



Australia and New Zealand Dialysis and Transplant Registry

SURVEY PERIOD

01-Jan-2007 to 31-Dec-2007

COMPLETION DATE - 31-MAR-2008

If possible, please make a photocopy of your sheets, in case originals are lost in transit

Return sheets in a PLASTIC SATCHEL and

Only by REGISTERED POST or COURIER

RETURN TO

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NOTE: Blank forms / Privacy Information / Consent Forms are available via the ANZDATA Website. Go to www.anzdata.org.au

Select – Australia and New Zealand Dialysis and Transplant Registry
 Select – ANZDATA Database Structure and Data Entry Forms
 Select – Privacy and Consent Forms

QUESTION 6 PRIMARY RENAL DISEASE*For Codes see 6 - back of survey form*

It is most important that this section is accurately reported.

Any aetiological diagnosis **must** be secure: if uncertain then enter 001 and write in presumed diagnosis.

Make sure histological classification of **glomerulonephritis** is accurate.

If there was NO biopsy or nephrectomy specimen for histological examination, **code as 100**.

Please ensure that **analgesic nephropathy** is well documented: eg intake, radiographic or biopsy, or nephrectomy appearance.

In cases of **obstructive uropathy**, indicate cause from codes 031 to 039 or 700 (calculi).

Results of ANCA (Anti Neutrophil Cytoplasmic Antibody) test in association with any glomerulonephritis should be entered in box marked OTHER.

QUESTION 10 POSTCODE

Postcode at Entry – this entry will remain unchanged throughout the patient's life.

Postcode at End of Survey – **enter a tick if postcode the same OR enter new postcode.**

QUESTION 11 CO-MORBID CONDITIONS

All sections in this question require completion for new patients starting renal replacement therapy and updating for existing patients for Chronic Lung, Coronary Artery, Peripheral Vascular, Cerebrovascular Disease and Diabetes.

Previous entries will be printed under Last Survey, and where Yes or Suspected are entered, these will be printed under current Survey. Previous entries with No will be blank and entries with Suspected will be asterisked for updating where necessary.

A change in Diabetic status from Non Insulin to Insulin Requiring, or vice versa, should be recorded in Current Survey. For kidney/pancreas transplant patients – enter N for diabetes if the pancreas transplant is functioning and glycaemic control is normal.

Other Co-morbid conditions will be printed as usual, but any new events during the survey period should be recorded in Current Survey.

QUESTION 12 CENTRE OF TREATMENT AT END OF SURVEY

Record the centre administering treatment at the end of the survey, eg satellite centre, regional hospital.

If Centre of Treatment has not changed since last survey – tick the box.

QUESTION 13 COURSE OF TREATMENT - requires accurate date sequence**APD / IPD CODES A, C, E**

Enter relevant DATES for commencement of **automated/intermittent peritoneal dialysis**, in hospital, transfer to a satellite, or transfer to home.

CAPD CODES L, M

Enter relevant DATES for commencement of **continuous ambulatory peritoneal dialysis**, in hospital, or transfer to home.

HD CODES B, D, F

Enter relevant DATES for commencement of **haemodialysis**, in hospital, transfer to a satellite, or transfer to home.

*** **Home haemodialysis patients** dialysed in the **hospital centre for less than one month** should still be regarded as home patients. If they stay on hospital haemodialysis for more than one month, record 'B' and the appropriate date.

*** **CAPD / APD patients** requiring temporary in-centre PD, or HD for **less than one month**, should be regarded as continuing CAPD/APD treatment.

REASON FOR DIALYSIS MODALITY CHANGE

*** **Note: Reason for transfer between modes of dialysis, now include changes from HD to CAPD or APD. Several NEW CODES have been added**

Please attempt to select the major cause for withdrawal *For Codes see 13—back of survey form*

From CAPD	to APD
From APD	to CAPD
From CAPD or APD	to HD
From HD to PD	

TRANSPLANTATION DATES

A graft is **functioning adequately** if clearing creatinine is lower than pre-transplant level.

If a patient requires dialysis after a period of satisfactory graft function record 'T' at date of first dialysis, Followed by 'H' when function recovers sufficiently to cease dialysis.

CODE 'X' = "TRANSPLANT OVERSEAS"

These patients are not generally included in ANZDATA survival analyses.

Code 'X' is for patients dialysing in Australia/New Zealand, who go overseas for a donor transplant, then return to their parent hospital for follow up care.

Please record the **country** of Transplant in Qu.46 (Transplant Hospital).

Code 'X' is also used for those patients who have moved/immigrated from overseas to Australia/New Zealand with a functioning transplant.

Please record the **country** of Transplant in Qu.46 (Transplant Hospital).

CODE 'Z' = DATE OF DEATH

When death has occurred, enter Code 'Z' and the DATE OF DEATH.

The cause of death should be recorded in Question 16.

QUESTION 14 HEPATITIS C ANTIBODYAll patients

This question is to record the prevalence of positive results.
Please ensure any conversion during the survey is recorded.

Where differing antibody results have been obtained by first, second or third generation test kits, enter the results obtained with the latest method.

QUESTION 16 CAUSE OF DEATH*For Codes see 16 - back of survey form*

The prime cause of death should be entered.
If there are significant secondary factors involved please indicate, eg **dialysis dementia**.

If death is due to infection,
code according to the site of infection
code according to the type of infection
and record the **NAME OF THE ORGANISM** in the box marked OTHER.

PLEASE ENSURE that the **presumed source of SEPTICAEMIA** is recorded.

QUESTION 18 PARENTHOOD

Parenthood forms are enclosed to record all new conceptions and pregnancy outcomes during the survey.

QUESTIONS 19 - 41

ALL HAEMODIALYSIS AND ALL PERITONEAL DIALYSIS

In the event of any patient having haemodialysis and/or peritoneal dialysis during the survey period
Please complete Questions 19 to 41 inclusive

Record the information from the last dialysis treatment, at the end of the survey, at transplantation or death.

QUESTION 19 TYPE OF DIALYSIS

This question reflects the last dialysis at the end of the survey, at transplantation or death.

For Codes see 19 – back of survey form

QUESTION 20 DRY WEIGHT

Enter target dry weight at the end of the survey, at transplantation or death.

QUESTION 21 UNCORRECTED CALCIUM

Not corrected for Albumin.

Midweek, predialysis and closest to the end of the survey.

QUESTION 22 PHOSPHATE

Midweek, predialysis and the closest to the end of the survey.

QUESTION 23 HAEMOGLOBIN (gms/litre)

Midweek, predialysis and the closest to the end of the survey.

QUESTION 24 Erythropoietic Agent

Record Yes or No if patient was having Erythropoietin (alpha or beta) or Darbepoietin or Eprex or Aranesp at any time during the survey period.

QUESTION 25 FERRITIN

Please enter level within the last 3 months of the survey.

Record **N/D (not done)** if none performed. [mg/litre or ng/ml]

QUESTION 26 % Saturation Iron

Please enter 0-99% within the last 3 months of the survey or record **N/D (not done)**.

Some laboratories report this as transferrin saturation.

QUESTIONS 27 – 32 HAEMODIALYSIS*See separate Dialyser Codes List***QUESTION 27 DIALYSER BRAND**

You may either use the codes supplied or write in the Brand Name and Model. Enter the dialyser used for the last dialysis at the end of the survey, at transplantation, or death.

QUESTION 28 BLOOD FLOW RATE (pump speed is not effective blood flow rate)

Please record BFR as * blood pump speed, or
* effective blood flow rate.

QUESTION 31 UREA REDUCTION RATIO % or Kt/V*Refer to 31 - back of survey form*

Please complete this question for all patients who have haemodialysis treatment during the survey period. If urea ratio or Kt/V were not performed, enter **N/D (not done)** so further follow up is not required.

Quoted from National Kidney Foundation DOQI Guideline

“Acceptable Methods for BUN Sampling (Evidence)

Blood samples for BUN Measurement must be drawn in a particular manner.

Pre-dialysis BUN samples should be drawn immediately prior to dialysis, using a technique that avoids dilution of the blood sample with saline or heparin.

Post-dialysis BUN samples should be drawn using the Slow Flow/Stop Pump Technique that prevents sample dilution with recirculated blood and minimises the confounding effects of urea rebound.

Key Elements of Rationale

1. Pre- and post-dialysis sampling techniques must control for the site of the blood draw, needle or catheter preparation, blood and dialysate pump flow rates, ultrafiltration rate, and the timing of the blood sampling with respect to the initiation and completion of haemodialysis.
2. Pre-dialysis BUN **must** be measured before haemodialysis begins to prevent the sample from reflecting any impact of dialysis.
3. The Slow Flow/Stop Pump Technique for post-dialysis BUN sampling is sufficiently reproducible and simple to be implemented in clinical settings. It also supports use of formal urea kinetic modelling techniques. (For a complete explanation of this technique, see NKF-DOQI Clinical Practice Guidelines for Haemodialysis Adequacy, Guideline 8, pp.53-60.)”

QUESTION 32 ACCESS IN USE

AT FIRST HAEMODIALYSIS - this is a once only entry

ONLY complete this box if patient is having haemodialysis for **THE VERY FIRST TIME EVER**

ONLY use codes – (**DO NOT enter Yes or No**)

1 = Native A-V fistula / 2 = Synthetic A-V graft / 3 = Tunnel CV catheter / 4 = Non tunnel CV catheter

AT LAST HAEMODIALYSIS

Record for **ALL** patients who had haemodialysis during the survey.

If the procedure was undertaken more than once, enter the procedure closest to the end of the survey, change to PD, death or transplantation.

QUESTIONS 33 – 41 ALL PERITONEAL DIALYSIS - CAPD / APD**QUESTION 33 PET TEST***For Codes see 33 - back of survey form*

Prospective and once only for new PD patients, within the first six months of PD treatment.
Please enter results between 0.1 – 2.5. (**DO NOT enter** Yes or No)

QUESTION 34 CONNECTION SYSTEM*See separate Dialyser codes list*

Record the connection system employed and manufacturer.
You may either use the code or write in the connection system and manufacturer.
The main purpose of this question is to identify different connect/disconnect systems.

QUESTION 35 DATE OF FIRST PERITONITIS**For All forms of PD**

The date of the first infection after commencing PD allows calculation of survival without infection

QUESTION 36 NUMBER OF EPISODES OF PERITONITIS**For All forms of PD**

Record the number of episodes of peritonitis **for all patients** having any form of PD during the survey period.

Please complete a Peritonitis Form for **each episode** of peritonitis.

NOTE: Record ONLY those episodes whilst actually having PD

QUESTION 37 TOTAL VOLUME OF WEEKLY EXCHANGES (Litres / week)

Complete for **all PD** - total volume of exchanges per week – enter fluid input, **NOT output**.

QUESTION 38 CREATININE CLEARANCE - DIALYSATE ONLY (per week)

Refers to **dialysis clearances only**

QUESTION 39 WEEKLY Kt/V - DIALYSATE ONLY*See back of form***QUESTION 40 RESIDUAL CREATININE CLEARANCE** (per week)*See back of form***QUESTION 41 PD SOLUTIONS**

Please enter **Y**es or **N**o in each box

Low GDP lactate fluids include Balance (Fresenius) and Gambrosol Trio (Gambro).
Low GDP bicarbonate fluid is Physioneal (Baxter).

QUESTIONS 42 – 59 TRANSPLANTATION**QUESTION 47 RECIPIENT ANTIBODY STATUS CMV / EBV**

Enter positive or negative status as assessed by your hospital's laboratory
Testing should be for IgG antibody for both viruses not IgM.
IgG positive or negative should be recorded.

QUESTION 48 NUMBER OF REJECTION EPISODES THIS SURVEY

Please complete a Rejection Form for each episode

QUESTION 49 SOURCE OF DONOR KIDNEY

NOTE: Cadaver Donors are now known as DECEASED DONORS [DD]
Deceased, related or unrelated live donors. *For Codes see 49 - back of survey form*

Any related live donor, where a code is not supplied should be entered as Code 8,
and specify relationship, eg aunt, grandmother, grandfather, etc.

Any unrelated live donor should be entered as Code 14, and specify relationship,
eg altruistic, friend, family friend, etc.

QUESTION 50 TOTAL ISCHAEMIA

Refer to 50 - back of survey form

QUESTION 51 IMMEDIATE FUNCTION

For Codes see 51 - back of survey form

Classify graft function into one of four categories.

QUESTION 52 DISEASE IN GRAFT

For Codes see 52 – back of survey form

This question includes **de novo glomerulonephritis** and **glomerulonephritis in graft - primary renal disease unknown**, as well as histologically proven evidence of disease recurrence.

BK Virus nephropathy has also recently been included.

QUESTION 53 DATE RECURRENCE FIRST PROVEN

Enter the date of the first occurrence of graft disease that was biopsy proven.

QUESTION 54 CAUSE OF GRAFT FAILURE

For Codes see 54 – back of survey form

In the event of **permanent** graft failure during an intercurrent illness eg. septicaemia, haemorrhage **SPECIFY** if **graft loss** was due to rejection, acute ischaemic damage or other cause.

CURRENT GRAFT

In the event of both graft failure and further transplantation in this survey – use two forms (ONE for failed graft, ONE for new graft).

QUESTION 55 MONOCLONAL / POLYCLONAL THERAPY *Refer to 55 – back of survey form*

This question has THREE PARTS to each section (Agent, Number of Doses and Reason), with the option to enter up to three different types of treatments.

If the patient received **NO** therapy, please **ENTER 0**.

QUESTION 56 TOTAL DAILY DRUG DOSE *Refer to 56 - back of survey form*

DO NOT enter the intravenous loading doses administered at, or shortly after transplantation

At 'Initial Oral Dose' enter the **FIRST TOTAL DAILY ORAL** maintenance drug dose

Drug doses at the completion of the previous survey are recorded on the form for the **current** graft
Enter the drug(s) dose in the appropriate time column

If a drug is **NOT USED** enter 0 in the appropriate column. eg

Name of Drug	Initial ORAL Dose	1 Month	2 Month
CyA or Neoral	900	260	200
Azathioprine (AZA)	0	50	50
Prednisolone (PRED)	0	20	0
Tacrolimus (FK506)	10	6	4
Mycophenolate Mofetil (MMF)	2000	3000	3000
Sirolimus (Rapamycin)	6	4	2
OTHER—enter name of drug & dose Belatacept (LEA29Y) Betamethasone Chlorambucil Cyclophosphamide Everolimus (RAD) FTY 720 Leflunomide (Arava) Myfortic (Mycophenolate Sodium)

*** **NOTE** **Mycophenolate Mofetil (MMF)** **is not** Myfortic (Mycophenolate Sodium)
Enter Myfortic under “Other”

** **Patients in Drug Trials** – Under 'Other' specify drug and enter 9999 for doses

If **graft fails or the patient dies with a functioning graft within the first six months**
enter drug dose(s) in the appropriate time column nearest to date of failure or death.

CANCER SURVEY SHEET

SECTION 1 Tumour in Donor. This information is entered by the Registry.

SECTION 2 **Primary Non-Skin Tumours and Melanomas (See Code List A)**

Melanomas are recorded in this section and have been allocated Code 13.

Non-Hodgkins Lymphoma, Microglioma of the brain and Lymphoproliferative disease require additional information to be added to the database.

Please include a copy of the **Histological Report** and the Registry will decide which extra data it will record.

Cancer Staging is histological staging from Code List B at the bottom of the page and is only required for entries in the Primary Non-Skin and Melanoma Section. Extra codes have been added for **Cervical Cancer** to accommodate the CIN categories.

Type of Treatment. Refer to Code List C at the bottom of the page.

Dates are required for the **first metastases** to local lymph nodes, the **first systemic metastasis** and the **first local recurrence**.

**** Did this cancer cause/contribute to original renal failure? Yes / No**

This question supplements Question 6 (Primary Renal Disease) on the main form. This will assist in determining whether cancer is related to renal failure but is not the primary cause; eg analgesic nephropathy is the primary cause leading to nephrectomy for transitional cell carcinoma.

**** Did this cancer cause or contribute significantly to death? Yes / No**

This supplements the Question "Cause of death?" on the main form and allows more accurate assessment of cancer morbidity; e.g. cause of death was sepsis secondary to anti-cancer cytotoxic therapy.

SECTION 3 **Primary Skin Tumours (Enter only if Histologically Proven)**

Do not enter Bowen's Disease, Keratoacanthoma, Solar Keratosis or Hyperkeratosis

This section collects data on the **FIRST INSTANCE of Squamous Cell (SCC), Basal Cell (BCC) or Other Skin Tumours**, which may include Hutchison's Freckle, Merkel Cell or Spindle Cell tumours within three periods:

Pre Entry to ESRF Program
Dialysis Treatment
Post Transplant

Dates of Metastases are required for the first instance of spread for SCC, BCC or Other Skin tumour to local lymph nodes and systemic sites.

If any skin tumours caused or contributed to death, please enter YES in the appropriate box for the relevant type