



ANZDATA: A recipe for how it works

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What do I want to get out of the day?

- Let people know what ANZDATA is and does
- Highlight the changes in direction over the past 10 years
 - growth of a “research” agenda
- Discuss some of the challenges
 - Data collection
 - Electronic capture
 - Centre Reports

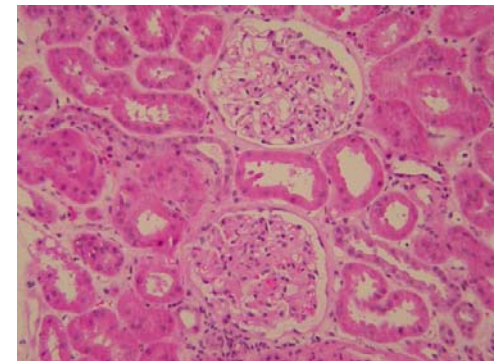
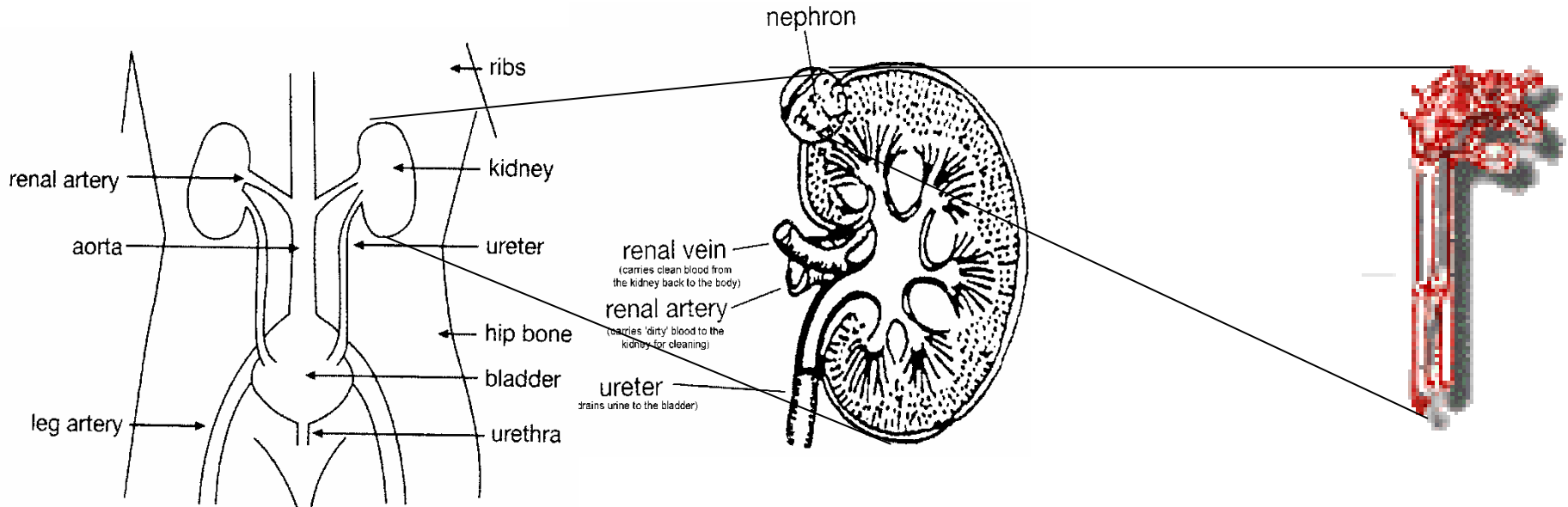


What do we do?

- Collection of data
 - data on all people in Australia and New Zealand receiving chronic renal replacement therapy
- Outputs
 - Reports
 - Data analyses
 - Datasets
 - Research output

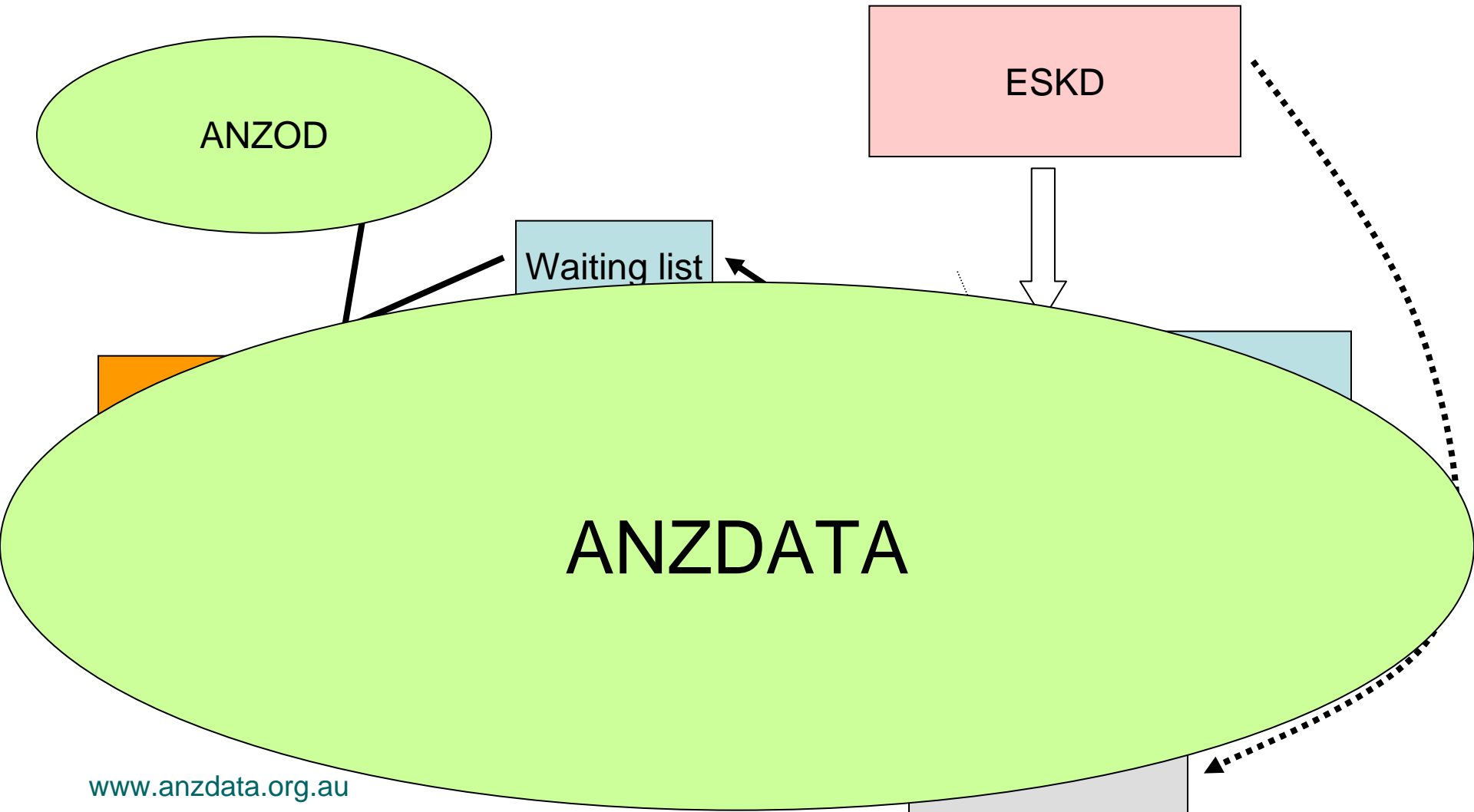


Renal = Kidneys = Nephrology





A 1-slide course in end-stage kidney disease





Why is renal disease important?

- For much of its history, nephrology was seen as a boutique specialty treating exotic and rare diseases with high technology



ANZDATA Registry

- Disease Registry for treated ESKD
- Formed in 1975 by combination of dialysis and transplant Registries
 - Coverage of all renal replacement therapy in Australia and New Zealand
 - Data since inception
 - Inclusion of all units in Australia & New Zealand
 - Funded by Australian and NZ Departments of Health, Kidney Health Australia
- Also responsible for ANZOD, ANZLKDR



Data collected

- All patients in all units in Australia / NZ
 - Cross sectional survey (now yearly)
 - Key events in “real time”

2002 AUST. & N.Z. DIALYSIS AND TRANSPLANT SURVEY
THIS SECTION FOR ALL PATIENTS

REGISTRY NUMBER: [] INITIAL HOSPITAL: [] CURRENT PARENT HOSPITAL: [] Physician (Optional): []

1. PATIENT INFORMATION: [] DATE OF BIRTH: [] SEX: []

2. RACIAL ORIGIN: [] PRIMARY RENAL DISEASE: [] BIOPSY: [] SE. CREATININE: []

3. COUNTRY OF BIRTH: [] POSTCODE AT Entry: [] POSTCODE AT End Survey: []

11. CO-MORBID CONDITIONS AT ENTRY: []

12. DISEASE AT ENTRY AND DURING CURRENT SURVEY: []

13. HEPATITIS C ANTIBODY: []

14. COURSE OF TREATMENT: COMPLETE ACCORDING TO CODE

Code	Day	Wk	Mo	Yr	Code	Day	Wk	Mo	Yr	Code	Day	Wk	Mo	Yr
A Hospital APD / PD	1st	1st	1st	1st	1st	1st	1st	1st	1st	1st	1st	1st	1st	1st
B Satellite APD / PD	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd	2nd
C Home APD / PD	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd	3rd
D Home CAPD	4th	4th	4th	4th	4th	4th	4th	4th	4th	4th	4th	4th	4th	4th
E Hospital HD	5th	5th	5th	5th	5th	5th	5th	5th	5th	5th	5th	5th	5th	5th
F Satellite HD	6th	6th	6th	6th	6th	6th	6th	6th	6th	6th	6th	6th	6th	6th
G Home HD	7th	7th	7th	7th	7th	7th	7th	7th	7th	7th	7th	7th	7th	7th
H Date of last post graft dialysis	8th	8th	8th	8th	8th	8th	8th	8th	8th	8th	8th	8th	8th	8th
I Transplant Outcome	9th	9th	9th	9th	9th	9th	9th	9th	9th	9th	9th	9th	9th	9th
J Graft function - Transplant	10th	10th	10th	10th	10th	10th	10th	10th	10th	10th	10th	10th	10th	10th
K Date of last visit	11th	11th	11th	11th	11th	11th	11th	11th	11th	11th	11th	11th	11th	11th
L Date of last visit - From 1st follow up	12th	12th	12th	12th	12th	12th	12th	12th	12th	12th	12th	12th	12th	12th
M Date of last visit - From 1st follow up	13th	13th	13th	13th	13th	13th	13th	13th	13th	13th	13th	13th	13th	13th
N Date of last visit - From 1st follow up	14th	14th	14th	14th	14th	14th	14th	14th	14th	14th	14th	14th	14th	14th
O Date of last visit - From 1st follow up	15th	15th	15th	15th	15th	15th	15th	15th	15th	15th	15th	15th	15th	15th
P Date of last visit - From 1st follow up	16th	16th	16th	16th	16th	16th	16th	16th	16th	16th	16th	16th	16th	16th
Q Date of last visit - From 1st follow up	17th	17th	17th	17th	17th	17th	17th	17th	17th	17th	17th	17th	17th	17th

15. CANCER EVER? Y/N [] 16. CAUSE OF DEATH: [] 17. WAS GRAFT SUSTAINING LIFE? []

18. PARENTHOOD: []

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

19. TYPE OF DIALYSIS: [] 20. DRY WEIGHT AT ENTRY: [] 21. UNCONNECTED: [] 22. CALCIUM: [] 23. PHOSPHATE: [] 24. HAEMOGLOBIN: [] 25. EPO AGENT: [] 26. FERROUS: [] 27. % SATURATION: []

27. DIALYSER BRAND: [] 28. BLOOD FLOW RATE: [] 29. SESSIONS PER WEEK: [] 30. HOURS PER SESSION: [] 31. UREA REDUCTION: []

32. ACCESS IN USE: [] 33. ACCESS IN USE: [] 34. CONNECTION SYSTEM: [] 35. PERITONITIS: [] 36. NUMBER OF EPISODES OF PERITONITIS: [] 37. TOTAL VOLUME OF WEEKLY CHANGES: []

38. DIALYSATE: [] 39. DIALYSATE DAILY: [] 40. RESIDUAL RENAL FUNCTION: [] 41. REASON FOR TRANSFER: []

42. GRAFT NUMBER: [] 43. DATE OF THIS TRANSPLANT: [] 44. REFERRING HOSPITAL: [] 45. DONOR HOSPITAL: [] 46. TRANSPLANT HOSPITAL: [] 47. RECIPIENT ANTIBODY STATUS: [] 48. NUMBER REACTION EPISODES THIS SURVEY: []

49. DONOR DETAILS: [] 50. TOTAL IMMEDIATE REACTION: [] 51. DISEASE PATTERN: [] 52. DATE FIRST PROVEN: [] 53. CAUSE OF GRAFT FAILURE: []

54. MONOCLONAL POLYCLONAL THERAPY: []

55. COURSE: []

56. TOTAL DAILY DRUG DOSE (mg): []

57. CYA SPARING DRUG: []

58. BODY WEIGHT (kg): []

59. SEBUM CREATININEM: []

60. HAEMOGLOBIN: []

61. FOR OFFICE USE ONLY: []

62. PRA AND CROSSMATCH: []

https://survey.anzdata.org.au - ANZDATA Registry - Microsoft Internet Explorer

Welcome, Stephen McDonald (STEPHENM)

08-APR-2006

Real Time Data Entry

Search for Patients for Real Time Entry of Key Events

Enter Search Criteria

Registry #: []

Surname: []

Given Name: []

Date of Birth: [] to []

Hospital at start of Survey: []

Search Clear Form

Full Survey Data Entry

New Patient Complete

Show Patients Remaining In Survey

Search for a Patient

start Form_revisions My Music Windows Me... Microsoft Po... ANZDATA... https://surv... 11:42 PM



How do we differ

- Participation

- By all units

- Voluntary
 - “pressure of conformity”

- Contrast

- Cancer Registries
 - Other renal Registries
 - US compulsory
 - UK voluntary
 - Other Registries

*“OWNED AND OPERATED....
BY THE RENAL COMMUNITY”*

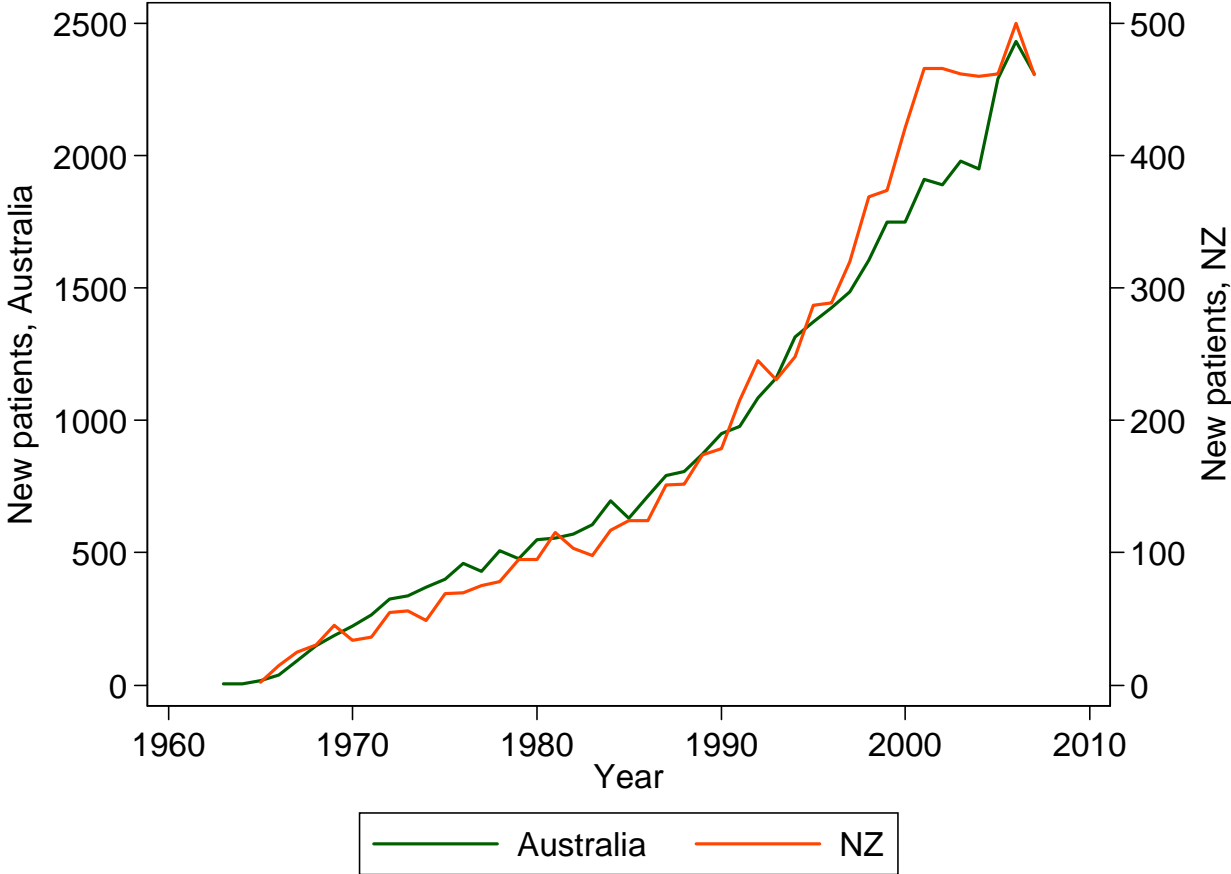


What to we actually do

- Outputs
 - Reports (prepared in-house & printed externally)
 - Renal units
 - Annual reports
 - Interim summaries

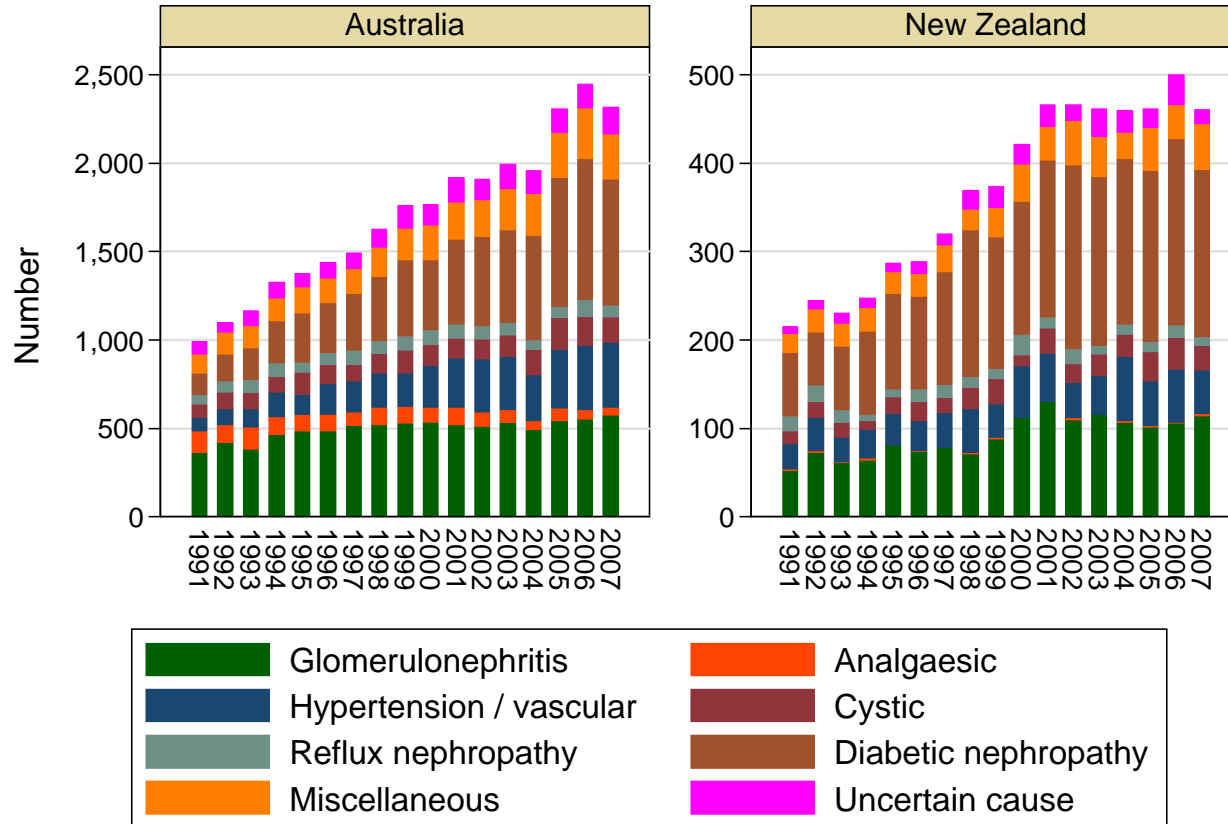


Annual Report 2008





Annual Report 2008 - 2





Annual report 2008

- 10-12 chapters
- Somewhat eclectic content
- Extensive data tables
 - Now in CD
- All elements available on-line at www.anzdata.org.au
- Now only about 350 copies printed
 - Increasing emphasis on WWW for dissemination



Outputs 2

- Research
 - Datasets
 - Deidentified datasets for bespoke analyses
 - Routine data feeds
 - Analyses
 - For external requests
 - For internal projects



Research output

- Major emphasis in last 10 years
- Deliberate effort to utilise dataset to address clinically relevant questions
- Coincides with major changes within nephrology
 - Thrust to create an evidence base
 - Recognition of a “population based” perspective



What does a Registry have to offer to the “evidence base”

- For most interventions an RCT is considered essential
 - However for very considerable areas of clinical practice an RCT is not feasible, or is unlikely to be performed
 - Within nephrology, several examples
 - Mortality benefit of transplantation
 - Haemodialysis vs peritoneal dialysis
 - ...?Dialysis itself (in some groups)



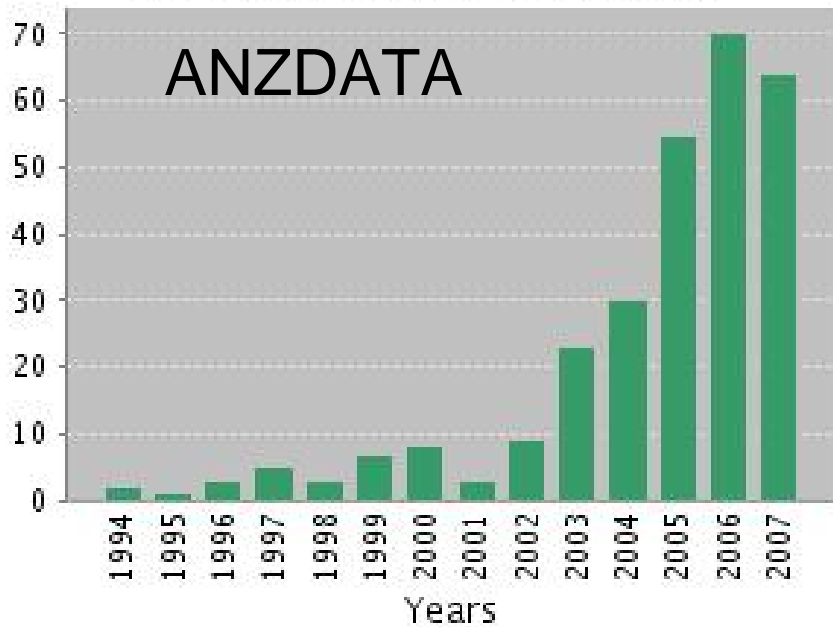
Research strengths

- Completeness and long term followup are substantial strengths
- Local practice differences offer opportunities
- Other areas where local data / outcomes of intrinsic importance

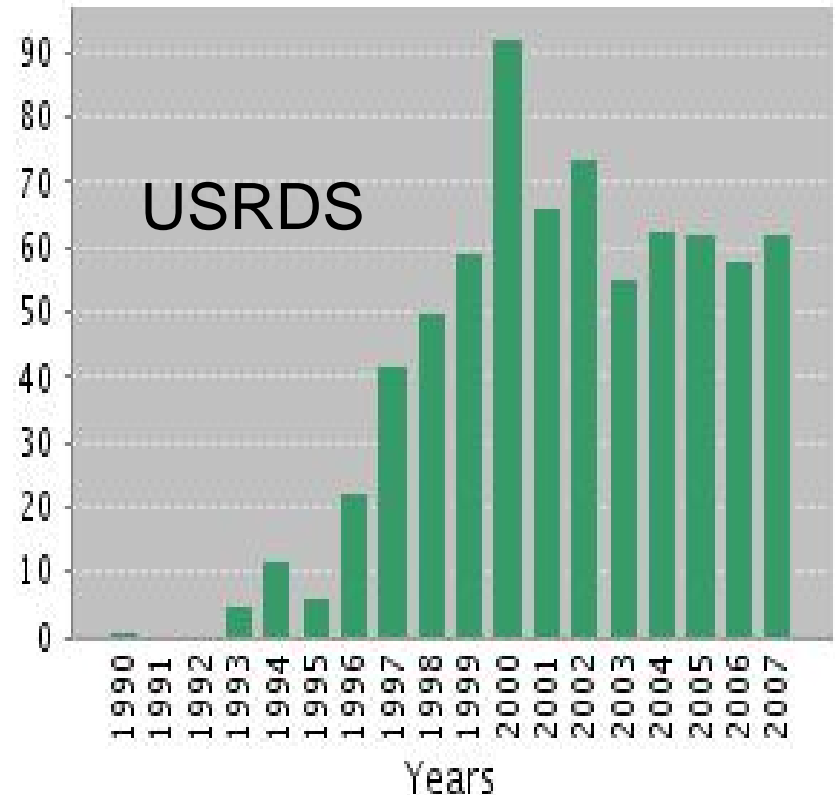


Citations – ANZDATA vs USRDS

Citations in Each Year



Citations in Each Year





Example 1

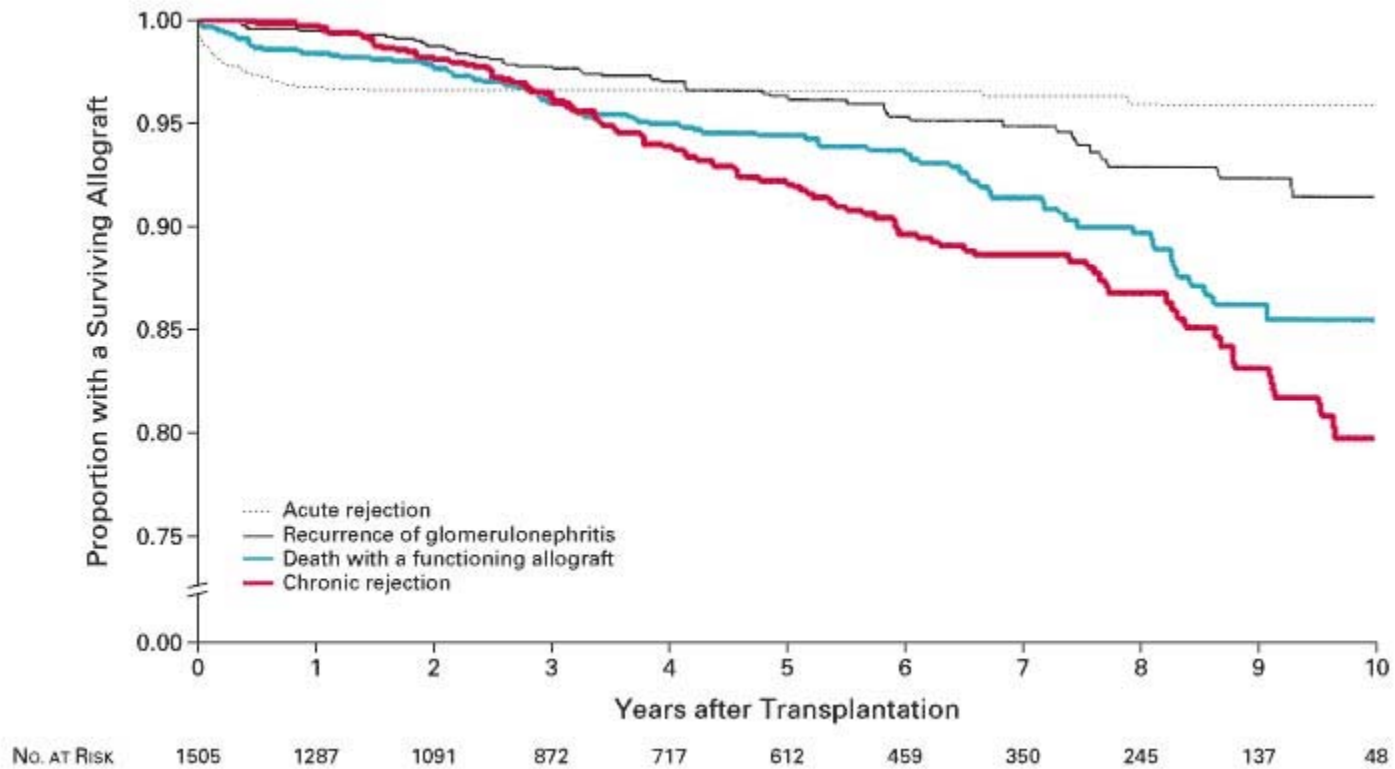


Figure 1. Kaplan–Meier Analysis of Allograft Loss Due to Recurrence of Glomerulonephritis, Acute Rejection, Chronic Rejection, and Death with a Functioning Allograft. Briganti, Russ, McNeil, Atkins & Chadban, NEJM 2002

Table 2. Unadjusted Long-Term Survival among Children with End-Stage Renal Disease in Australia and New Zealand, According to Age at the Start of Renal-Replacement Therapy.

Age (Yr)	Survival			
	5 Yr	10 Yr	15 Yr	20 Yr
	<i>percentage (95 percent confidence interval)</i>			
<1	73 (54–85)	67 (46–81)	67 (46–81)	—
1–4	79 (70–86)	78 (68–85)	74 (66–83)	74 (61–83)
5–9	87 (81–91)	79 (73–85)	73 (66–80)	72 (64–79)
10–14	88 (85–91)	79 (74–83)	70 (65–75)	68 (62–73)
15–19	86 (83–88)	79 (76–82)	72 (68–75)	65 (60–69)
0–19	86 (84–88)	78 (76–80)	71 (69–74)	66 (63–69)

Example 2

Table 3. Age-Specific Rate Ratios for Death within 10 Years among Children Who Started Renal-Replacement Therapy in Australia in the Period from 1963 to 2002, as Compared with Age-Specific Mortality among the General Australian Population.*

Decade Therapy Started	Rate Ratio for Death			
	0–4 Yr	5–9 Yr	10–14 Yr	15–19 Yr
1963–1972	116 (37–358)	236 (98–566)	111 (64–198)	52 (36–75)
1973–1982	63 (26–151)	122 (75–199)	71 (49–104)	20 (14–28)
1983–1992	30 (16–57)	30 (13–73)	37 (23–59)	19 (13–27)
1993–2002	32 (17–59)	94 (39–226)	35 (16–78)	30 (18–49)

* Numbers in parentheses are 95 percent confidence intervals.



Example 3

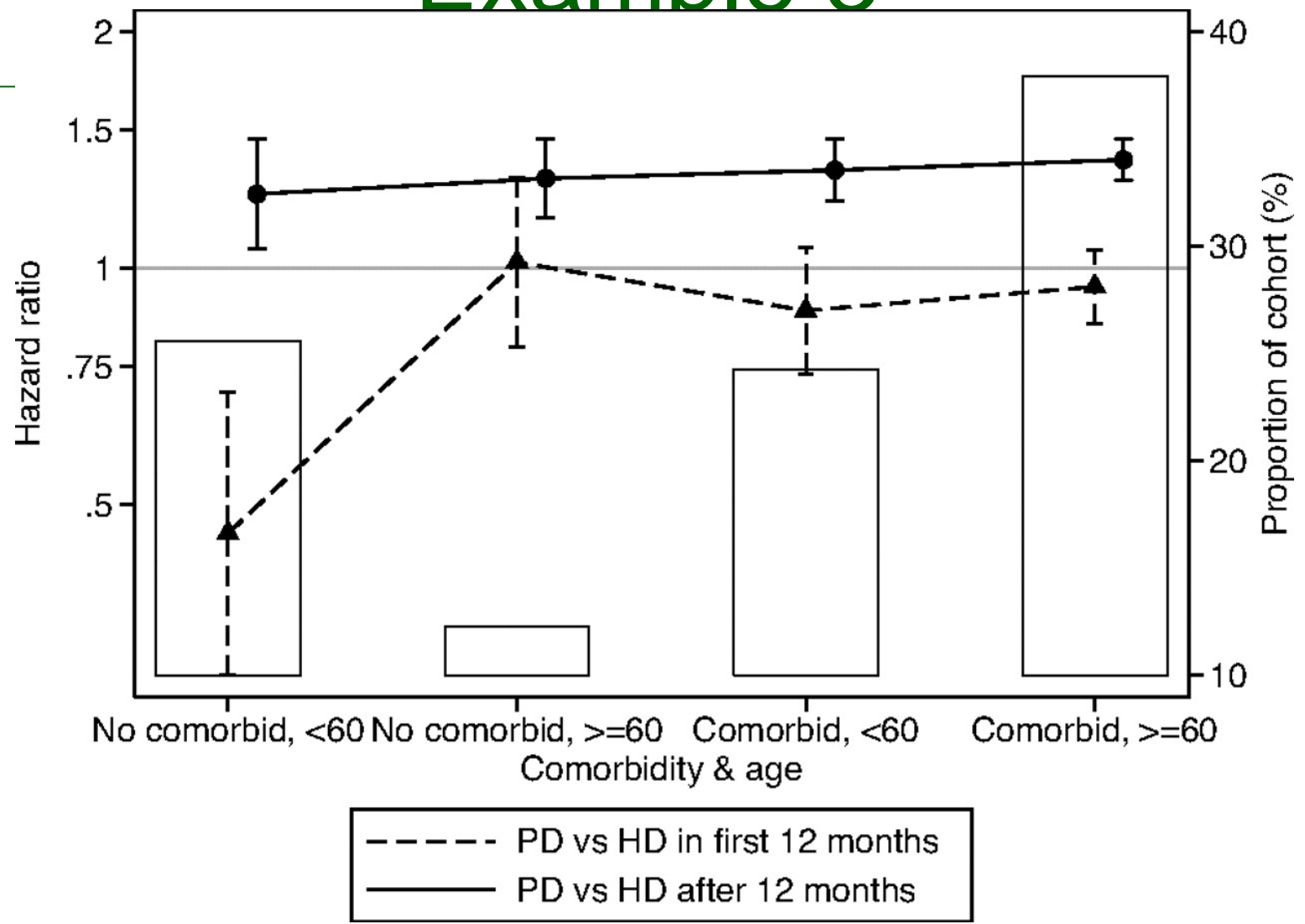
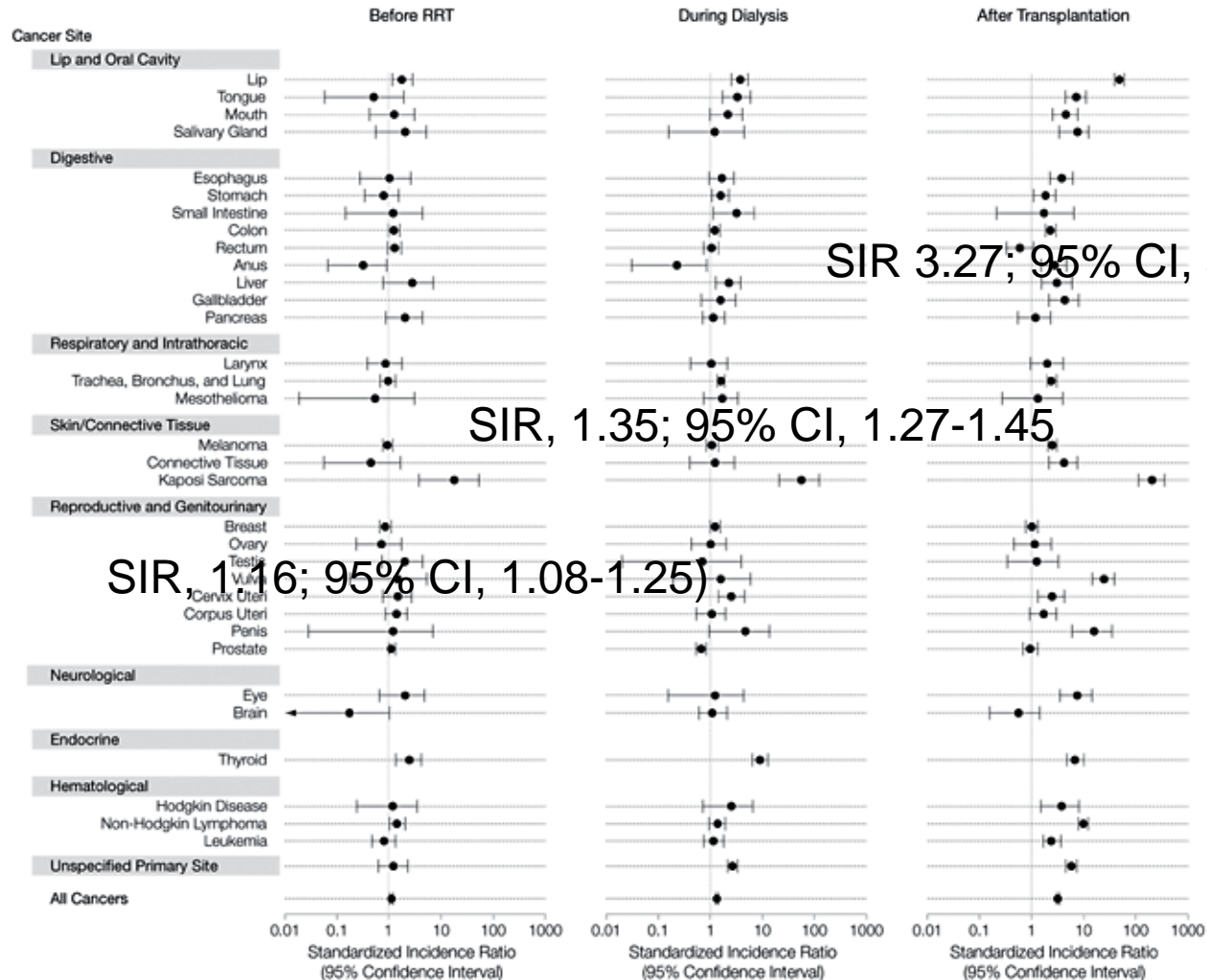


Figure 4. Risk of PD compared with HD stratified by age and the presence of any comorbidity. McDonald, Marshall, Johnson & Polkinghorne, J Am Soc Nephrol, 2009



Example 4



Risk of Cancer in Australian Patients With ESKD. Vajdic, McDonald, McCredie, van Leeuwen, Stewart, Law, Chapman, Webster, Kaldor, Grulich, JAMA 2006



Underlying approach

- Develop in-house expertise
- Change attitudes to use of data
- Create policies to allow release and use of data externally
 - More use = better value
 - Contributor use = virtuous circle
 - Greater appreciation of the value of the data
 - Increase in sophistication and skill level



Further research directions

- Network of “working groups” responsible for various areas within ANZDATA
 - Broaden involvement to
 - Get more ideas
 - Get more done
- Data linkage
 - Cancer completed
 - Tb in progress



Centre reports

- Area of substantial work over recent time
- Growing interest in evaluating unit-specific results
- For each unit, yearly production of
 - Transplant report
 - Dialysis report

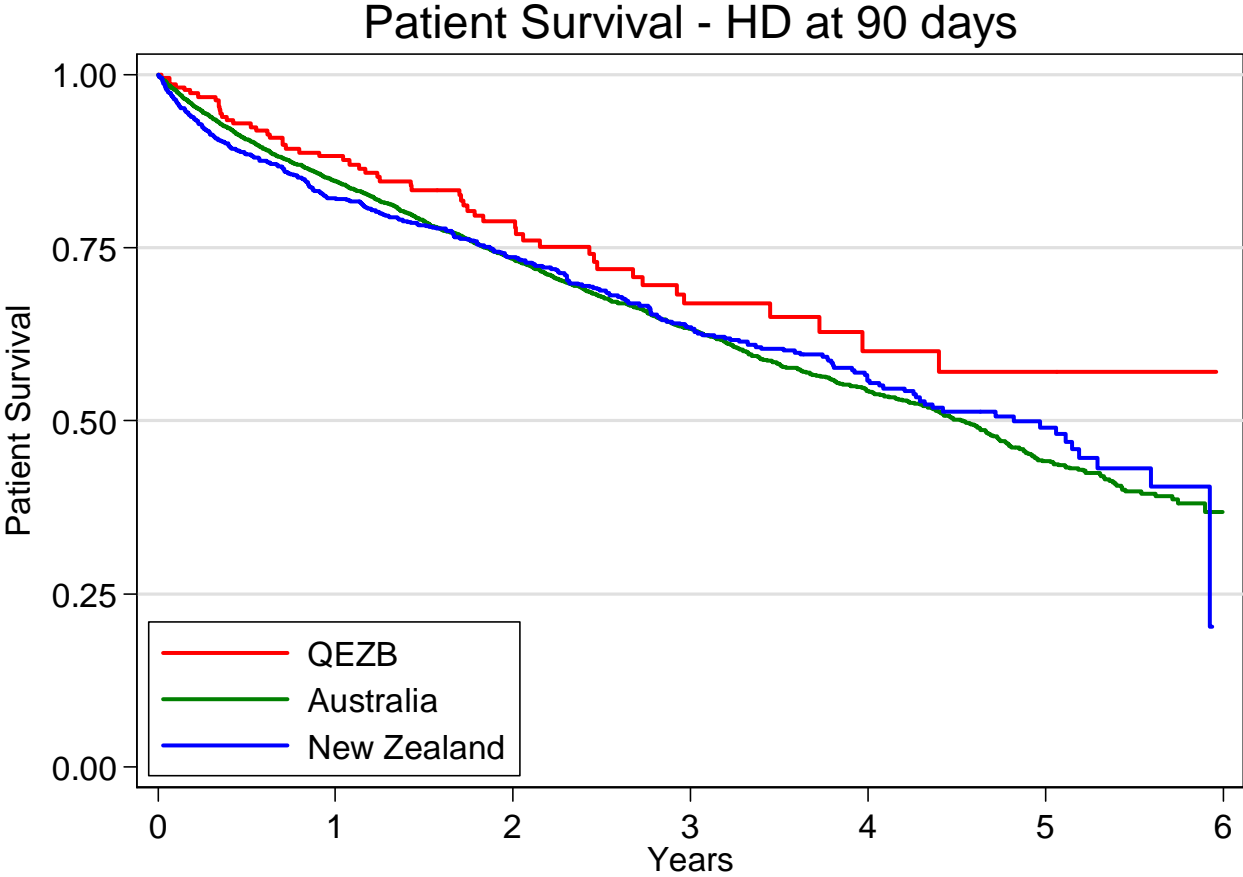


Centre reports

- Have been produced for many years
 - Format evolving
 - Now analysed in Stata, compiled from Stata to LaTeX
 - Facilitates inclusion of broader range of data in better format
 - Currently only limited adjustment for comorbidities



Centre report –example



Patient survival during HD from [current QEH centre report](#)



Comparing centres

- Important theoretical and practical aspects to comparisons of centre performance
- Currently results released only back to individual centres
 - They can choose further distribution at their discretion
 - Future direction is to more identification
 - Will shortly be naming the best 5 units in each report



Centre reports – overseas

- International trends are to identify and release data
 - US ([link](#))
 - UK



Medicare.gov - Dialysis Facility Compare - Geography Questions - Windows Internet Explorer
http://www.medicare.gov/Dialysis/Include/DataSection/Questions/SearchCriteria.asp?version=default&browser=IE%7C7CWIndows+Vista&language=English&
Norton Phishing Protection on Identity Safe Log-ins
Medicare.gov - Dialysis Facility Compare - Geogr...

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Dialysis Facility Compare

[Mailing List](#) [E-mail This Page](#)

- [Find](#)
- [About](#)
- [Data Details](#)
- [Resources](#)

Welcome to Dialysis Facility Compare

This website provides important information and resources for patients and family members who want to learn more about chronic kidney disease and dialysis.

Look at the information on Dialysis Facility Compare carefully. Use it with other information as you compare facilities and decide where to get dialysis. You should also:

- Visit facilities that interest you,
- Talk to dialysis facility staff and patients,
- Talk to your doctor and,
- Contact kidney disease groups. The phone numbers and website for some of the kidney disease groups are found in the [Resources](#) section of this website.

Print out information you will find useful on this website and bring it with you when you visit facilities or talk with doctors, staff, other patients, or kidney disease groups.



Weak points

- Data collection
 - Unfunded
 - Increasingly burdensome for units
 - Each year, more difficult
 - Despite substantial changes to data collection about 5 years ago (single yearly collection etc)
 - Paradoxically, more and more suggestions
 - ?Victim of success



Weak points

- Funding
 - Yearly contract from DOHA & NZ Govt
- Staffing
 - Project Manager
 - Database Manager
 - Admin x 1.0 + ~0.6 Casual
 - Biostatistician x 0.6
 - Epi Fellow
- What is critical mass?



Future directions for data

- Development of real-time data entry
 - Web-based
 - Key events
- Still retain cross sectional survey
 - Presently paper based
- In an ideal world...
 - Online transfer from clinical information systems




Welcome, Stephen McDonald (STEPHENM)

02-SEP-2005


Real Time Data Entry

[Real Time Entry
New Patient](#)[Real Time Entry
Amend New
Patient](#)[Real Time Entry
Key Events for
Patients](#)[Real Time Entry
Transfer
Notification](#)

Search for Patients for Real Time Entry of Key Events

 [email](#)[help](#)

Enter Search Criteria

Registry #:	<input type="text"/>
Surname:	<input type="text"/>
Given Name:	<input type="text"/>
Date of Birth:	<input type="text"/> to <input type="text"/>
Hospital at start of Survey:	<input type="text"/> 

Full Survey Data Entry

[New Patient
Complete](#)[Show Patients
Remaining In
Survey](#)[Search for a
Patient](#)


[email](#) [help](#)
Real Time
Data Entry
[Real Time Entry
New Patient](#)
[Real Time Entry
Amend New
Patient](#)
[Real Time Entry
Key Events for
Patients](#)
[Real Time Entry
Transfer
Notification](#)
Full Survey
Data Entry
[New Patient
Complete](#)
[Show Patients
Remaining In
Survey](#)
[Search for a
Patient](#)

Enter Details for the New Real Time Entry Patient

Initial Hospital, State, Unit Number		Current Parent Hospital, State, Unit Number		Physician
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Surname	Given Names	Date of Birth	Gender	
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
Racial Origin	Primary Renal Disease	Biopsy	Serum Creatinine At Entry: $\mu\text{mol/L}$:	
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
Other: <input type="text"/>	Other: <input type="text"/>			
Country of Birth		Postcode		
Aust / NZ	Other - please Specify			
<input type="text"/>	<input type="text"/>	<input type="text"/>		

Co-morbid Conditions At Entry

Late Referral:	Height (cm):	Weight (kg):	Smoking:	Hypertension Requiring Tension:
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Chronic Lung:	Coronary Artery:	Peripheral Vascular:	Cerebro Vascular:	Diabetes:
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Mode of First Treatment:	Date of First Treatment:	If First Treatment Haemodialysis what ACCESS was used:		
<input type="text"/>	<input type="text"/>	<input type="text"/>		

Create New Patient Details

Clear Form



ANZDATA Registry - Logged In

[email](#) [help](#)[Logout](#)**Collection Centre Applications****Australia & NZ Dialysis and Transplant Survey**[Start Web Data Entry Application](#)**Reports**

Discoverer functionality for reporting on your data is under construction

[Patient List](#)[Discoverer Plus](#)[Discoverer Viewer](#)[Statistics for Current Survey](#)[Summary Statistics](#)**Data Extraction**[ASCII File Generation](#)**ANZDATA Applications****Maintain Reference Tables**[Reference code maintenance](#)**Maintain Users**[Create a New User](#)[Modify an Existing User](#)[Delete an Existing User](#)**Washing**

Set status to lock patients

[Wash/Accept by Individual Patient](#)[Wash/Accept by Hospital](#)**New Survey Period**

Prepare the system for a new survey - check the number of months this survey field first

[Roll-Over Survey](#)





Weak Points

- Understaffed for long term improvement
 - Development of new concepts / improvement / updating dependent on contributions of others
- Isolation
 - How do make people aware of your work
 -



Does it work?

- How do you know whether something is working
 - We are a monopoly provider
 - We do some things well, other things less well
- Key question: have we made a difference?
 - To hospitals
 - To government
 - To clinicians