	EHRS
Epworth Hospital	EPWT
Forest Hill Dialysis Centre (Fresenius)	FORE
Geelong Hospital	GLNG
Kew Private Dialysis Centre	KEWP
Malvern Dialysis Centre (Fresenius)	MALV
Monash Medical Centre – Adult	MMCA
Monash Medical Centre – Paediatric	MMCP
North Melbourne Dialysis Clinic (Diaverum)	NMDC
North West Dialysis Service	NWDS
Royal Melbourne Hospital	RMBH
Royal Children's Hospital	RCHL
St. Vincent's Hospital	SVIN
Western Health	WSTH

TRANSPLANTING UNIT	Unit Code
Alfred Hospital Commercial Road Prahran 3181	ALFD
Austin Health Burgundy Road Heidelberg 3084	AUST
Monash Medical Centre (Paediatric) 246 Clayton Road Clayton 3165	MMCP
Monash Medical Centre (Adult) 246 Clayton Road Clayton 3165	MMCA
Royal Children's Hospital Flemington Road Parkville 3052	RCHL
Royal Melbourne Hospital Parkville 3052	RMBH
St. Vincent's Hospital 41 Victoria Parade Fitzroy 3065	SVIN

SATELLITE DIALYSIS UNITS	Unit Code
Broadmeadows Satellite	BRDM
Brunswick Satellite	BRUN
Casey Hospital	CASE
Casterton Hospital	CAST
Caulfield General Medical Centre	CAUL
Coburg Satellite	COBG

SATELLITE DIALYSIS UNITS	Unit Code
Cohuna Hospital	COHU
Colac Hospital	COLA
Corryong Satellite	CORR
Craigieburn Satellite	CRAI
Cranbourne Satellite	CRAN
Dandenong Satellite	DAND
Daylesford Hospital	DAYL
Donald Hospital	DONA
Eastern Health Incentre Dialysis	EHUB
Echuca Hospital	ECHU
Edenhope Hospital	EDEN
Epping Dialysis Unit	EPPG
Frankston Satellite	FRAN
Goulburn Valley Hospital	GVAL
Hamilton Hospital	HAML
Hastings Hospital	HSTG
Heidelberg Hospital	HEDG
Horsham Satellite	HORS
Kyabram Satellite	KYAB
Kyneton Hospital	KYNE
Latrobe Regional Satellite	LATR
Mansfield District Hospital	MANS
Maroondah Satellite	MARO
Maryborough Hospital	MRYB
Melton Hospital	MELT
Mildura Hospital	MILD
Moorabbin Satellite	MOOR
Myrtleford Hospital	MYRT
Newcomb Satellite	NCOM
Nhill Hospital Satellite	NHIL
Northern Hospital Satellite	NSAT
North East Kidney Service	NEKS
Orbost Hospital	ORBO
Peter James Centre	PJAM
Portland District Health	PORT
Robinvale Hospital	ROBV
Rosebud Hospital	ROSE
Sale Hospital	SALE
Sandringham Satellite	SNDR
Seymour Hospital	SEYM
South Geelong Satellite	SGEO
St. George's Hospital	SGRU
Sunbury Satellite	SUNB
Sunshine Satellite Centre	SUNS
Swan Hill Hospital	SWAN
Terang Hospital	TERA
Wagga Hospital	WAGG
Wangaratta Hospital	WANG
Warnnambool Hospital	WARN
Werribee Mercy Hospital	WERR
Western Gippsland Hospital	WGIP
Williamstown Satellite	WILL
Wodonga Regional Health Service	WDGA
Wonthaggi Hospital	WONT
Yarawonga District Hospital	YARA
Yarram Hospital	YARM

New South Wales (State code 2)

PARENT HOSPITALS	Unit Code
Dubbo Base Hospital	DUBB
East Coast Renal Service	
Prince of Wales Hospital	POWH
St. George Hospital	STGH
St. Vincent's Hospital	STVI
Sydney Children's Hospital	SCHL
Wollongong Hospital	WGNG
Gosford Hospital	GOSF
Lismore Hospital	LISM
Lismore Private Dialysis Clinic	LPDC
Macleay Dialysis Centre - Kempsey	MACL
Manning Rural Referral Hospital	MANN
Mater Misericordiae Hospital	MATR
Mayo Private - Taree	MAYO
Newcastle Nephrocare	NCAS
Port Macquarie Base Hospital	PTMQ
Port Macquarie Private Hospital	PMPH
Royal North Shore Hospital	RNSH
South West Sydney Renal Services	SSYD
Liverpool Hospital	LVPL
Statewide Renal Services	SWRS
Royal Prince Alfred Hospital	RPAH
Sydney Adventist Hospital	SADV
Tamworth Hospital	TAMW
The Children's Hospital at Westmead	NEWC
The Tweed Hospital	TWHD
Western Renal Network	
Nepean Hospital	NEPN
Orange Hospital	ORAN
Westmead Hospital	WEST

TRANSPLANTING UNIT	Unit Code
John Hunter Hospital Newcastle 2304	HUNT
Prince of Wales Hospital Randwick 2031	POWH
Royal North Shore Hospital St Leonards 2065	RNSH
Statewide Renal Services Royal Prince Alfred Hospital Camperdown 2050	SWRS RPAH
Sydney Children's Hospital C/- Prince of Wales Hospital Randwick 2031	SCHL
The Children's Hospital at Westmead Westmead 2145	NEWC
Westmead Hospital Westmead 2145	WEST

SATELLITE DIALYSIS UNITS	Unit Code
Armidale Hospital	ARMD
Auburn Satellite	AUBN
Ballina Hospital	BLNA
Bankstown Hospital	BANK
Bathurst Satellite Dialysis Centre	BATH
Bega Satellite	BEGA
Blacktown Regional Dialysis	BLAK
Bondi Dialysis Unit (Diaverum)	BOND
Brewarrina Hospital	BREW
Broken Hill Hospital	BROK
Campbelltown Satellite	CAMP
Concord Repatriation Satellite Unit	CRSU
Condobolin Hospital	COND
Coonamble Hospital	COON
Dame Eadith Walker	DEWE
Eora Satellite	EORA
Fairfield Satellite	FAIR
Forbes Hospital	FORB
Gilgandra Satellite	GILG
Gosford Satellite	GOSS
Goulburn Satellite (Fresenius)	GLBN
Grafton Hospital	GRFT
Griffith Base Hospital	GRIF
Invarell Satellite	INVR
Lakehaven Satellite	LAKE
Lanceley Cottage	LANC
Liverpool Community Centre	LCOM
Maitland Hospital	MAIT
Mona Vale Satellite	MNVL
Moree Satellite	MORE
Moruya Satellite (Fresenius)	MORU
Muswellbrook	MUSW
Norfolk Island Hospital	NORF
Penrith Community Dialysis Centre	PCDC
Queanbeyan Dialysis Centre	QBEY
Shellharbour	SHEL
Shoalhaven Satellite (Nowra)	SHOA
Singleton Satellite	SING
Sutherland Hospital	SUTH
Sydney Dialysis Centre	SYDC
Taree Community Dialysis	NITA
Wagga Wagga Base Hospital	WAGG
Wansey Satellite	WANS
Wellington Hospital	WGTN
Wollongong Satellite	WSAT

New Zealand (Code 8)

PARENT HOSPITALS	Unit Code
Auckland City Hospital	AUCK
Starship Children's Hospital	STAR
Christchurch Hospital	CHCH
Dunedin Hospital	DUND
Hawkes Bay Hospital	HAWK
Middlemore Hospital	MIDM
Palmerston North Hospital	PALM
Taranaki Base Hospital	TARA
Waikato Hospital	WKTO
Wellington Hospital	WELN
Whangarei Area Hospital	WHAN
Waitemata	WMAT

SATELLITE DIALYSIS UNITS	Unit Code
Auckland Home Training Unit	AHOM
Bay of Islands Hospital	BAYI
Carrington Satellite	CARR
Grafton Training Unit	GRAF
Greenlane Hospital	GLNE
Kaitaia Hospital	KAIT
Kawakawa Hospital	KAWA
Manukau Satellite	MANU
Nephrocare	NEPH
Nelson Hospital	NELS
Porirua Community Dialysis	PORI
Rotarua Hospital	ROTO
Tauranga Hospital	TAUR
Waitakere Satellite	WAIT

TRANSPLANTING UNIT	Unit Code
Auckland City Hospital Director - Dr Ian Dittmer Park Road Grafton, Auckland	AUCK
Christchurch Hospital Director - Dr David McGregor Riccarton Avenue Christchurch	CHCH
Starship Children's Hospital Director - Dr William Wong Park Road Grafton, Auckland	STAR
Wellington Hospital Director - Dr Grant Pidgeon Riddiford Street Newtown, Wellington South	WELN

Chapters and Appendices

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2012

AUST. & N.Z. DIALYSIS AND TRANSPLANT SURVEY

THIS SECTION FOR ALL PATIENTS

REGISTRY NUMBER | **1 INITIAL HOSPITAL** (Hospital/State; Hosp. Unit No.) | **CURRENT PARENT HOSPITAL** (Hospital/State; Hosp. Unit No) | Physician (Optional)

2 Surname; Given Names | **3 DATE OF BIRTH** | **4 SEX**

5 RACIAL ORIGIN (Record from list) OTHER | **6 PRIMARY RENAL DISEASE** (Record from list) OTHER | **7 BIOPSY** Y/N | **8 SE. CREATININE** AT ENTRY

9 COUNTRY OF BIRTH (If Australia or NZ - Tick box) AUST | NZ | OTHER COUNTRY (Please specify)

10 POSTCODE At Entry | **POSTCODE At End Survey**

11 CO-MORBID CONDITIONS AT ENTRY

LATE REFERRAL (<3 MTHS BEFORE FIRST TREATMENT) (Y/N) | HEIGHT (cms) | WEIGHT (kg) | CIGARETTE SMOKING (N=Never F=Former C=Current)

DISEASE AT ENTRY AND DURING CURRENT SURVEY

Y=Yes N=No S=Suspected

	CHRONIC LUNG Y/S/N	CORONARY ARTERY Y/S/N	PERIPHERAL VASCULAR Y/S/N	CEREBRO VASCULAR Y/S/N	DIABETES N=No O=Type 1 Insulin dependent P=Type 2 Non Insulin requiring Q=Type 2 Insulin requiring
AT ENTRY					
LAST					
CURRENT					

OTHER CO-MORBID CONDITIONS (Write In)

AT ENTRY	
PREVIOUS ENTRIES	
CURRENT	

12 CENTRE OF TREATMENT

Enter geographical location at Death or End of Survey

	HOSPITAL / CENTRE NAME (Write In or Tick if same)	CENTRE CODE	DATE TRANSFER
CURRENT			
LAST			

13 COURSE OF TREATMENT

COMPLETE ACCORDING TO CODE

A APD / IPD Hospital
C APD / IPD Satellite
E APD / IPD Home
L CAPD Hospital Outpatient
M CAPD Home
BC HD Hospital Conventional
DC HD Satellite Conventional
FC HD Home Conventional
BQ HD Hospital Quotidian
DQ HD Satellite Quotidian
FQ HD Home Quotidian
G Transplant in AUST/NZ
H Date of last post graft dialysis
X Transplant Overseas
I Graft function temporary/permanently ceased (date dialysis required)
K Date of last visit if lost to follow up
Z DATE OF DEATH

REASON FOR DIALYSIS MODALITY CHANGE from CAPD to APD / APD to CAPD / Any PD to HD / HD to any PD. Enter Reason for Change FROM Previous Modality TO Current Modality. Refer to codes on back of form

SEQ. No.	CODE	DAY	MTH	YR	REASON
1					
2					
3					
4					
5					
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7					
8					
9					
10					
11					
12					
13					
14					
15					
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30					
31					
32					
33					
34					

14 HEPATITIS C ANTIBODY

1=Positive 2=Negative 3=Not done

	CURRENT	LAST

SEQ. No.	CODE	DAY	MTH	YR	REASON
35					
36					
37					
38					

15 CANCER EVER? Y/N — If Yes, please complete Cancer Form

16 CAUSE OF DEATH (Record from list) OTHER

17 WAS GRAFT SUSTAINING LIFE? Without dialysis at time of death Y=Yes N=No

18 PARENTHOOD

HAS THIS PATIENT BECOME PREGNANT OR FATHERED A CHILD DURING THIS SURVEY — Y=Yes N=No — If Yes, please complete a Parenthood Outcome form — DATE OF LAST OUTCOME

THIS SECTION FOR ALL PATIENTS DIALYSED AT ANY TIME DURING THE SURVEY PERIOD

19 TYPE OF DIALYSIS (See list) | **20 DRY WEIGHT AT LAST DIALYSIS** kg (HD and PD Patients) | **21 UNCORRECTED CALCIUM** mmol/l | **22 PHOSPHATE** mmol/l (See instructions on the back of the form) | **23 HAEMOGLOBIN** g/l Last Available | **24 EPO AGENT** Y=Yes N=No | **25 FERRITIN** ug/l Within last 3 mths of Survey or record not done | **26 % SATURATION IRON** (Transferrin Saturation)

HAEMODIALYSIS

27 DIALYSER BRAND (Write In) CODE; BRAND NAME AND MODEL | **28 BLOOD FLOW RATE** Pump Speed (mls/min) | **29 SESSIONS PER WEEK** | **30 HOURS PER SESSION** | **31 UREA REDUCTION or Kt/V Method** (See List); **Value**

32 ACCESS IN USE (Functioning only) Enter for **ALL PATIENTS ON HAEMODIALYSIS** AT ANY TIME DURING THIS SURVEY PERIOD

AT FIRST HD | AT LAST HD | 1=Native 2=Synthetic 3=Tunnel CV Catheter 4=Non Tunnel CV Catheter

FOR FISTULAS AND GRAFTS ONLY: DECLOTTED during Survey Y=Yes N=No D=Declotted and revised | REVISED during Survey N=No S=Surgical A=Angioplasty B=Both

IN THE EVENT OF THE PATIENT HAVING BOTH HD AND PD, AND A TRANSPLANT DURING THE SURVEY COMPLETE SECTIONS 19-41 INCLUSIVE

ALL PERITONEAL DIALYSIS

33 PET TEST (Once Only) Within first 6 mths (Dx / Plasma Creatinine at 4 hours) | **34 CONNECTION SYSTEM** CODE (Write In) | **35 PERITONITIS** DATE OF FIRST EPISODE | **36 NUMBER OF EPISODES OF PERITONITIS** During this Survey | **37 TOTAL VOLUME OF WEEKLY CHANGES** (Litres/week)

38 CREATININE CLEARANCE Dialysate ONLY — Adjusted for Body Surface Area (Litres/week/1.73 m²) Range 10-200 Litres/Week

39 WEEKLY Kt/V Dialysate ONLY (Range 0.1 - 5.0)

40 RESIDUAL RENAL FUNCTION (Creatinine Clearance) — Adjusted for Body Surface Area (Litres/week/1.73 m²)

41 PD SOLUTIONS - Y=Yes N=No (Please fill in all boxes): Glucose | Icodextrin | Low GDP Lactate | Low GDP Bicarbonate | OTHER

CURRENT GRAFT

(IN THE EVENT OF BOTH GRAFT FAILURE AND RETRANSPLANT IN THIS SURVEY - USE A NEW FORM)

42 GRAFT NUMBER | **43 DATE OF THIS TRANSPLANT** | **44 REFERRING HOSPITAL** | **45 DONOR HOSPITAL** | **46 TRANSPLANT HOSPITAL** | **47 RECIPIENT ANTIBODY STATUS AT GRAFT** CMV EBV (1=Positive 2=Negative 3=Not done) | **48 NUMBER REJECTION EPISODES THIS SURVEY** (Complete acute rejection form for each episode) (at any time)

49 DONOR DETAILS SOURCE (See list) | AGE | SEX | **50 TOTAL ISCHAEMIA** (Hours) | **51 IMMEDIATE FUNCTION** (See list) | **52 DISEASE IN GRAFT** If Yes (See list) | **53 DATE FIRST PROVEN** (eg. Graft biopsy) | **54 CAUSE OF GRAFT FAILURE** OTHER (Record from list)

55 MONOCLONAL / POLYCLONAL THERAPY (Record from list)

COURSE	DATE	AGENT	OTHER	NUMBER OF DOSES GIVEN	REASON	OTHER
1st						
2nd						
3rd						

56 TOTAL DAILY DRUG DOSE (mg)

	TOTAL INITIAL ORAL DOSE	1 MTH	2 MTH	3 MTH	6 MTH	1 YR	2 YR	3 YR	5 YR	7 YR	10 YR	15 YR	20 YR	25 YR	30 YR	35 YR
CYA																
AZA																
PRED																
TACROL																
MMF																
SIROL																
OTHER																

57 CYA SPARING DRUG 0=NOT GIVEN 1=GIVEN (eg DILTIAZEM - KETOCONAZOLE - VERAPAMIL)

58 BODY WEIGHT (kg)

59 SERUM CREATININE µmol/L

FOR OFFICE USE ONLY

60 HLA TYPING

	BLOOD GROUP	A		B		DR		DQ	
RECIPIENT									
DONOR									

62 PRA AND CROSSMATCH

MAXIMUM	CURRENT

Data Collection Form

INSTRUCTIONS FOR DIALYSIS AND TRANSPLANTATION SURVEY COMPILATION
PLEASE READ THE EXPLANATORY NOTES BEFORE COMMENCING TO FILL IN THE FORMS
Please complete the form using neat capitals

5 – RACIAL ORIGIN
1 Caucasoid
2 Australian Aborigine
3 Chinese
4 Maori
5 Arab
61 Cook Islander
63 Samoan
64 Tongan
65 Torres Strait Islander
69 Pacific People – other (**specify**)
7 Indian
8 Indonesian
9 Malay
10 Filipino
11 Vietnamese
20 Other (**specify**)
00 Patient objects to answering question

Mixed race coded by patient's assessment

6 - PRIMARY RENAL DISEASE
Results of ANCA (Anti Neutrophil Cytoplasmic Antibody) test in association with glomerulonephritis should be entered in box marked OTHER

100 Presumed GN, type undefined histologically (no biopsy)
110 Focal sclerosing GN (including hyalinosis)
111 Primary focal sclerosing GN or focal glomerular sclerosis
112 Secondary focal sclerosing GN
121 Mesangiocapillary GN with subendothelial deposits (double contour)
122 Mesangiocapillary GN with intramembranous deposits (dense deposit disease)
130 Membranous GN
140 Extra and intra capillary GN (extensive crescents - clinically rapidly progressive)
151 Mesangial proliferative (IgA+ positive)
152 Mesangial proliferative (IgA- negative)
153 Mesangial proliferative (no I.F. studies)
160 Focal and segmental proliferative GN (including focal necrotising)
170 Advanced GN (unclassified = end stage)
180 GN with systemic disease (**specify**)
181 Goodpasture's syndrome with linear IgG and lung haemorrhage
182 Proliferative GN with linear IgG -no lung haemorrhage
183 SLE
184 Henoch-Schonlein purpura
185 Wegener's Granulomatosis
186 Microscopic Polyarteritis
187 Scleroderma
190 GN other (**specify**)
191 Familial GN (**specify Alport's - yes or no**)
200 Analgesic nephropathy
300 Renal vascular disease due to malignant hypertension (NO primary renal disease)
301 Renal vascular disease – type unspecified
302 Renal vascular disease – due to hypertension (nephrosclerosis) (NO primary renal disease)
303 Atheroembolic disease (cholesterol emboli)
304 Bilateral renal artery stenosis
400 Polycystic kidney disease
401 Medullary cystic disease
402 Infantile/juvenile polycystic kidney disease
500 Reflux nephropathy
600 Pyelonephritis
700 Calculi
701 Gout
801 Diabetes – Type 1 (insulin dependent) **[Juvenile onset]**
802 Diabetes – Type 2 (non-insulin requiring)
803 Diabetes – Type 2 (insulin requiring) **[Mature onset]**
000 Other (**specify**)
001 Uncertain diagnosis
002 Lead nephropathy
003 Cadmium toxicity
004 Renal tuberculosis
005 Amyloid disease
006 Haemolytic uraemic syndrome
007 Cortical necrosis
008 Interstitial nephritis
009 Congenital renal hypoplasia and dysplasia
010 Loss of single kidney **(specify - e.g. trauma, surgery)**
011 Megaureter
012 Oxalosis
013 Cystinosis
014 Balkan nephropathy
015 Renal cell carcinoma (GRAWITZ)
016 Transitional cell carcinoma of urinary tract
017 Paraproteinaemia (including multiple myeloma)

PRIMARY RENAL DISEASE cont.
018 Light chain nephropathy (benign)
019 Lithium toxicity
020 Post partum nephropathy
021 Sarcoidosis
031 Posterior urethral valves
032 Pelvi-ureteric junction obstruction
033 Obstructed megaureter
034 Neuropathic bladder
035 Non-obstructed dilated bladder and ureters (megacystitis – megaureter)
036 Spina bifida or myelomeningocoele
037 Bladder neck obstruction (incl. prostatomegaly)
039 Other lower urinary tract abnormalities (with secondary reflux) (**specify**)
040 Ureteric obstructive nephropathy
041 Obstructive nephropathy

13 – REASON FOR MODALITY CHANGE
From CAPD to APD
From APD to CAPD
From any form of PD to HD
From HD to any form of PD

10 Recurrent / persistent peritonitis
11 Acute peritonitis
15 Tunnel / exit site infection
16 Diverticulitis
20 Inadequate solute clearance
21 Inadequate fluid ultrafiltration
22 Excessive fluid ultrafiltration
27 Abdominal abscess
30 Dialysate leak
31 Catheter block
32 Haemoperitoneum
33 Catheter fell out
35 Hernia
36 Abdominal pain
40 Abdominal surgery
41 Sclerosing peritonitis
42 Peritoneal infection
43 Multiple adhesions
44 Pregnancy
45 Haematuria
46 Pleural effusion
47 Cardiovascular instability
48 Geography – poor access to dialysis services
49 Vascular access problems
50 Patient preference
51 Unable to manage self-care
60 Recovery of renal function
70 Transplantation
80 Death
81 Transfer outside Australia or New Zealand
82 Other surgery
83 Hydrothorax
85 Poor nutrition
86 Scrotal oedema
90 Planned transfer after acute PD start
91 Planned transfer after acute HD start
99 Other (**specify**)

16 - CAUSE OF DEATH
CARDIAC
10 Myocardial ischaemia (presumed)
11 Myocardial ischaemia and infarction
12 Pulmonary oedema
13 Hyperkalaemia
14 Haemorrhagic pericarditis
15 Hypertensive cardiac failure
16 Cardiac arrest – cause uncertain
17 Other causes of cardiac failure (**specify**)

VASCULAR
21 Pulmonary embolus
22 Cerebrovascular accident
23 Gastrointestinal haemorrhage
24 Haemorrhage from dialysis access site
25 Haemorrhage from transplant artery
26 Aortic aneurysm – rupture
27 Haemorrhage from elsewhere (**specify**)
28 Bowel infarction

INFECTION
Please enter code for nature of infective organism, after the code for site of infection Please **specify type of organism**
eg Staph, CMV, Candida, etc

eg 321 Lung infection – bacterial (staph)
322 Lung infection – viral (CMV)

31	CNS	1 Bacterial
32	Lung	2 Viral
33	Urinary tract	3 Fungal
34	Wound	4 Protozoa
35	Shunt	5 Other
36	Peritoneum	

CAUSE OF DEATH cont.
37 Septicaemia – site unknown (**specify organism**)
38 Liver (incl. viral hepatitis) (**specify** A, B, CMV, herpes, etc)
39 Other site (**specify**)

SOCIAL
40 Withdrawal for psycho-social reasons
41 Patient refused further treatment (**specify reason**)
42 Suicide
43 Therapy ceased for any other reason (**specify reason**)
44 Accidental death (**specify**)
45 Withdrawal for cardiovascular comorbid conditions
46 Withdrawal for cerebrovascular comorbid conditions
47 Withdrawal for peripheral vascular comorbid conditions
48 Withdrawal related to malignancy
49 Withdrawal related to dialysis access difficulties (AVF, Tenckhoff, etc)

MISCELLANEOUS
50 Hepatic failure (**specify**)
51 Uraemia caused by graft failure
52 Pancreatitis
53 Bone marrow depression
54 Cachexia
55 Unknown
56 Malignant disease
57 Perforation of abdominal viscus – peptic ulcer, diverticulum, appendix
58 Dialysis dementia (aluminium)
59 Other (**specify**)
60 Immunodeficiency due to viral infection (**specify organisms involved**)
61 Chronic respiratory failure
62 Sclerosing peritonitis

19 – TYPE OF DIALYSIS
11 Haemodialysis – plate dialysers
12 Haemodialysis – hollow fibre dialysers
15 Haemofiltration
16 Haemodiafiltration
19 C.V.V.HD (Intensive Care Unit)
20 Peritoneal – bags no cycler
21 Peritoneal – continuous ambulatory (CAPD)
22 Peritoneal – automated (APD)
23 Peritoneal – intermittent cycler (IPD)
25 Peritoneal – other (**specify**)

20 – DRY WEIGHT
At end of survey, transplantation or death.

21 – UNCORRECTED CALCIUM
Not corrected for albumin
Midweek, predialysis and closest to end of survey, transplantation or death.

22 – PHOSPHATE
Midweek, predialysis and closest to end of survey, transplantation or death.

23 – HAEMOGLOBIN
Midweek, predialysis and closest to end of survey, transplantation or death.

31 – URR or Kt/V **Please enter method used**
A Urea Reduction Ratio % (URR%)
B Kt/V (by BIOSTAT)
C Kt/V (by UKM)
D Kt/V (by DAUGIRDAS – single pool)
E Kt/V (other method – **specify**)

Kt/V (for HD patients) Range 0.5 – 2.2

UREA REDUCTION RATIO %
(Pre dialysis urea – post dialysis urea) x 100 = **URR%**
Pre dialysis urea

Pre dialysis urea:
Blood should be drawn from the 'arterial' needle immediately prior to dialysis, at a mid-week dialysis session

Post dialysis urea:
Blood is again drawn from the 'arterial' needle and this should occur **within 20 seconds** after cessation of the blood pump (alternatively the pump can be turned down to 50 ml/min) – this is to avoid problems with recirculation

32 – ACCESS IN USE
Type at First HD - leave blank if initial renal replacement treatment was not haemodialysis.

Type at Last HD - enter for all patients on haemodialysis at any time during the survey. Enter the procedure closest to the end of survey, change to PD, transplantation, or death.

33 – PET TEST (Required **Once Only** per patient)
Standard Peritoneal Dialysis Equilibration Test
performed 1-6 months after initiation of PD
(2.5% 2 litre exchanges)

Provide dialysis/plasma creatinine at 4 hours
Range 0.1 – 1.2

38 to 40 – PD CLEARANCE STUDIES
Generated from a 24 hour collection of PD effluent and urine

NOTE: Dialysate Creatinine Clearance and Kt/V both refer to dialysis clearances ONLY (NOT the total of dialysis and renal clearances).

38 **CREATININE CLEARANCE (Dialysate only)**
Range 10 - 200 litres/week
Litres /week / 1.73m² Body Surface Area

39 **WEEKLY Kt/V (Dialysate only) - Range** 0.1 – 5.0

40 **RESIDUAL RENAL FUNCTION (Creatinine Clearance)**
Litres /week / 1.73m² Body Surface Area

49 – SOURCE OF DONOR KIDNEY
1 Deceased Donor
2 Sister (if twin, record 6 or 7)
3 Brother (if twin, record 6 or 7)
4 Mother
5 Father
6 Monozygotic (identical) twin
7 Dizygotic (non-identical) twin
8 Other related living donor (**specify**)
9 Son
10 Daughter
11 Husband
12 Wife
13 Cousin
14 Unrelated living donor (**specify**)

50 – TOTAL ISCHAEMIA (HOURS)
From time of donor renal artery interruption or aortic clamp, until time of release of renal artery in the recipient (clamp off)

51 – IMMEDIATE FUNCTION
1 Spontaneous fall in se.creatinine by 10% within 24 hours
2 Spontaneous fall in se.creatinine by 10%, first recorded between 25-72 hours
3 Poor immediate function. No spontaneous fall in se.creatinine within 72 hours; but no dialysis needed
4 No immediate function. No spontaneous fall (> 10%) in se.creatinine; dialysis required within 72 hours

52 – DISEASE IN GRAFT **Histologically proven**
Complete this section for **FUNCTIONING or FAILED GRAFTS**

Please enter **Date first proven (e.g. Graft Biopsy)**

B = BK virus nephropathy in graft
Y = Disease recurrence – primary renal disease and disease in graft the same
D = De novo glomerulonephritis – primary renal disease known and not the same
G = Glomerulonephritis in graft – primary renal disease unknown or not biopsied

In cases of glomerulonephritis, where histological confirmation of recurrence may be uncertain, enter as G

54 – CAUSE OF GRAFT FAILURE
REJECTION
10 Hyperacute rejection (within 48 hours of transplantation)
20 Acute rejection at anytime, causing graft failure
40 Chronic allograft nephropathy (slow progressive loss of renal function, not due to recurrent original disease or acute rejection)

VASCULAR
50 Renal artery stenosis
51 Renal artery thrombosis
52 Renal vein thrombosis
53 Renal vessel haemorrhage (primary)
54 Renal vessel haemorrhage (secondary)
55 Embolus – thrombo
56 Embolus – cholesterol
57 Haemolytic uraemic syndrome

TECHNICAL
60 Non-viable kidney (due to pre-transplant cortical necrosis)
61 Cortical necrosis post transplant (not due to rejection)
70 Ureteric and bladder problems

GLOMERULONEPHRITIS
82 Mesangiocapillary GN with subendothelial deposits
83 Mesangiocapillary GN with intramembranous deposits (dense deposit disease)
84 Focal sclerosing GN (including hyalinosis)
85 Membranous GN
86 Mesangial proliferative GN (IgA positive)
87 Goodpasture's syndrome
88 Intra and extra capillary GN with extensive crescents (clinically rapidly progressive)
89 Other (**specify**)

DRUG THERAPY
90 Complications of drug therapy requiring reduction or withdrawal of steroid and/or immunosuppressants
91 Non-compliance with therapy – causing graft failure
92 Rejection following I/S reduction due to malignancy
93 Rejection following I/S reduction due to infection

MISCELLANEOUS
00 Other (**specify**)
01 Donor malignancy
02 Malignancy invading graft
05 BK virus nephropathy

55 – MONOCLONAL / POLYCLONAL THERAPY
Record in order of administration, each separate course of such drugs; a second course of the same drug should be separately recorded
Complete the requested details regarding, date, identity of drug, number of doses given, and reason for administration, according to the following codes

TYPE OF AGENT	NUMBER OF DOSES
2 Daclizumab (Zenepax)	
4 OKT3	
5 Intravenous Immunoglobulin	Record actual
6 Basiliximab (Simulect)	number of doses given
7 Rituximab	
8 Polyclonal anti T cell	
9 Other monoclonal (**specify**)	

REASON FOR USE
1 Prophylaxis
7 Treatment for acute rejection
8 Other (**specify**)

56 – TOTAL DAILY DRUG DOSE
Enter the total daily dose for each drug where applicable; if an unlisted drug is used, enter the name in the space provided marked **OTHER**

Only those drugs taken at the listed intervals should be entered; where necessary provide the dose recorded on the closest day preceding the requested time interval

The initial drug dose (at zero months) is **the first oral maintenance dose**; do **NOT** enter the intravenous loading doses administered at or shortly after transplantation

(2007)

Data Collection From (Back Side)