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SCOTTISH RENAL REGISTRY

SECOND ANNUAL REPORT - 1999

Scottish Renal Registry Report 1999

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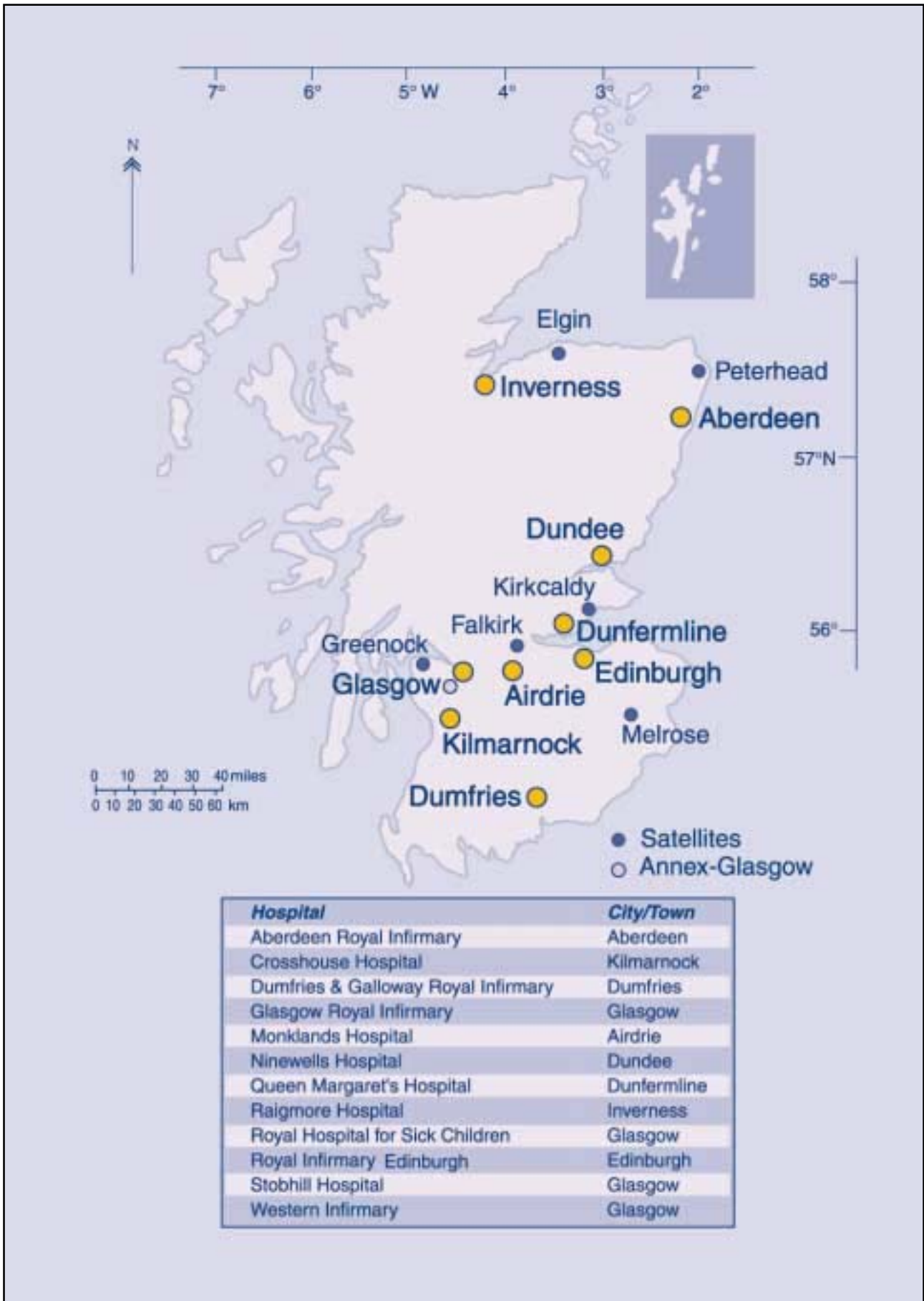
Some data in this report are reproduced with kind permission from the Registrar General in Scotland.

Keith Simpson, Consultant Physician and Chair of the Scottish Renal Registry

Wendy Metcalfe, Specialist Registrar in Nephrology, Bristol

Gordon Prescott, Medical Statistician, Department of Public Health, University of Aberdeen

Report Editorial Group



EXECUTIVE SUMMARY

The first patient was dialysed for end stage chronic renal disease in Scotland in 1960. 7571 patients had been accepted for long-term renal replacement therapy up to 31 December 1999. The median age for new patients starting renal replacement therapy has risen from 24 in 1964 to 66 in 1999. 3036 patients were receiving renal replacement therapy for end stage renal disease on 31 December 1999. The take on rate for new patients was 108 per million of the population in 1999. There is no sign yet that the take on rate has reached a plateau. In 1999 47% of patients had a functioning kidney transplant, 38% were being treated with haemodialysis and 15% with peritoneal dialysis.

There are now 11 adult and one paediatric renal units in Scotland with seven satellite or annex units. They all contribute fully to the Scottish Renal Registry and all patients receiving renal replacement therapy for end stage renal disease are registered.

Since 1994, a marked improvement in the treatment of hospital haemodialysis patients has been documented using the urea reduction ratio as a measure of quality assurance in haemodialysis. For the first time we report on the basis of a similar quality assurance audit for patients treated with peritoneal dialysis.

INTRODUCTION

This second annual report from the Scottish Renal Registry (SRR) follows the previous outline and presents information about the causes, incidence, prevalence, distribution, methods of treatment and outcome of patients receiving renal replacement therapy (RRT) for end stage renal disease (ESRD) between 1960 and 31st December 1999. There is no information about patients with acute renal failure (ARF) or those with chronic renal failure (CRF) before RRT is required.

Funding

The Information and Statistics Division (ISD) of the National Health Service Scotland (NHSScotland) assumed overall responsibility and funding for the SRR in April 1999. The Audit of Renal Management in Scotland (ARMS) research project, which ran between 1997 and 2000, was separately funded by a research grant from the office of the Chief Scientist in Scotland.¹ Each Renal Unit also pays for at least one computer terminal on which they can view Registry data. Some renal units maintain an electronic patient record and little extra cost is incurred downloading data to the SRR. Renal Units maintaining paper patient records re-enter their data manually on the registry computer terminal. We are not charged for our use of the NHS computer communications network. In the period covered by this report, no financial assistance was received from commercial organisations.

Conflict of interest

The SRR chair, executive and report editorial group do not have any conflicting interests.

Database

The database and computer server have not changed since the 1998 report¹. We are moving our communications from the X-25 network to the newer NHS computer network. Many new online and immediate feedback methods have been introduced for data validation. We also now send monthly reports to each renal unit to confirm complete registration of new patients and lists of new patients with ESRD, registering for RRT are inspected during peer review visits and any discrepancies are noted. The accuracy and completeness of data recorded from each renal unit is reported and reviewed at an annual meeting.

Data

The historic epidemiologic data have been retrieved from the ERA-EDTA database and from a variety of sources in each renal unit. In 1999 and 2000, further work was done to improve the quality of the historic data. In particular, valid postcodes were recorded for 96% of patients in the Registry. From this Health Boards of residence, social deprivation score and local population statistics can be derived. A core data set has been defined for prospective collection and is

reproduced in appendix 1. This is used for the basic epidemiology report. Other data are collected when required for specific projects.

Office

The SRR has two offices in the renal unit at the Glasgow Royal Infirmary (GRI). One is a general office for the SRR. The other is devoted to the peer review project. An annual rent covers the cost of the accommodation, heating, lighting and stationary, but the SRR is autonomous

Staff

One full time senior administrative assistant is employed to run all aspects of the registry. Bespoke software is commissioned when needed although this can often be produced in house using the software tools available. A professional academic statistician is employed one day per week. A full time administrative assistant is employed to co-ordinate the peer review project.

The collection and collation of the data in each renal unit is carried out under the supervision of the consultant member of the SRR steering group. The work is undertaken by many members of staff in each unit.

Much of this work is necessary to allow the smooth running of a renal unit. Some extra work is required and this is organised and funded locally. We recognise that this is an inescapable cost of participating in a national audit and that the benefits of such an audit would not be available without these local personnel and funds.

Organisation

Each renal unit elects one consultant nephrologist to serve on the SRR steering group, which meets twice a year. A senior nurse, laboratory scientist and two consultants in public health medicine also serve on the steering group. Three patients or their representatives serve on the Scottish Renal Association (SRA) peer review group which is closely associated with the SRR. A smaller executive committee meets on another two occasions each year and the chairman supervises the day to day affairs of the registry. The full composition, names and addresses of the steering group and executive committee are shown in appendix 2. All major decisions including initiating new projects, releasing data to third parties and approving manuscripts for publication are taken by the steering group. The SRR operates within the SRA and under the auspices of ISD. The SRA and the SRR are affiliated to the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA).

Publications

A report on the activities of the SRR is presented to a half-day academic meeting of the SRA every November. This report is published every year and specific projects are published on behalf of the SRR. These are detailed in appendix 3.

¹ Grant awarded to Alison MacLeod, Izhar Khan and Keith Simpson from the Clinical Resource & Audit Group of the Scottish Office Department of Health. Grant No CA97/13 for £138,937 (1997) for 3 years. Improving the management of End Stage Renal Disease in Scotland: A national audit.

Security & patient confidentiality

The computer server and a verified cycle of daily backup tapes are physically secure and stored in different locations. Access to the communication network and database is protected by passwords at a number of levels. A password is issued only against a request document, which is countersigned by a member of our steering group for whom a specimen signature is held in the SRR office. Database users can view anonymous summary data for the whole registry and patient specific data only for patients in the renal unit to which they are affiliated. Rights to view or add to the data for patients attending a renal unit are granted by the consultant member of the steering group for that renal unit. In general, access to data on the registry is granted to staff who have access to the same data in their renal unit. The database can maintain an audit trail of all additions and deletions. Security procedures have been discussed by our steering group and will be inspected along with our quality assurance (QA) scheme by a trusted member of a foreign renal registry, which is also affiliated to the ERA-EDTA. The SRR is registered under the UK data protection act. Patient confidentiality is very important and is rigorously protected. We are mindful of the difficult balance between confidentiality for patients and our important duty to use the data to the best advantage of our patients, the scientific community and society. The interpretation of the laws concerning data protection in Scotland are currently being re-examined as they are in England, Wales and Northern Ireland. As an initial step to inform patients about the work of the SRR, we have prepared a notice that will be displayed in every renal unit and could be distributed as a letter. The text of this notice is in appendix 4.

Data release

We have a well organised method of obtaining written consent for release of data from the consultant members of the steering group. Applications stating the data required and the reason is sent to each consultant member of our steering group. A standard form giving or withholding their consent or requesting further information is returned to the SRR office. Anonymous summary data as approved by the steering group are published in this report, in the medical literature and are readily available. Other data are released to bona fide research workers, health boards, the ISD of the NHSScotland, the ERA-EDTA registry, the UK Renal Registry, the UKTSSA and to our members when they are pursuing particular projects. These organisations are listed in appendix 5. The SRR is also pleased to receive copies of published reports from sister organisations. These are listed in appendix 6.

Renal Unit anonymity

When the SRR was first established, it was agreed that the identity of renal units would remain confidential. This restricted the type of reports that could be produced because the different patient populations and RRT methods available made it ease to identify renal units from most reports. After discussion and agreement at the steering group, renal units

were named on a few graphs showing basic demographic details in our 1998 report. It has now been agreed that where appropriate, renal units will be identified after three cycles of an audit project. Full publication of these details may at times have to be restricted in order to preserve patient confidentiality where small numbers of patients are involved.

Quality assurance

The further you are from the source of the data, the harder QA becomes. Running a registry emphasises how much informal data validation and QA goes on in renal units where personal knowledge of the circumstances and the history of the patient (and the data) are used to support what are at times quite inadequate medical records. When the data are viewed outwith the context of the unit where they were collected, a more formal mechanism is required. We have a large series of internal validity checks that run automatically every night. Actual, probable or possible errors are flagged and reported back to the liaison person in each renal unit for correction or verification. These include obvious errors such as a date of first RRT, which is earlier than the date of birth, to unlikely but not impossible situations such as three changes in RRT method within a week. We have a complex method of detecting possible duplicate patient entries but this remains a major challenge for all registries. Failure in this simple measure results in an incorrect denominator for every published statistic. Outlying data are often apparent during the production of reports. They can be checked for validity but invalid data points near the mode will not be spotted in this way. A description of the errors for which we check and the methods used is available to legitimate enquirers.

As well as this internal validity check, we have introduced a method of confirming the correct registration of patients and the correct recording of data for a random sample of patients. This check is run in each renal unit as part of a general peer review programme, which has been established by the SRA. In this scheme, a team comprising of patient representatives, nurses, nephrologists and a representative from the SRR will visit each renal unit.

Data held in a registry are never perfect but we hope that these techniques will both reduce our errors and enable us to quantify them so that they can be taken into account when predictions are being made. The continuing work to improve the quality of existing data inevitably results in slight differences when the same statistic is reported in subsequent years. Rates based on population size may also change slightly if the population estimates are revised. We try to use the most up to date estimates of population size available. The sources of population statistics are given.

SUMMARY OF DATA

Total patients.

7571 patients have been registered with the SRR from its inception in 1991 until 31 December 1999 when the data for this report were collated.

Data pertaining to events prior to 1991 were incorporated retrospectively from the ERA-EDTA registry.² These data have proved patchy, incomplete and on occasion inaccurate. Data since 1991 have been entered manually or electronically from each of the 12 renal units in Scotland. The earliest date a patient is recorded as starting RRT for end-stage CRF in Scotland is October 1960.

Deaths.

4342 patients of the 7571 included in this report are known to be dead.

The total number of deaths in 1999 was 404.

Exclusions from analyses.

161 patients have uncertain status, that is their current location is not known and it is not known if they are alive or dead. These 161 patients include 94 whose data were obtained from the ERA-EDTA registry and for whom no further data are available. The remaining 67 have either moved outwith Scotland or are truly lost to follow-up.

Patients with uncertain status are censored within survival analysis at the date they are lost.

158 patients are recorded as having a renal transplant as their first mode of RRT in Scotland.

14 of these patients had a pre-emptive transplant. The remainder started RRT outwith Scotland and arrived in Scotland with a functioning transplant. At the time of publication, details of their RRT histories outwith Scotland were not available. These 144 patients have been excluded from the incidence figures and survival analyses but included in prevalence figures.

Patients recovering renal function.

Patients who recovered function within 90 days of starting RRT and have not yet required to restart RRT were excluded from the analysis.

Patients who recovered but required more than 90 days RRT remain in the data set.

For patients who had to restart RRT, after initial recovery within a 90-day treatment period, the date of first starting RRT was considered as beginning at the period of treatment that lasted more than 90 days.

Primary Renal Diagnoses

A diagnosis code for the primary renal disease (PRD) has been chosen by the nephrologists responsible for the care of the patient from the code list published by the ERA-EDTA.

To simplify analysis of the data these codes have been grouped into five categories: glomerulonephritis, interstitial nephritis, diabetic nephropathy, multi-system disorders and unknown diagnosis.

It is often not possible to make a precise diagnosis for patients presenting with ESRD because the subtle signs of the original disease may have been obscured. Most end stage kidneys look the same. Attributing the cause of renal failure to PRD does not tell us anything about the presence or absence of comorbid illnesses. For example, a patient with vascular disease or diabetes mellitus may have a different cause for their renal failure.

The full code list and subdivisions are shown in appendix 7.

Missing Data

Some patients have data missing from the registry. The majority of these missing data are historic and pertain to patients retrospectively registered from the ERA-EDTA registry. There are 163 such patients who have no recorded location, date or mode of starting RRT, 1 of whom also has no date of birth recorded on the SRR.

Missing basic data items are summarised below.

Table 1 Missing Data Items

Data Item	Total number missing	Number missing from patients alive on 31 December 1999
Mode of first RRT	18	12
Date of Death (n=4342)	0	0
Primary Renal Diagnosis	61	24
Missing Historic Data	163	0
Date of Birth	1	1

Presentation of the data

Throughout the report numeric data are shown either on the charts or in a separate table. In many charts the data are shown in five year bands. In order to present all the available data, the first time band represents six years. The statistical methods used for the report are described in appendix 8.

Abbreviations

Throughout this report for brevity and ease of reading some abbreviations are used. These are listed in full in appendix 9.

² The ERA-EDTA registry is held on an independent computer database located in Amsterdam Medical Centre in the Netherlands. Reports are published annually as an appendix to the journal Nephrology Dialysis and Transplantation.

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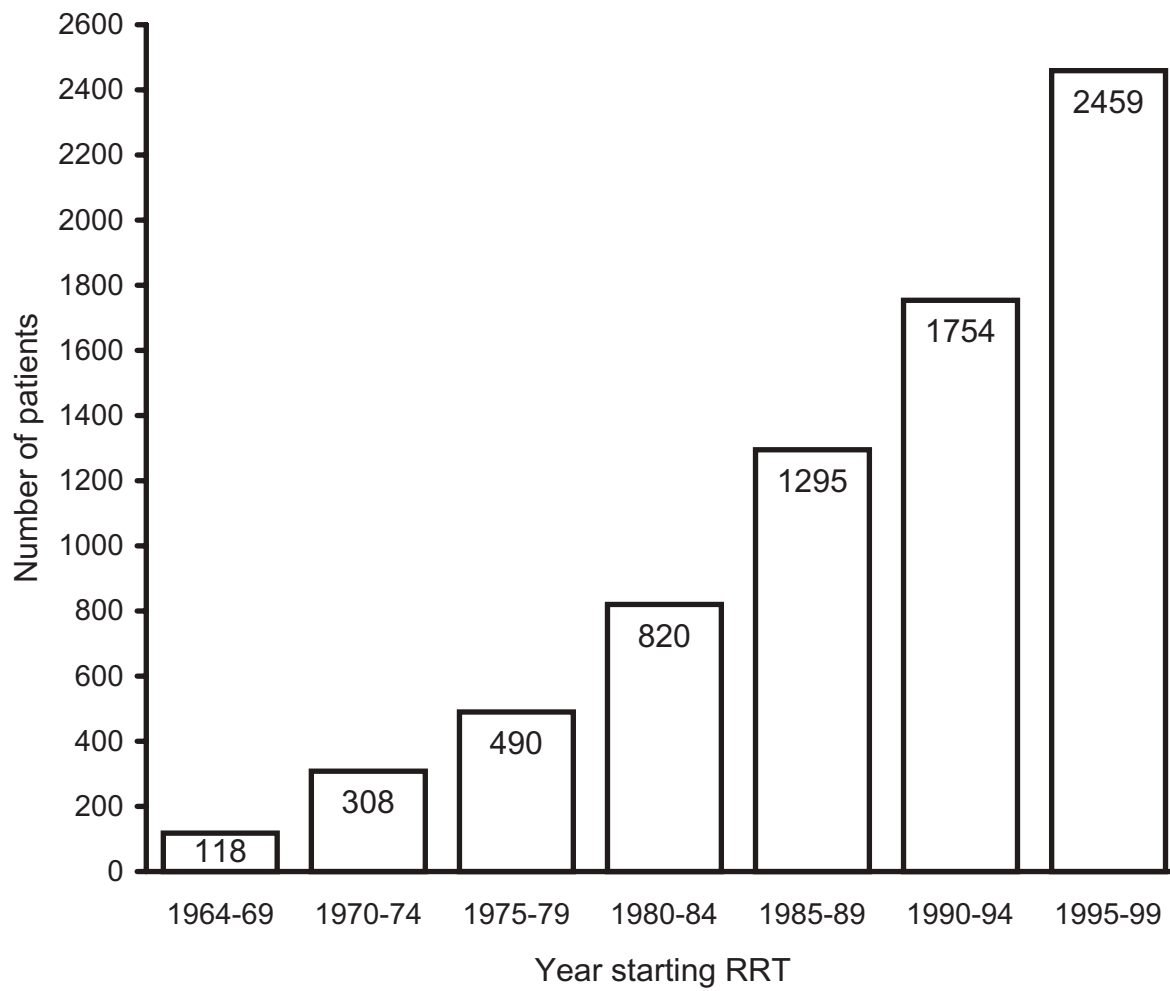
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A INCIDENCE

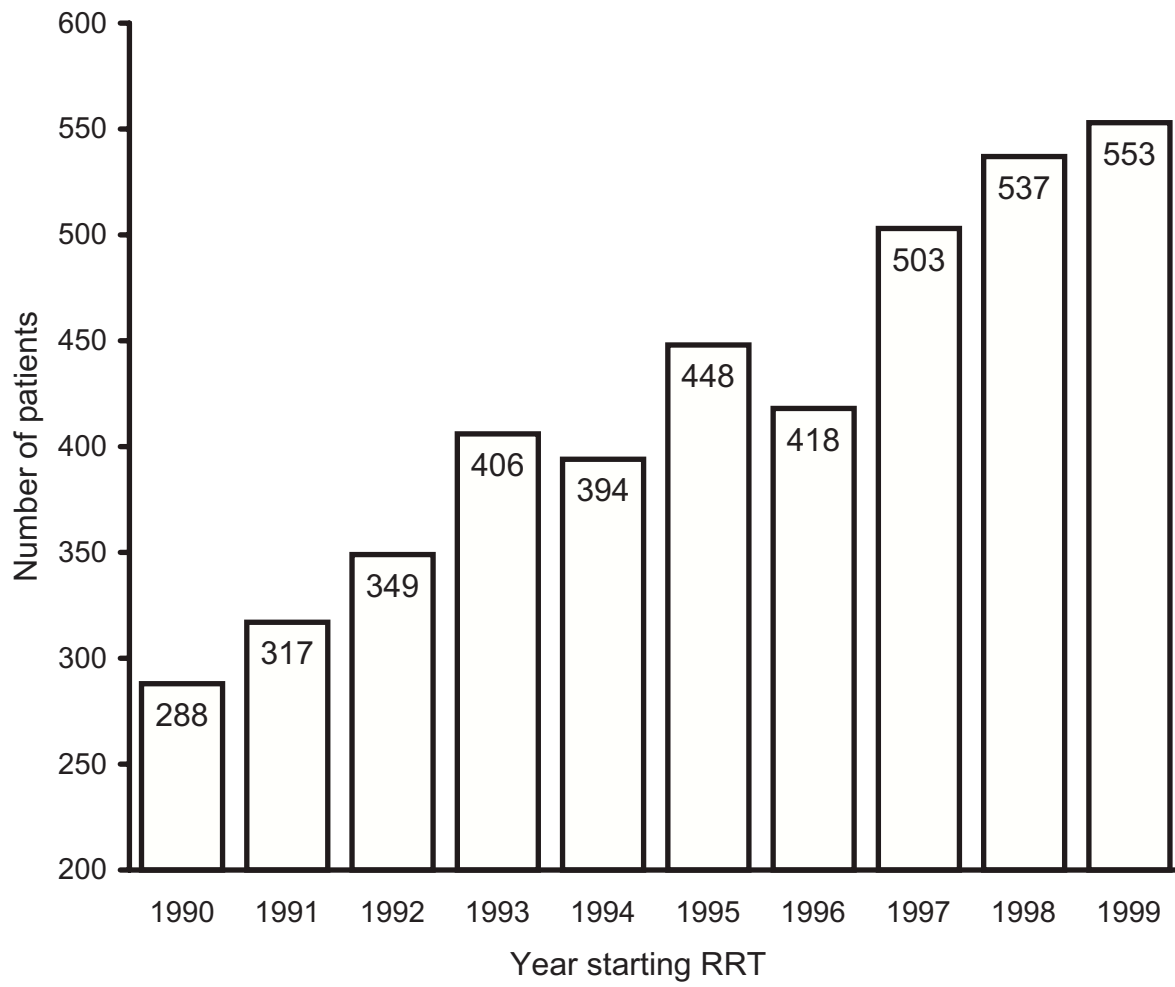
A1 INCIDENCE OF NEW PATIENTS STARTING RRT

The number of patients starting RRT continues to increase. Whilst there are fluctuations in the rate of increase year on year, there is no evidence of any plateau. Throughout the 36 years shown the distribution of males: females starting RRT has remained at around 60% : 40%.

A1.1 Incidence of new patients starting RRT 1964-1999

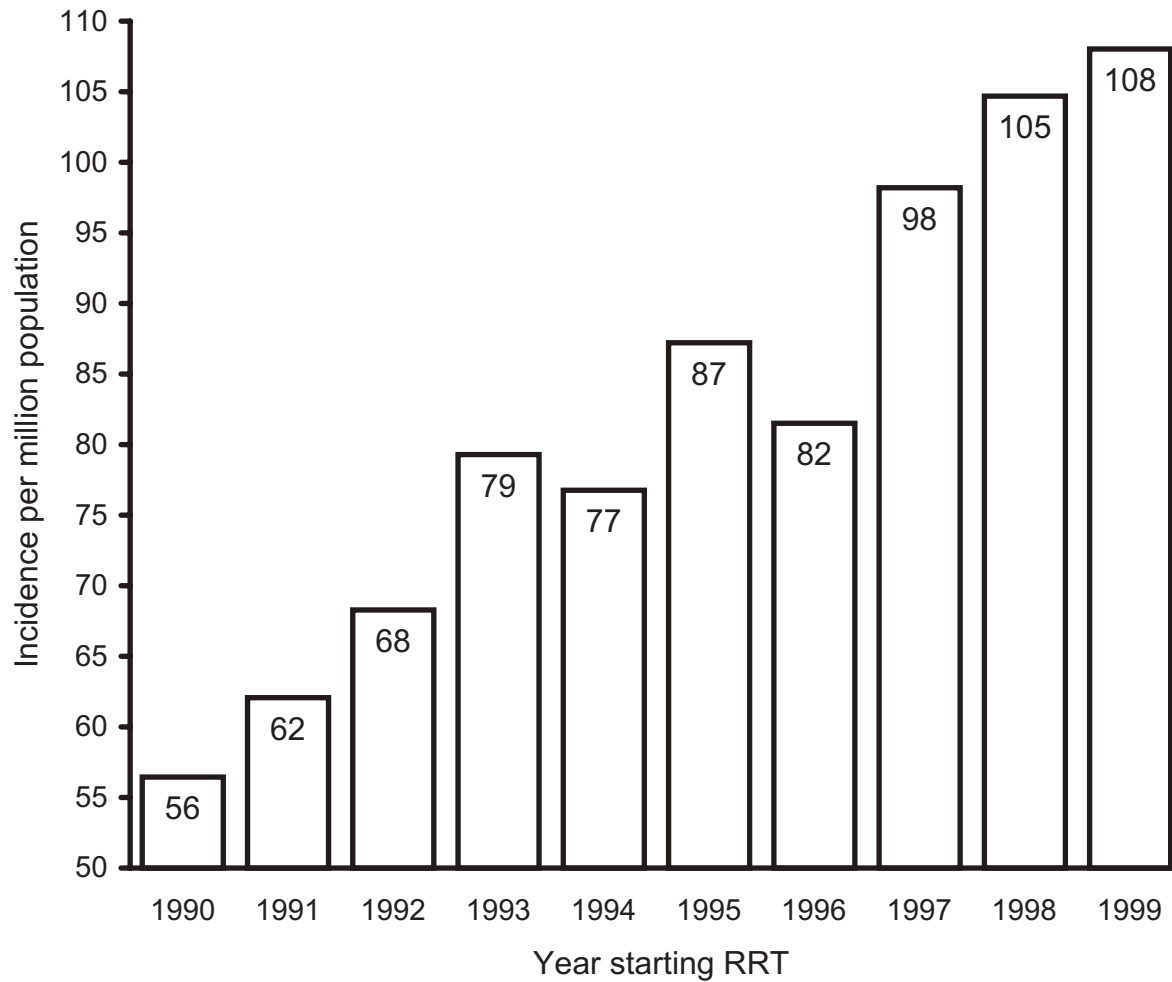


A1.2 Incidence of new patients starting RRT 1990-1999



A1.3 Annual incidence per million population of new patients starting RRT 1990-1999

Population figures are from the Registrar General for Scotland.³ They are population estimates for the 30 June of each year. The incidence of patients starting RRT per million of the population continues to rise.



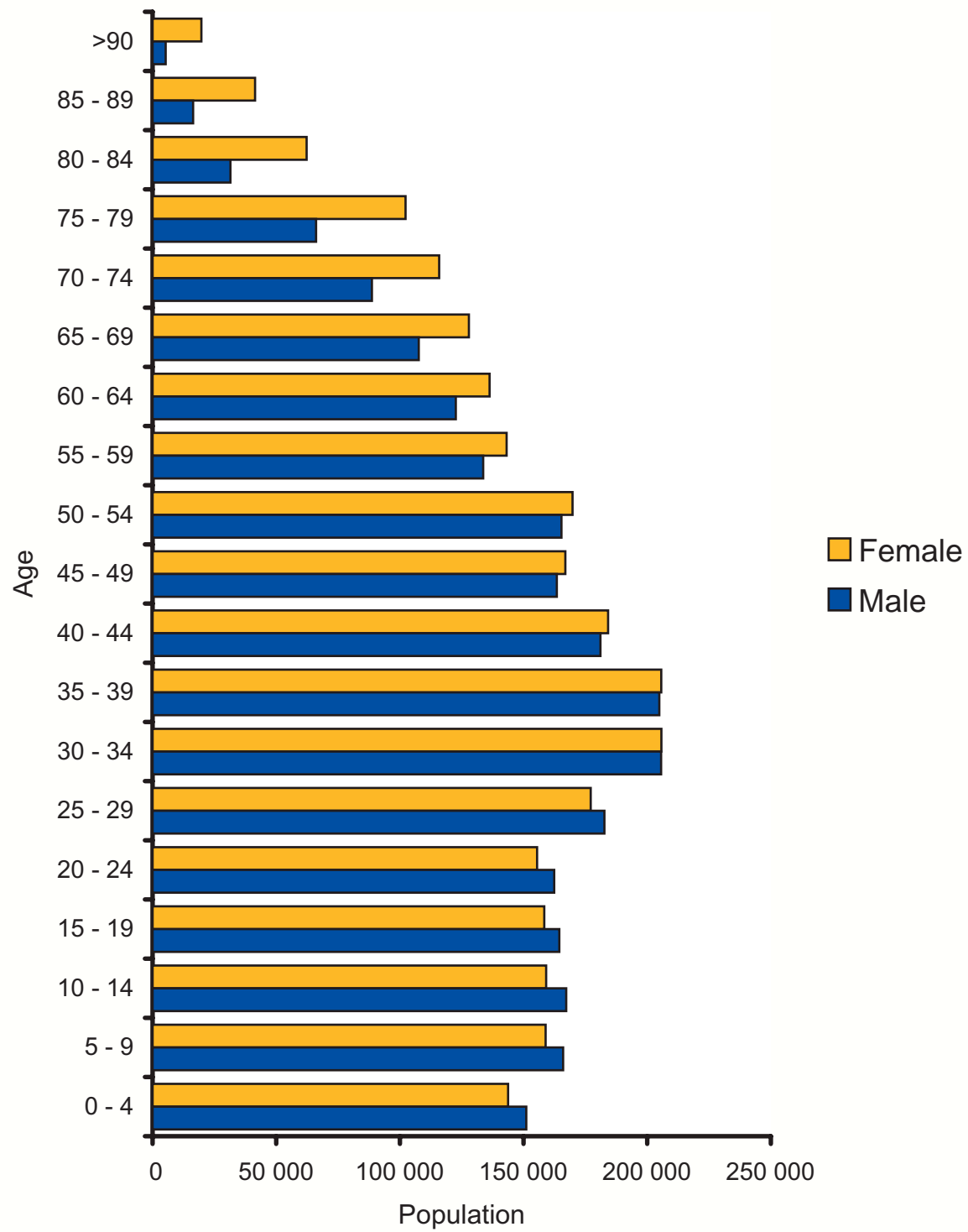
A1.4 Annual incidence per million population of new patients starting RRT 1990-1999

Year	Number starting RRT	Population of Scotland	Incidence per million
1989	310	5 096 600	61
1990	288	5 102 200	56
1991	317	5 107 000	62
1992	349	5 111 200	68
1993	406	5 120 200	79
1994	394	5 132 400	77
1995	448	5 136 600	87
1996	418	5 128 000	82
1997	503	5 122 500	98
1998	537	5 120 000	105
1999	553	5 119 200	108

³ Mid-1999 Population Estimates Scotland. Registrar General for Scotland. Population Statistics Branch, General Register Office for Scotland, Ladywell House, Ladywell Road, Edinburgh EH12 7TF. Reproduced with permission.

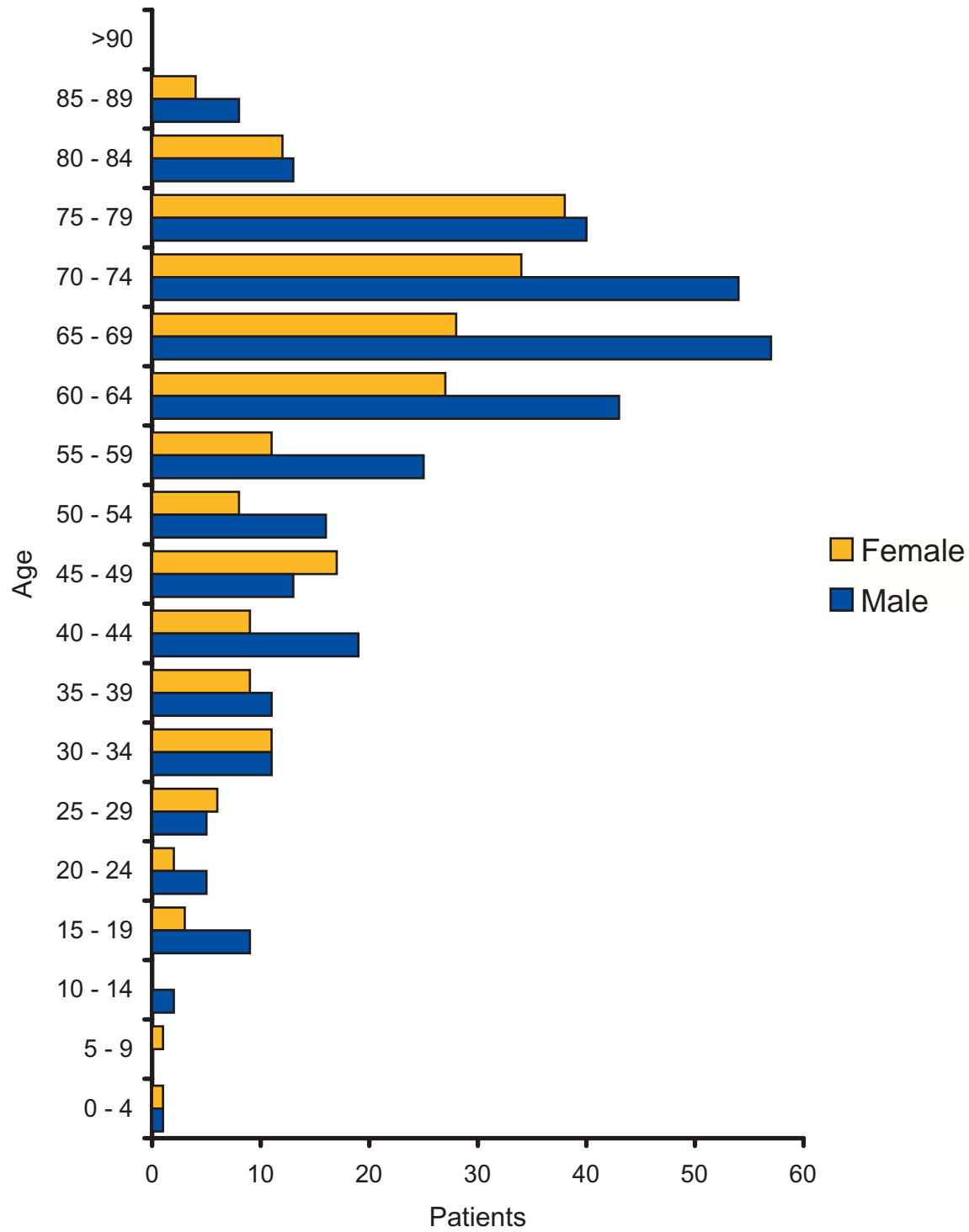
A2 GENERAL POPULATION AND INCIDENT RRT POPULATION 1999

A2.1 Estimated Population of Scotland 1999 (Registrar General for Scotland)



A2.2 Incident RRT population of Scotland 1999

In the incident RRT population, unlike the general population, males predominate in all age groups. This is particularly noticeable in those aged 65 years and over. The graph also demonstrates the increase in treated ESRD as the population ages.



A2.3 Incident RRT population of Scotland 1999

Age Band	Male	Female	Total
>90	0	0	0
85-89	8	4	12
80-84	13	12	25
75-79	40	38	78
70-74	54	34	88
65-69	57	28	85
60-64	43	27	70
55-59	25	11	36
50-54	16	8	24
45-49	13	17	30
40-44	19	9	28
35-39	11	9	20
30-34	11	11	22
25-29	5	6	11
20-24	5	2	7
15-19	9	3	12
10-14	2	0	2
5-9	0	1	1
0-4	1	1	2
Total	332	221	553

A2.4 Age specific incidence and prevalence of RRT patients in 1999

The table shows the age specific incidence and prevalence of patients receiving RRT per million population in 1999. The highest incidence of new patients starting RRT is in the 65-75 years age group whilst patients aged 50-64 predominate in the prevalent RRT population. 582 patients, per million population of all ages, were receiving RRT in Scotland in 1999.

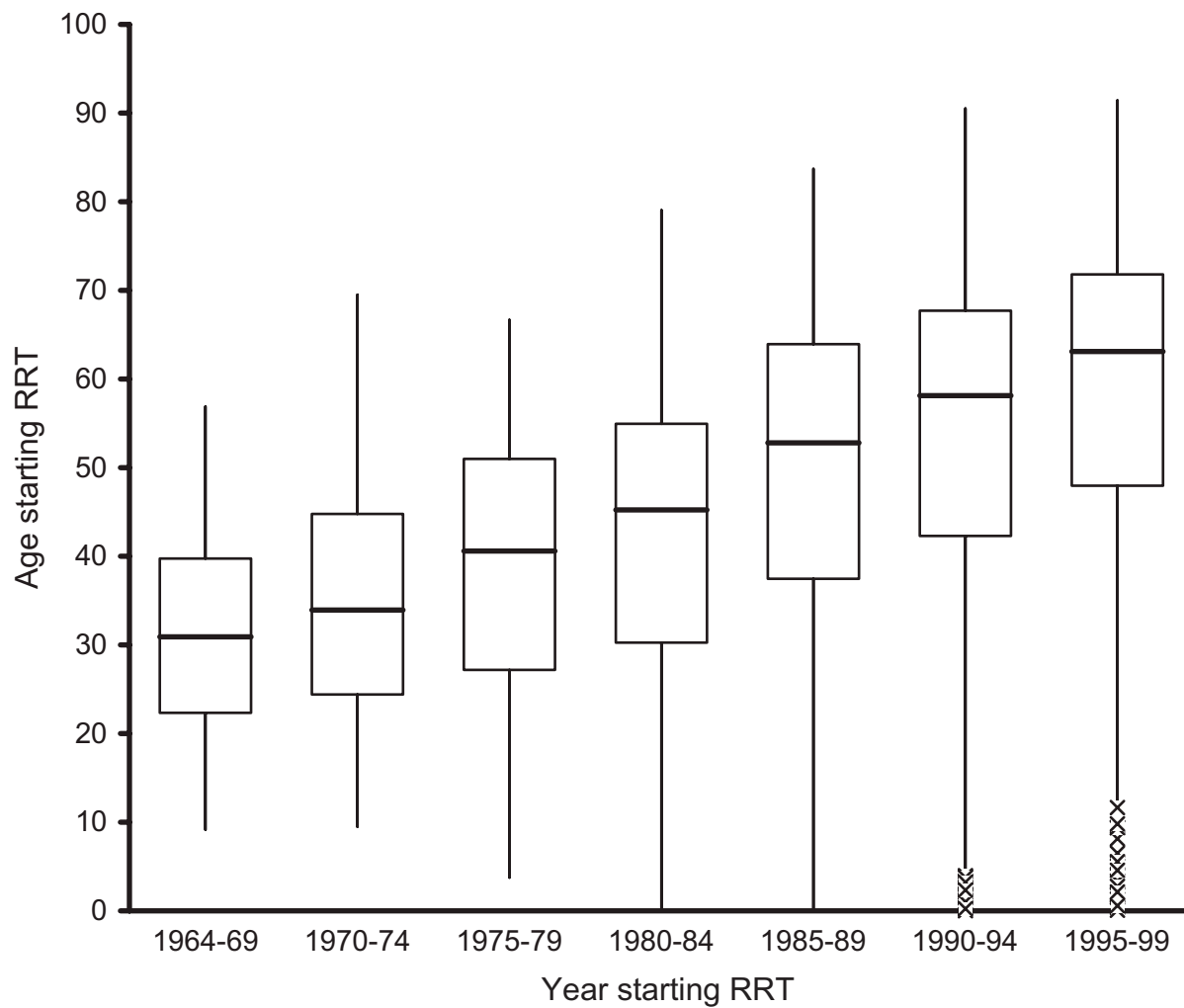
Age Group	Estimated Population 1999	Number starting RRT 1999	Incidence per million population of each age	All patients receiving RRT on 30/6/1999	Prevalence per million population of each age band
> 75 years	344 767	115	334	238	690
65 - 75 years	440 018	173	393	535	1216
50 - 64 years	870 660	130	149	882	1013
< 50 years	3 463 755	135	39	1336	386

A3 MEDIAN AGE OF PATIENTS WHEN STARTING RRT

The following graphs show median age (thick black line), inter-quartile range (box) and the last value falling within 1.5 times the inter-quartile range (whiskers). Values lying outwith 1.5 times the inter-quartile range are shown as 'x'. The outliers at the lower end of a range represent children.

Patients in their nineties are now occasionally being accepted for RRT and there has been a steady increase in median age and the upper ages of patients starting RRT.

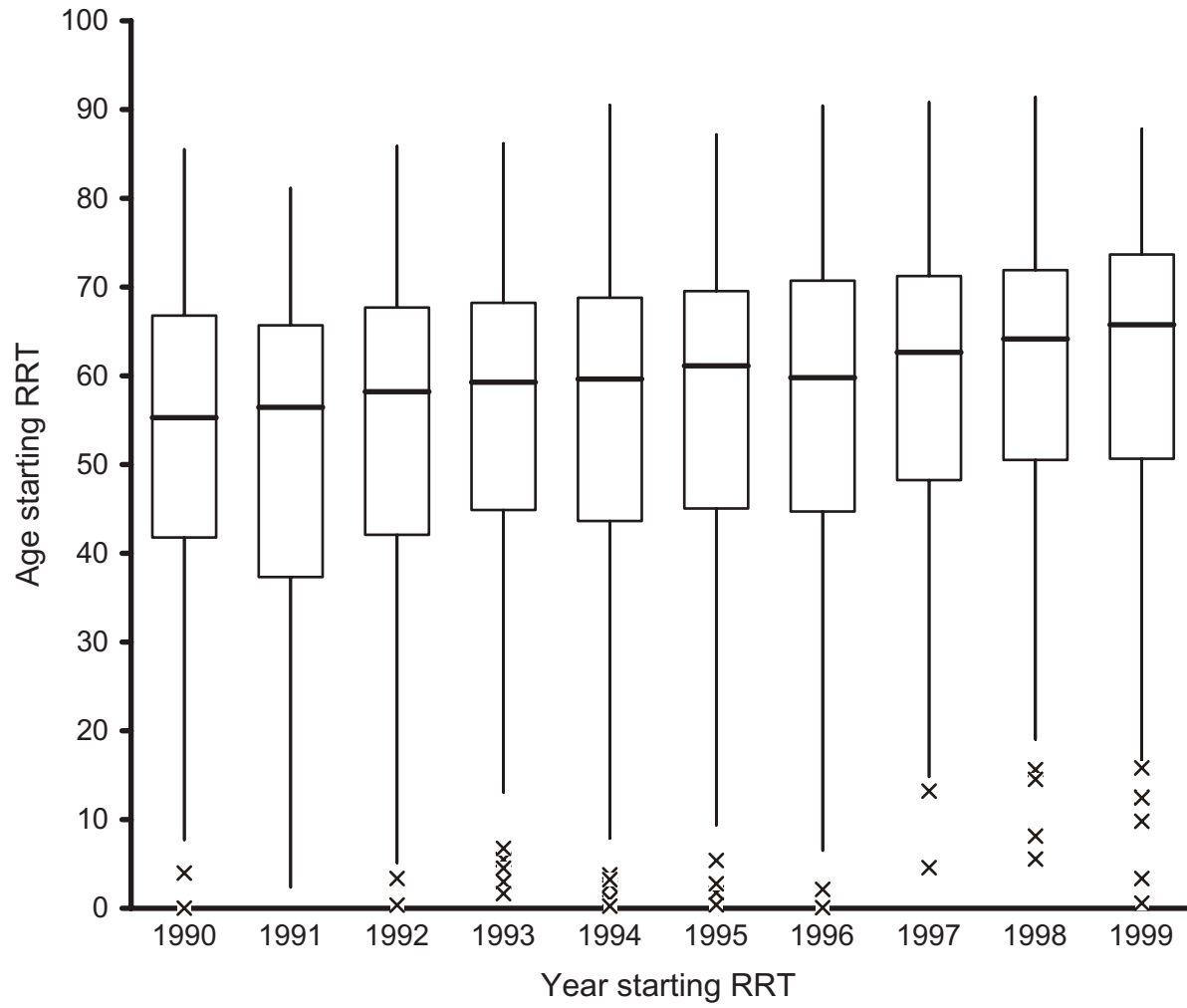
A3.1 Median age of patients when starting RRT 1964-1999



A3.2 Median age range of patients when starting RRT 1964-1999

	1964-69	1970-74	1975-79	1980-84	1985-89	1990-94	1995-99
Median	30.9	33.9	40.6	45.2	52.8	58.1	63.1

A3.3 Median age of patients starting RRT 1990-1999



A3.4 Median age range of patients when starting RRT 1990-1999

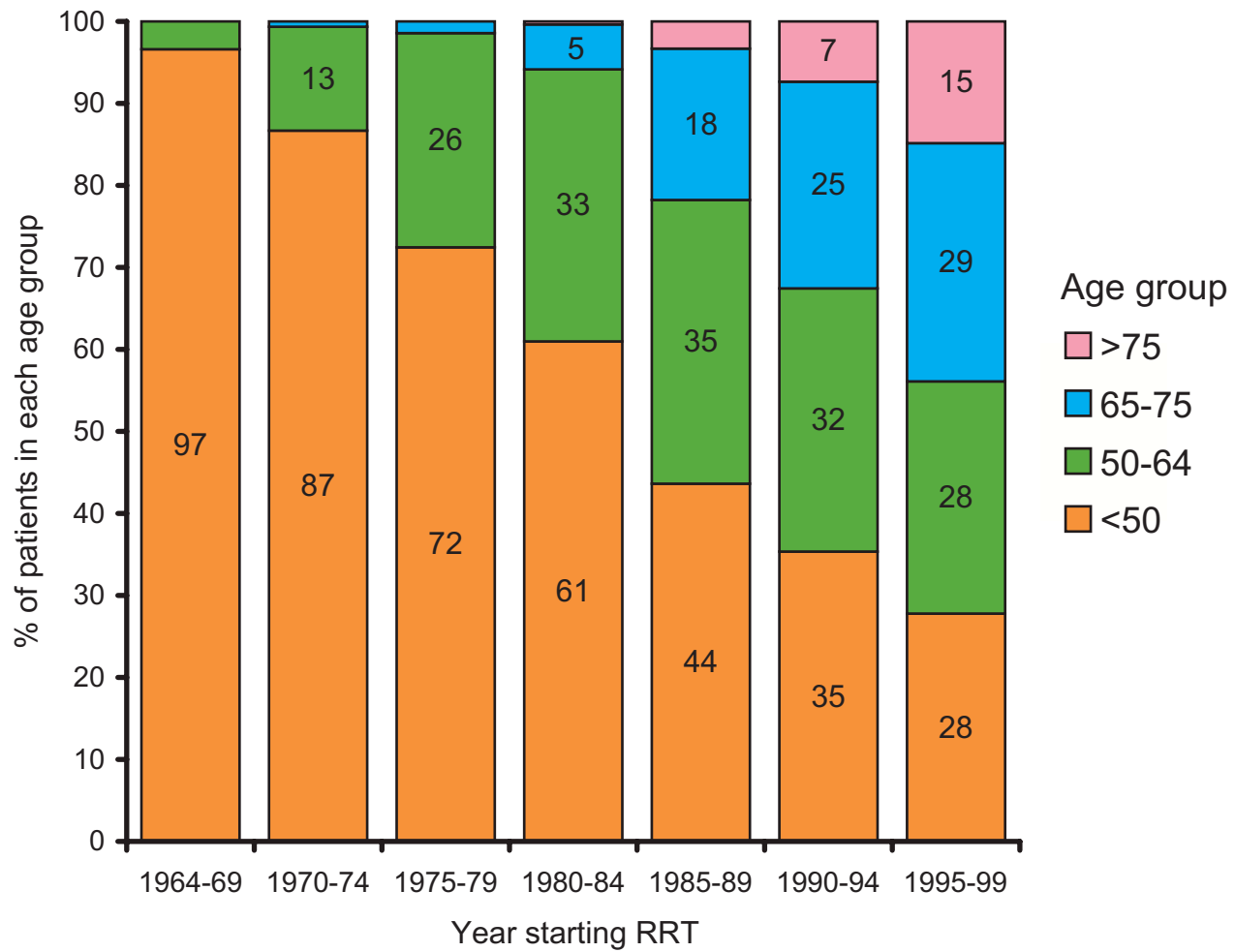
	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
Median	53.3	56.5	58.2	59.3	59.6	61.1	59.8	62.7	64.2	65.8

A4 AGE DISTRIBUTION OF PATIENTS WHEN STARTING RRT

The total numbers of patients are the same as shown in graphs A1.1 and A1.2.

The proportion of older patients in the incident RRT population is increasing. The proportion of patients in the younger age group is falling steadily, however the absolute number is still increasing slightly.

A4.1 Age distribution of patients when starting RRT 1964-1999

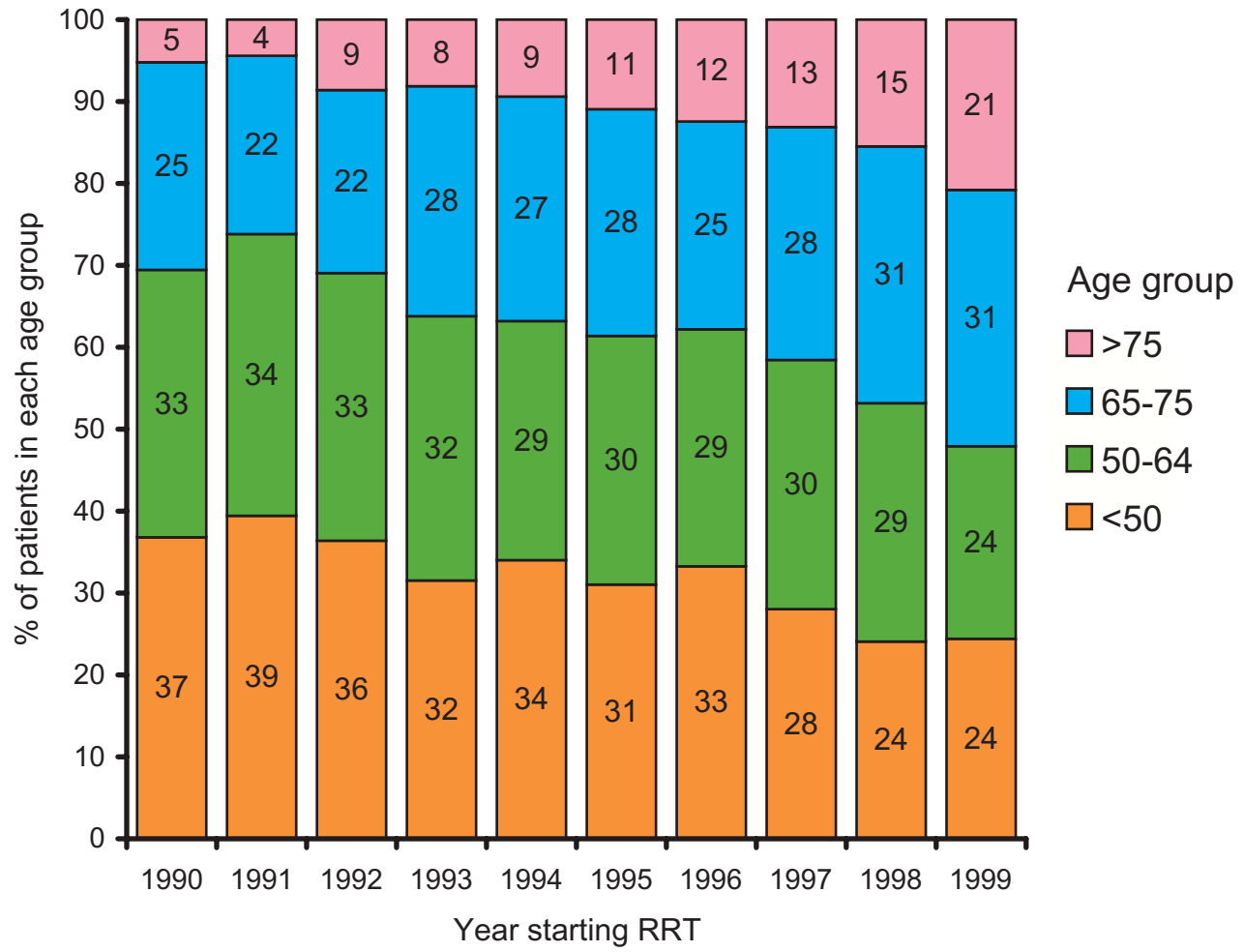


A4.2 Percentage age distribution of patients when starting RRT 1964-1999

Year of start RRT	<50	50-64	65-75	>75
1964-69	97	3	0	0
1970-74	87	13	1	0
1975-79	72	26	1	0
1980-84	61	33	5	N
1985-89	44	35	18	3
1990-94	35	32	25	7
1995-99	28	28	29	15

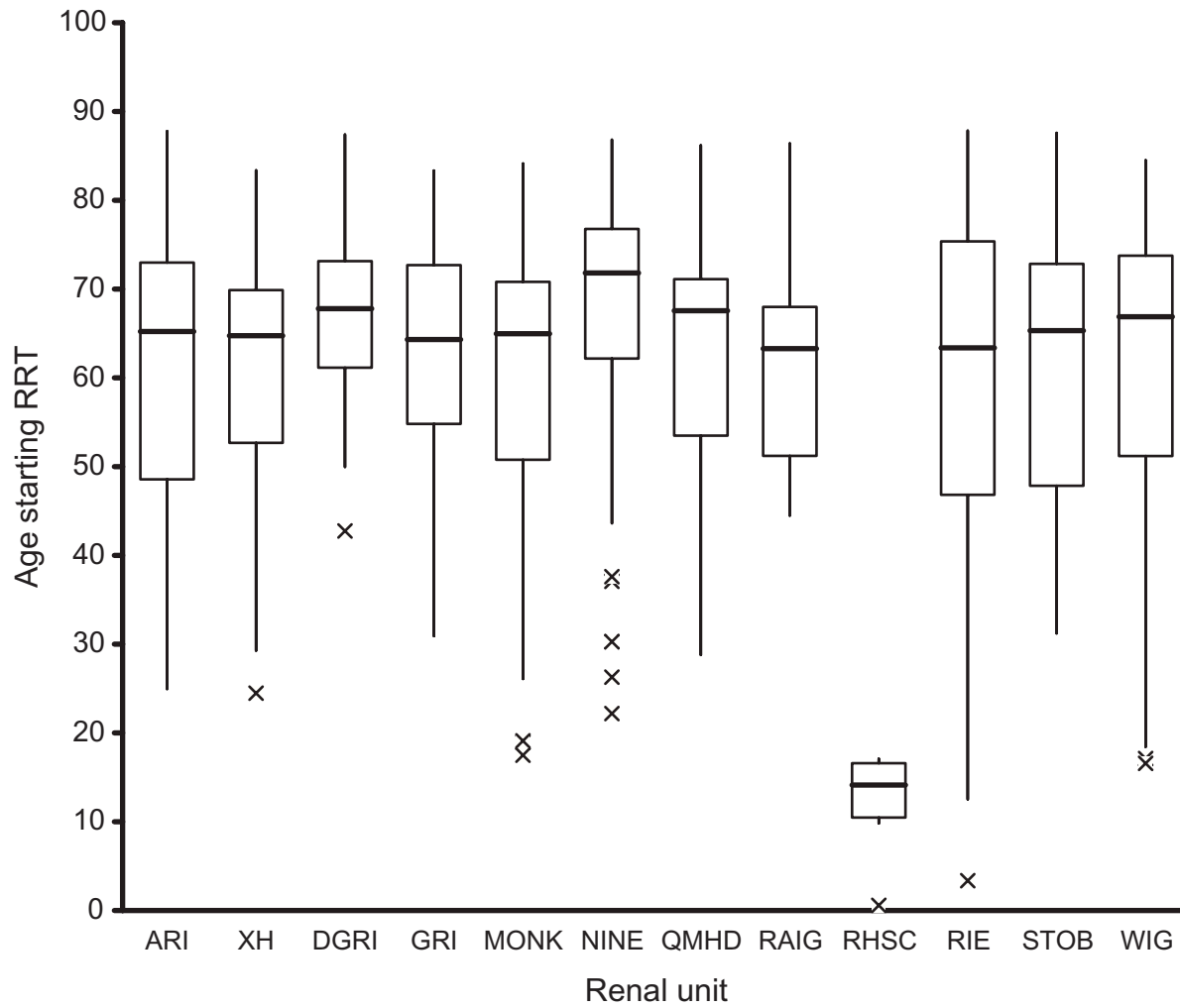
N 3 patients receiving RRT >75 years 1980-84

A4.3 Age distribution of patients when starting RRT 1990-1999



A4.4 Median age of patients starting RRT by renal unit 1999

There was no significant difference between the median ages of new patients starting RRT at the 11 adult renal units.



A4.5 Median age range of patients starting RRT by renal unit 1999

	ARI	XH	DGRI	GRI	MONK	NINE	QMHD	RAIG	RHSC	RIE	STOB	WIG
Median	65.2	64.8	67.8	64.3	65.0	71.8	67.6	63.3	14.1	63.4	65.3	66.9

A5 PRIMARY RENAL DIAGNOSIS OF PATIENTS STARTING RRT

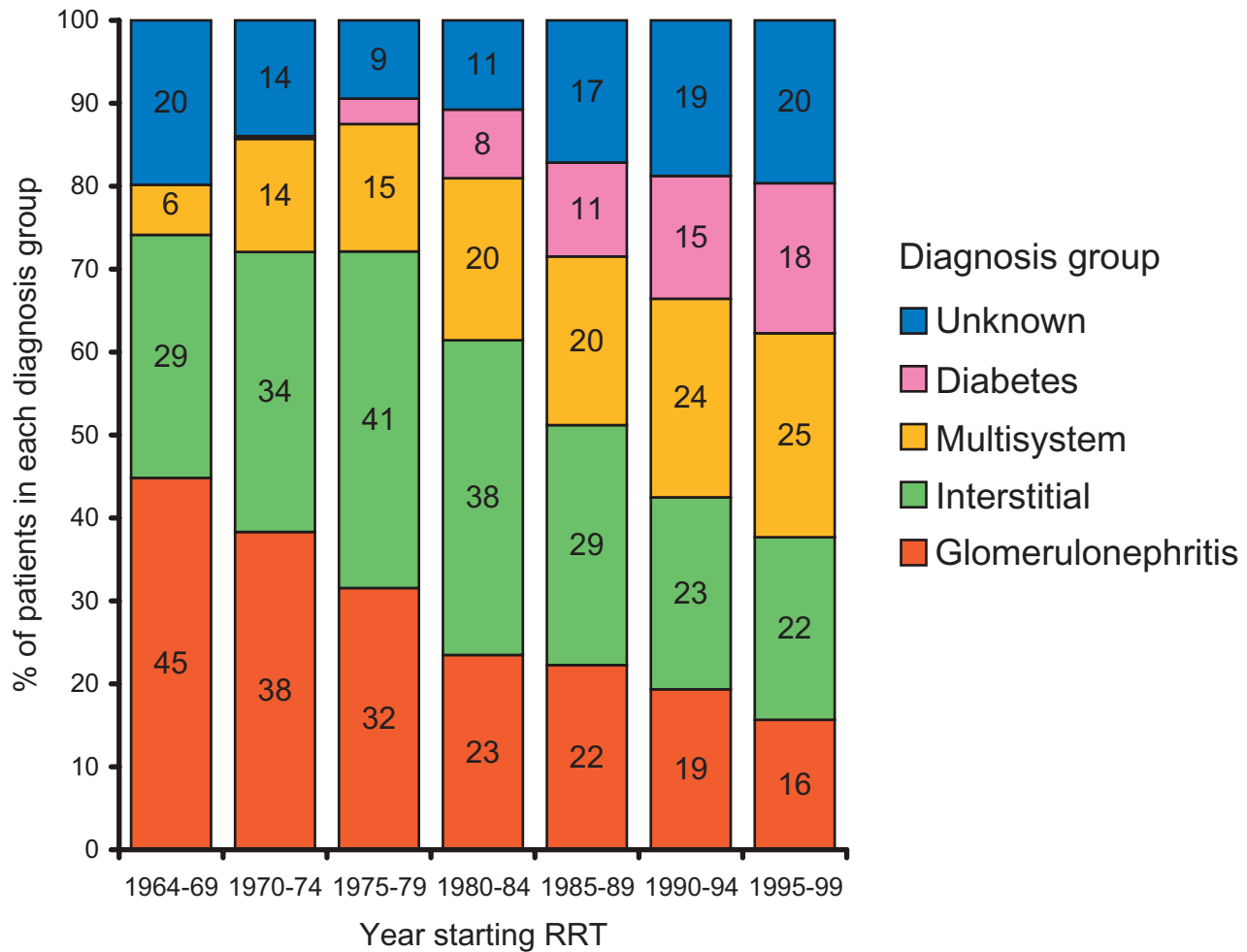
Graphs A 5.1 and A 5.2 represent the same data displayed as proportion of patients and absolute numbers respectively.

The necessity of rationalising PRD into the 5 groups used throughout the report obscures the fact that diabetic nephropathy is now the largest single named PRD in patients starting RRT. There remains a large proportion of patients in whom a definitive diagnosis has not been made.

ERA-EDTA PRD codes and groupings are reproduced in appendix 6.

A5.1 Percentage of patients in each PRD group 1964-1999

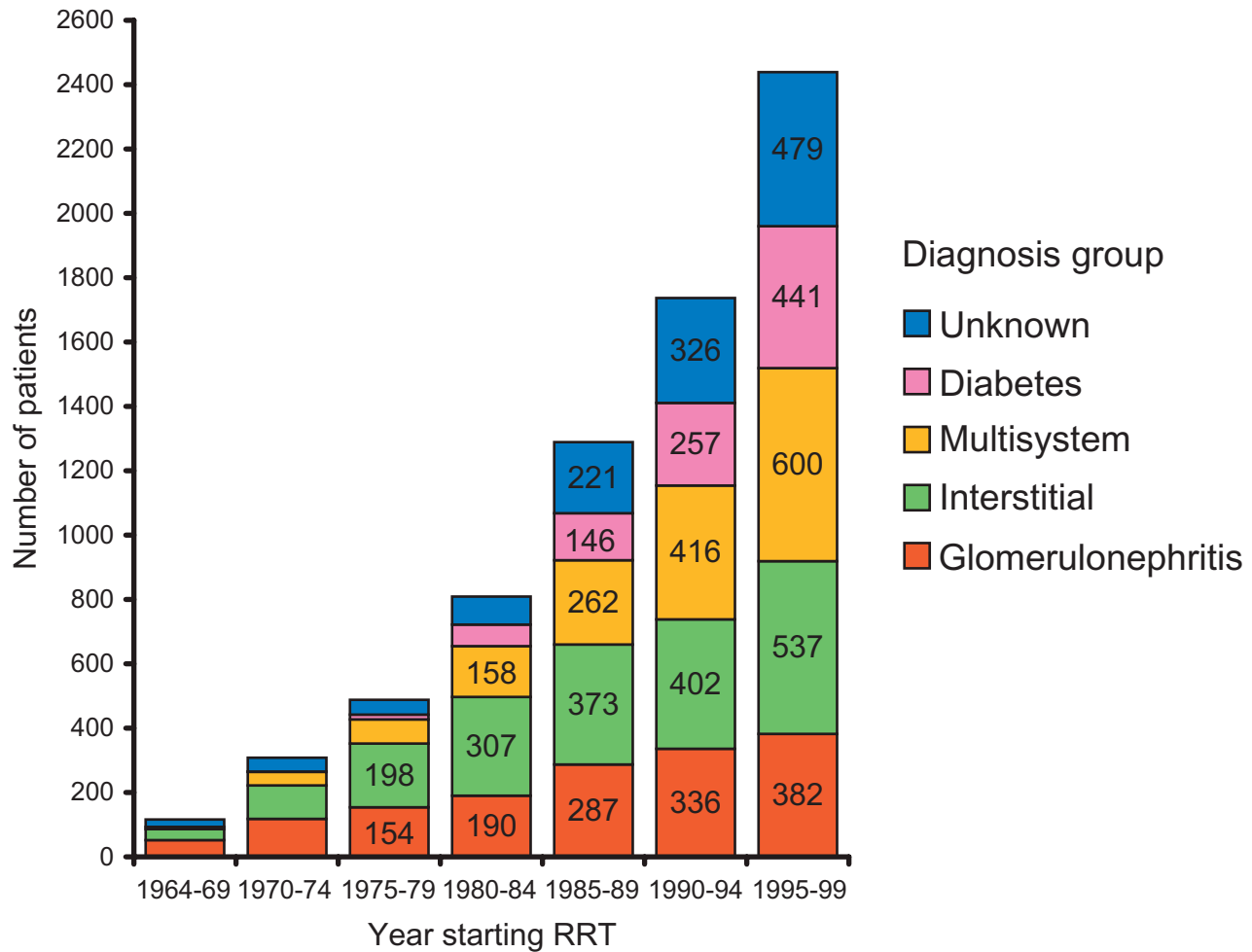
The proportions of patients with glomerulonephritis and interstitial nephritis are falling; this is almost certainly due, not to a change in the epidemiology of renal failure, but due to changing clinical practices and increased acceptance of patients with diabetes and other multisystem disorders for RRT.



A5.2 Number of patients in each diagnosis group starting RRT 1964-1999

The overall number of patients in each diagnosis group is increasing with time.

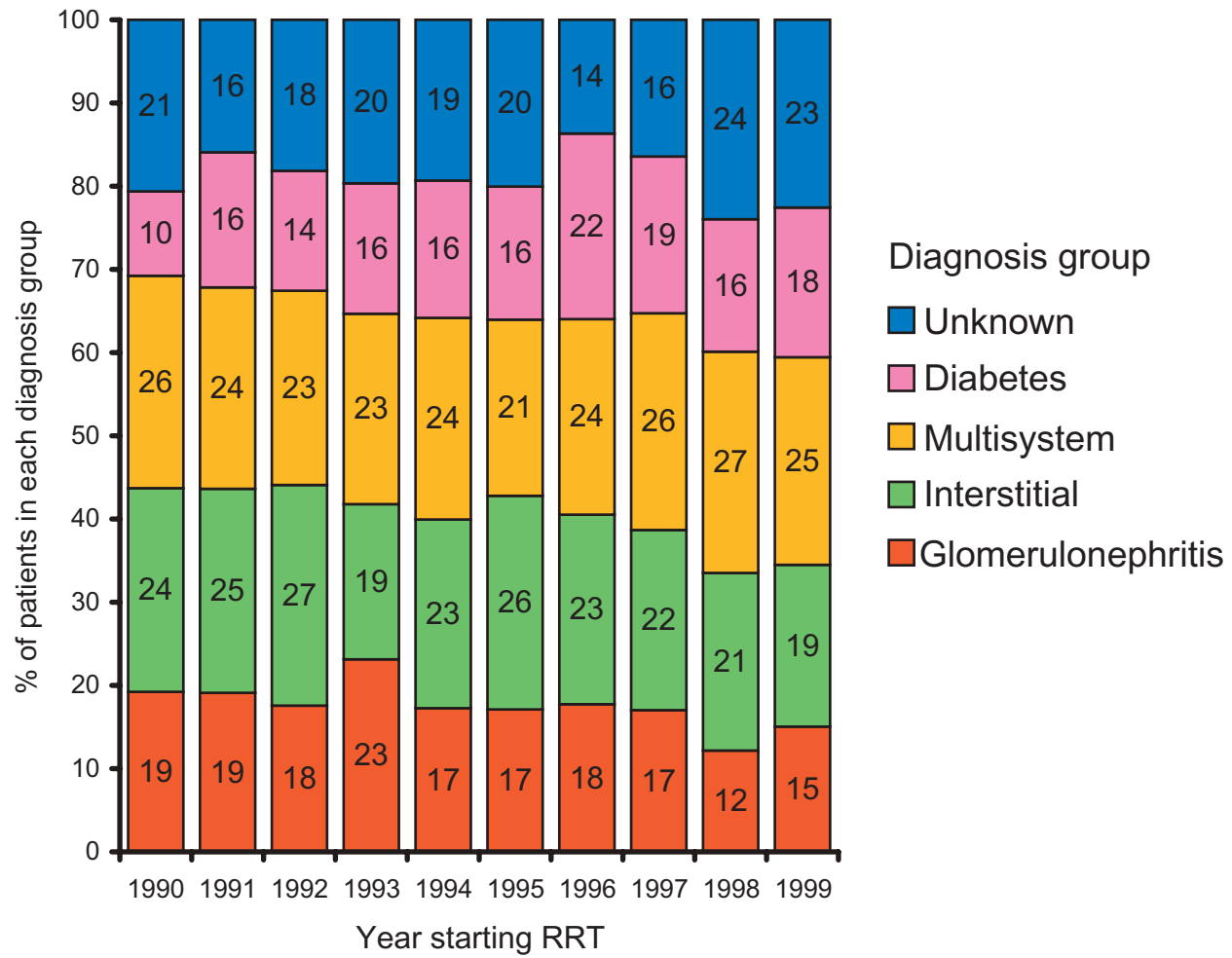
The proportion of older patients in the incident RRT population is increasing. The proportion of patients in the younger age group is steadily falling, however the absolute number is increasing.



A5.3 Number of patients in each diagnosis group starting RRT 1964-1999

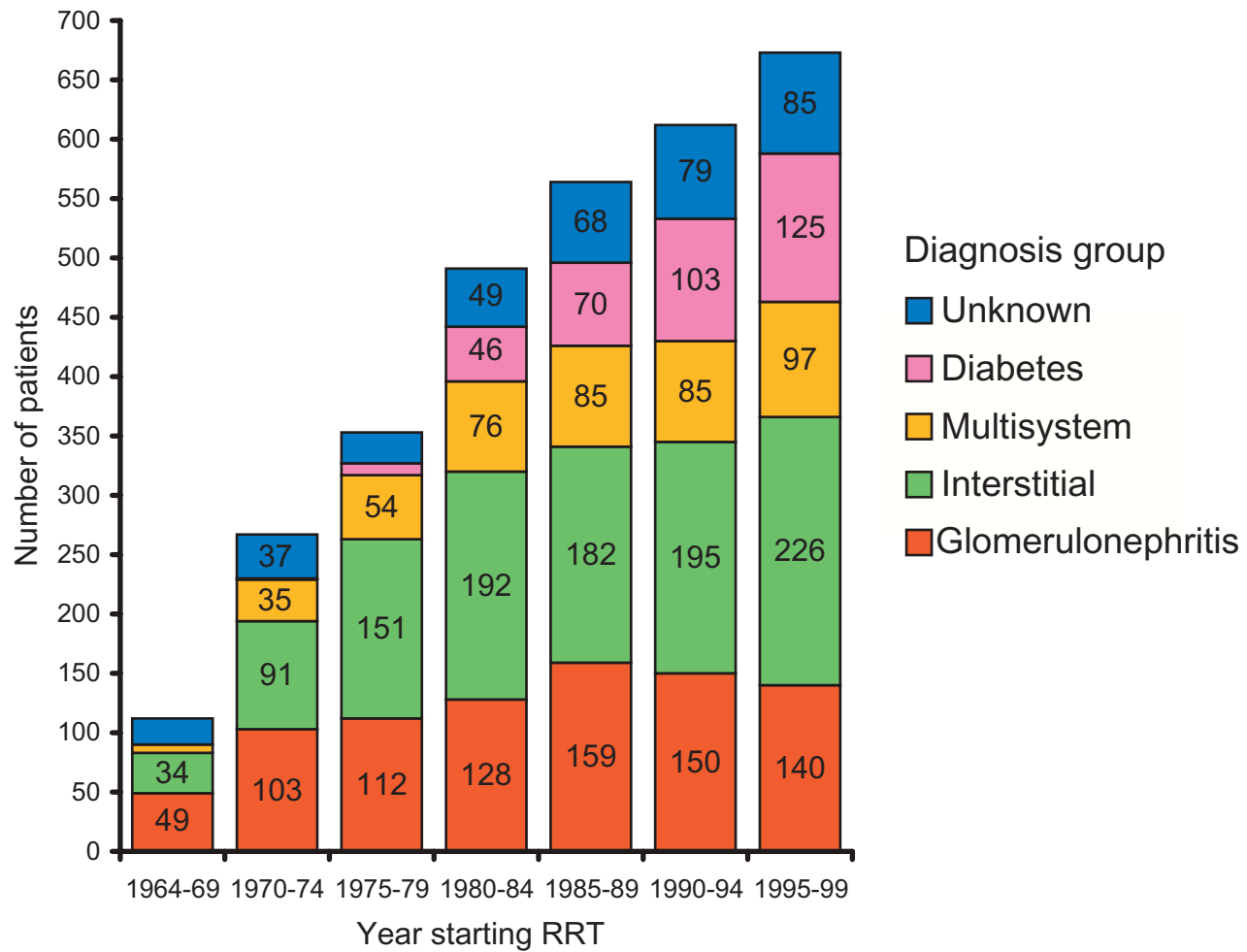
Year starting RRT	Glomerulonephritis	Interstitial	Multisystem	Diabetes	Unknown	Total
1964-69	52	34	7	0	23	116
1970-74	118	104	42	1	43	308
1975-79	154	198	75	15	46	488
1980-84	190	307	158	67	87	809
1985-89	287	373	262	146	221	1289
1990-94	336	402	416	257	326	1737
1995-99	382	537	600	441	479	2439

A5.4 Percentage of patients in each PRD group 1990-1999



A5.5 Primary renal diagnosis of patients aged less than 50 years starting RRT 1964-1999

It appears that the number of patients aged under 50 in whom the PRD is glomerulonephritis has plateaued. This suggests that the rate of provision of RRT for these patients is now meeting the incidence.

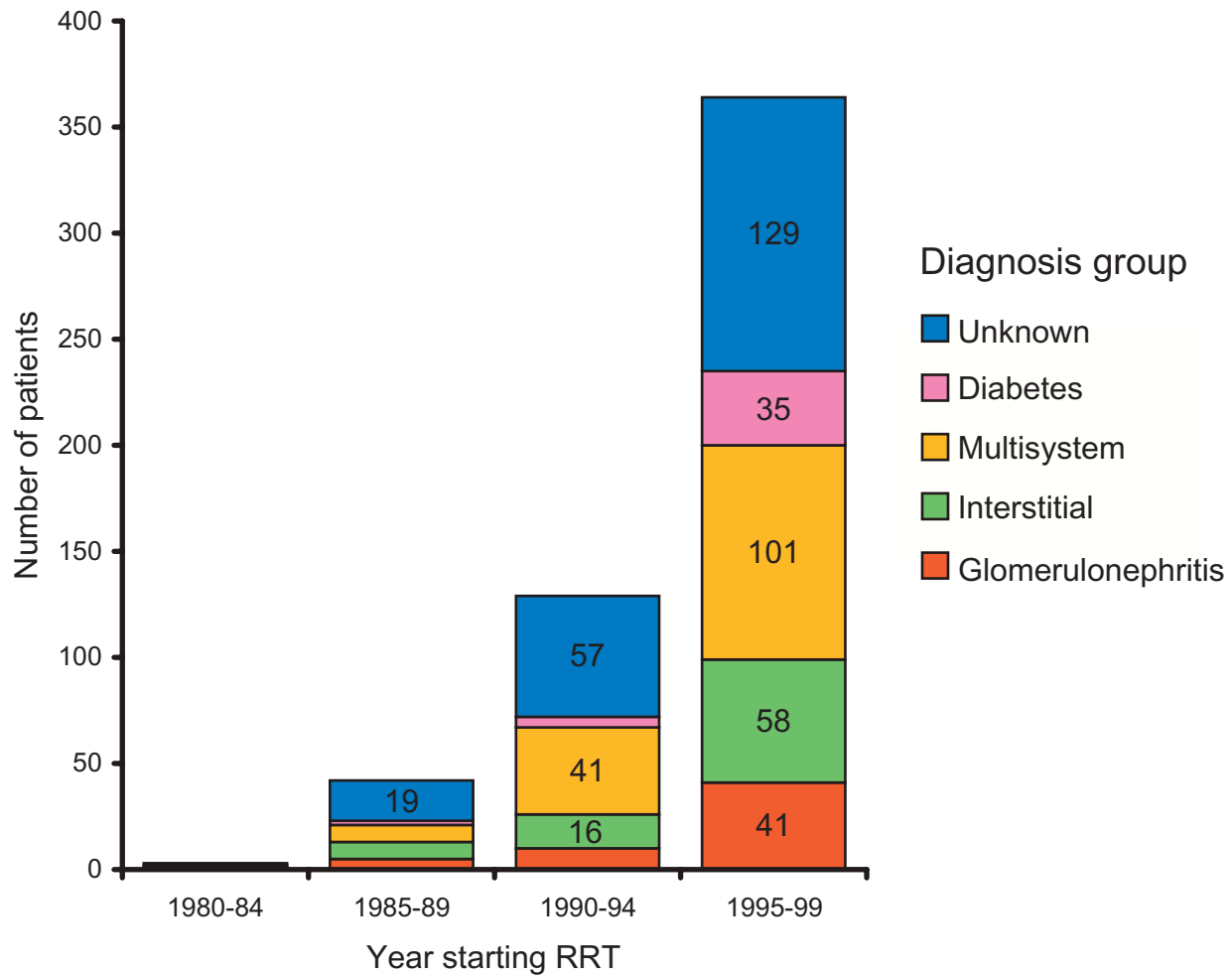


A5.6 Primary renal diagnosis of patients aged less than 50 years starting RRT 1964-1999

Year starting RRT	Glomerulonephritis	Interstitial	Multisystem	Diabetes	Unknown	Total
1964-69	49	34	7	0	22	112
1970-74	103	91	35	1	37	267
1975-79	112	151	54	10	26	353
1980-84	128	192	76	46	49	491
1985-89	159	182	85	70	68	564
1990-94	150	195	85	103	79	612
1995-99	140	226	97	125	85	673

A5.7 Primary renal diagnosis of patients aged over 75 years starting RRT 1980-1999

In contrast to patients aged less than 50 years, the rate of provision of RRT continues to increase for all diagnostic groups in patients over 75 years.



A5.8 Primary renal diagnosis of patients aged over 75 years starting RRT 1980-1999

Year starting RRT	Glomerulonephritis	Interstitial	Multisystem	Diabetes	Unknown	Total
1980-84	0	1	1	0	1	3
1985-89	5	8	8	2	19	42
1990-94	10	16	41	5	57	129
1995-99	41	58	101	35	129	364

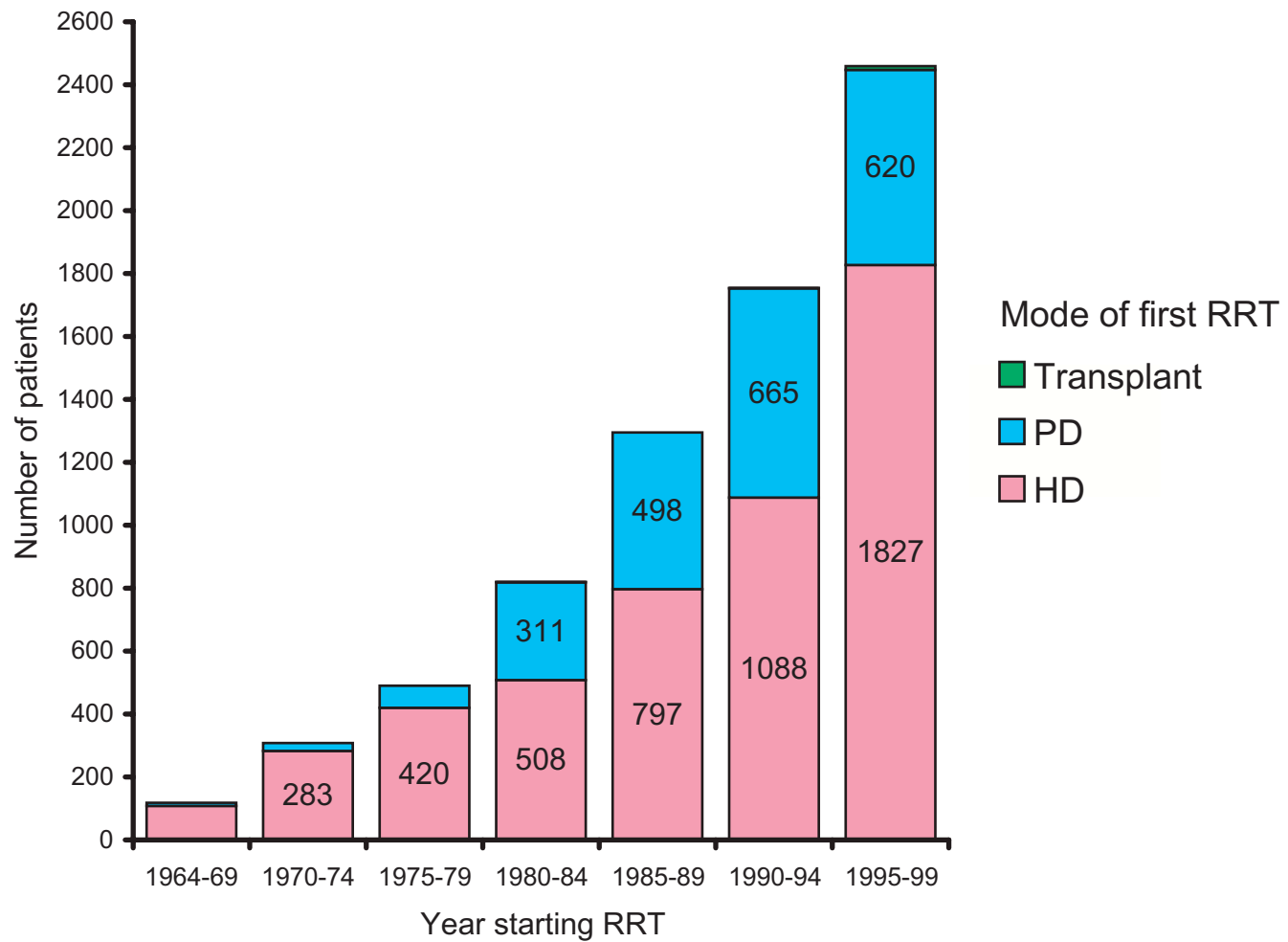
A6 MODALITY OF RRT

There are three principal types of RRT:

Haemodialysis (HD) is normally performed in a hospital but can be undertaken in a patient’s home. Peritoneal dialysis (PD) is normally performed by the patient in their home using the technique of continuous ambulatory peritoneal dialysis (CAPD); the dialysate exchanges can be performed semi automatically by a machine in the variant known as automated peritoneal dialysis (APD). Renal transplants are normally donated from a cadaver, but occasionally by a living person.

In total 14 patients have received a pre-emptive transplant, the first was in 1982. Hospital HD remains the most common first mode of RRT. Peritoneal dialysis was introduced in 1968; the use of PD both as the first mode of RRT and amongst prevalent patients has levelled off.

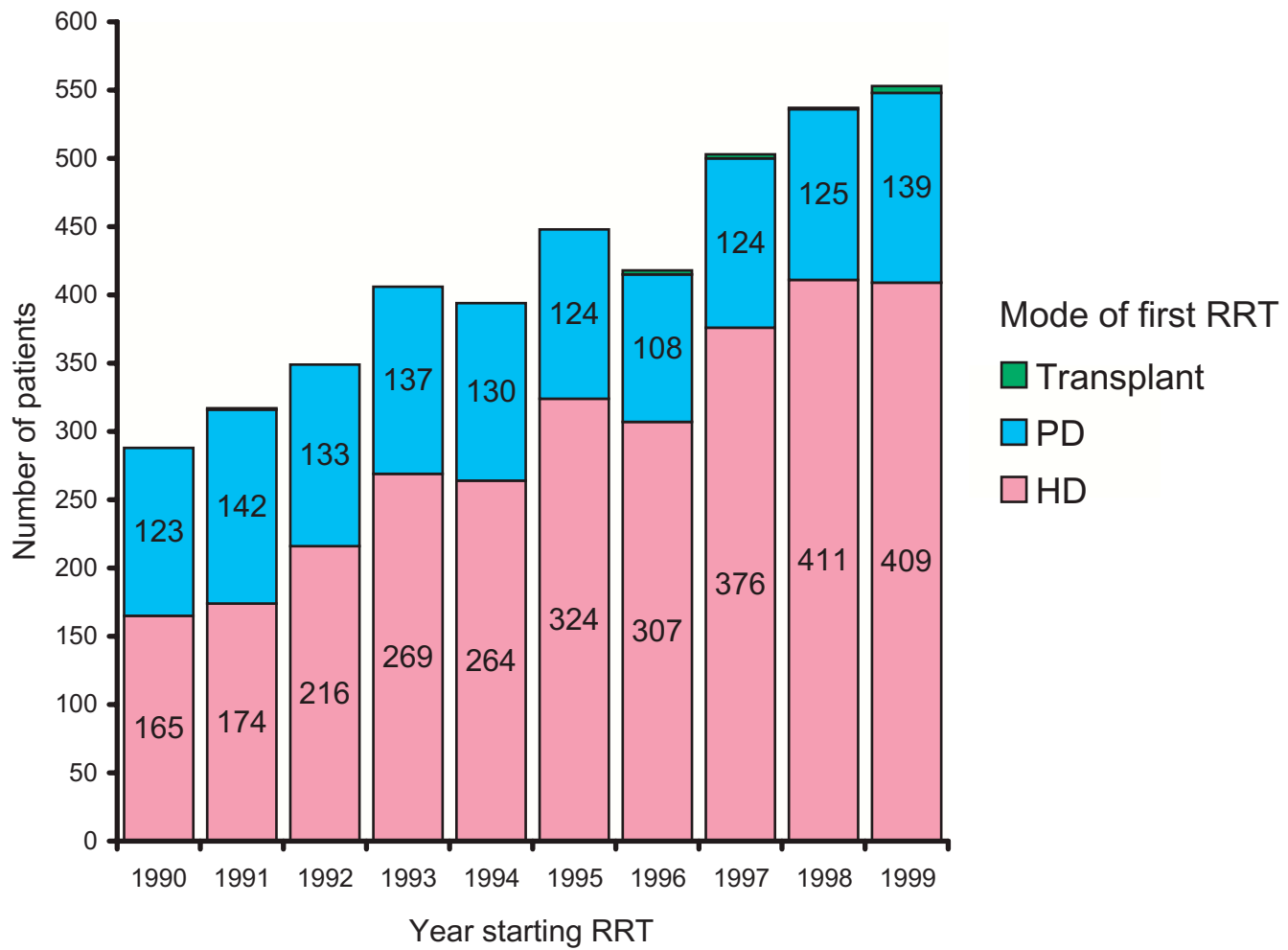
A6.1 Mode of first RRT 1964-1999



A6.2 Mode of first RRT 1964-1999

Year starting RRT	HD	PD	Transplant	Total
1964-69	108	10	0	118
1970-74	283	25	0	308
1975-79	420	70	0	490
1980-84	508	311	1	820
1985-89	797	498	0	1295
1990-94	1088	665	1	1754
1995-99	1827	620	12	2459

A6.3 Mode of first RRT 1990-1999



A6.4 Mode of first RRT 1990-1999

Year starting RRT	HD	PD	Transplant	Total
1990	165	123	0	288
1991	174	142	1	317
1992	216	133	0	349
1993	269	137	0	406
1994	264	130	0	394
1995	324	124	0	448
1996	307	108	3	418
1997	376	124	3	503
1998	411	125	1	537
1999	409	139	5	553

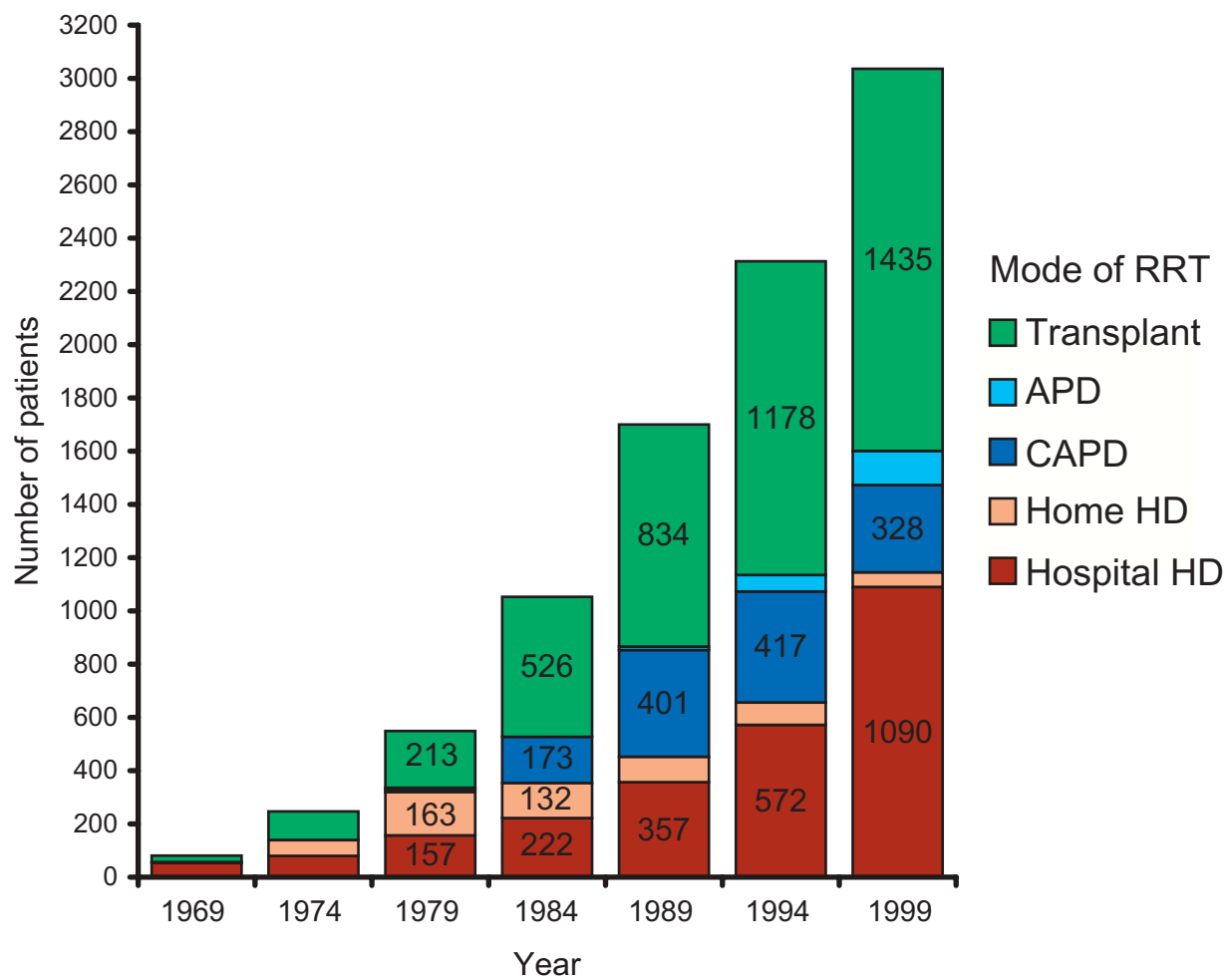
B PREVALENCE

B1 PATIENTS RECEIVING RRT IN SCOTLAND ACCORDING TO MODALITY OF TREATMENT ON 31ST DECEMBER

Patients have been included only if the renal unit at which they are being treated in Scotland is known. This criterion has been imposed more strictly than in the 1998 report. This explains the apparent drop in prevalence. Patients recorded as having used IPD are shown together with patients who have been treated with APD.

The numbers of patients receiving RRT in the form of a renal transplant and hospital based HD is continuing to increase.

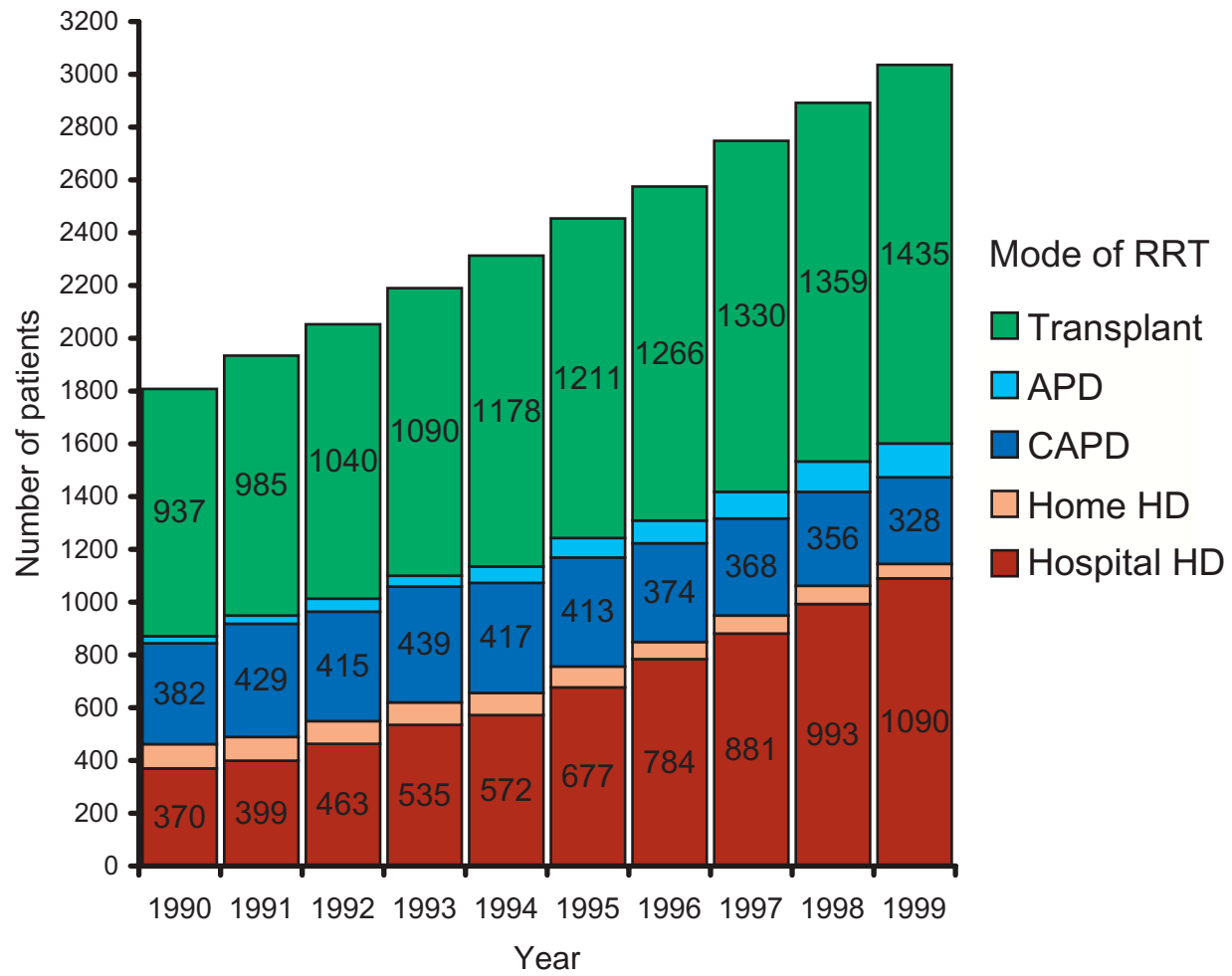
B1.1 Prevalent patients every fifth year between 1969-1999



B1.2 Prevalent patients every fifth year between 1969-1999

Year	Hospital HD	Home HD	CAPD	APD	Transplant	Total
1969	53	4	0	0	24	81
1974	80	59	0	1	107	247
1979	157	163	11	5	213	549
1984	222	132	173	0	526	1053
1989	357	95	401	13	834	1700
1994	572	84	417	62	1178	2313
1999	1090	55	328	128	1435	3036

B1.3 Prevalent patients every year between 1990-1999



B1.4 Prevalent patients every year between 1990-1999

Year	Hospital HD	Home HD	CAPD	APD	Transplant	Total
1990	370	92	382	27	937	1808
1991	399	90	429	31	985	1934
1992	463	86	415	49	1040	2053
1993	535	85	439	41	1090	2190
1994	572	84	417	62	1178	2313
1995	677	79	413	74	1211	2454
1996	784	65	374	86	1266	2575
1997	881	68	368	101	1330	2748
1998	993	69	356	115	1359	2892
1999	1090	55	328	128	1435	3036

B2 PREVALENT PATIENTS AT EACH RENAL UNIT

The total number of patients treated at each renal unit differs considerably.

To make even very simple comparisons it is important to have some background information about local and national working practices. Transplants are only performed at three renal units in Scotland: Aberdeen Royal Infirmary (ARI), Royal Infirmary Edinburgh (RIE) and Western Infirmary Glasgow (WIG). Patients with a functioning renal transplant are followed up as noted below.

RENAL UNIT

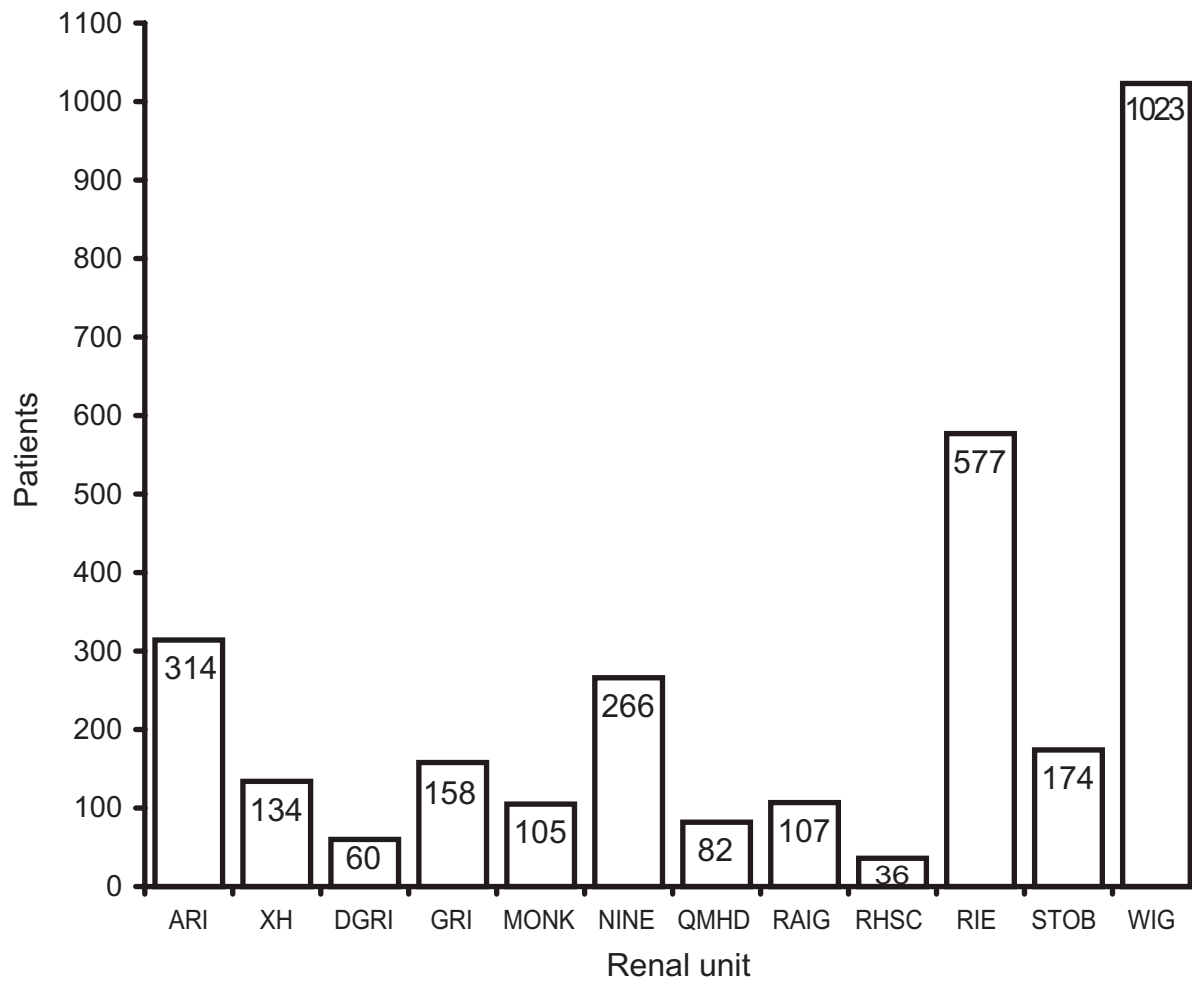
Raigmore Hospital	Many patients live in geographically isolated areas and for this reason PD is often favoured.
Royal Infirmary of Edinburgh	Performs both transplants and follow-up of patients previously dialysed at Queen Margaret Hospital Dunfermline. Performs transplants but not follow-up of patients previously dialysed at Ninewells Hospital Dundee.
Stobhill Hospital	Treats all Home HD patients from Glasgow Royal Infirmary (GRI), and the Western Infirmary Glasgow.
Western Infirmary Glasgow	Performs transplants and subsequent follow-up of patients previously dialysed at GRI, Monklands Hospital and Stobhill Hospital. Performs transplants but not follow-up or share follow up of patients previously dialysed at Dumfries and Galloway Royal Infirmary and Crosshouse Hospital.

Whilst all patients treated at the Royal Hospital for Sick Children Glasgow (RHSC) are children, some children are treated by other renal units and are included in the figures of the unit they attend.

The high proportion of younger patients in the Western Infirmary Glasgow, Aberdeen Royal Infirmary and the Royal Infirmary of Edinburgh (Graph B2.2) is at least in part due to the large number of patients with functioning transplants being treated by these units. (Graph B2.5)

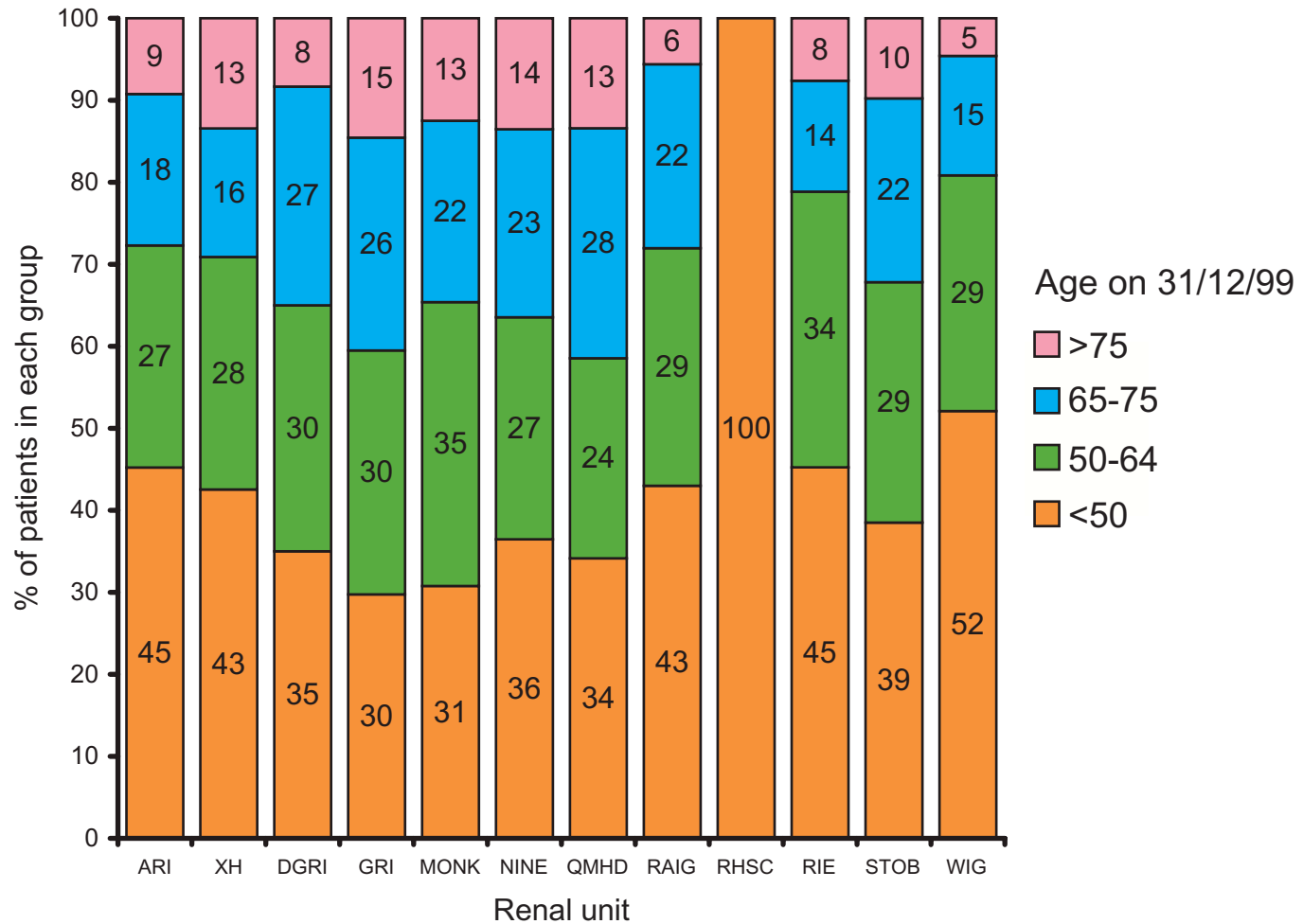
To explain fully the difference in the treatment patterns between renal units would require more information about patient comorbidity, domicile and individual patient choice.

B2.1 Numbers of patients receiving RRT on 31st December 1999



Number of patients receiving RRT on 31 December 1999: 3036

B2.2 Age of patients receiving RRT at each renal unit on 31st December 1999

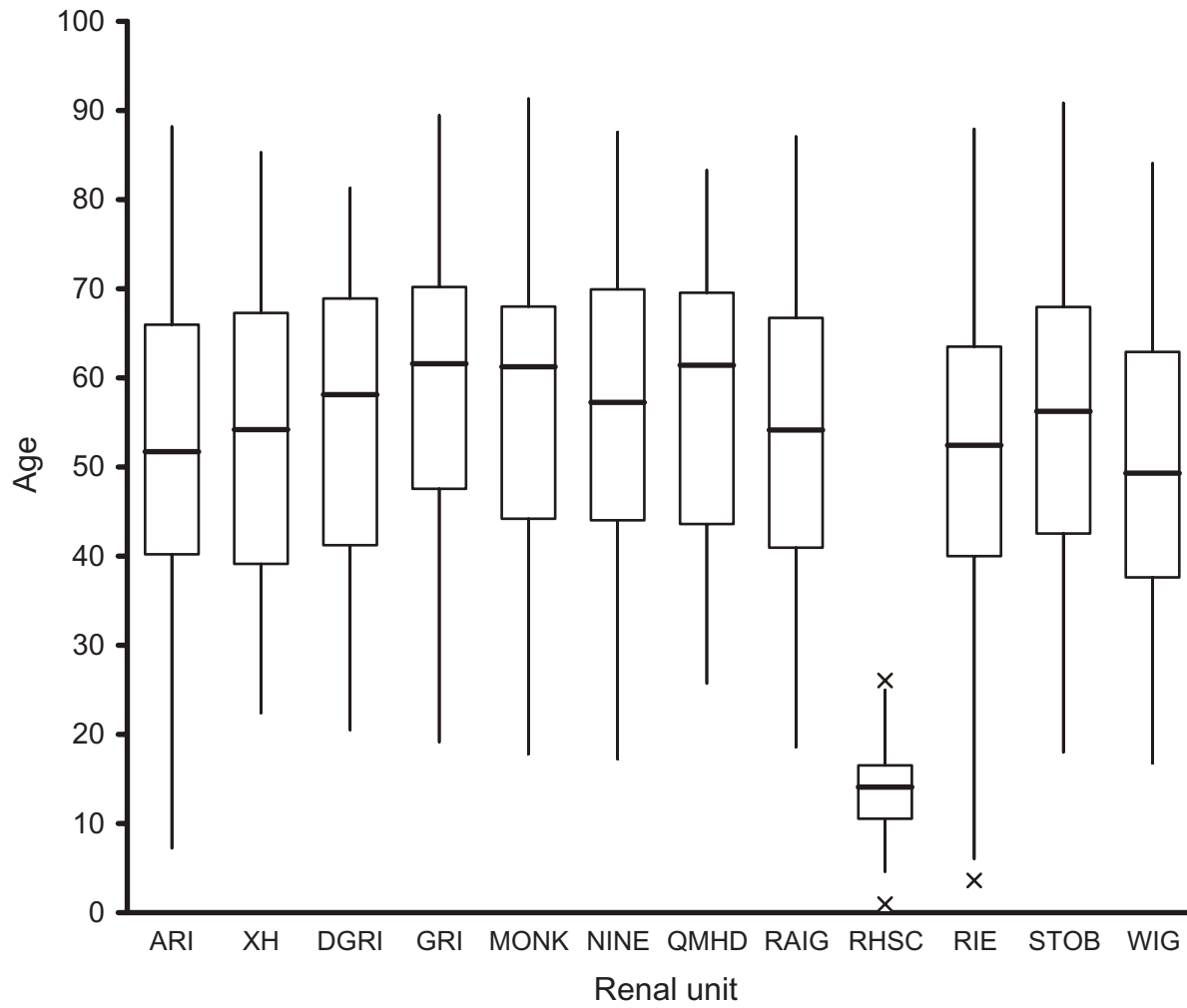


B2.3 Number of patients receiving RRT at each renal unit on 31st December 1999

AGE	ARI	XH	DGRI	GRI	MONK	NINE	QMHD	RAIG	RHSC	RIE	STOB	WIG	TOTAL
>75	29	18	5	23	13	36	11	6	0	44	17	47	249
65-75	58	21	16	41	23	61	23	24	0	78	39	149	533
50-64	85	38	18	47	36	72	20	31	0	194	51	294	886
<50	142	57	21	47	32	97	28	46	36	261	67	533	1367
	314	134	60	158	104	266	82	107	36	577	174	1023	3035⁴

4 1 patient missing date of birth

B2.4 Age range of prevalent patients at each renal unit on 31st December 1999



Number of patients: 3035⁵

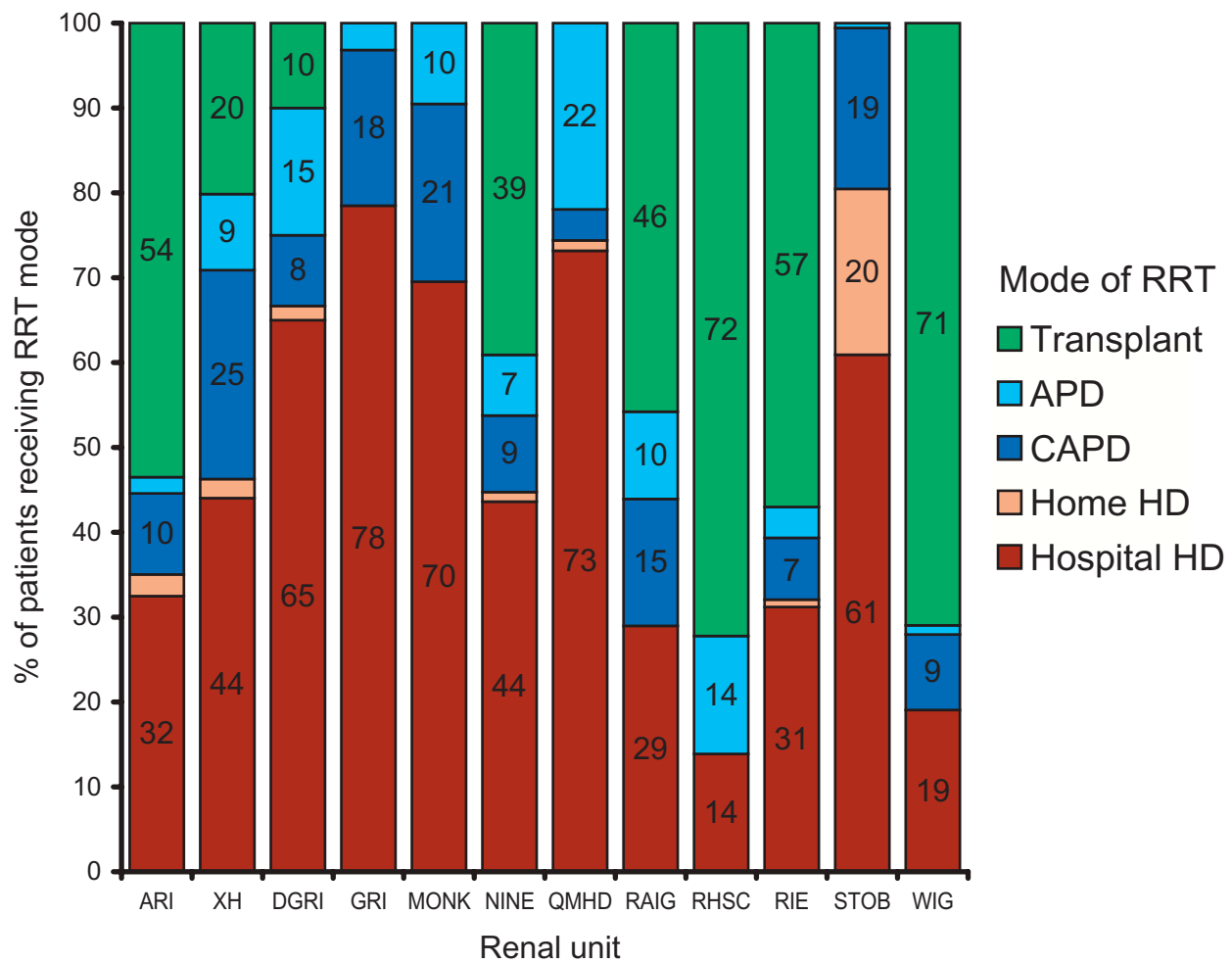
B2.5 Median age range of prevalent patients at each renal unit on 31st December 1999

	ARI	XH	DGRI	GRI	MONK	NINE	QMHD	RAIG	RHSC	RIE	STOB	WIG
Median	51.7	54.2	58.1	61.6	61.3	57.2	61.4	54.2	14.1	52.4	56.3	48.9

⁵ 1 patient missing date of birth

B2.6 Mode of RRT and renal unit providing treatment on 31st December 1999

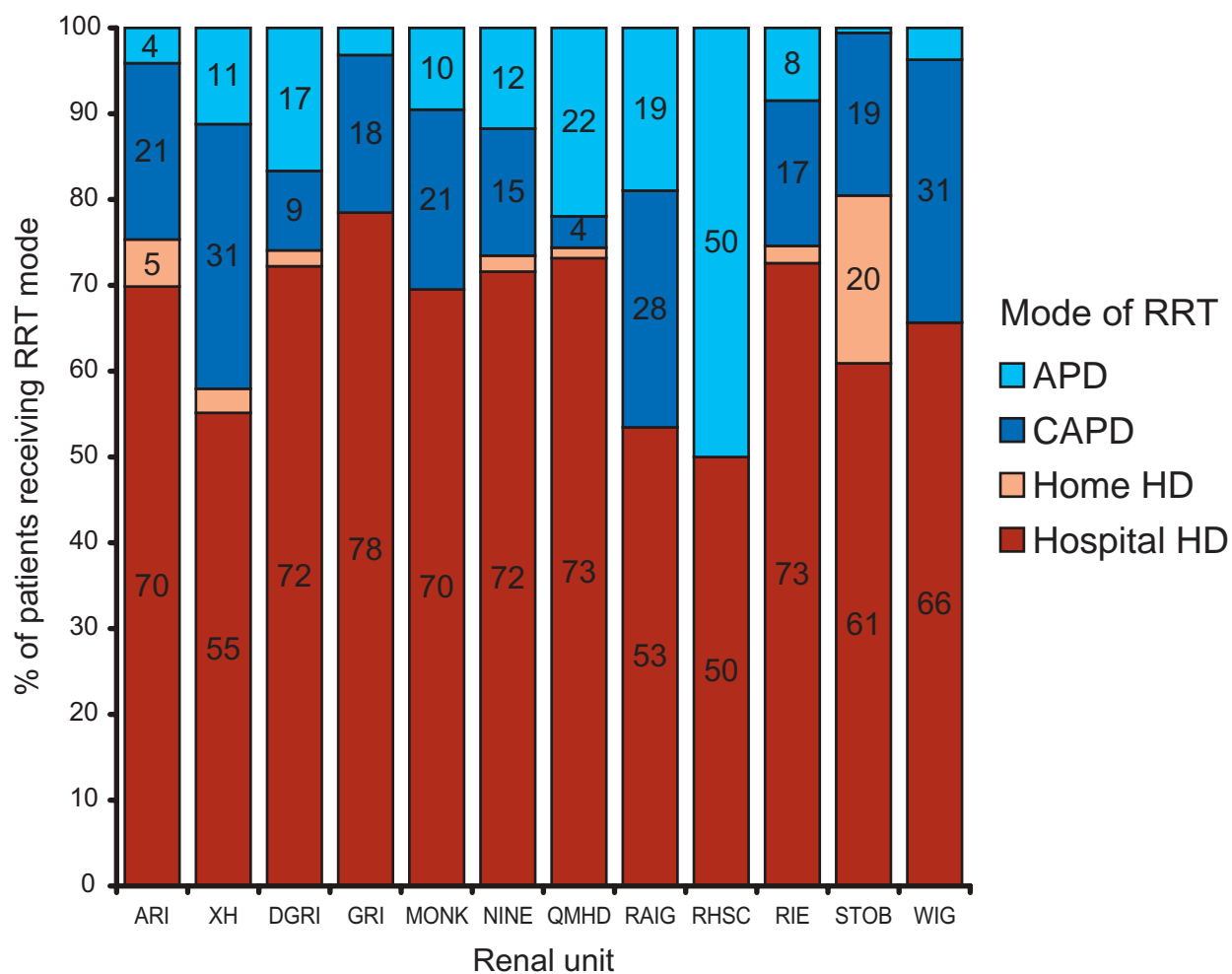
It appears from graphs B2.2 and B2.4 that those units with a high proportion of patients receiving HD are also the units with a high proportion of elderly patients.



B2.7 Mode of RRT and renal unit providing treatment on 31st December 1999

	ARI	XH	DGRI	GRI	MONK	NINE	QMHD	RAIG	RHSC	RIE	STOB	WIG
Transplant	54	20	10	0	0	39	0	46	72	57	0	71
APD	2	9	15	3	10	7	22	10	14	4	1	1
CAPD	10	25	8	18	21	9	4	15	0	7	19	9
Home HD	3	2	2	0	0	1	1	0	0	1	20	0
Hospital HD	32	44	65	78	70	44	73	29	14	31	61	19

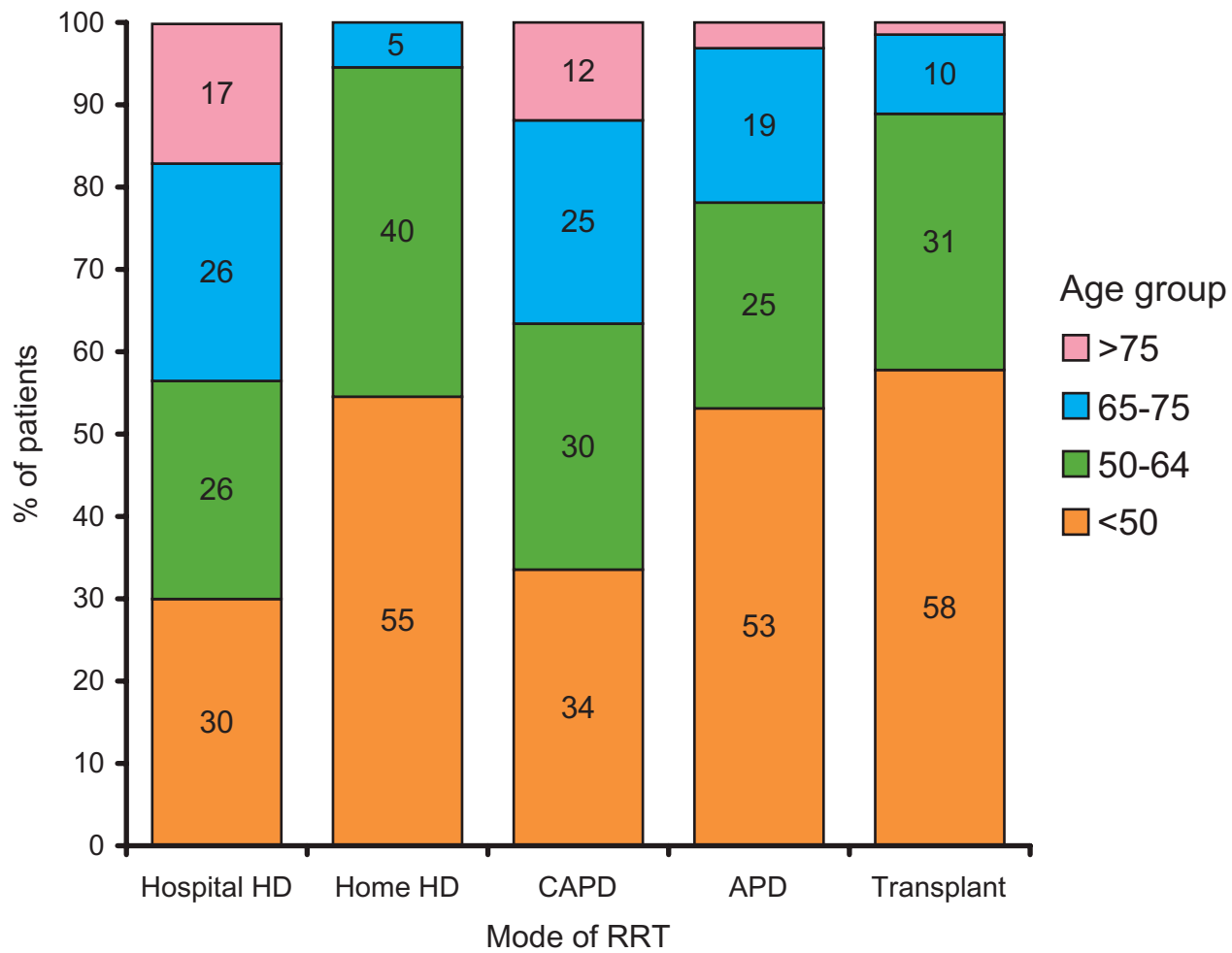
B2.8 Mode of RRT and renal unit providing treatment on 31st December 1999 (excluding Transplant)



B2.9 Mode of RRT and renal unit providing treatment on 31st December 1999 (excluding Transplant)

	ARI	XH	DGRI	GRI	MONK	NINE	QMHD	RAIG	RHSC	RIE	STOB	WIG
APD	4	11	17	3	10	12	22	19	50	8	1	4
CAPD	21	31	9	18	21	15	4	28	0	17	19	31
Home HD	5	3	2	0	0	2	1	0	0	2	20	0
Hospital HD	70	55	72	78	70	72	73	53	50	73	61	66

B2.10 Age of patients and mode of RRT on 31st December 1999



B2.11 Median age on 31 December 1999 by mode of RRT

The median ages of patients receiving all treatment modalities on 31 December 1999 were compared and found to be significantly different. ($p < 0.001$ Kruskal Wallis)

Mode of RRT	Number of patients	Median Age	Age Range
Transplant	1435	46.5	5.3 - 79.7
APD	128	48.9	1.0 - 82.1
CAPD	328	60.3	7.5 - 85.3
Home HD	55	49.2	21.7 - 72.0
HD	1090	62.2	5.3 - 91.3

B2.12 Deaths in each age group in 1999

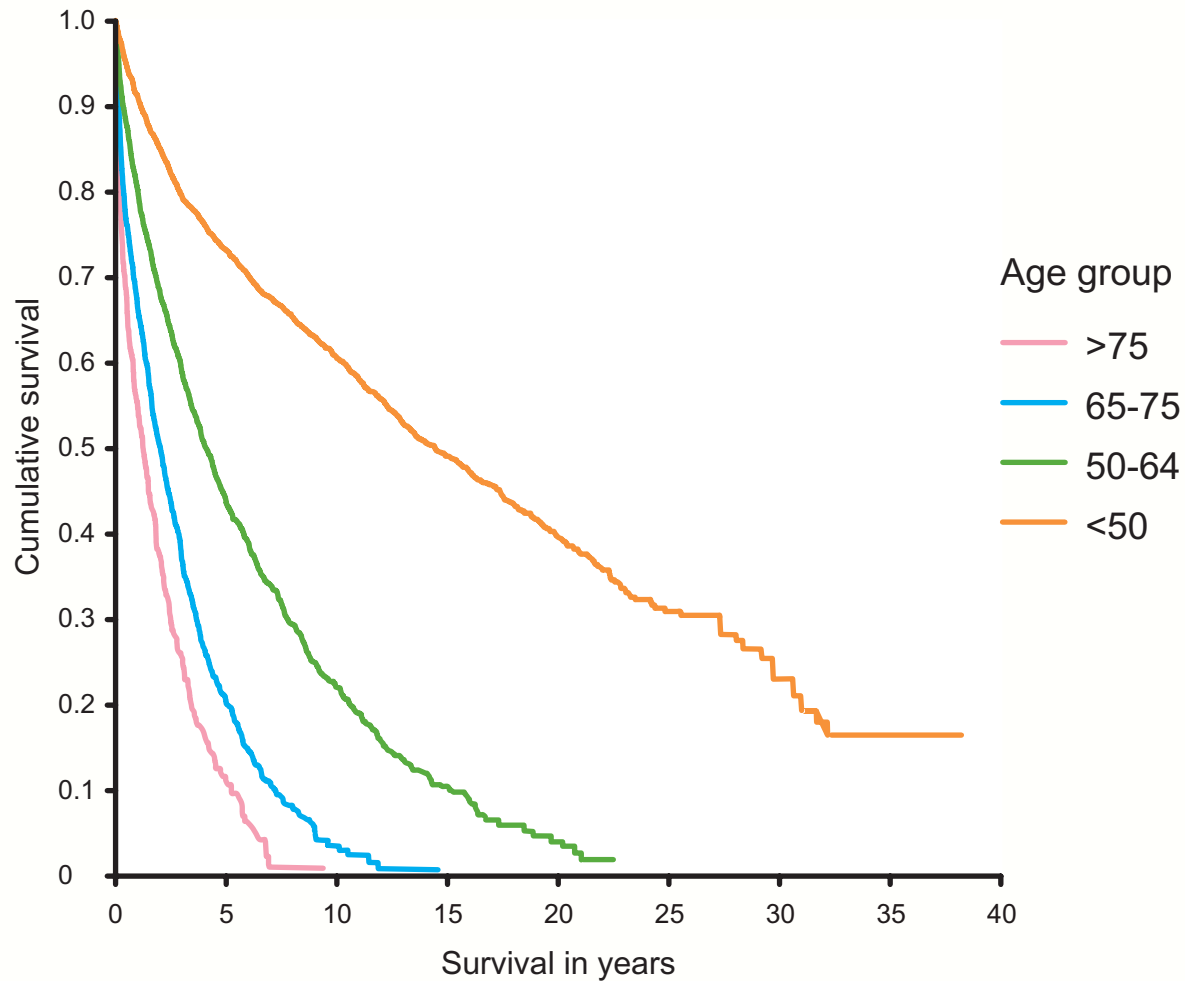
Age Group	Number of Deaths	Percentage
>75	116	29
65-75	151	37
50-64	101	25
<50	36	9

C SURVIVAL

C1 SURVIVAL ANALYSES

The log rank test for comparison of the survival curves had a p-value <0.0001 indicating a significant difference in survival between these age groups (at the start of RRT). Median survival decreased with increasing age at the time of starting RRT.

C1.1 Survival by age when starting RRT



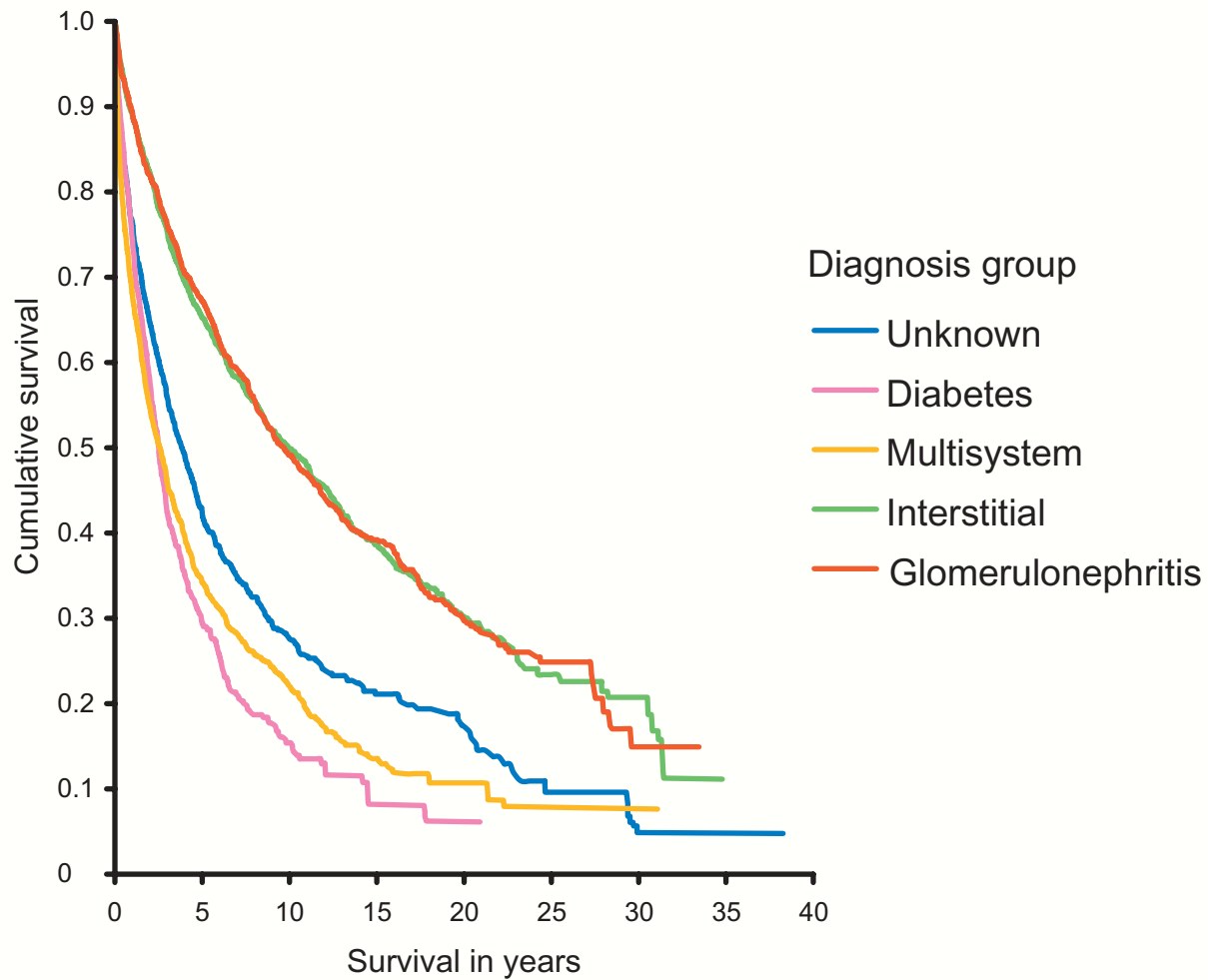
C1.2 Survival of all patients by age when starting RRT

Only patients with complete data are eligible for survival analysis. The total number of patients in this section will therefore be slightly less than the totals reported in the incidence and prevalence sections.

Age Group	Number Starting RRT	Number dead by 31/12/99	Median survival (years)	95% CI for median survival	
>75 years	541	383	1.3	1.0	1.5
65-75 years	1450	1045	2.0	1.8	2.2
50-64 years	2154	1410	4.0	3.8	4.4
<50 years	3108	1286	14.4	13.3	15.6
	7253	4124	5.2	4.9	5.6

C1.3 Survival of all patients by primary renal diagnosis group

A wide range of expected survival is evident between the different renal diagnoses groups.



C1.4 Survival of all patients by primary renal diagnosis group

The log rank test for comparison of survival curves had a p-value <0.0001, indicating a significant difference in survival between the 5 diagnosis groups. On average patients with glomerulonephritis or interstitial nephritis survived longer than those in the other diagnosis groups.

Diagnosis Group	Number Starting RRT	Number dead by 31/12/99	Median survival (years)	95% CI for median survival	
Unknown	1227	734	3.8	3.4	4.3
Diabetes	928	611	2.5	2.3	2.8
Multisystem	1562	1060	2.6	2.3	2.9
Interstitial	1957	946	10.0	8.9	11.0
Glomerulonephritis	1521	736	9.7	8.6	10.8
	7195	4087	5.3	5.0	5.6

C1.5 Survival by age and diagnosis group

The table shows the independent effect on survival of age and diagnosis. The general pattern seen in graphs C1.1 and C1.3 is reflected in each of the age groups separately.

The lack of significant difference in survival between diagnosis groups in patients aged over 75 might be due to the smaller number of patients involved, or it might be a real effect therefore these figures should be interpreted with caution.

Age Group	Diagnosis Group	Number Starting RRT	Number dead by 31/12/99	Median survival (years)	95% CI for median survival		Log Rank
All ages	All diagnosis	7195	4087	5.3	5.0	5.6	
>75 years	Unknown	206	148	1.2	0.7	1.7	p=0.16
	Diabetes	43	32	1.1	0.6	1.5	
	Multisystem	151	109	1.0	0.3	1.6	
	Interstitial	83	54	1.8	1.3	2.4	
	Glomerulonephritis	56	38	1.2	0.4	2.0	
65-75 years	Unknown	325	223	2.5	2.1	2.9	p<0.0001
	Diabetes	184	125	1.6	1.3	2.0	
	Multisystem	470	359	1.3	1.0	1.6	
	Interstitial	264	191	2.8	2.4	3.3	
	Glomerulonephritis	197	140	3.0	2.3	3.7	
50-64 years	Unknown	328	217	4.5	3.8	5.1	p<0.0001
	Diabetes	346	250	2.3	2.0	2.7	
	Multisystem	502	361	2.9	2.3	3.5	
	Interstitial	539	330	6.3	5.5	7.2	
	Glomerulonephritis	426	242	6.1	5.0	7.2	
<50 years	Unknown	368	146	19.1	13.7	24.6	p<0.0001
	Diabetes	355	204	4.6	3.4	5.8	
	Multisystem	439	231	8.6	6.6	10.7	
	Interstitial	1071	371	18.8	16.7	20.8	
	Glomerulonephritis	842	316	17.6	15.7	19.5	

C1.6 Life expectancy for the general Scottish population 1997-1999

For comparison with patients receiving RRT, life expectancy for the general population of Scotland between 1997-99 by sex, at the exact age given are shown. Life expectancy for patients receiving RRT is much less than the general population. The excess mortality in renal patients may partly be attributed to comorbid illness. These are sometimes caused by the renal failure but are often coincident and may indeed cause the renal failure.

Age	Life expectancy males	Life expectancy females
85	4.9	5.7
75	8.6	10.7
65	14.2	17.4
45	30.1	34.5

C2 SURVIVAL OF PATIENTS AGED 50-64 WHEN STARTING RRT OVERTIME

We aimed to determine whether survival has improved for patients starting RRT in more recent years.

The data were divided into groups according to year of starting RRT. These year groups have obviously been followed-up for different periods therefore a standard Kaplan-Meier analysis would give a misleading estimate of survival. The most recent data relating to patients starting RRT between 1995-1999 were excluded to ensure a minimum of 5 years of follow-up was available for analysis. We are aware that this reduces the power for finding a significant improvement in survival with starting RRT recently.

Logistic regression was used to see whether the probability of dying within 5 years of starting RRT, in patients aged 50-64 years, with a diagnosis of glomerulonephritis has changed over time. Odds ratios were calculated for death by 5 years.

C2.1 Odds ratio of death by 5 years of RRT for patients aged 50-64 with a diagnosis of Glomerulonephritis

An initial group of 426 patients who had a PRD of glomerulonephritis and were of age 50-64 years when starting treatment were identified for analyses. However, 126 of this number started treatment between 1995 and 1999 and were excluded to ensure a minimum of 5 years of follow-up RRT. A further 9 patients had either recovered, moved outwith Scotland or had been lost to follow-up and were therefore ineligible. Of the remaining 291 people, 128 died within 5 years of beginning RRT.

None of the odds ratios are significantly different to a ratio of 1.0.

Date of starting RRT	Patients	Dead by 5 years of RRT	Odds ratio of death	95% CI ratio of odds of death		p value
1990-1994	110	43	1.00	reference		
1985-1989	77	33	1.17	0.65	2.11	0.61
1980-1984	47	24	1.63	0.82	3.24	0.17
1964-1979	57	28	1.50	0.79	2.87	0.22

This analysis was repeated for patients of the same age when starting RRT but with a diagnosis of diabetic nephropathy. Such patients have only been treated in appreciable numbers for the last 16 years.

C2.2 Odds ratio of death by 5 years of RRT for patients aged 50-64 with a diagnosis of diabetic nephropathy

346 patients had a PRD of diabetic nephropathy and belonged to the 50-64 years age band when starting treatment. This group included 166 people who had not received 5 years of RRT, 17 patients who started RRT before 1984 and a further 2 people lost to follow-up. All of these are excluded from the analyses. Of the remainder, 129 died within 5 years of RRT start.

None of the odds ratios are significantly different to 1.0.

For patients aged 50-64 when starting RRT, with diabetic nephropathy, the probability of dying within 5 years was essentially the same regardless of when RRT was started.

Date of starting RRT	Patients	Dead by 5 years of RRT	Odds ratio of death	95% CI ratio of odds of death		p value
1993-1994	41	31	1.00	reference		
1991-1992	38	31	1.43	0.48	4.23	0.52
1989-1990	32	24	0.97	0.33	2.83	0.95
1984-1988	50	43	1.98	0.68	5.78	0.21

The 5 year survival of patients aged 50 – 64 years when starting RRT has not increased over the last 30 years although the number of patients starting RRT in the 1960s was very small.

D QUALITY ASSURANCE

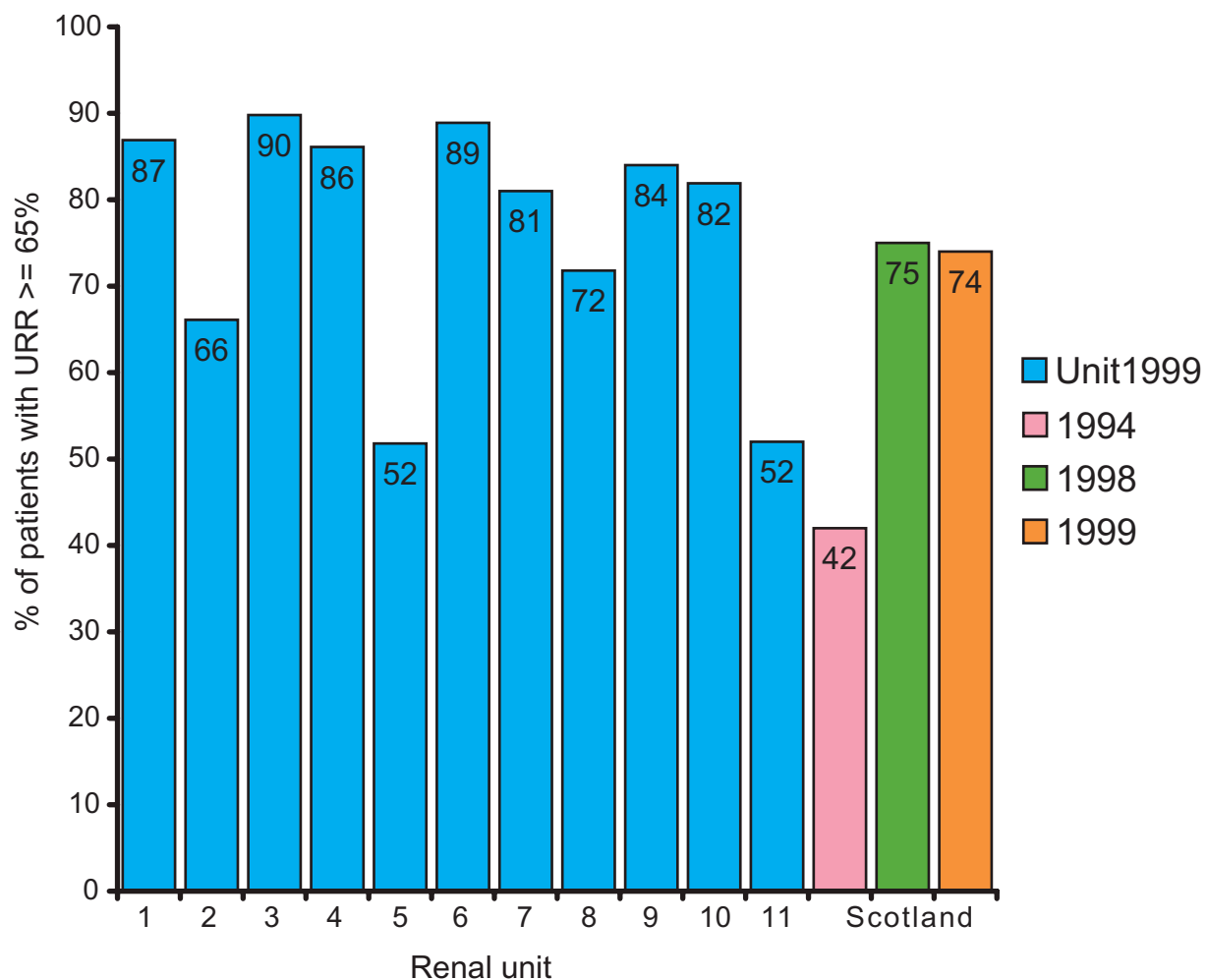
D1 HOSPITAL HAEMODIALYSIS USING THE UREA REDUCTION RATIO

The quality of haemodialysis can be assessed by the percentage reduction in the serum urea concentration during a dialysis session. This is also called the urea reduction ratio (URR) = $100 \times (1 - \text{post dialysis [urea]} / \text{pre dialysis [urea]})$. URR has been shown to correlate with patient survival (3).

The SRR is adhering to the current edition of the UK Renal Association Guidelines (1997) that recommend a target URR of greater than 65% for all patients receiving hospital haemodialysis three times a week (4). A standard method for collecting the blood samples has been adopted. Results are available for 909 patients or 83% of the total on hospital HD in September 1999 in the 11 Scottish adult units. Unit identity has again been protected, but a commitment from all units will permit the removal of anonymity in future reports

A URR of greater than or equal to 65% was achieved in 74% of adult hospital HD patients in 1999. This compares with 75% in 1998 and 42% in 1994 (1). This project demonstrates the benefits of a sustained quality improvement programme that is supported by all members of our multi-disciplinary teams and by patients.

D1.1 Percentage of hospital haemodialysis patients achieving a URR $\geq 65\%$ in 1999



D2 PERITONEAL DIALYSIS AUDIT

This is the first year in which the nationwide peritoneal dialysis audit has been performed and therefore in keeping with SRR policy the results are published anonymously. A prospective audit of peritonitis, catheter function and adequacy of dialysis involving all patients on peritoneal dialysis in the 11 adult renal units in Scotland was performed during 1999. The audit was co-ordinated by a lead peritoneal dialysis nurse.

Data on all prevalent patients on peritoneal dialysis on December 31st 1998 and all incident patients during 1999 were available for analysis. The number of patients reported in this audit does not tally exactly with the numbers reported elsewhere in this report. This is because numbers of patients are constantly changing and the survey periods were slightly different. The total number of patients receiving peritoneal dialysis remained stable throughout the year, 435 on 31/12/1998, 439 on 30/06/1999 and 427 on 31/12/1999. This gives a prevalence of slightly greater than 80 peritoneal dialysis patients per million of the population. There was a small increase in the proportion of patients treated with APD during the year, from 27% on 31/12/1998 to 28% on 30/06/1999 and 35% on 31/12/1999. A relatively stable number of patients on peritoneal dialysis were maintained because of the high turnover.

D2.1 Patients starting and discontinuing peritoneal dialysis in 1999

Number of patients starting PD in 1999		Number of patients stopping PD in 1999	
New patients	165	Patient death	71
Transfer from HD	56	Transfer to HD	117
Failed renal transplant	18	Renal transplant	54
Transfer from another renal unit	2	Transfer to other renal unit	3
		Recovery of renal function	4
Total	241	Total	249

D2.2 Cause of technique failure of peritoneal dialysis in 1999

Peritoneal dialysis technique failure (defined as transfer to haemodialysis for at least 2 months or the patients decision to stop dialysis) occurred in 117 (17%) of the 676 patients at risk (435 prevalent patients on 31/12/1998 and 241 incident patients during 1999). The major causes of technique failure in the patients that transferred to haemodialysis are shown below. The main cause (38%) of technique failure was PD-related peritonitis.

Cause of technique failure	Number of patients	% PD technique failure
Peritonitis	44	38
Failed peritoneal access	20	17
Underdialysis	18	16
Patient preference for HD	12	10
Complication of high intraperitoneal pressure	12	10
Ultrafiltration failure	6	5
Patients decision to stop	5	4

17% of the peritoneal dialysis patients at risk during 1999 transferred to haemodialysis for at least 2 months.

The mean interval between episodes of peritonitis in PD patients in Scotland during 1999 was 18.2 months. This is similar to the UK Renal Association guideline standard of one episode every 18 months (table D2.3) (4). Peritonitis was defined as any two of the following criteria; symptoms indicative of peritonitis, total dialysate effluent white cell count greater than 100/ml and positive culture from dialysate effluent. Recurrent episodes of peritonitis within 4 weeks of stopping antimicrobial therapy are included in these results. There were a total of 40 episodes of recurrent peritonitis and the peritonitis rate would improve to 1 episode every 21.1 months if recurrent peritonitis episodes were excluded from analysis.

D2.3 Variation in peritonitis and technique failure rates in adult renal units 1999

During 1999 there was a threefold variation (11.4 – 36.8 patient months between episodes) in the incidence of peritonitis between the individual renal units. Similarly, there was variation in the technique failure rate (censored for renal transplantation, recovery of renal function and patient death) expressed as a proportion of all of the patients treated by peritoneal dialysis during 1999 in the individual units. These differences are at least in part due to the small numbers of patients treated by PD in each unit.

Renal unit number	Peritonitis rate (months between episodes)	Technique failure rate (percentage of at risk patients)
1	16.4	32
2	22.4	13
3	13.8	33
4	14.0	10
5	24.3	8
6	11.4	18
7	16.0	11
8	19.9	13
9	36.8	15
10	13.1	25
11	16.7	12
National average	18.2	17

Units are allocated a random number.

D2.4 Causal organisms and clinical outcomes of the peritonitis episodes

The causative organisms of peritoneal dialysis related peritonitis and clinical outcomes during 1999 are summarised in the supporting table. Five patient deaths secondary to single cases of S. aureus, methicillin resistant S. aureus, fungal, mixed growth and culture negative peritonitis are included in the catheter removal subgroup of outcomes. The proportion of culture negative episodes of peritonitis (13%) exceeded the 10% guideline of the Renal Association standard whilst the initial cure rate equalled the minimum of 80% of episodes with resolution of peritonitis without resorting to catheter removal.

Causative Organism	Number of patients (% peritonitis)		Initial cure (% of this organism)		Catheter removal (% of this organism)	
S. epidermidis	89	(31%)	78	(88%)	11	(12%)
S. aureus	65	(22%)	50	(77%)	15	(23%)
Gram –ve bacilli	41	(14%)	25	(61%)	16	(39%)
Fungi	7	(2%)	2	(29%)	5	(71%)
Other	50	(17%)	44	(88%)	6	(13%)
Culture negative	39	(13%)	34	(87%)	5	(13%)
Total	291	(100%)	233	(80%)	58	(20%)

D2.5 Peritoneal dialysis adequacy in the first and second 6 months of 1999

The adequacy of peritoneal dialysis was evaluated by measuring total creatinine clearance expressed as litres/week/1.73m² body surface area. Residual renal function was estimated as the mean of urinary urea and creatinine clearance calculated from 24 hour urine collections and peritoneal clearance was estimated from 24 hour effluent dialysate collections using standard methods. The proportion of the patients on peritoneal dialysis on the census dates (30/06/1999 and 31/12/1999) who had an assessment of adequacy of dialysis within the preceding 6 months was 63% and 65% respectively. The percentage of patients undergoing an assessment of the adequacy of dialysis varied within the 11 units from 0% to 100%. The results of the latest adequacy test of the patients who had been assessed in the 6 months preceding 30/06/1999 and 31/12/1999 are presented in the following table.

Total creatinine clearance (litres/week/1.73m²)	Number of patients on 30/06/1999	Number of patients on 31/12/1999
< 50	44	38
50-60	49	61
61-70	50	53
> 70	135	125
Not assessed	161	150
Total	439	427

Laboratory results for peritoneal dialysis patients

The most recent laboratory results of 429 of the 439 prevalent patients on June 30 were audited. The latest haemoglobin was below 10 g/dl in 39% of the patients and varied greatly from 0% in one of the smaller units to 49%. Only one unit achieved the UK Renal Association standard of more than 85% of patients with a haemoglobin concentration above 10 g/dl (4). The unit with the lowest haemoglobin levels had very few patients (7%) with serum ferritin concentrations below 100 mg/l. Erythropoietin had only been prescribed for 22% of these patients whereas the national average was 64%. Serum ferritin levels were below 100 mg/l in 27% (range 10 to 44%) of peritoneal dialysis patients. Serum phosphate concentration was above 1.8 mmol/l in 36% of PD patients (range 23% - 57%). Adjusted serum calcium was greater than 2.6 mmol/l in 57 of the 429 patients and was below 2.2 mmol/l in 65 patients. The proportion of patients with hypoalbuminaemia (serum albumin < 35g/l) varied greatly among the units (range 10% to 84%; mean 32%). Some of the variation in serum albumin concentrations was due to differences in the method used by the local biochemistry services to measure albumin concentrations.

The audit has shown that across Scotland the rate of peritonitis compares favourably with that recommended by the UKRA recommended standard (4). There are large variations between units but the small number of patients treated by some units should be borne in mind when interpreting these results. Wide variations in practice for assessing dialysis adequacy exist between units and a large proportion of patients had no measure of adequacy made during the year audited. This study provides the foundation upon which future comparative audits can be built.

For comparison with patients receiving RRT, life expectancy for the general population of Scotland between 1995-97 by sex, at the exact age given are shown in Table 9. The excess mortality in renal patients may partly be attributed to comorbid illness. These are sometimes caused by the renal failure but are often coincident and may indeed cause the renal failure. The wide range of expected survival with different renal diagnoses is shown in graph 13. Life expectancy for patients receiving RRT is much less than the general population.

APPENDIX 1

CORE DATA SET

The Scottish Renal Registry collects data approved by the Steering Group. A set of data definitions is being prepared for each of the mandatory data items. A system is available for automatic validation, checking of unlikely or incompatible data and completion of missing data. The Steering Group can add new items to the mandatory data set. These can be either permanent or temporary for the duration of approved studies.

For patients receiving RRT for ESRD

1. Surname
2. Forename
3. Date of birth
4. Sex
5. Ethnic group (Race) – selected from list published by Registrar General for Scotland
6. Address
7. Postcode
 - From which the SRR can derive:
 - Health Board of residence
 - Deprivation score
8. Hospital number for all hospitals attended as a renal patient
9. Primary renal diagnosis - ERA-EDTA codes
10. Date of death
11. Cause of death: ERA-EDTA codes
12. Dialysis and transplantation events

Report all changes in methods or place of renal replacement therapy

Data collected on specified dates throughout the year

13. Dialysis adequacy:
 - Haemodialysis – URR
 - Peritoneal dialysis – Kt/V
14. Adjusted serum calcium concentration
15. Serum phosphate concentration
16. Serum albumin concentration
17. Haemoglobin concentration

Data collected for approved studies

1. ARMS Study:
 - Hospital admissions
 - Comorbidity
 - Quality of life using SF-36
2. Incidence of cancer in patients receiving RRT:
 - Date of diagnosis
 - Site
 - Morphology of malignancy

APPENDIX 2

NAMES, ADDRESSES AND STEERING GROUP MEMBERS OF CONTRIBUTING RENAL UNITS

The one paediatric and all 11 adult renal units have contributed fully to the SRR and to the production of this report.

The Renal units are listed below with their address and the addresses of other sites at which they organise dialysis either in an annex to their main site or in a remote satellite unit. The names of the consultant physician members of the steering group is also listed and those on the SRR executive committee are indicated *.

	Renal Unit	Address	Date unit opened	Steering Group member and method of transferring data to the SRR
1	Aberdeen Royal Infirmary	Foresterhill ABERDEEN AB25 2ZD	Jan 1967	Prof. Alison MacLeod * Prof. of Medicine & Therapeutics Honorary Consultant Physician and Nephrologist mmd175@abdn.ac.uk Data re-keyed manually
		Satellites: Dr Gray's Hospital Elgin IV30 ISN	May 1994	
		Peterhead Community Hospital Links Terrace Peterhead AB42 2XB	May 1997	
2	Crosshouse Hospital	Crosshouse Kilmarnock KA2 0BE	Jan 1990	Dr Andrew Innes Consultant Renal Physician Electronic Data Transfer to SRR
3	Dumfries & Galloway Royal Infirmary	Bankend Road Dumfries DG1 4AP	Nov 1990	Dr Sue Robertson (Medical Representative) Suerobertson@hotmail.com Dr Chris Isles (Consultant Representative) c.isles@dgri.scot.nhs.uk Electronic Data Transfer to SRR
4	Glasgow Royal Infirmary	Castle Street Glasgow G4 0SF	Mar 1967	Dr Robert Mactier (Consultant Representative) Consultant Nephrologist Robert.Mactier@NorthGlasgow.Scot.NHS.UK Electronic Data Transfer to SRR
		Satellite: Falkirk and District Royal Infirmary Major's Loan FK1 5QE	April 1999	

continued

APPENDIX 2 *CONTINUED*

	Renal Unit	Address	Date unit opened	Steering Group member and method of transferring data to the SRR
5	Monklands Hospital	Monkscourt Avenue Airdrie ML6 0JS	Oct 1989	Dr Bill Smith Consultant Physician and Nephrologist William.Smith@laht.scot.uk Data re-keyed manually
6	Ninewells Hospital	Ninewells Avenue Dundee DD1 9SY	Jun 1964	Dr Ellon McGregor * Consultant Nephrologist ellonm@tuht.scot.nhs.uk Data re-keyed manually
7	Queen Margaret's Hospital	Whitefield Road Dunfermline Fife KY12 0SU	Jan 1995	Dr David Jenkins Consultant Renal Physician Electronic data transfer to SRR
		Satellite: Victoria Hospital Highfield Road Kirkcaldy KY2 5AH	Jan 1990	
8	Raigmore Hospital	Old Perth Road Inverness IV2 3UJ	Jan 1976	Dr John Burton Consultant Physician Data re-keyed manually
9	Royal Hospital for Sick Children	Yorkhill Glasgow G3 8SJ	Jan 1972	Dr Jim Beattie Consultant Paediatrician and Nephrologist Jim.Beattie@yorkhill.scot.nhs.uk Electronic data transfer to SRR
10	Royal Infirmary of Edinburgh	Lauriston Place Edinburgh EH2 9YW	Jan 1960	Dr Robin Winney * Consultant Representative Consultant Renal Physician R.J.Winney@ed.ac.uk Electronic data transfer to SRR
		Satellites: Western General Hospital Crewe Road South Edinburgh EH4 2 XU	Oct 1986	
		Borders General Hospital Melrose TD6 9BD	Mar 1989	

continued

APPENDIX 2 *CONTINUED*

Renal Unit	Address	Date unit opened	Steering Group member and method of transferring data to the SRR
11	Stobhill Hospital Balornock Road Glasgow G11 6NT	Sep 1968	Dr Robert Mactier Consultant Nephrologist Robert.Mactier@NorthGlasgow.Scot.NHS.UK Electronic data transfer to SRR
12	Western Infirmary Glasgow Dumbarton Road Glasgow G11 6NT	1970	Dr Brian Junor * Consultant Nephrologist brian.junor.wg@northglasgow.scot.nhs.uk Electronic data transfer to SRR
	Annex: Gartnavel General Hospital Great Western Road Glasgow G12 0YN	Nov 1994	
	Satellite: Inverclyde Royal Hospital Larkfield Road Greenock PA16 0XN	July 1999	

Dr John Logan, Consultant in Public Health Medicine also serves on the Steering group where he represents the health boards. In 1999 Dr Marion Bain, Consultant in Public Health Medicine joined the steering group to represent ISD and Dr John Seth, Clinical Scientist in Clinical Chemistry at the Royal Infirmary of Edinburgh, joined to advise on matters relating to laboratory methods. A nurse representative will join the Steering Group in 2001.

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e-mail: jseth@ed.ac.uk

APPENDIX 3

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Metcalfe W, Khan IH, Prescott G, Simpson K, MacLeod AM. On behalf of the Scottish Renal Registry. 90 day mortality on RRT - A prospective national study. ASN, November 1999, Miami. (Poster)

Metcalfe W, Khan IH, Prescott G, Simpson K, MacLeod AM. On behalf of the Scottish Renal Registry. Early mortality on renal replacement therapy: A national prospective study. XXXVI Congress of the ERA-EDTA, September 1999, Madrid. *Nephrol Dial Transplant* 1999; 14(9): A143

Metcalfe W, Khan IH, Simpson K, Prescott G, MacLeod AM. On behalf of the Scottish Renal Registry. 90 day outcomes of RRT in Scotland. The Scottish Renal Association, May 1999, Dunfermline. *Nephrol Dial Transplant* 1999; 14(10): 2542

APPENDIX 4

CONFIDENTIALITY OF PATIENT DATA

Text of a notice that will be displayed in every renal and satellite unit in Scotland from 1st July 2001.

SCOTTISH RENAL ASSOCIATION

SCOTTISH RENAL REGISTRY

PATIENT CONFIDENTIALITY

This renal unit along with every other renal unit in Scotland is affiliated to the Scottish Renal Association and the Scottish Renal Registry. These organisations are run by doctors and nurses from the Scottish renal units. In order to maintain and improve the quality of diagnosis, treatment and staff training we maintain a confidential computer register of patients receiving dialysis and those with a kidney transplant. Regular reports about the quality of the renal service are published and are available on request or on the internet (<http://www.show.scot.nhs.uk/srr>). No patient can be identified from these reports.

As well as producing reports referring only to Scotland, the Scottish Renal Registry participates in a UK wide Registry and also contributes anonymous information to the European Renal Registry and the International Federation of Renal Registries. These bodies have similar aims of improving the quality of renal services.

This notice has been produced so that patients are aware of this important quality assurance scheme which may obviously contain information about them. If you would like any further details about the Scottish Renal Registry please ask your kidney unit consultant.

The SRR office can provide the text of this poster in LARGE PRINT and may be able to arrange for translation into foreign languages on request.

APPENDIX 5

ORGANISATIONS WITH WHICH THE SCOTTISH RENAL REGISTRY RECEIVES OR EXCHANGES DATA

All renal units in Scotland

Dutch Renal Registry - RENINE

European Renal Association – European Dialysis and Transplant Association

Information and Statistics Division of the NHS in Scotland

Registrar General for Scotland (via ISD)

Scottish Cancer Registry

Scottish Health boards

UK Renal Registry

UK Transplant Support Service Authority

United States Renal Data System

APPENDIX 6

REPORTS RECEIVED FROM OTHER RENAL REGISTRIES DURING 1999

We are very grateful to the following organisations for sending a copy of their annual report or other publications to the SRR. Copies of these reports can be seen on request at the SRR office.

Australia and New Zealand Renal Registry

Catalan Renal Registry

Dutch Renal Registry - RENINE

European Renal Association – European Dialysis and Transplant Association

Finnish Registry of Kidney Diseases

Italian Renal Registry

Lombardy Regional

Quasi Niere Renal Replacement Therapy in Germany

UK Renal Registry

UK Transplant Support Service Authority

United States Renal Data System

APPENDIX 7

ERA-EDTA PRIMARY RENAL DIAGNOSIS CODES AND GROUPINGS

GROUP 1: PRIMARY GLOMERULONEPHRITIS

- 10 Glomerulonephritis; histologically NOT examined
- 11 Focal segmental glomerulosclerosis with nephrotic syndrome in children
- 12 IgA nephropathy (proven by immunofluorescence, not 85)
- 13 Dense deposit disease; membranoproliferative GN; type II (proven by immunofluorescence and/or electron microscopy)
- 14 Membranous nephropathy
- 15 Membranoproliferative GN; type I (proven by immunofluorescence and/or electron microscopy - not code 84 or 89)
- 16 Crescentic (extra-capillary) glomerulonephritis (type I, II, III)
- 17 Focal segmental glomerulosclerosis with nephrotic syndrome in adults
- 19 Glomerulonephritis; histologically examined, not given above

GROUP 2: INTERSTITIAL NEPHROPATHIES

- 20 Pyelonephritis cause not specified
- 21 Pyelonephritis associated with neurogenic bladder
- 22 Pyelonephritis due to congenital obstructive uropathy with/without vesico-ureteric reflux
- 23 Pyelonephritis due to acquired obstructive uropathy
- 24 Pyelonephritis due to vesico-ureteric reflux without obstruction
- 25 Pyelonephritis due to urolithiasis
- 29 Pyelonephritis due to other cause
- 30 Interstitial nephritis (not pyelonephritis) due to other cause, or unspecified (not mentioned below)
- 31 Interstitial nephropathy due to analgesic drugs
- 32 Interstitial nephropathy due to cis-platinum
- 33 Interstitial nephropathy due to cyclosporin A
- 34 Lead induced interstitial nephropathy
- 39 Drug induced interstitial nephropathy not mentioned above
- 40 Cystic kidney disease - type unspecified
- 41 Polycystic kidneys; adult type (dominant)
- 42 Polycystic kidneys; infantile (recessive)
- 43 Medullary cystic disease; including nephronophthisis
- 49 Cystic kidney- disease - other specified type
- 50 Hereditary/Familial nephropathy - type unspecified
- 51 Hereditary nephritis with nerve deafness (Alport's Syndrome)
- 52 Cystinosis
- 53 Primary oxalosis
- 54 Fabry's disease
- 59 Hereditary nephropathy - other specified type

- 61 Oligomeganephronic hypoplasia
- 63 Congenital renal dysplasia with/without urinary tract malformation
- 66 Syndrome of agenesis of abdominal muscles (Prune Belly)
- 92 Gout nephropathy (urate)
- 93 Nephrocalcinosis and hypercalcaemic nephropathy

GROUP 3: MULTISYSTEM DISEASES

- 70 Renal vascular disease - type unspecified
- 71 Renal vascular disease due to malignant hypertension (No PRD)
- 72 Renal vascular disease due to hypertension (No PRD)
- 73 Renal vascular disease due to polyarteritis
- 74 Wegeners Granulomatosis
- 75 Ischaemic renal disease / cholesterol embolisation
- 76 Glomerulonephritis related to liver cirrhosis
- 78 Cryoglobulinaemic glomerulonephritis
- 79 Renal vascular disease - due to other cause (not given above and not code 84-88)
- 82 Myelomatosis/light chain deposit disease
- 83 Amyloid
- 84 Lupus erythematosus
- 85 Henoch-Schonlein purpura
- 86 Goodpasture's Syndrome
- 87 Systemic sclerosis (scleroderma)
- 88 Haemolytic uraemic Syndrome (including Moschcowitz Syndrome)
- 89 Multi-system disease - other (not mentioned above)
- 90 Tubular necrosis (irreversible) or cortical necrosis (different from 88)
- 91 Tuberculosis
- 94 Balkan nephropathy
- 95 Kidney tumour
- 96 Traumatic or surgical loss of kidney

GROUP 4: - DIABETES

- 80 Diabetic glomerulosclerosis or diabetic nephropathy

GROUP 5: - NOT KNOWN AND OTHER

- 00 Chronic renal failure; aetiology uncertain/unknown/unavailable
- 60 Renal hypoplasia (congenital) - type unspecified
- 99 Other identified renal disorders

APPENDIX 8

STATISTICAL METHODS FOR THE REPORT

In most medical studies there is a population of interest to the investigators. We would like to measure or question the whole population of interest, but funding and time limitations usually will not permit this. A random sample of this population is selected for closer examination which we hope is representative of the larger population. The results of the analysis of data from the sample, such as estimates and confidence intervals, and the expertise of the investigators are combined to make inferences about values that would have been obtained if we were able to measure the entire population of interest.

The SRR, like the British Census, is an attempt to examine data on the whole population of interest. This population includes all people who have received RRT for ESRD in Scotland. In this type of study every attempt is made to obtain a comprehensive database of the required population. If the registry includes every patient who has received RRT then we no longer need to make inferences in the usual way from the values obtained.

After extensive checking and validation we have had to believe that these data are valid and that there are no simple ways of obtaining the missing information.

Median ages and interquartile ranges have been reported in most cases because the distribution of ages for the patients receiving RRT is skewed with the majority being older patients. A few extreme values in a distribution have a much greater influence on a mean than a median value making the mean less representative.

A Kruskal-Wallis test rather than an analysis of variance was used to compare ages receiving different treatment modalities because the ages of patients are not normally distributed.

It is usual to report median survival times from Kaplan-Meier analyses rather than means because there may be a small number of individuals with extremely long survival. The median is more representative of survival and is easily interpreted as the time by which we would expect half of the patients to have died.

A logrank or Mantel-Cox test (5) is the most widely used method of comparing two or more survival curves. If there is no difference in the risk of death in two groups of patients then the corresponding survival curves should only differ due to chance variation. In this situation the logrank test should indicate no significant difference between the curves. There are other tests available such as the Tarone-Ware test or the Wilcoxon or Breslow test. The logrank test gives equal weighting to events (deaths) throughout the whole time period whereas the others give greater weighting to events that occur in the earlier parts of the survival curves. The other tests would be more appropriate if we were particularly interested in certain parts of the curves, e.g. when considering early deaths. The p-values for all three tests were compared and found to be similar for the comparisons of survival in the different age and diagnosis groups within our data.

We wished to investigate whether survival was improving when starting RRT in more recent years. A different approach had to be taken because we had periods of follow-up varying from less than 5 years (starting in 1994-1998) to more than 20 years. When comparing survival for groups with different periods of follow-up, standard Kaplan-Meier analyses can give misleading results due to the very different amounts of censoring. Censoring occurs at the end of the follow-up period or when a patient leaves the study for reasons other than the event of interest. Different amounts of censoring are very likely to be found in prospective studies, like ours, when many patients have recently been entered and there has not been sufficient time for the critical events to occur.

continued

APPENDIX 8 *continued*

We chose to investigate whether the proportions of patients who had died within 5 years of treatment differed according to the year when they started RRT. The starting times were divided into several year bands. A logistic regression analysis was used to see whether prediction of death within 5 years of RRT was improved by knowing the time band when starting RRT. Patients starting in 1994-1998 were excluded because they did not have 5 years of follow-up.

The output of a logistic regression analysis is given as odds or odds ratios. The odds is the ratio of the number of times an event occurs to the number of times it does not occur, out of a given number of chances. It may also be thought of as the probability of an event divided by one minus that probability. Odds are used to convey the idea of 'risk' although the odds and risk are calculated differently. For a common event the probability or risk might be 0.5 or 50%, but the equivalent odds would be 1 (50:50). The odds ratio is the ratio of two odds and is used to compare two groups. It conveys an idea of the additional risk of being in one group over the risk of being in the other. If the odds of an event, such as death, are similar in the two groups then the odds ratio will be close to 1.

If the confidence interval for an odds ratio includes 1 then there is no significant difference between the odds in the two groups being compared. Instead of treating the time bands of starting RRT as separate categories an alternative approach would be to take the mid-point of each time band and fit these as a continuous variable in the logistic regression. We could also just use the year from the dates of starting RRT and fit this as a continuous variable in the logistic regression. These methods would allow us to look at deaths within 5 years of starting RRT with different starting years and to see whether there was a significant decreasing trend in the risk of dying with more recent starting date. These methods confirmed our earlier findings that suggested no significant improvement in the proportion surviving 5 years of RRT. These analyses gave little additional information and so are not presented in detail.

APPENDIX 9

ABBREVIATIONS USED IN THE TEXT

Abbreviation	Definition
APD	Automated Peritoneal Dialysis Previously called Continuous Cyclic Peritoneal Dialysis (CCPD)
ARF	Acute Renal Failure
ARI	Aberdeen Royal Infirmary
ARMS	Audit of Renal Management in Scotland (a prospective cohort research study)
CAPD	Continuous Ambulatory Peritoneal Dialysis
CRAG	Clinical Resource and Audit Group
CRF	Chronic Renal Failure
DGRI	Dumfries and Galloway Royal Infirmary
ERA-EDTA	European Renal Association-European Dialysis and Transplant Association
ESRD	End Stage Renal Disease
GRI	Glasgow Royal Infirmary
HD	Haemodialysis
IPD	Intermittent Peritoneal Dialysis
ISD	Information and Statistics Division (of the NHSScotland)
MONK	Monklands Hospital, Lanarkshire
NHS	National Health Service
NHSScotland	National Health Service in Scotland
NINE	Ninewells Hospital, Dundee
PD	Peritoneal Dialysis
PRD	Primary Renal Diagnosis
QA	Quality Assurance
QMHD	Queen Margaret's Hospital, Dunfermline
RAIG	Raigmore Hospital, Inverness
RHSC	Royal Hospital for Sick Children Glasgow
RIE	Royal Infirmary of Edinburgh
RRT	Renal Replacement Therapy
STOB	Stobhill Hospital, Glasgow
SRA	Scottish Renal Association
SRR	Scottish Renal Registry
WIG	Western Infirmary Glasgow
UK	United Kingdom
UKTSSA	United Kingdom Transplant Support Service Authority
URR	Urea Reduction Ratio
XH	Crosshouse Hospital, Kilmarnock

