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Containing data from 1960 up to 31 December 1998  
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of the National Health Service in Scotland.

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Mrs Lynne Saker and Colleagues at the European Renal Association - European Dialysis and Transplant Association registry helped by providing a file of all the data that had previously been contributed from Scottish renal units as far back as 1960. This got us off to a flying start and also made us realise the importance of data accuracy, verification and quality assurance. Our database (Proton®) has been licensed from Clinical Computing Ltd. Their staff have given helpful advice and support despite our unceasing desire to make the database do things for which it was not initially designed. These schemes have all worked well and we thank them for their tolerance. The software tools for downloading information directly from other renal unit computer systems was largely written by Rob Kings (Greymouse International Computers Ltd). His skill, ingenuity and patience are remarkable. The data collection in each renal unit is supervised by the consultant nephrologist on our steering group but much of the work of collecting and checking the data is done by other staff. Each renal unit has appointed a liaison person who deals with the day to day contact with the SRR. Without their skill, hard work and intimate knowledge of the structure of the data in their hospitals, the registry project could not succeed.

Nephrology perhaps more than most other medical specialties is multi-disciplinary. The doctors, nurses, dieticians, secretarial, administrative, technical and computing staff who run the renal units have all contributed to the accuracy of the data and the success of the project.

Dr Wendy Metcalfe (Nephrology Research Fellow, Department of Medicine and Therapeutics, University of Aberdeen) is currently undertaking a prospective audit of all patients starting renal replacement therapy in Scotland over a one year period. The output from that project will be published separately but her drive, enthusiasm and skill have also been responsible for bringing a set of interesting data together in the form published here. No mean feat! Central responsibility for our registry has recently been passed from the Health Boards who looked after us very well, to the Information and Statistics Division of the NHS in Scotland. Mr Graham Mitchell is the principal statistician and Dr Marion Bain is a consultant public health physician both of whom now have particular responsibility for the SRR. In the short period that we have been closely associated with the ISD we have received invaluable help, particularly in the publishing and printing of this report.

My consultant colleagues at the renal units at Glasgow Royal Infirmary and Stobhill General Hospital Glasgow have helped in more ways than they realise. They encouraged me in my belief that electronic patient records and registries are the only way to keep track of things, even when initially this undoubtedly caused them some extra work. They have also allowed me to attend local and international meetings to present work from the registry at the same time graciously minding my clinical responsibilities and foregoing the chance of attending the meetings themselves. I am immensely grateful.

Statistical analysis in the report was carried out by Mr Gordon Prescott, Statistician, Department of Public Health, University of Aberdeen. He is an invaluable member of our team. The graphic design, layout and publishing of the report was performed by Chris Dunn at ISD. We are grateful for his skill and patience.

Finally, the registry is run day to day by our administrative assistant Mrs Jackie McDonald. Her tact, patience and organising skills are deployed to the full! All involved in the SRR recognise that she is central to the whole project and we owe her a big thank you.

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

**Keith Simpson**  
**Chairman Scottish Renal Registry**





## **EXECUTIVE SUMMARY**

The first patient was dialysed for end stage chronic renal disease in Scotland in 1960. 6977 patients had been accepted for long-term renal replacement therapy up to 31 December 1998. The median age for new patients starting renal replacement therapy has risen from 24 in 1964 to 64 in 1998. 2956 patients were receiving renal replacement therapy for end stage renal disease on 31 December 1998. The take on rate for new patients was 102 per million of the population in 1998. There is no sign as yet that the take rate has reached a plateau. In 1998 47% of patients had a functioning kidney transplant, 37% were being treated with haemodialysis and 16% with peritoneal dialysis.

There are now 11 adult and one paediatric renal units in Scotland. 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.

## INTRODUCTION

### History of the Scottish Renal Registry (SRR)

Nephrologists in Scotland have always collected epidemiologic data. Initially, a small data set was sent to the European Renal Association - European Dialysis Transplant Association (ERA-EDTA) registry<sup>1</sup> which is housed at St Thomas' Hospital London. Data from Scottish renal units are available back to 1960 which is the year regular and routine renal replacement therapy (RRT) for end stage renal disease (ESRD) started in Scotland.

### Funding

In 1991 the committee of the Scottish Renal Association established a computer based registry for patients receiving RRT for ESRD in Scotland. The Registry was set up with a grant from the Clinical Resource and Audit Group (CRAG) of the National Health Service in Scotland (NHSiS). Since then the project has been funded for a period by a grant from all the Scottish Health boards. In April 1999 overall responsibility and funding for the registry was transferred to the Information and Statistics Division (ISD) of the NHSiS.

### Database

The Registry is organised and stored on a highly configurable commercial database (Proton®, Clinical Computing Ltd.) running under the IBM Unix operating system AIX on an RS 6000 minicomputer. All Scottish renal units have contributed fully from the outset. Data are downloaded automatically from renal unit computer systems where these are available in eight units using configurable data transfer software. The configuration routines are held in mapping tables on the registry computer and a simple data mapping file is transferred to each renal unit computer before downloading data. The data extraction programs on each renal unit computer are identical and software maintenance and version control is very easy.

### Computer communication & Data entry

All renal units have access to data about their own patients on the registry via a terminal which is connected to the registry computer via the secure NHSiS X-25 communications network. Renal units that do not maintain their own database enter their data manually by re-keying at their terminal. No paper data collection documents are returned to the SRR office. We continue in our attempts to run a paperless registry.

### Data Set

The historic epidemiologic data have been retrieved from the ERA-EDTA database and from a variety of sources in each renal unit. A basic data set has been defined for prospective collection. This is used for the basic epidemiology report. Other data are collected when required for specific projects. We plan to expand slowly, ensuring that we achieve full patient registration if possible. This will be examined in a quality assurance scheme. Specific projects are addressed using the data set required and on a properly chosen sample or a full census of all patients as advised by our statistician. The hospital haemodialysis quality assurance programme using urea reduction ratio (URR) is a good example of this method.

### Office

The SRR has a small office in the renal unit at the Glasgow Royal Infirmary. An annual rent covers the cost of the accommodation, heating lighting etc but the SRR is autonomous and operates within the Scottish Renal Association.

### Staff

One full time 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. Advice from a professional academic statistician is readily available and the SRR pays a small fee to his academic department.

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. Much of this work would be necessary in any case to allow the smooth running of the renal unit. Some extra work is obviously necessary 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 this local personnel and financial support.

### Organisation

Each renal unit elects one consultant nephrologist to serve on the SRR steering committee which meets twice a year. A smaller executive committee meets on another two occasions each year and the chairman supervises the day to day affairs of the registry. All major decisions including initiating new projects and releasing data to third parties are taken by the steering group with whom communication is maintained by email and post. The SRR operates under the auspices of the Scottish Renal Association. The SRA and the SRR are affiliated to the ERA-EDTA. A report on the activities of the SRR is presented to a half day academic meeting of the SRA every November.

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1 The ERA-EDTA registry is held on an independent computer database located in St. Thomas' Hospital, London. Reports are published annually as an appendix to the journal 'Nephrology Dialysis and Transplantation'.

**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 the consultant 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 are granted by the consultant member of the steering group. 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 are described in full in a separate document which it would be imprudent to publish. They have been discussed by our steering group and will be inspected along with our quality assurance scheme by a trusted member of a foreign renal registry which is also affiliated to the ERA-EDTA. The SRR is registered under UK Data protection act and we are examining the implications of the Caldicott report.

**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. This method has proved rather slow at times and has undoubtedly caused some irritation to legitimate enquirers for which we apologise. It has however ensured that data are only released with unanimous agreement. 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 NHSiS, the ERA-EDTA registry, the UK Renal Registry, the UKTSSA and to our members when they are pursuing particular projects. Patient confidentiality is paramount and rigorous protection does not pose any problems. We are however mindful of the difficult balance between confidentiality for the renal units and our important duty to use the data to the best advantage of our patients, the scientific community and society who pay both for the registry and for NHS treatment.

**Quality assurance (QA)**

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 which 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 are introducing a method of confirming the correct registration of patients and the correct recording of data for a random sample of patients. The sampling frame for this audit of our data will be designed by our statistician. It will be run in each renal unit as part of a general peer review programme which is being established by the SRA. In this scheme each renal unit will be visited by a team comprising; a patient representative, a nurse, a nephrologist and a representative from the SRR.

Finally, we will invite occasional review by a representative from another well established national renal registry affiliated to the ERA-EDTA.

We recognise that 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.

**SUMMARY OF DATA**

**Total patients**

6977 patients have been registered with the Scottish Renal Registry from its inception in 1991 until 31 December 1998 when the data for this report were collated.

Data pertaining to events prior to 1991 were incorporated retrospectively from the ERA-EDTA registry<sup>1</sup>. 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 chronic renal failure in Scotland is October 1960.

**Deaths**

3915 patients of the 6977 included in this report are known to be dead.

**Exclusions from analyses**

162 patients have uncertain status, that is their current location is not known and it is not known if they are alive or dead. These 162 patients include 95 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 excluded from survival analyses.

154 patients are recorded as having a renal transplant as their first mode of RRT.

9 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 is not available. These 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 recovered within 90 days but then went on to restart RRT, the date of first RRT taken as the date starting an RRT session which lasted at least 90 days.

**Primary Renal Diagnoses**

A diagnosis code for the primary renal disease 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 end stage renal disease 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 one primary renal diagnosis (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 5.

**Missing Data**

Some patients have data items 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 165 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.

The missing basic data items are summarised in Table 1.

Data Item	Total number missing	Number missing from patients alive on 31 December 1998
Missing Historic Data	165	0
Date of Birth	4	1
Mode of first RRT	6	5
Primary Renal Diagnosis	125	19
Date of Death (n=3915)	5	

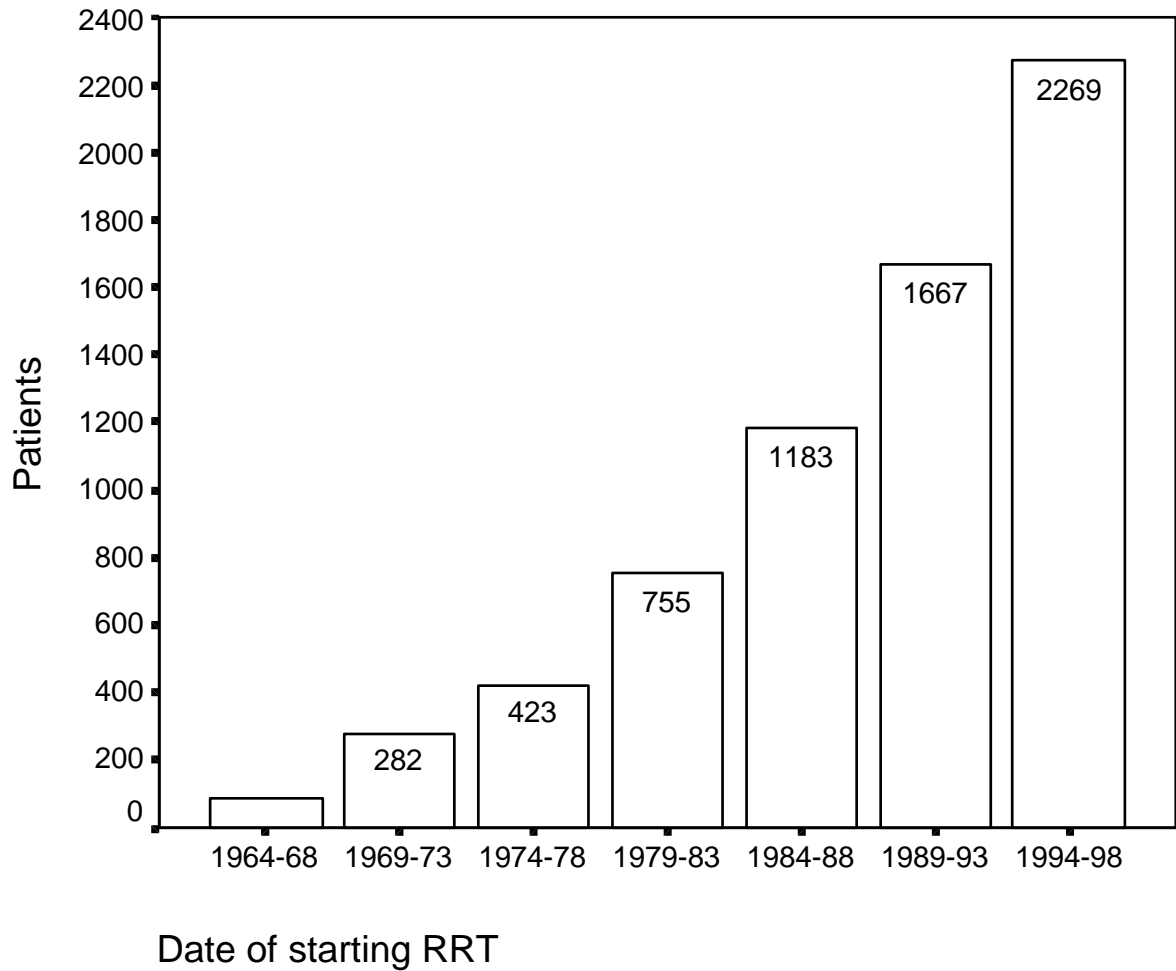
**Table 1 Missing Data Items**

**Abbreviations**

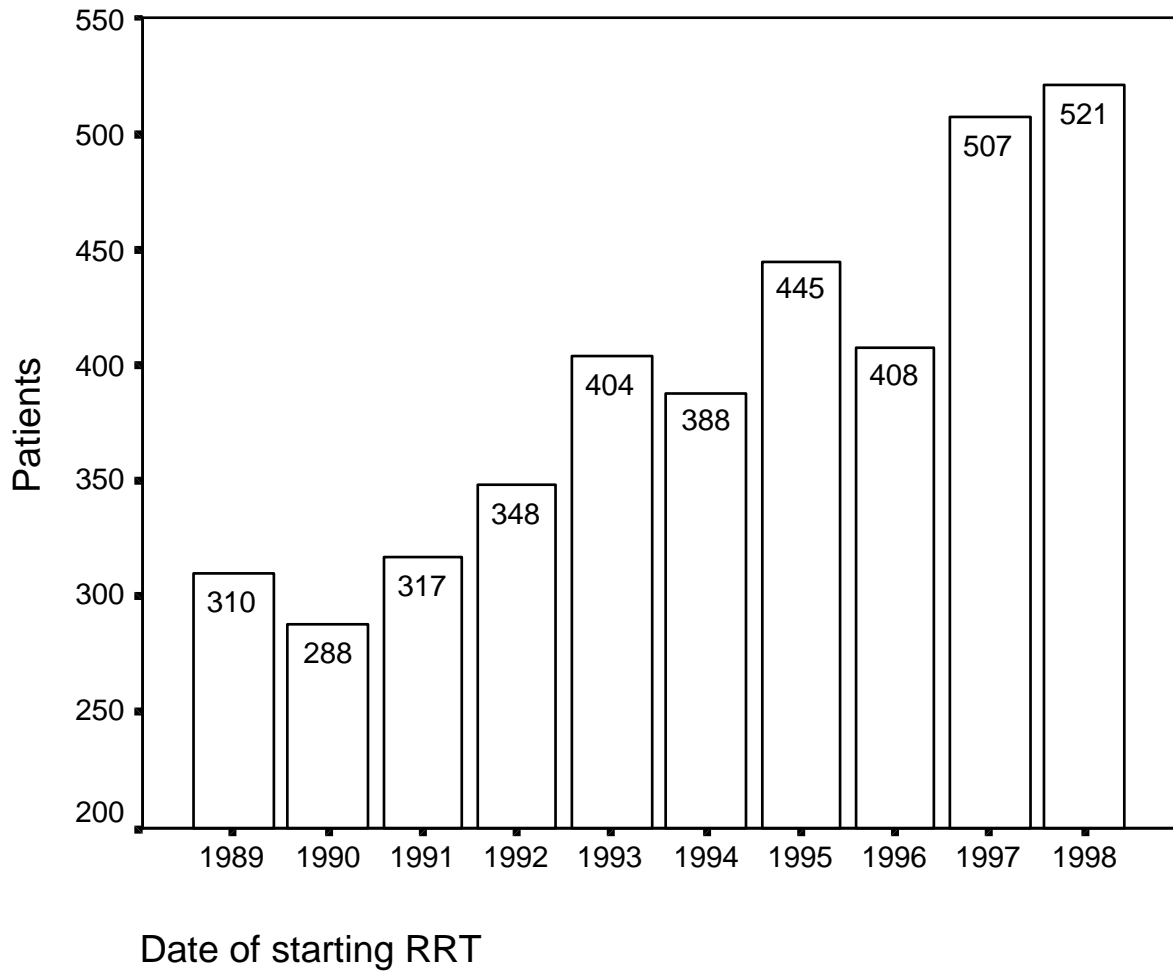
Throughout this report for brevity and ease of reading some abbreviations are used.

These are listed in full in appendix 6.

**INCIDENCE OF NEW PATIENTS STARTING RRT**

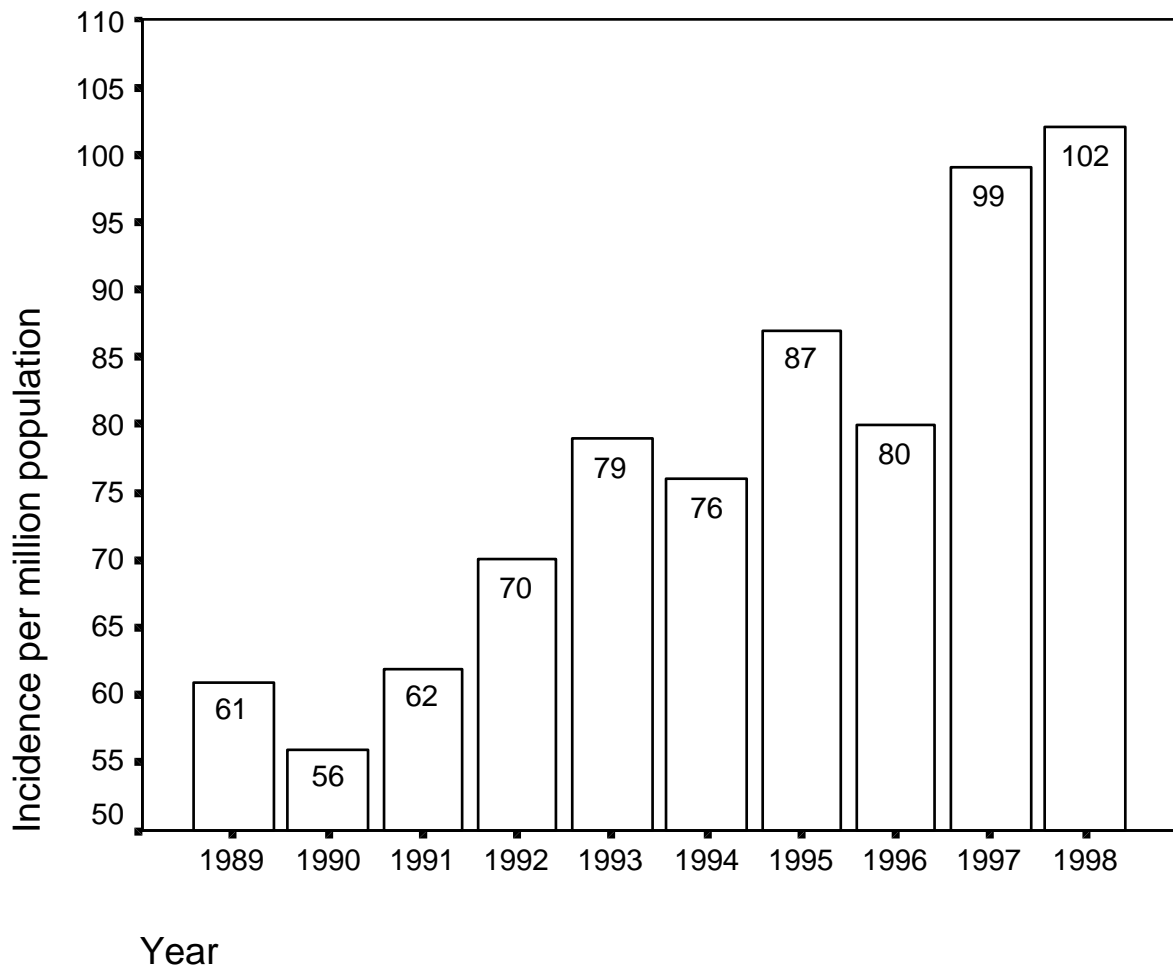


**Graph 1a**  
**Incidence of new patients starting rrt 1964-1998**  
**(87 patients started RRT between 1964-1968)**



**Graph 1b**  
**Incidence of new patients starting rrt 1989-1998**

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 35 years shown the distribution of males: females starting RRT has remained constant around 60%: 40%.



**Graph 2**  
Annual incidence per million population of new patients starting RRT 1989-1998 (n= 3936)

Year	Number Starting RRT	Population Scotland	Incidence per million
1989	310	5 096 600	61
1990	288	5 102 200	56
1991	317	5 107 000	62
1992	348	5 111 200	70
1993	404	5 120 200	79
1994	388	5 132 400	76
1995	445	5 136 600	87
1996	408	5 128 000	80
1997	507	5 122 500	99
1998	521	Not available	102*

Population figures are from the Registrar General for Scotland.<sup>2</sup> They are population estimates for the 30 June of each year. The population estimate for 1998 was not available at the time of going to press, therefore the 1998 figure has been calculated from the 1997 estimate.

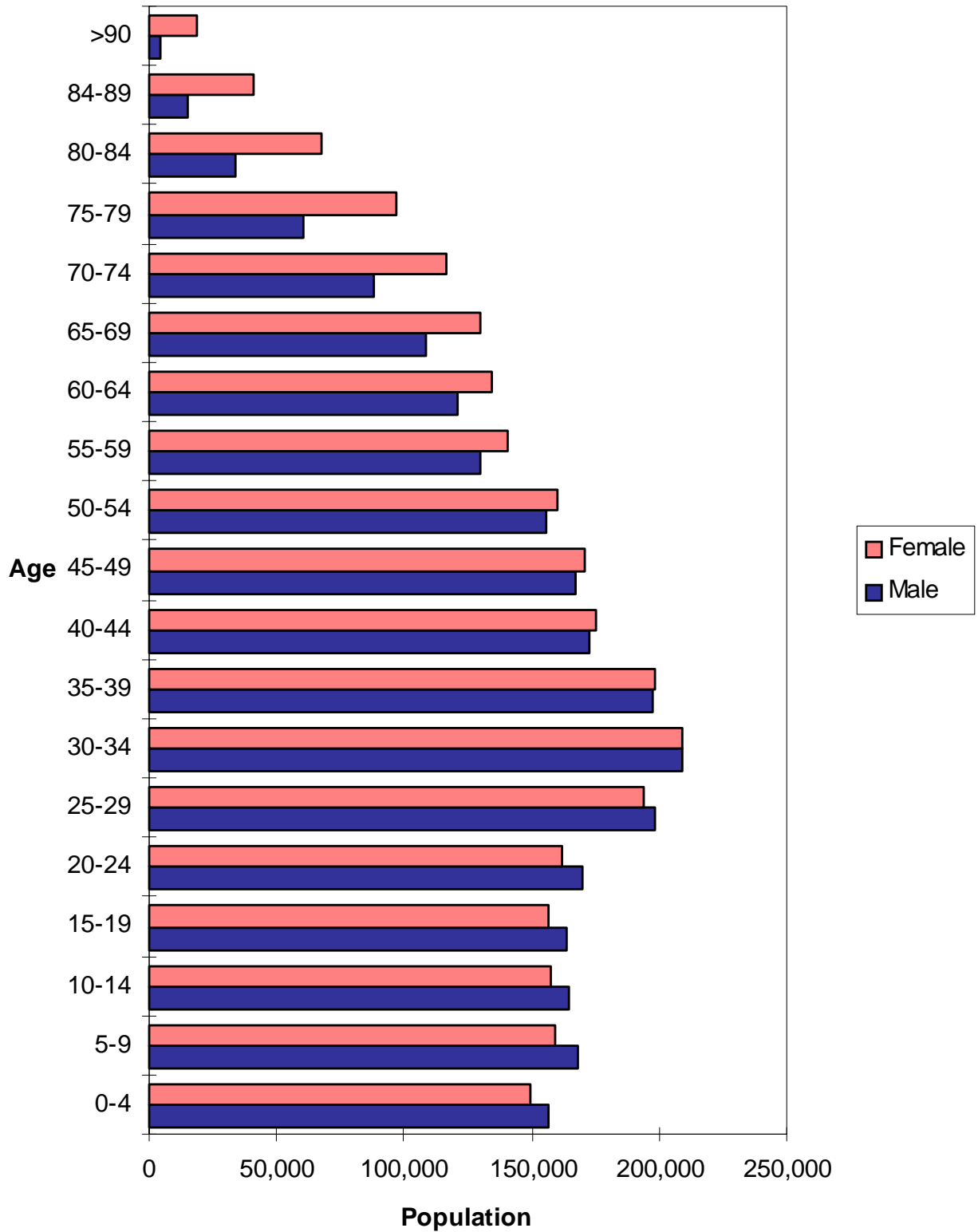
The incidence of patients starting RRT per million of the population continues to rise.

\*Based on 1997 population estimate.

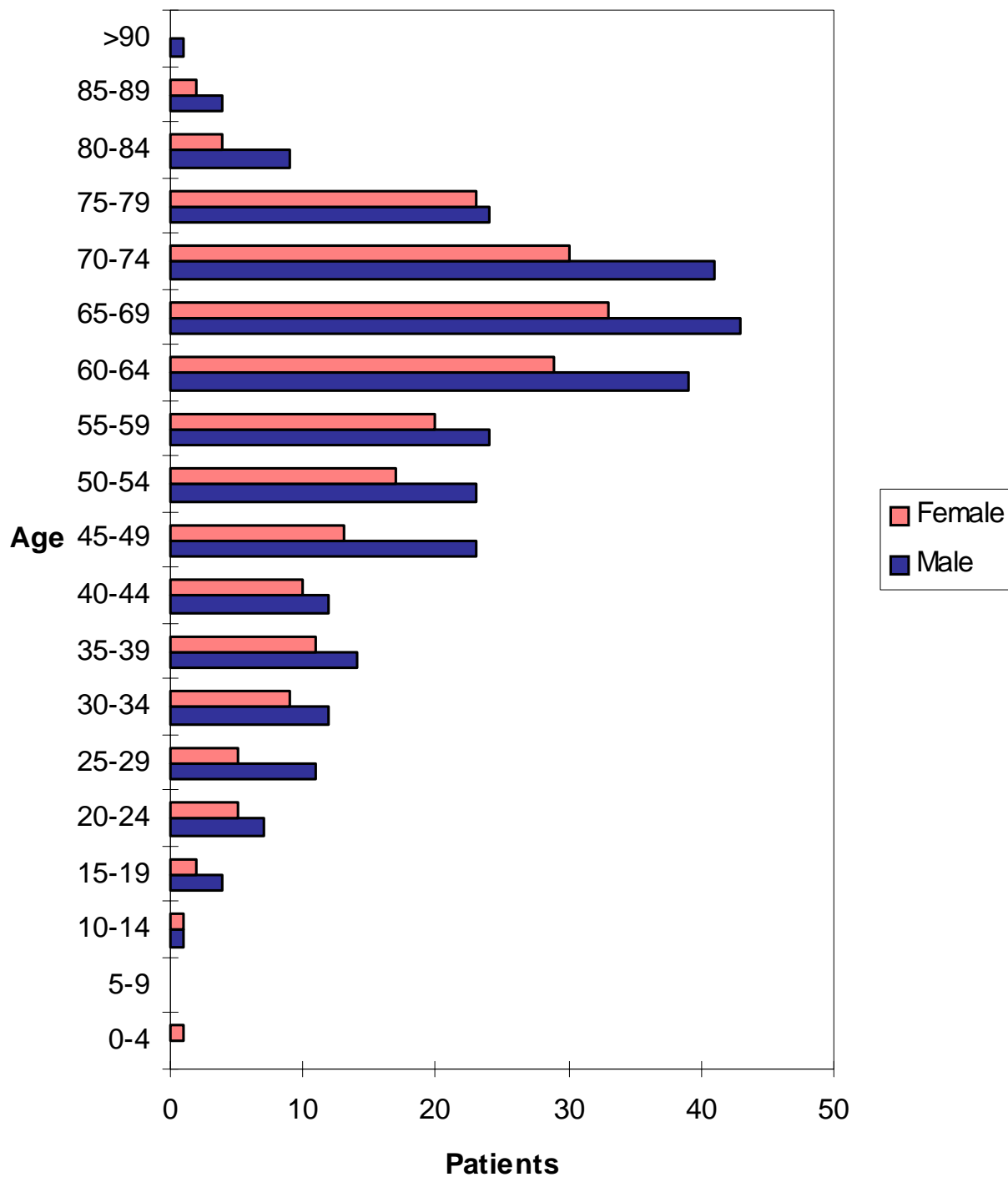
<sup>2</sup> Mid-1997 Population Estimates Scotland. Registrar General for Scotland. Population Statistics Branch, General Register Office for Scotland, Ladywell House, Ladywell Road, Edinburgh EH12 7TF. Reproduced with permission.

**Table 2**

**GENERAL POPULATION AND INCIDENT DIALYSIS POPULATION 1997**



**Graph 3a**  
**Estimated Population of Scotland 1997 (Registrar General for Scotland)**



**Graph 3b**  
**Incident RRT population of Scotland 1997**

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.

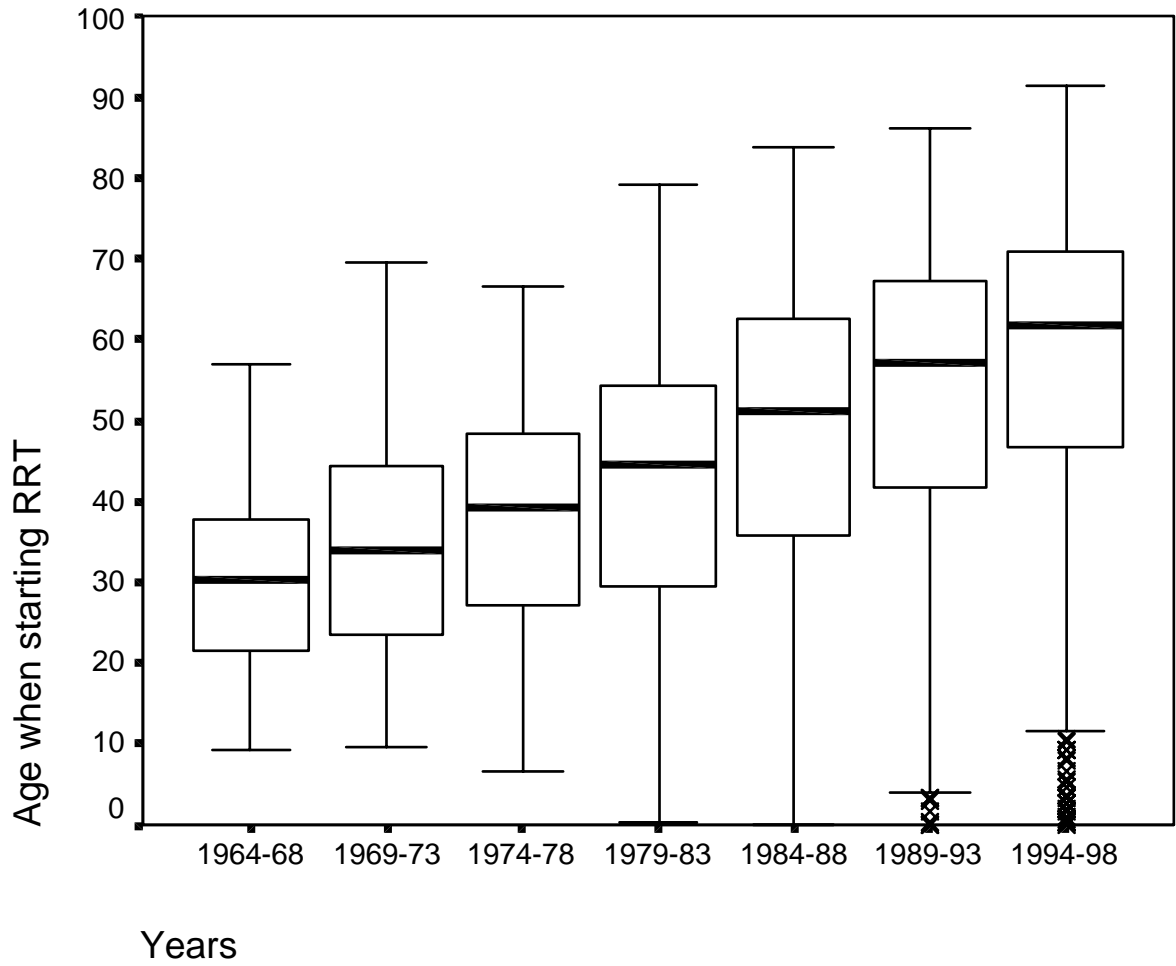
Graph 3b demonstrates the increase in treated end stage renal disease as the population ages.

Age Group	Estimated Population 1997	Number starting RRT 1997	<b>Incidence</b> per million population of each age band	All patients receiving RRT on 30/6/97	<b>Prevalence</b> per million population of each age band
< 50 years	3 499 259	141	<b>40</b>	1374	<b>393</b>
50-64 years	841 149	152	<b>181</b>	829	<b>986</b>
65-75 years	481 154	147	<b>306</b>	453	<b>941</b>
>75 years	300 938	67	<b>223</b>	159	<b>528</b>

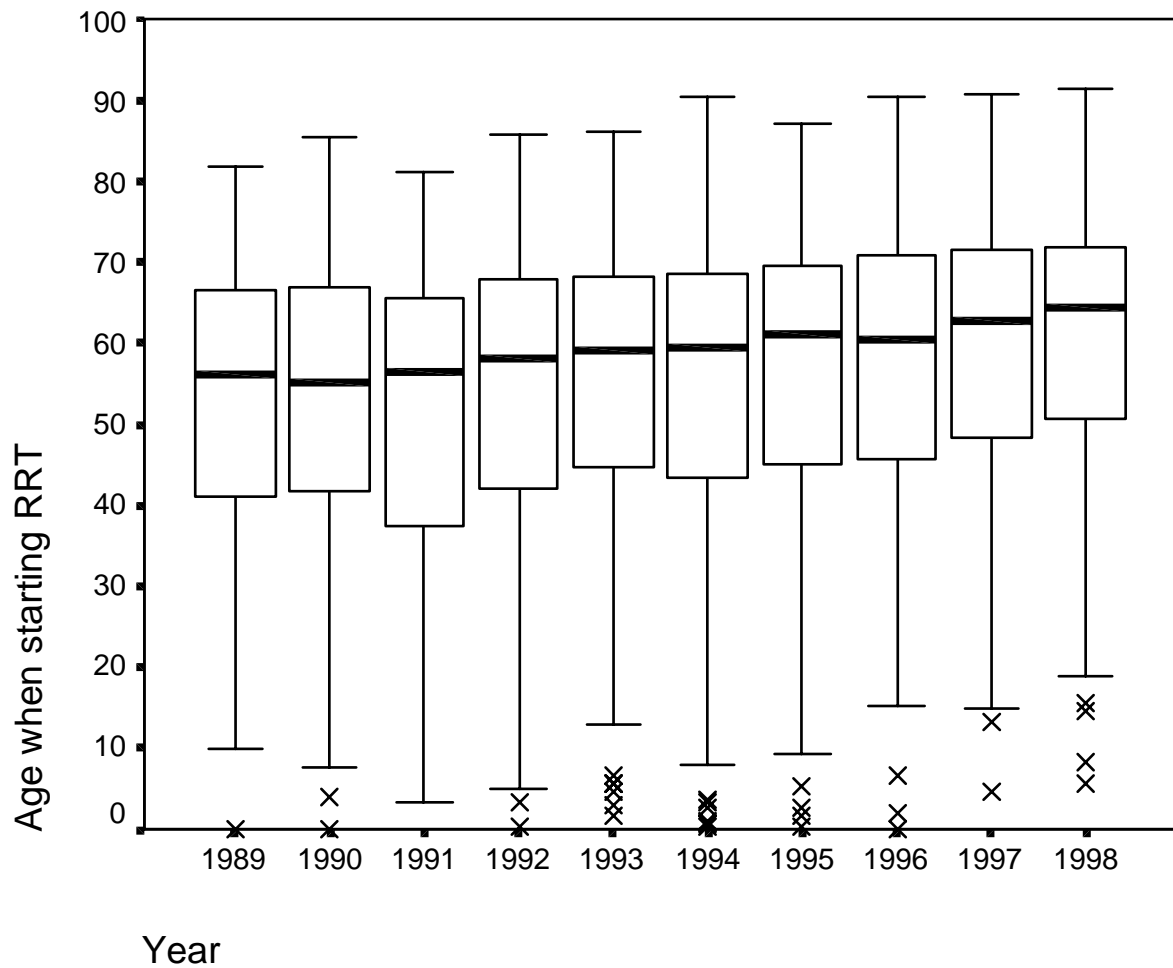
**Table 3**  
**Age specific incidence and prevalence of rrt patients in 1997**

Table 3 shows the age specific incidence and prevalence of patients receiving RRT per million population in 1997. 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. 550 patients, per million population of all ages, were receiving RRT in Scotland in 1997. All population statistics are again taken from the Mid-1997 population estimates Scotland published by the Registrar General for Scotland.

**MEDIAN AGE OF PATIENTS WHEN STARTING RRT**



**Graph 4a**  
**Median age of patients when starting RRT 1964-1998**

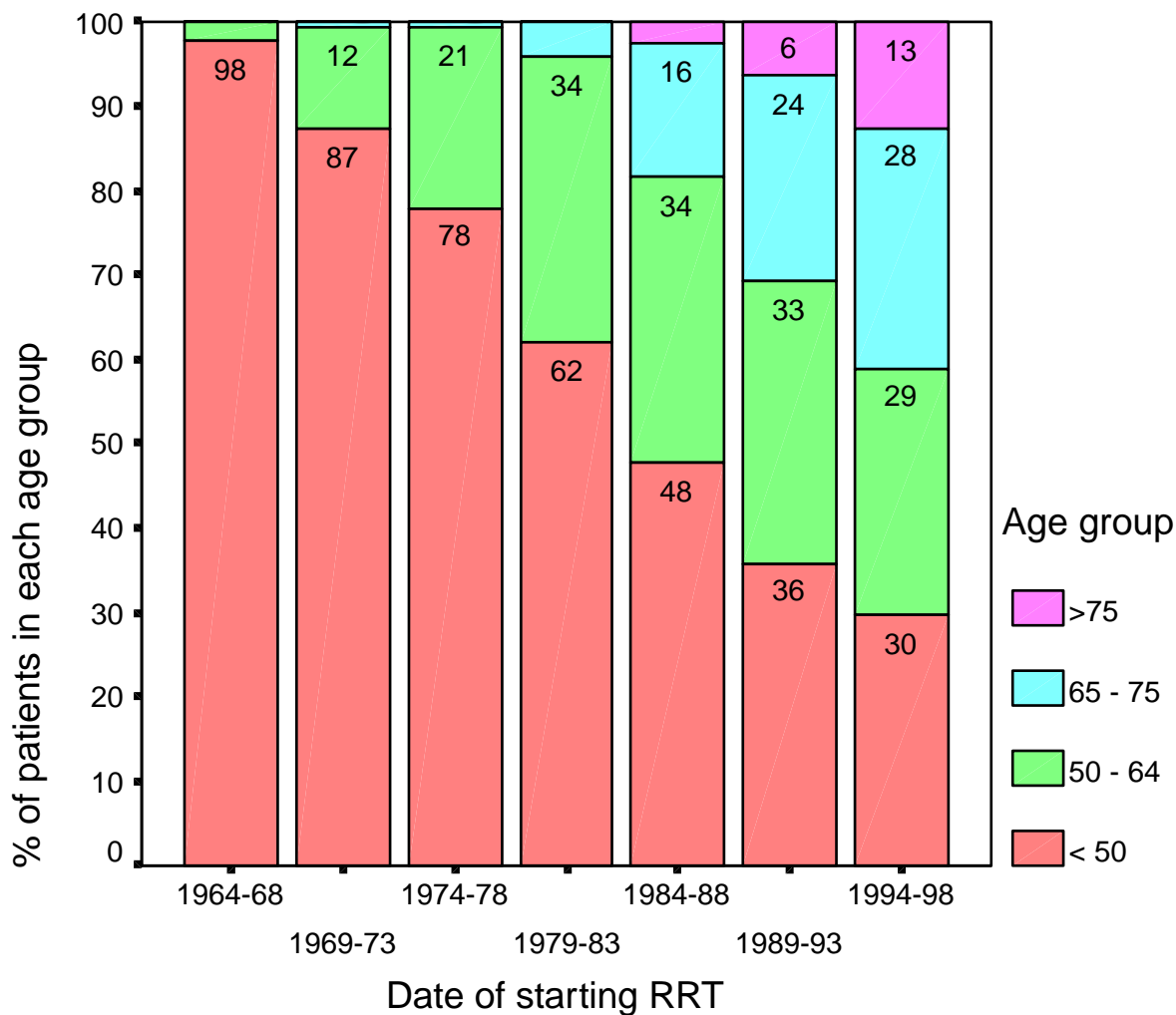


**Graph 4b**  
**Median age of patients when starting RRT 1989-1998**

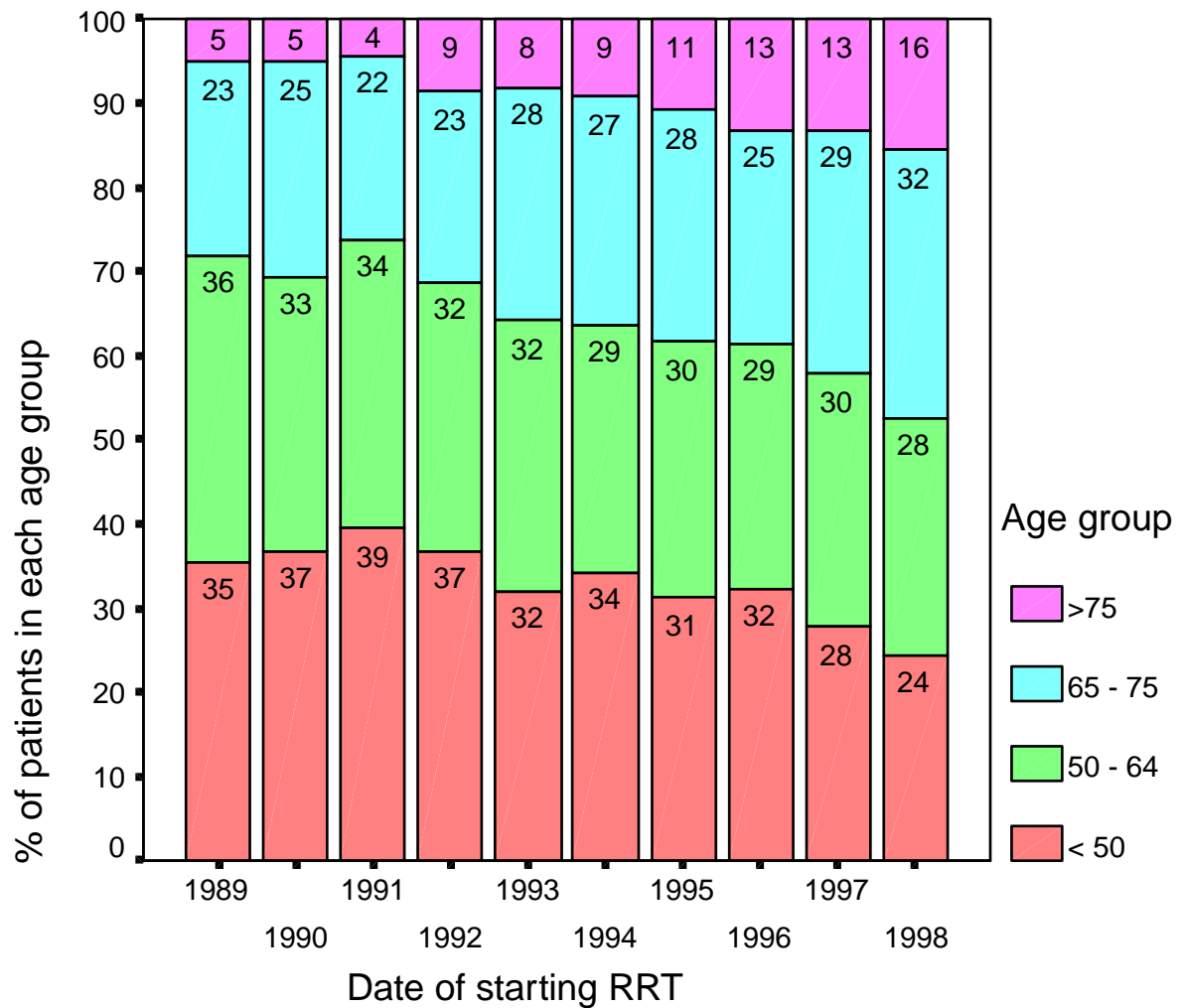
Graphs shows median age (black line), inter-quartile range (box) and the last value falling within 1.5 times the inter-quartile range (whiskers). Values lying outwith 1.5 times the inter-quartile range are shown as 'x'.

Patients in their 90's 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.

**AGE DISTRIBUTION OF PATIENTS WHEN STARTING RRT**



**Graph 5a**  
Age distribution of patients when starting RRT 1964-1998

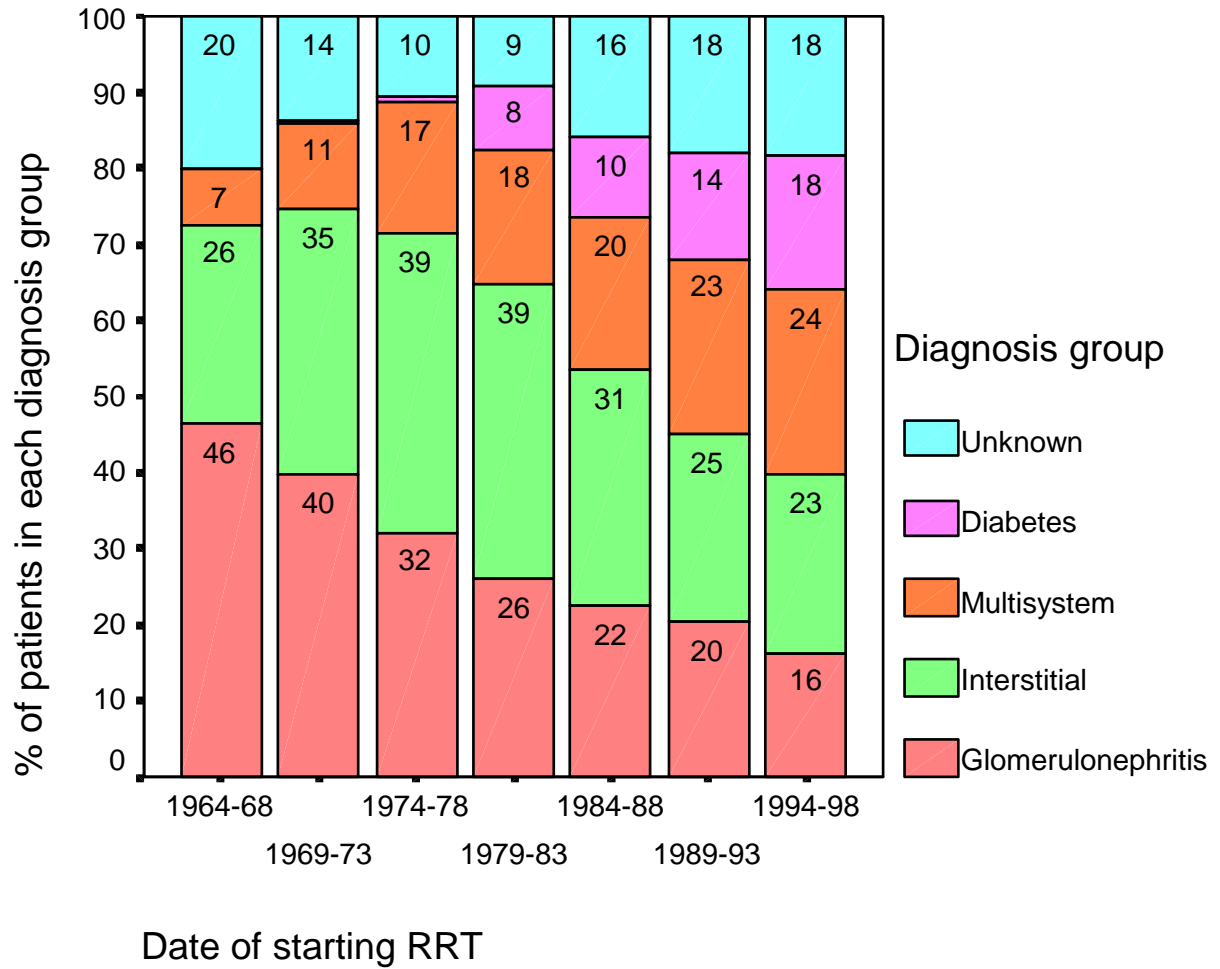


**Graph 5b**  
**Age distribution of patients when starting RRT 1989-1998**

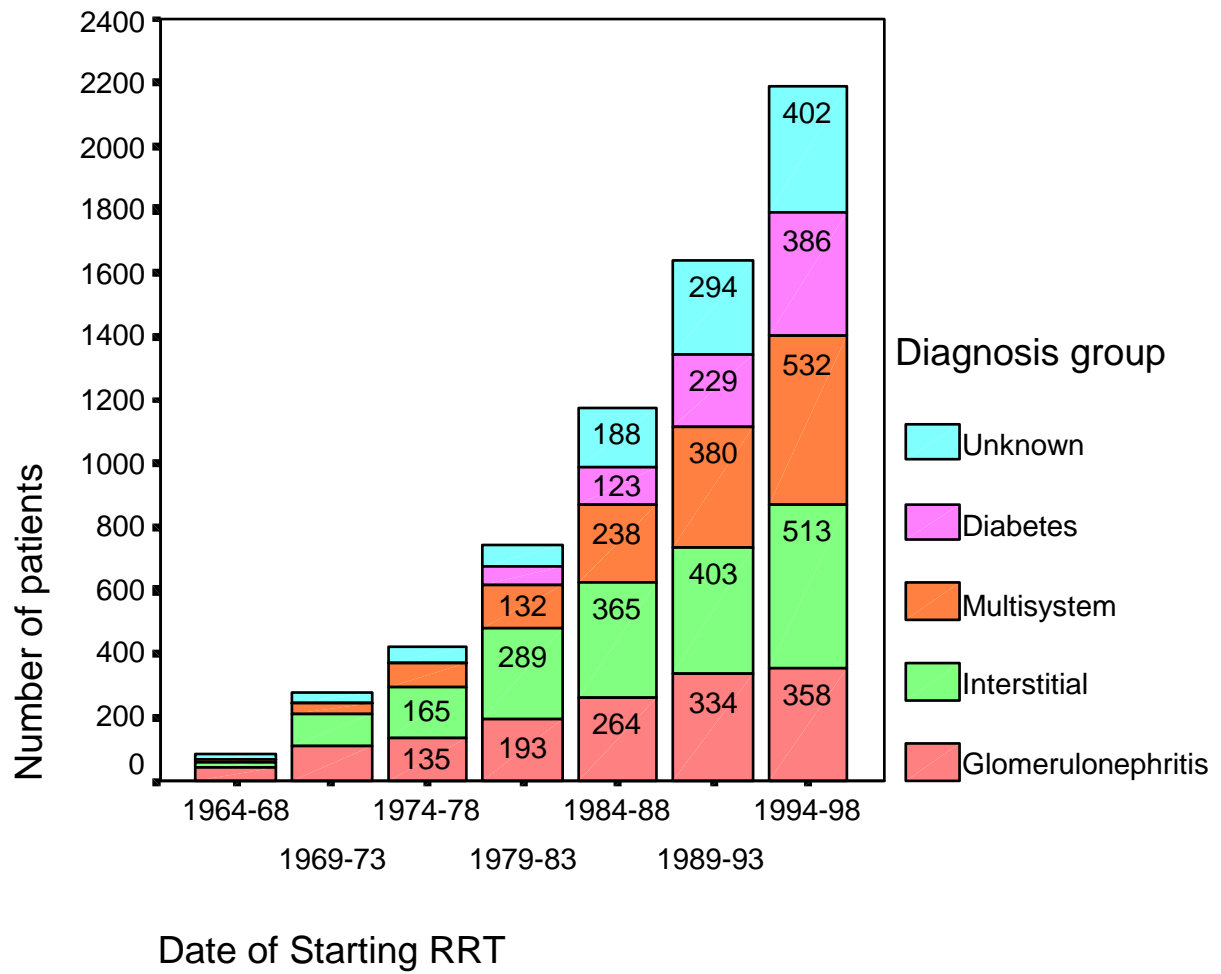
The total numbers of patients are the same as shown in graphs 1a and b.

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.

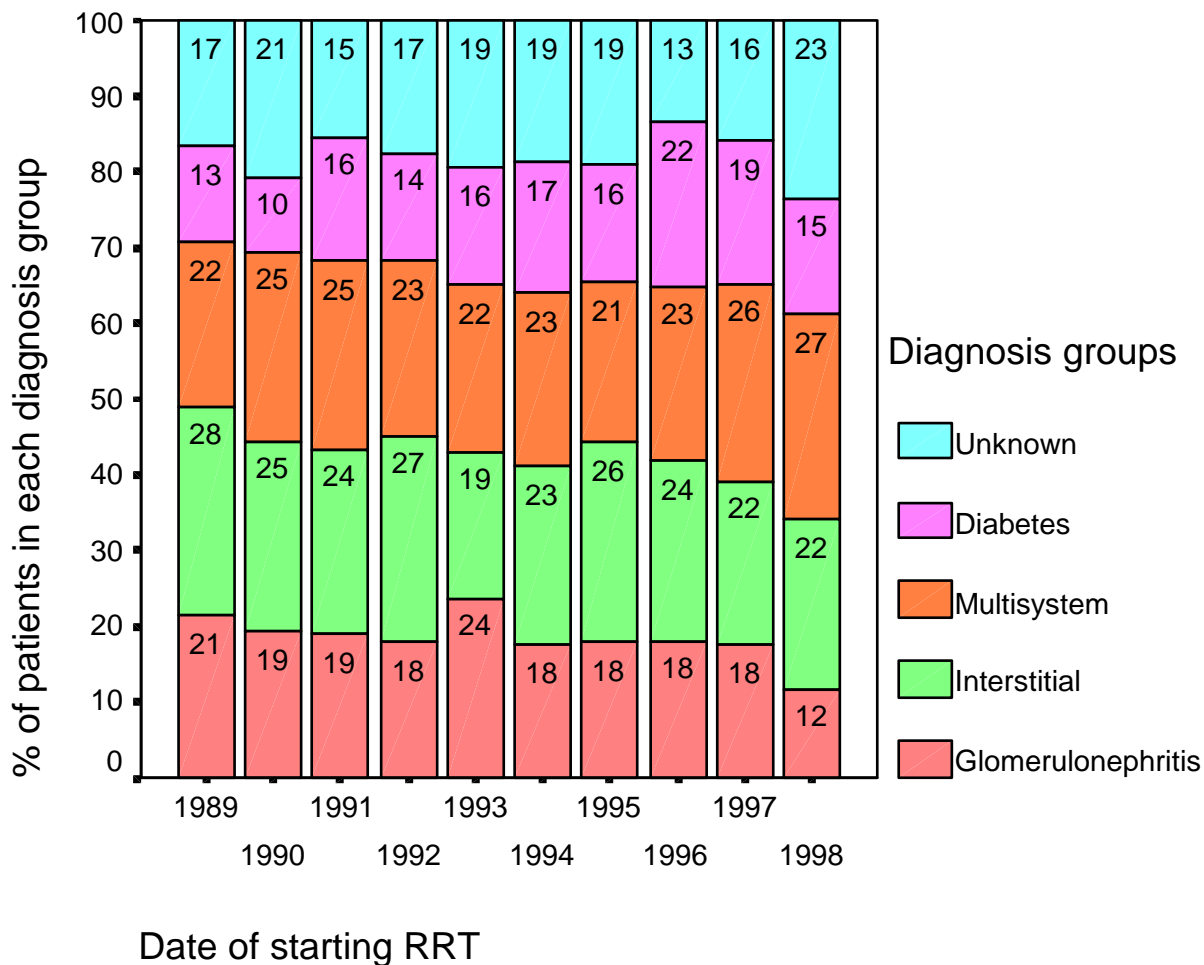
**PRIMARY RENAL DIAGNOSIS OF PATIENTS STARTING RRT**



**Graph 6a**  
% of patients in each PRD group 1964-1998



**Graph 6b**  
**Numbers of patients starting RRT 1964–1998 in each diagnostic group**



**Graph 6c**  
**% patients in each PRD group 1989-1998**

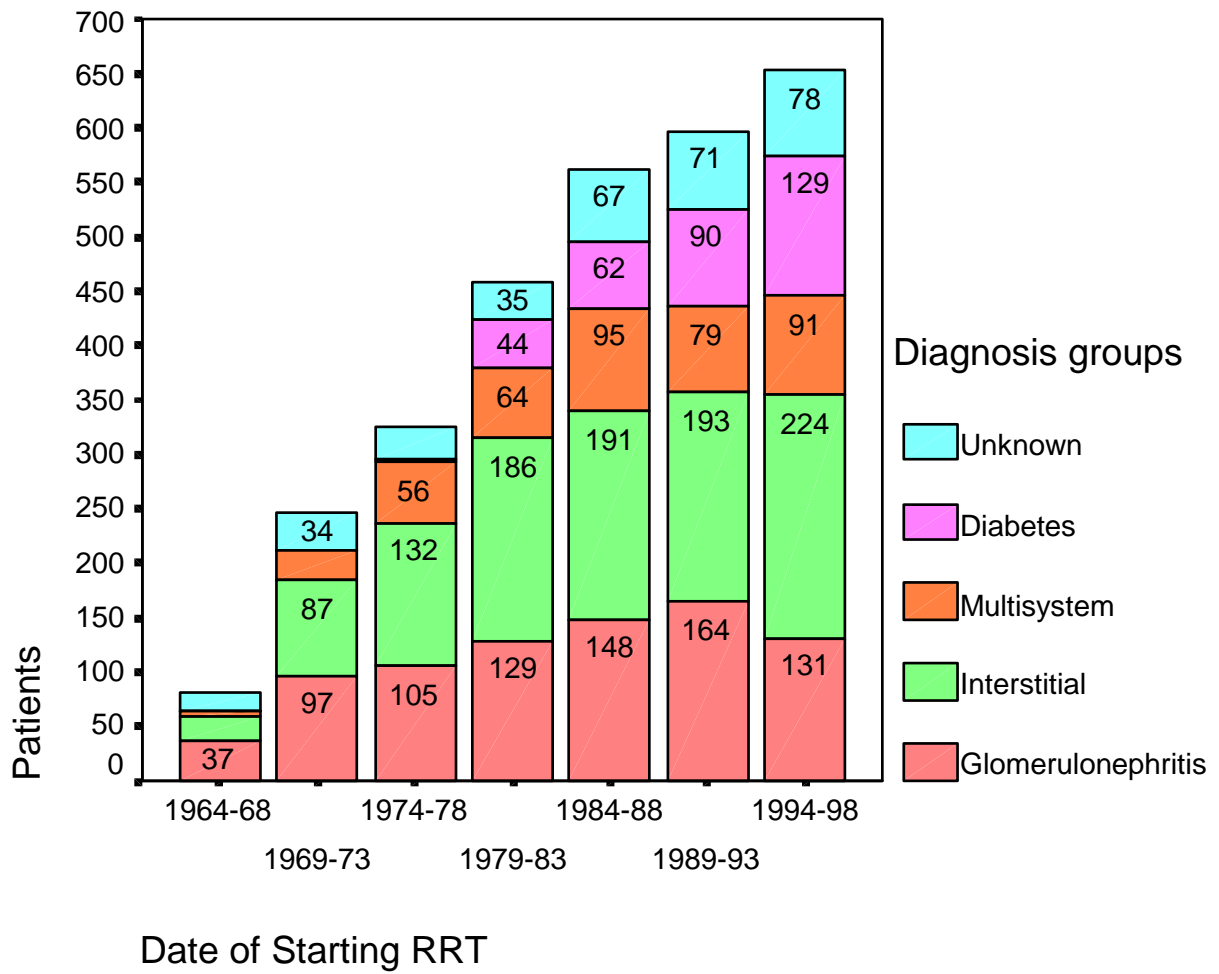
Graphs 6a and b represent the same data displayed as proportion of patients and absolute numbers respectively.

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

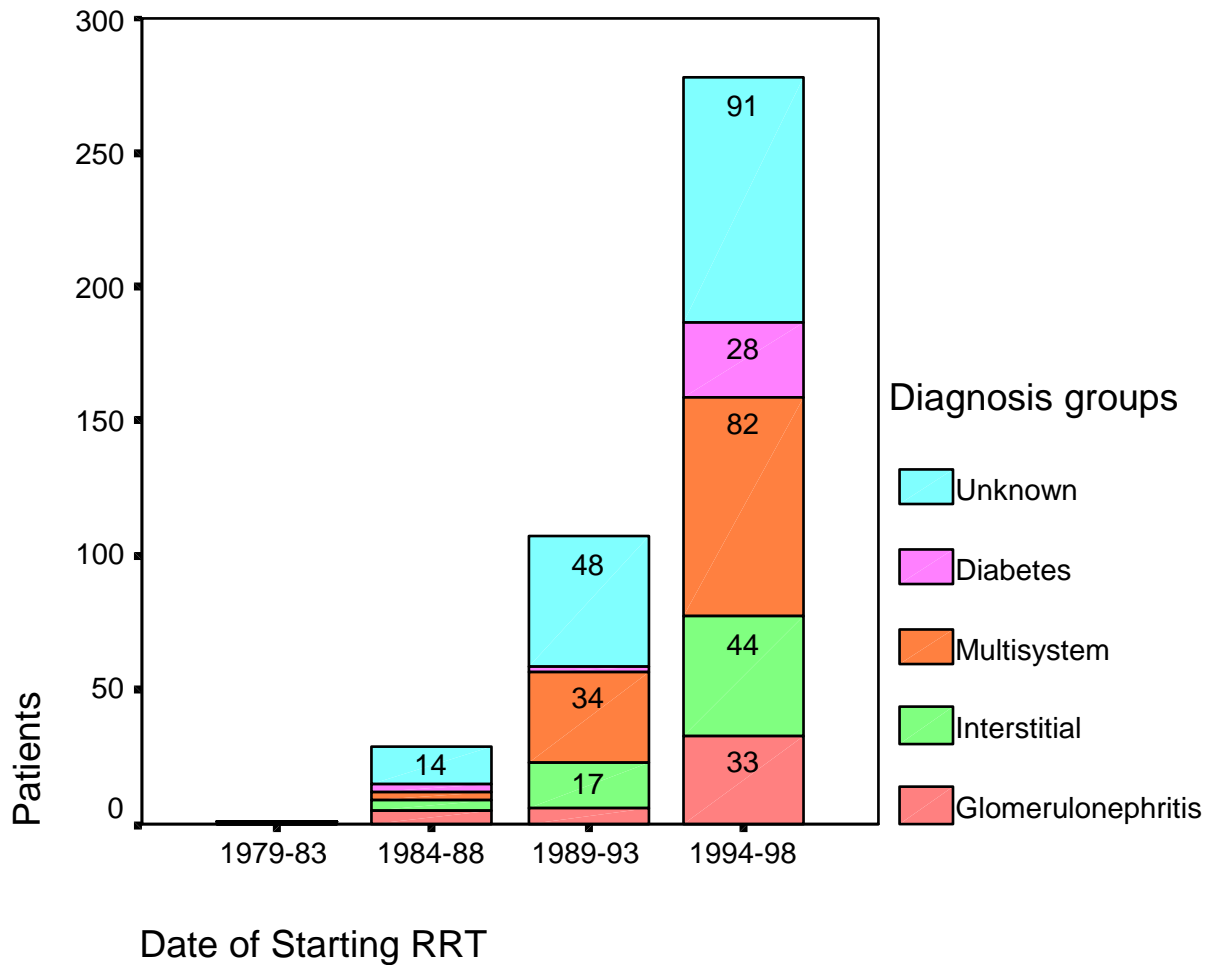
The groupings of other diagnoses obscures the fact that diabetic nephropathy is now the largest single named primary renal diagnosis in patients starting RRT.

The proportion of patients in whom it is not possible to make a diagnosis due to advanced disease at the time of presentation has not changed over the time, remaining at approximately 20%.

See appendix 5 for ERA-EDTA PRD codes and groupings.



**Graph 7a**  
**Primary renal diagnosis of patients starting RRT when aged less than 50 1964-1968**



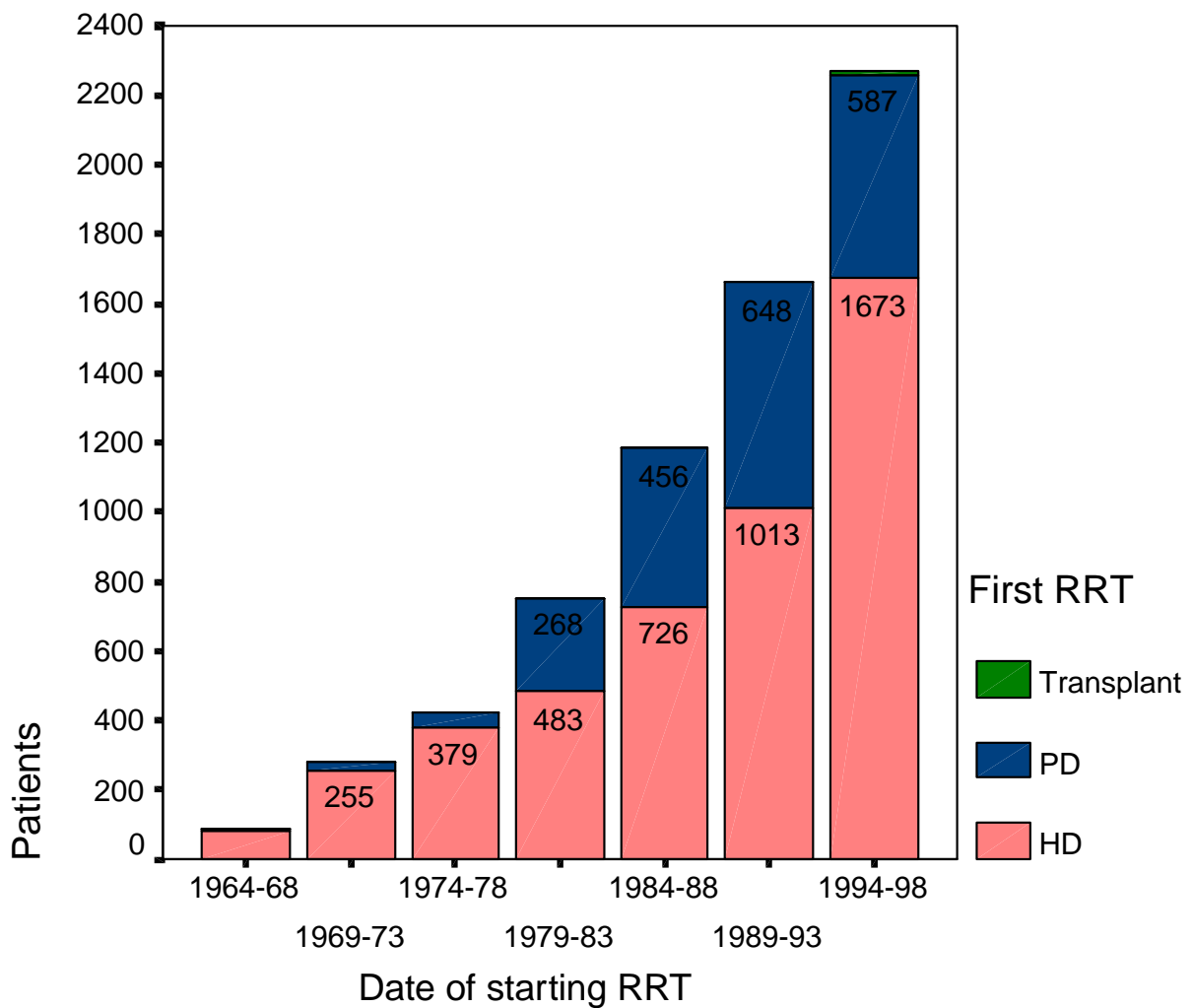
**Graph 7b**  
**Primary renal diagnosis of patients starting RRT when aged over 75 1979-1998**

It appears that the number of under 50 years old in whom the PRD is diabetic nephropathy or unknown continues to increase. In contrast the rate of provision of RRT for young patients in the other three diagnostic groups has levelled off. This suggests that the rate of provision of RRT for patients in these groups may now be meeting the incidence. In comparison in the over 75 years age group the rate of provision of RRT continues to increase for all diagnostic categories.

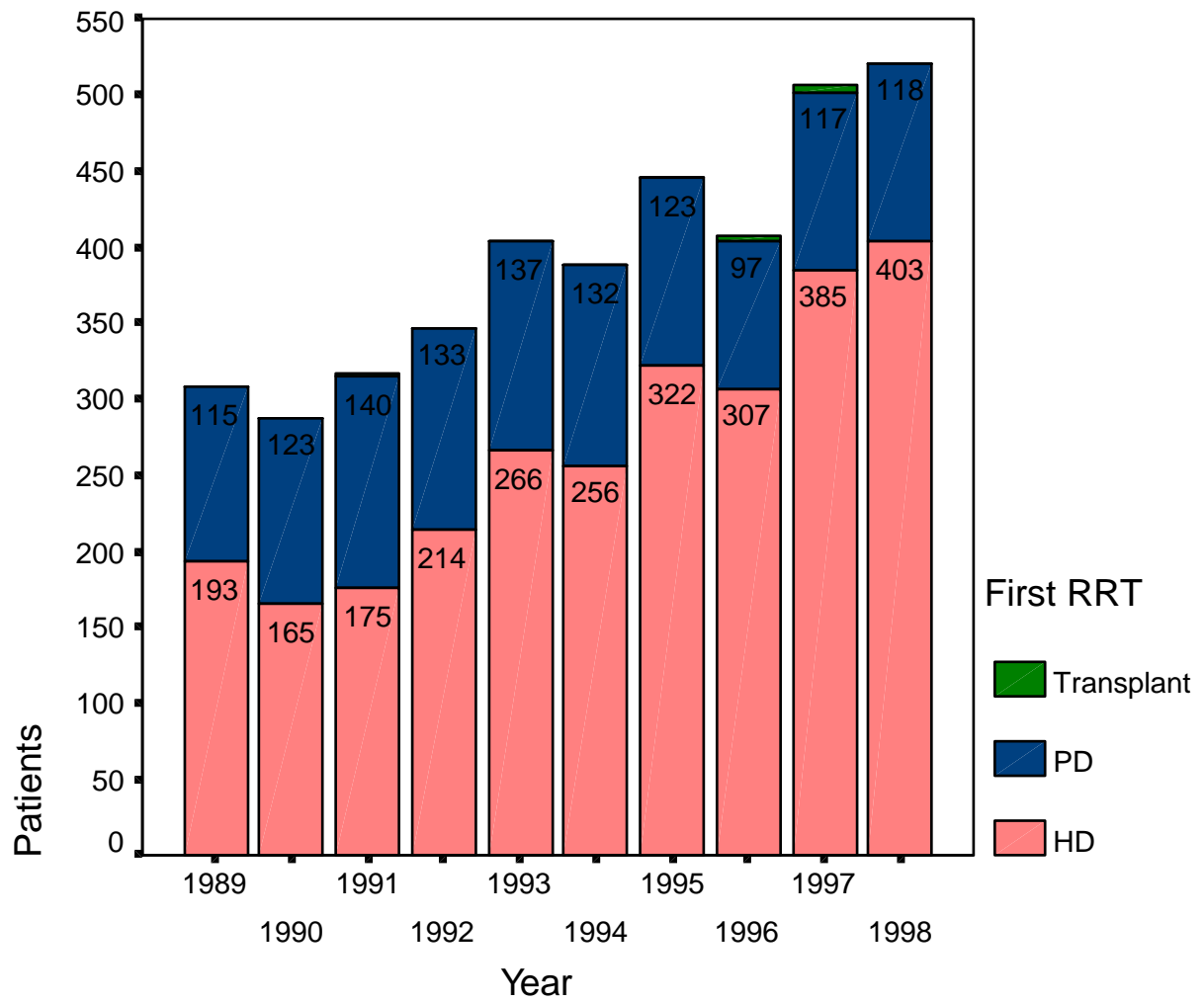
## MODALITY OF RRT

There are three principal types of renal replacement therapy:

haemodialysis is normally performed in a hospital but can be undertaken in a patients home, peritoneal dialysis is normally performed by the patient in their home using the technique of continuous ambulatory peritoneal dialysis. The dialysate exchanges can be performed semi automatically by a machine in the variant known as automated peritoneal dialysis. Renal transplants are normally donated from a cadaver but occasionally from a living donor.



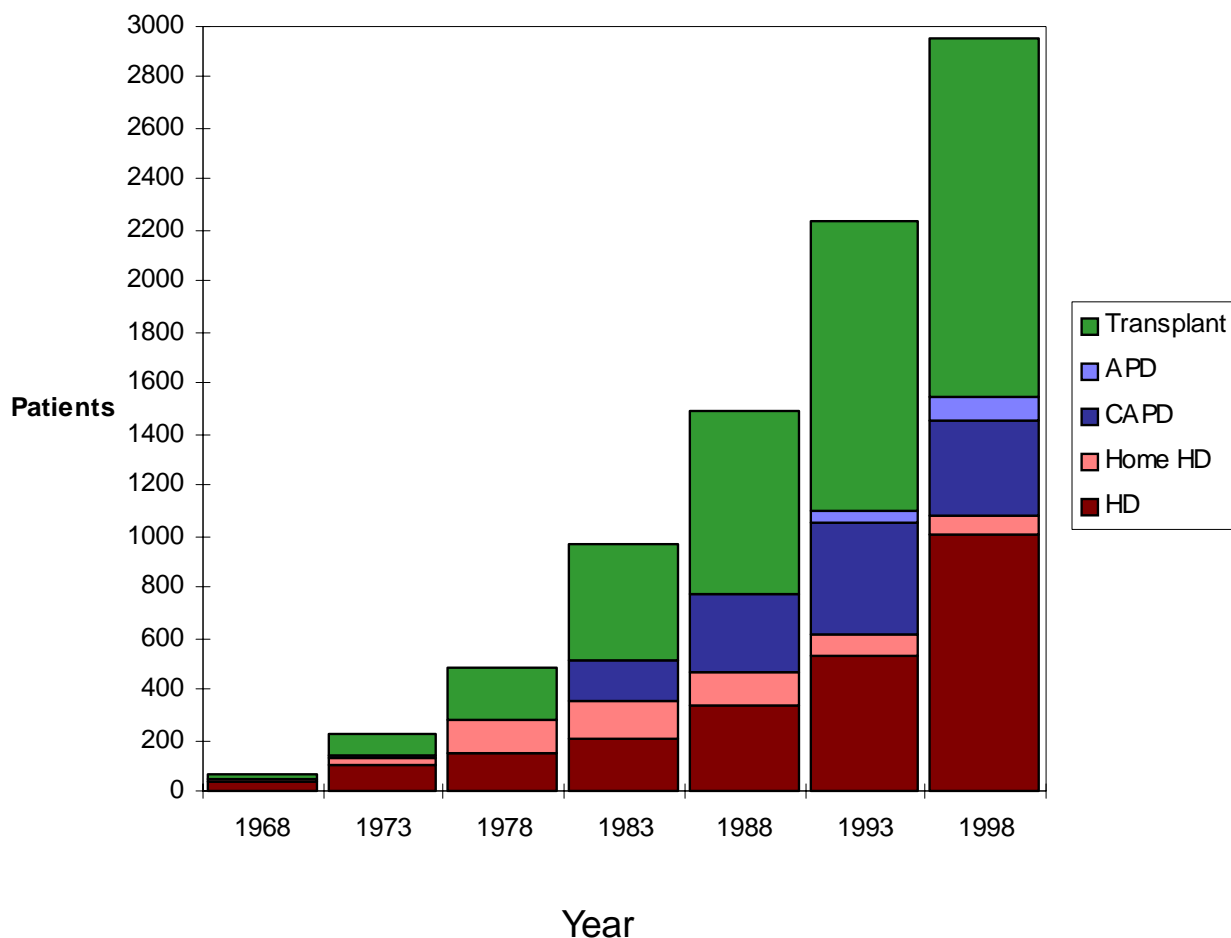
**Graph 8a**  
**Mode of first RRT 1964-1998**



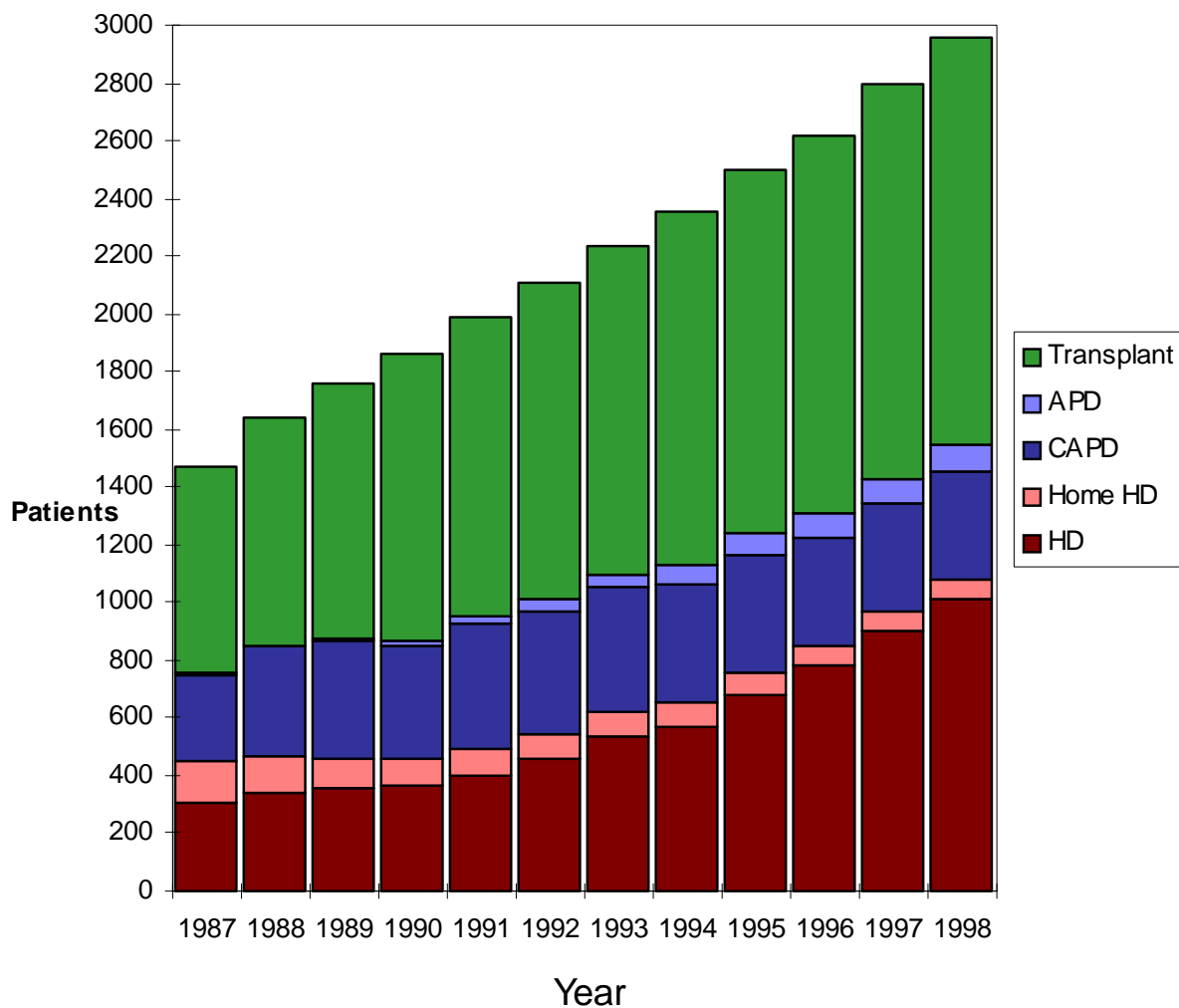
**Graph 8b**  
**Mode of first RRT 1989-1998**

In total 9 patients have received a pre-emptive transplant, the first in 1982. Hospital HD remains the most common first mode of RRT. Intermittent peritoneal dialysis was introduced in 1968, the use of PD as a first mode of RRT has stopped expanding and graph 9a shows that the use of PD in the stock of patients has likewise levelled off.

**PATIENTS RECEIVING RRT IN SCOTLAND ON 31<sup>ST</sup> DECEMBER 1968-1998**



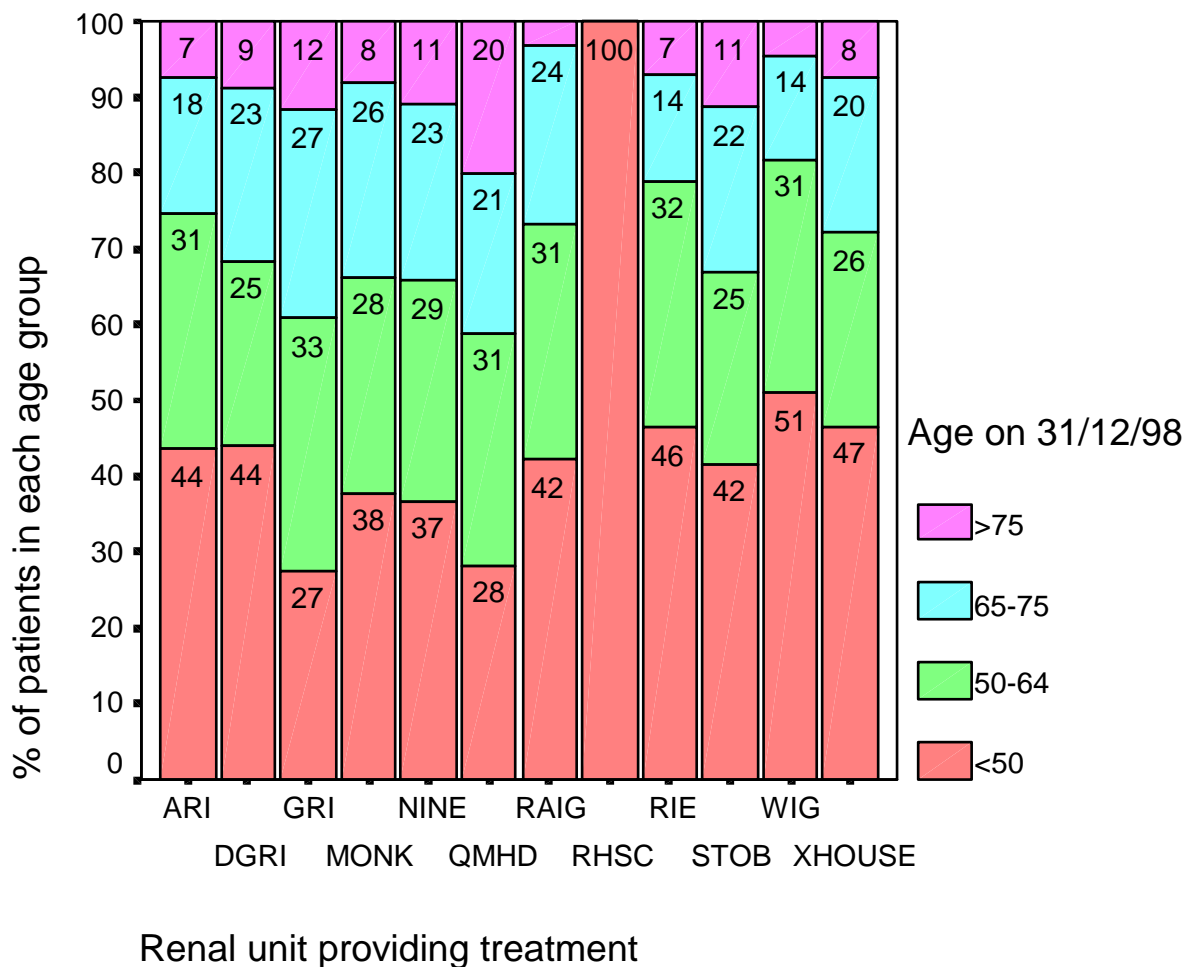
**Graph 9a**  
**Prevalent patients every fifth year between 1968 and 1998**



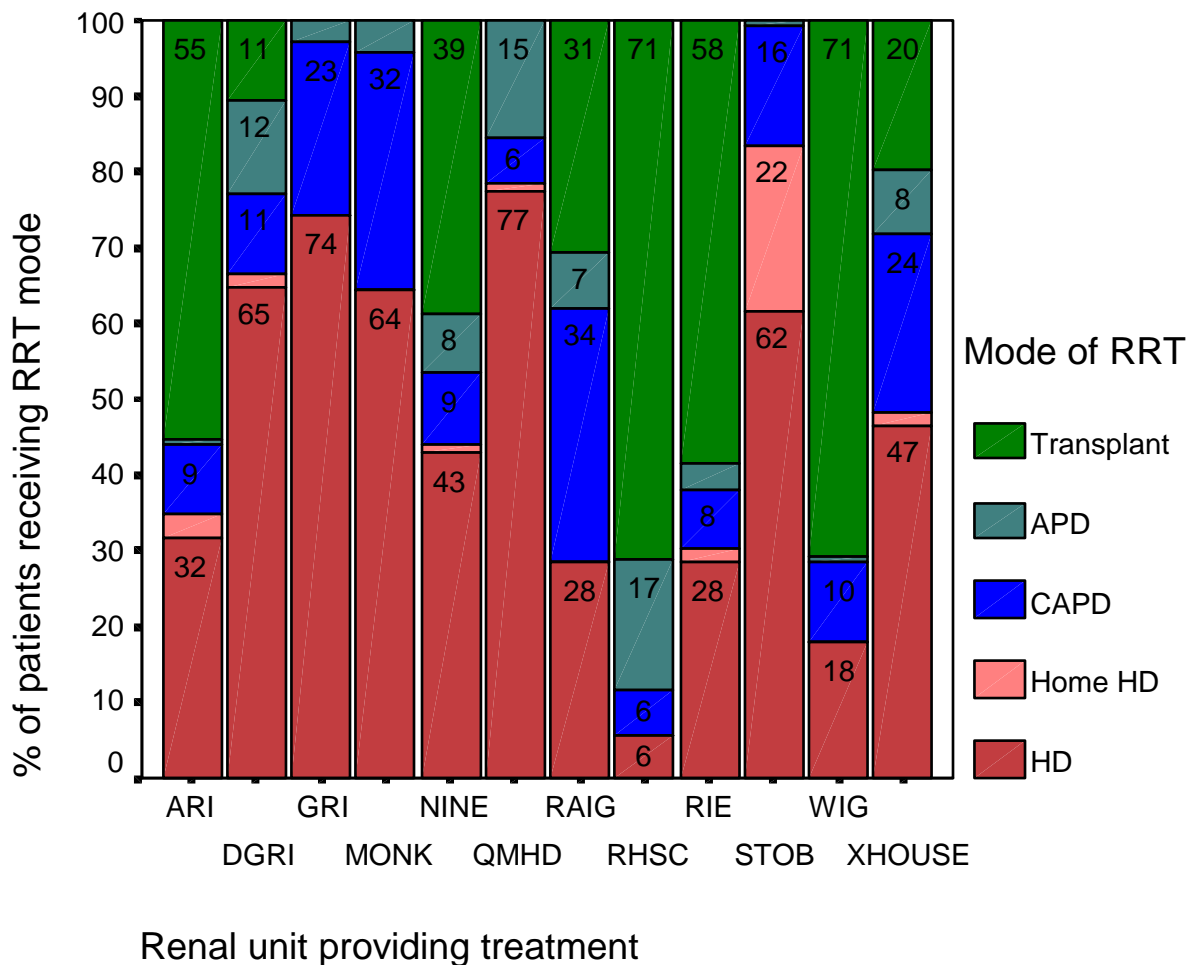
**Graph 9b**  
**Prevalent patients every year between 1987 and 1998**

The numbers of patients receiving RRT in the form of a renal transplant and hospital based HD are continuing to increase. CAPD was first introduced in 1975, APD was first introduced in 1983. The number of patients using all forms of peritoneal dialysis is no longer increasing.

**LOCATION OF RRT**



**Graph 10**  
Age on 31 December 1998 of patients receiving RRT by renal unit



**Graph 11**  
**Mode of RRT and renal unit providing treatment on 31 December 1998**

See appendix 6 for abbreviations of renal unit names.

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

Whilst all patients treated at the Royal Hospital 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.

To make even very simple comparisons it is important to have some background information about local and national working practices - see Table 4.

The high proportion of younger patients in Western Infirmary Glasgow (WIG) and Royal Infirmary Edinburgh (RIE) (Graph 10) is at least in part due to the large number of patients with functioning transplants being treated by these units. (Graph 11)

To explain fully the differences between renal units requires information about patient age, comorbidity, domicile and patient choice which is not available here.

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#### **Raigmore Hospital**

Many patients live in geographically isolated areas hence peritoneal dialysis often favoured.

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#### **Royal Infirmary Edinburgh**

Performs transplants and follow-up of patients previously dialysed in Queen Margaret Hospital Dunfermline (QMHD).

Performs transplants but not follow-up of patients previously dialysed in Ninewells Hospital Dundee (NINE).

Performs live donor transplants, including pre-emptive transplants as referred from across Scotland.

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#### **Stobhill Hospital**

Treats all Home HD patients from the Glasgow Royal Infirmary (GRI), Stobhill Hospital Glasgow (STOB) and the Western Infirmary Glasgow (WIG).

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#### **Western Infirmary Glasgow**

Performs transplants and subsequent follow-up of patients previously dialysed in Glasgow Royal Infirmary (GRI), Monklands Hospital Airdrie (MONK), Stobhill Hospital (STOB), Western Infirmary Glasgow (WIG).

Performs transplants of patients previously dialysed in Dumfries and Galloway Royal Infirmary (DGRI) and Crosshouse Hospital (XHOUSE) but not follow-up or share follow-up.

Performs live donor transplants as referred.

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#### **Table 4**

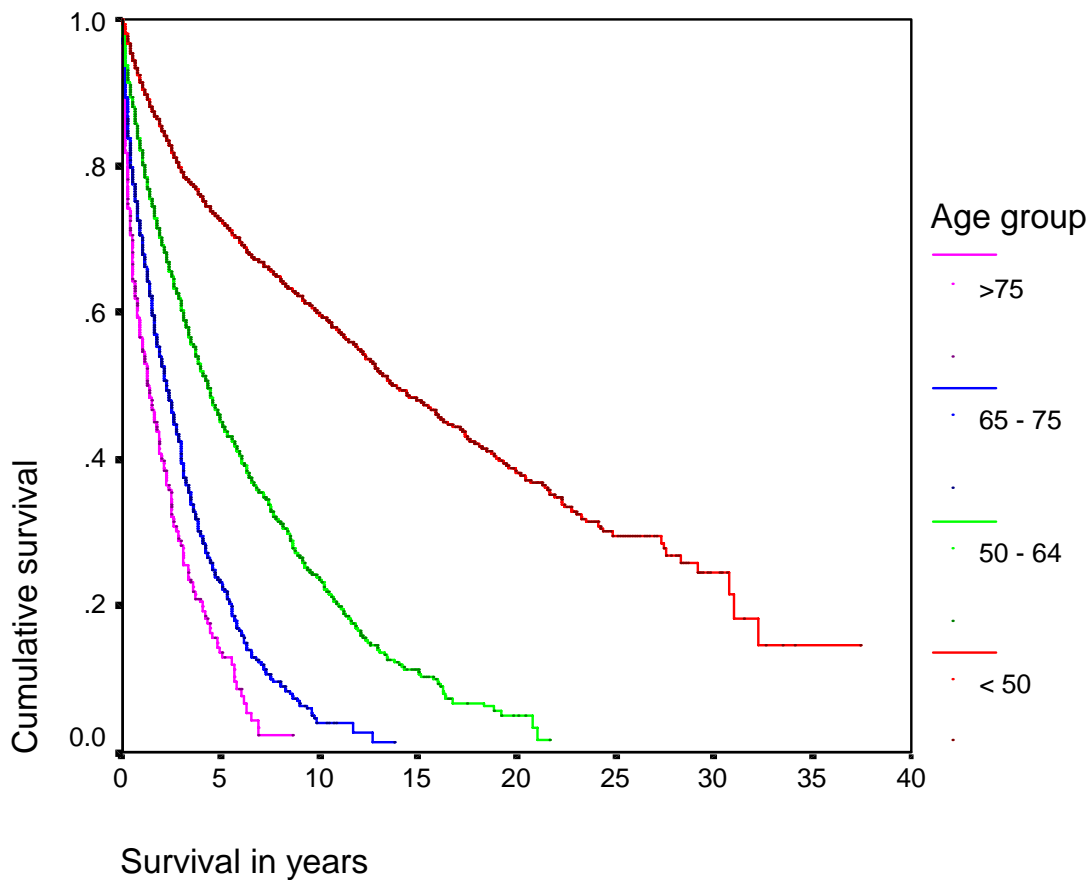
#### **Differences in renal unit patient mix**

It appears from graphs 10 and 11 that those units with a high proportion of patients receiving HD are also the units with a high proportion of elderly patients. The median ages of patients receiving all treatment modalities on 31 December 1998 were compared and found to be significantly different ( $p < 0.001$  Kruskal Wallis).

Mode of RRT	Median Age	Age Range on 31/12/98
Transplant	46.6	7.4 - 80.4
APD	46.1	3.6 - 81.1
CAPD	59.3	6.2 - 86.3
Home HD	47.6	20.7 - 78.9
HD	61.2	4.3 - 90.3

**Table 5** Median age on 31/12/98 by mode of RRT

**SURVIVAL ANALYSES**

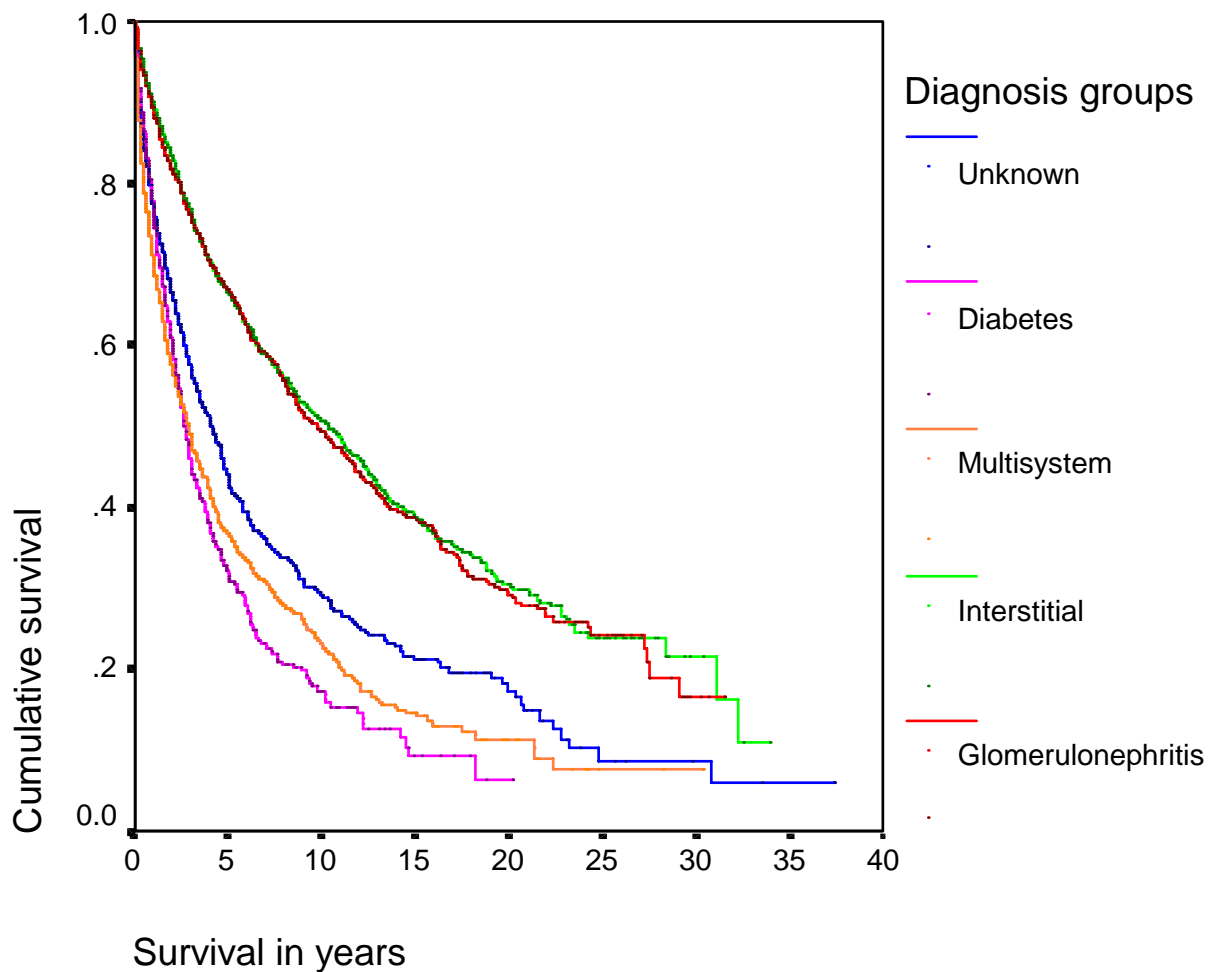


**Graph 12**  
Survival by age when starting RRT

Age Group	Number starting RRT	Number dead by 31/12/98	Median survival (years)	95% CI for median survival	
>75 years	412	292	1.3	1.0	1.6
65-75 years	1219	852	2.2	2.0	2.5
50-64 years	1936	1238	4.3	4.0	4.7
<50 years	2805	1195	13.8	12.7	14.8

**Table 6**  
**Survival of all patients by age when starting RRT**

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.



**Graph 13**  
**Survival of all patients by primary renal diagnosis group**

Age Group	Number starting RRT	Number dead by 31/12/98	Median survival (years)	95% CI for median survival	
Unknown	1030	621	4.1	3.6	4.6
Diabetes	803	516	2.7	2.4	2.9
Multisystem	1367	911	2.9	2.5	3.2
Interstitial	1807	858	10.3	9.2	11.4
Glomerulo-nephritis	1368	674	9.7	8.6	10.8

**Table 7**  
**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.

Age Group	Diagnosis Group	No. starting RRT	No. dead 31/12/98	Median survival (years)	95% CI for median survival		Log Rank
<b>All ages</b>	<b>All diagnoses</b>	<b>6372</b>	<b>3577</b>	<b>5.7</b>	<b>5.3</b>	<b>6.0</b>	
>75 years	Unknown	152	121	1.2	0.7	1.8	p=0.25
	Diabetes	33	22	1.0	0.0	2.1	
	Multisystem	117	77	1.4	0.8	2.0	
	Interstitial	66	39	2.0	1.5	2.4	
	Glomerulonephritis	44	33	0.8	0.4	1.2	
65-75 years	Unknown	268	180	2.7	2.3	3.0	p<0.0001
	Diabetes	148	103	1.6	1.3	1.9	
	Multisystem	387	283	1.5	1.2	1.8	
	Interstitial	242	165	3.0	2.4	3.5	
	Glomerulonephritis	174	121	3.0	2.3	3.7	
50-64 years	Unknown	291	182	4.7	4.0	5.3	p<0.0001
	Diabetes	294	205	2.5	2.0	2.9	
	Multisystem	458	328	2.9	2.3	3.5	
	Interstitial	499	306	6.3	5.6	7.1	
	Glomerulonephritis	394	217	6.4	5.2	7.5	
<50 years	Unknown	319	138	13.5	8.0	19.1	p<0.0001
	Diabetes	327	185	4.7	3.4	6.0	
	Multisystem	405	223	8.0	6.2	9.8	
	Interstitial	998	346	18.8	16.5	21.0	
	Glomerulonephritis	756	303	16.5	14.9	18.1	

**Table 8**  
**Survival by age and diagnosis groups**

Table 8 shows the independent effect on survival of age and diagnosis. The general pattern seen in graphs 12 and 13 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, therefore these figures should be interpreted with caution.

Age	Life Expectancy Males	Life Expectancy Females
85	4.7	5.7
75	8.4	10.7
65	13.9	17.3
45	29.7	34.3

**Table 9**  
**Life expectancy for the general Scottish population 1995-1997 (Registrar General for Scotland)**

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.

## **SURVIVAL OF PATIENTS WITH DIAGNOSES OF GLOMERULONEPHRITIS AND DIABETIC NEPHROPATHY, AGED 50-64 WHEN STARTING RRT, BY YEAR OF STARTING RRT.**

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 1994-1998 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.

Date of starting RRT	Patients	Dead by 5 years of RRT	Odds Ratio of death	95% CI ratio for odds of death		p value
1989-1993	99	42	1.00	-	-	reference
1984-1988	67	29	1.04	0.55	1.94	0.91
1979-1983	54	26	1.26	0.65	2.45	0.50
1964-1978	44	22	1.36	0.67	2.77	0.40

**Table 10**  
**Odds ratio of death by 5 years of RRT for patients aged 50-64 with a diagnosis of glomerulonephritis**

A significant odds ratio of 1.04 would suggest that the probability of death by 5 years of RRT was 4% greater in patients starting RRT between 1984-1988 than those starting RRT between 1989-1993.

However none of the odds ratios in table 10 are statistically significant to a ratio of 1.0, as can be seen from the 95% confidence intervals which all include 1.0 and the large p-values.

There appears to be an upward trend in the odds ratio values with more distant starting date of RRT, but analyses testing specifically for a significant trend did not reveal one.

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 past 15 years. Patients starting RRT between 1984 and 1993, (again to allow for 5 years of follow-up) were divided into 4 groups according to their date of starting RRT.

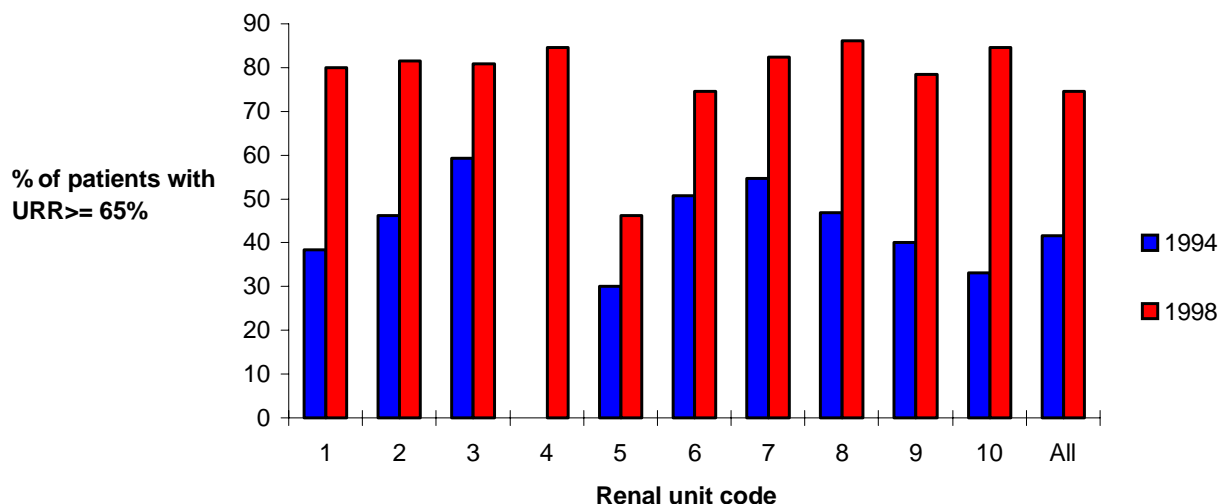
Date of starting RRT	Patients	Dead by 5 years of RRT	Odds Ratio of death	95% CI ratio for odds of death		p value
1992-1993	40	30	1.00	-	-	reference
1990-1992	31	26	1.73	0.52	5.72	0.14
1988-1989	35	26	0.96	0.34	2.73	0.94
1984-1987	35	21	2.58	0.73	9.14	0.37

**Table 11**  
Odds ratio of death by 5 years of RRT for patients aged 50-64 with a diagnosis of diabetic nephropathy

None of the odds ratios in table 11 are significantly different to 1.0. Therefore the probability of patients aged 50-64 when starting RRT, with diabetic nephropathy, dying within 5 years of starting RRT was essentially the same regardless of when RRT was started. Whilst the odds ratio for death was greatest for the earliest time period of starting RRT, no statistically significant trend was found.

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.

**QUALITY ASSURANCE PROGRAM FOR PATIENTS RECEIVING HOSPITAL HAEMODIALYSIS USING THE UREA REDUCTION RATIO**



**Graph 14**  
Percentage of hospital haemodialysis patients achieving a urea reduction ratio >= 65% in 1994 and 1998

The quality of haemodialysis can be assessed by the percentage reduction in the serum urea concentration over a single dialysis session (2). This is also called the urea reduction ratio (URR) ( $100 \times (1 - \text{post dialysis [urea]} / \text{pre dialysis [urea]})$ ). This has been shown to correlate with patient survival (3).

In 1994 a recommended standard for URR had not been published in the UK but in April 1995 the UK Renal Association and the Royal College of Physicians of London recommended a minimum of 55% for adult patients receiving hospital haemodialysis three times a week (4). In November 1997 the UK Renal Association and the Royal College of Physicians of London increased the recommended URR to a value of greater than 65% (5).

From July 1994 all adult renal units in Scotland reported their URR results on a regular basis to the SRR. Results for the individual units were compared to the standard and to the mean for all the patients in Scotland. Each unit received graphs showing the results for all the other units but only their own results were identified to them thus maintaining anonymity. The results were presented to the twice yearly meetings of the SRA after which a workshop was held to discuss the results and methods of improving the URR. In addition discussions took place and research was commissioned to identify the best means of standardising sampling methods and reducing errors.

In the initial study in July 1994 83% of patients in Scotland reached the standard required at that time (URR  $\geq 55\%$ ). By 1997 (2) an increased proportion of patients had reached this standard but it was noted that one unit (unit 4) consistently fell below the standards of the others and the minimum standard in the guideline. By 1998 (6) there had been a small further improvement in the overall figure with 89% of the patients achieving a URR greater than 55 and unit 4 had improved dramatically. The recommended standard had, by then, been increased to a URR of greater than 65% and this was achieved in only 59% of patients in Scotland at that time.

A further study in September 1998 shows a further marked improvement in URR. 437 patients were studied in the original audit and this had risen to 815 patients by September 1998 consistent with the expansion in haemodialysis (2). Graph 14 shows that a URR of  $\geq 65\%$  was achieved in 42% of the adult hospital haemodialysis patients in 1994 and that this had risen to 75% of the patients in September 1998. The most striking improvement has been in the results of the unit

which previously fell below the standard.

The overall quality of dialysis delivered has improved considerably. The results remain anonymous we are therefore unable to report the reasons but there have been trends within Scotland to increase both the blood flow through the dialysers and dialysis treatment time and also to use more efficient dialysers. In addition reviewing the results for individual units may have led to identification of patients in whom the dialysis access was providing unsatisfactory blood flow.

This project demonstrates the beneficial effect of a sustained programme of quality improvement which is supported by all members of our multi-disciplinary teams and by the patients.

## APPENDIX 1

### STATISTICS 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 Scottish Renal Registry (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 in Scotland. In this type of study every attempt is made to obtain an exhaustive 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 assume that these data are valid and that there are no simple ways of obtaining the remaining 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 (Graph 3b). 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 we knew that an assumption of a Normal distribution of ages was not valid.

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 (1) 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.

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 which suggested no significant improvement in the proportion surviving 5 years of RRT. These analyses gave little additional information and so were not presented in detail.

## **APPENDIX 2**

### **REPORTS RECEIVED FROM OTHER RENAL REGISTRIES DURING 1998**

We are very grateful to the following renal registries for sending a copy of their annual report to the SRR. Copies of these reports can be seen on request to the SRR office.

European Renal Association - European Dialysis and  
Transplant Association  
UK Renal Registry  
UK Transplant Support Service Authority  
Quasi Niere Renal Replacement Therapy in Germany  
Catalan Renal Registry  
Dutch Renal Registry  
Australia and New Zealand Renal Registry  
Lombardy Regional Report  
Finnish Registry of Kidney Diseases

## **APPENDIX 3**

### **ORGANISATIONS WITH WHICH THE SCOTTISH RENAL REGISTRY RECEIVES OR EXCHANGES DATA**

All renal units in Scotland

The Information and Statistics Division of the NHS in Scotland

The Registrar General for Scotland (via ISD)

The Scottish Cancer Registry

Scottish Health boards:

The UK Special Transplant Health Authority

The UK Renal Registry

The European Renal Association - European Dialysis and Transplant Association

The United States Renal Data System

## APPENDIX 4

### 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	Consultant member of the Steering Group
1	Aberdeen Royal Infirmary	Foresterhill ABERDEEN AB25 2ZD  Satellites: Dr Gray's Hospital Elgin IV30 ISN  Peterhead Community Hospital Links Terrace Peterhead AB42 2XB	Dr Alison MacLeod *
2	Crosshouse Hospital	Crosshouse Kilmarnock KA2 0BE	Dr Andrew Innes
3	Dumfries & Galloway Royal Infirmary	Bankend Road Dumfries DG1 4AP	Dr Sue Robertson (Medical Representative) Dr Chris Isles (Consultant Representative)
4	Glasgow Royal Infirmary	Castle Street Glasgow G4 0SF  Satellite Falkirk and District General Hospital Major's Loan. Falkirk FK1 5QE (Opened 12th April 1999)	Dr Keith Simpson *
5	Monklands Hospital	Monkscourt Avenue Airdrie ML6 0JS	Dr Bill Smith
6	Ninewells Hospital	Ninewells Avenue Dundee DD1 9SY	Dr Ellon McGregor *

*continued*

**APPENDIX 4** *CONTINUED*

	Renal Unit	Address	Consultant member of the Steering Group
7	Queen Margaret's Hospital	Whitefield Road Dunfermline Fife KY12 0SU Satellite: Victoria Hospital Highfield Road Kirkcaldy KY2 5AH	Dr David Jenkins
8	Raigmore Hospital	Old Perth Road Inverness IV2 3UJ	Dr John Burton
9	Royal Hospital for Sick Children	Yorkhill Glasgow G3 8SJ	Dr Jim Beattie
10	Royal Infirmary of Edinburgh	Lauriston Place Edinburgh EH2 9YW Satellites: Western General Hospital Crewe Road South Edinburgh EH4 2 XU Borders General Hospital Melrose TD6 9BD	Dr Robin Winney *
11	Stobhill Hospital	Balornock Road Glasgow G21 3UW	Dr Robert Mactier
12	Western Infirmary Glasgow	Dumbarton Road Glasgow G11 6NT Annex: Gartnavel General Hospital Great Western Road Glasgow G12 0YN Satellite: Inverclyde Royal Hospital Larkfield Road Greenock PA16 0XN (Planned to open 14 June 1999)	Dr Brian Junor *

## APPENDIX 5

### 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 Diabetes 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 6****ABBREVIATIONS USED IN THE TEXT**

<b>Abbreviation</b>	<b>Definition</b>
APD	Automated Peritoneal Dialysis Previously called Continuous Cyclic Peritoneal Dialysis (CCPD)
ARI	Aberdeen Royal Infirmary
CAPD	Continuous Ambulatory Peritoneal Dialysis
CRAG	Clinical Resource and Audit Group
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
ISD	Information and Statistics Division
MONK	Monklands Hospital, Lanarkshire
NHS	National Health Service
NHSiS	National Health Service in Scotland
NINE	Ninewells Hospital, Dundee
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
XHOUSE	Crosshouse Hospital, Kilmarnock

## APPENDIX 7

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