

## Chapter 3: New Adult Patients Accepted For Renal Replacement Therapy In 1998

### Introduction

During 1998 the 31 units contributing to the Registry started 2304 patients on treatment for end-stage renal failure. The figures are summarised in Table 3.1. Since all Scottish units contribute to the Registry the acceptance rate per million population can be given more accurately than for England & Wales, where only 30% of the units contribute and the catchment areas are estimates provided by the units themselves.

This analysis only includes adult patients (aged over 18) starting end stage renal replacement therapy for the first time as defined in appendix B, and does not include patients who transferred into centres participating in the Registry who had previously started on therapy elsewhere.

	England & Wales	Scotland	Total
<b>No. of units</b>	19	12	31
<b>No. of new patients</b>	1,788	516	2,304
<b>Catchment population million</b>	19.9	5.1	25.0
<b>New patients p.m.p.</b>	89.8	101.2	92.2
<b>(95% C.I.)</b>	(85.7 – 94.1)	(92.6 – 110.4)	(88.4 – 96.0)
<b>New patients per Unit</b>	94	43	

**Table 3.1 Summary of new patients accepted during 1998**

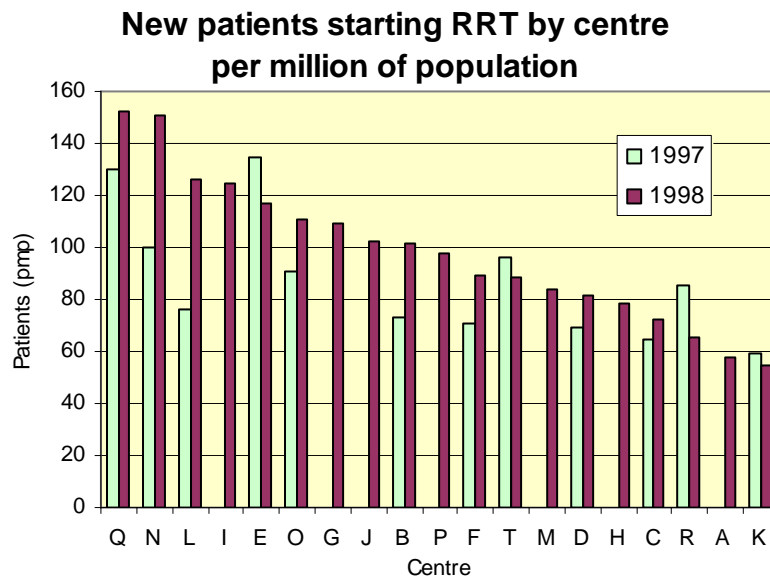
The Renal Association standards document recommends *a minimum annual acceptance rate of new patients with renal failure of 80 per million population, adjusted upwards as necessary for ethnic and age distribution of the population.*

Interpretation of apparent of the acceptance rates for individual units is very difficult for the following reasons :-

1. The catchment populations are ill-defined, the Registry relies on each unit's own estimation of its catchment area.
2. In large conurbations there are significant cross-boundary flows of patients.
3. The demand for treatment will vary with the age and ethnicity characteristics of the population served.
4. There variation in definition of "chronic renal failure", some units including patients others would define as "acute".
5. Resource constraints have significant effects. One of the centres with a low acceptance rate has lacked facilities for more patients and has been referring patients to nearby units. Thus the population has been served, but not by its local unit.

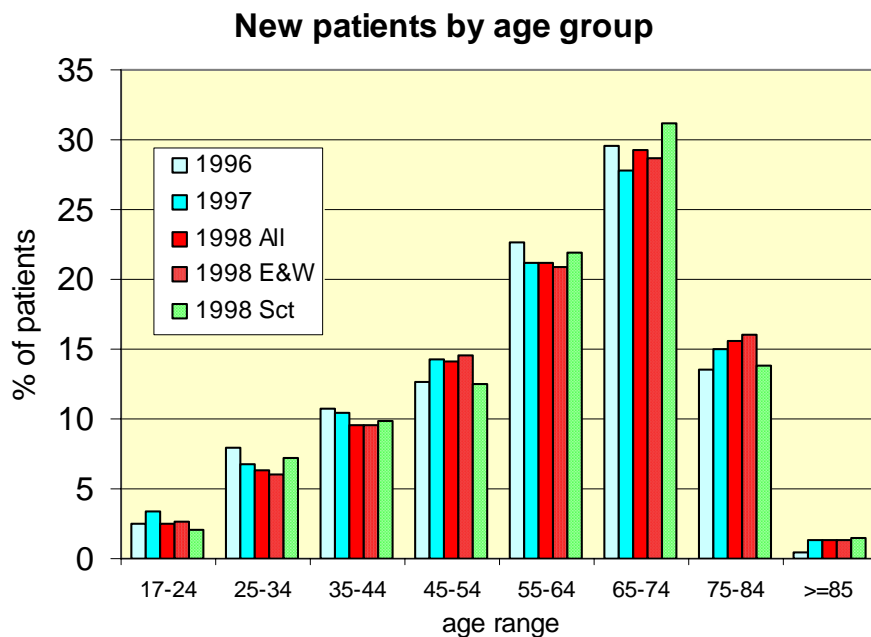
It is therefore not surprising that the calculated acceptance rates vary between the units from 50 to 150 patients per million population per year. This variation is illustrated in figure 3.1. As the Registry grows to cover larger contiguous areas of the UK, cross

boundary flows will become less significant. Analysis of treatment rates, on the basis of postcodes, will be performed for each health authority for next year's report.



**Figure 3.1** New patients starting RRT by centre per million of population

### Age of new patients



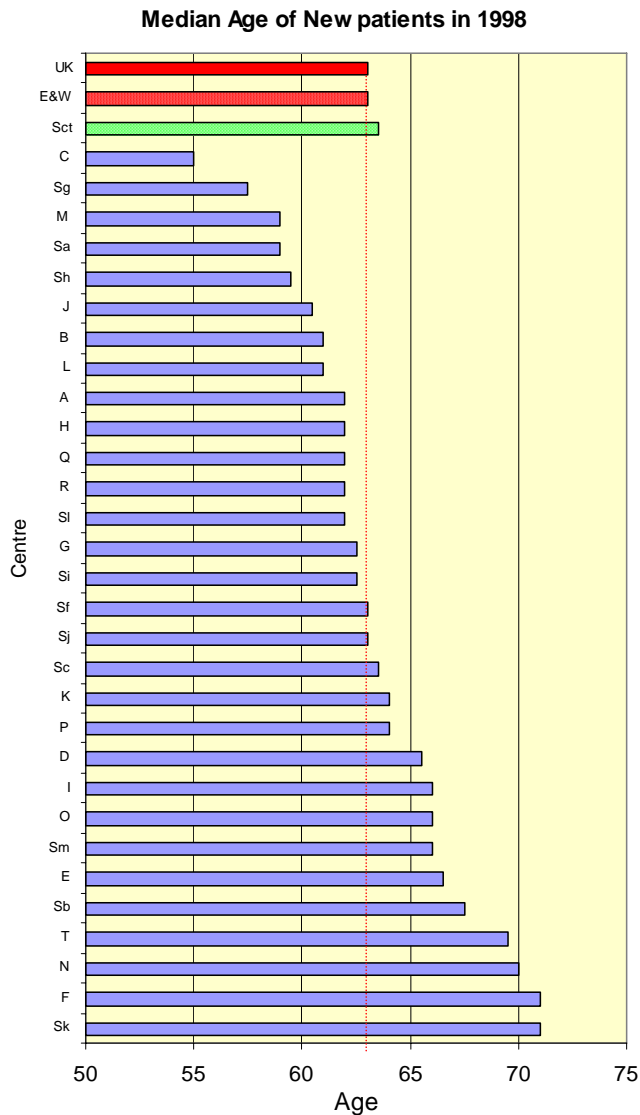
**Figure 3.2** New RRT patients by age group

The age distribution of new patients is illustrated in figure 3.2. The high incidence of end-stage renal failure in older age groups is demonstrated. At the start of treatment 46% of patients were aged 65 or more. This has slowly increased in recent years: in 1997 43% were aged 65 or over, compared with 41% in England in 1995, and 37% in 1993. There was little difference between England & Wales and Scotland in 1998. In

1998 33% of all new patients were aged 70 or over compared with 29% for England and Wales in 1997. Although the catchment populations for these figures differ, there appears to be a continuing trend for accepting older patients.

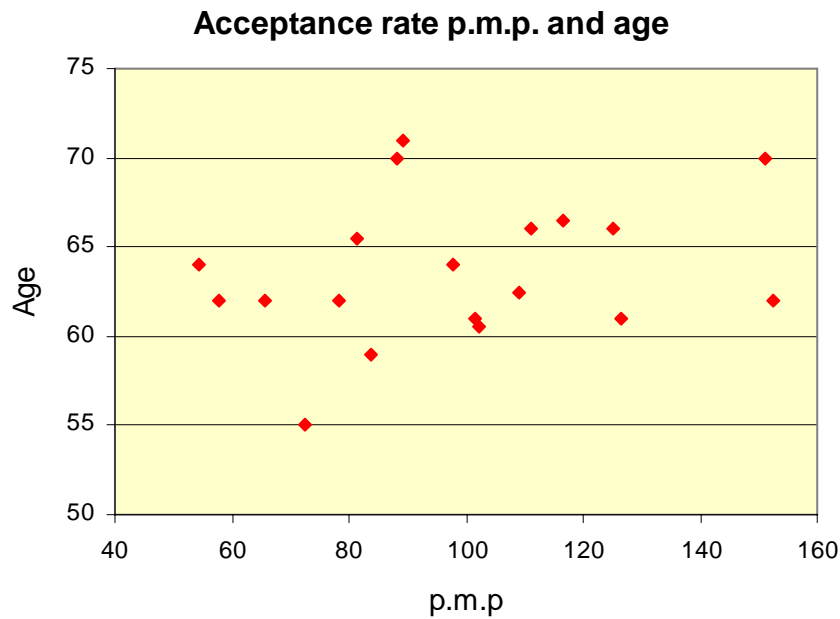
The median age for the UK was 63 years (63 for England & Wales; 64 for Scotland) - with a surprising degree of variation between units from 55 to 71 years (Figure 3.3). The median age of new patients differed significantly between the centres for England & Wales (Kruskal Wallis test,  $X^2=79$ , d.f=18,  $p<0.0001$ . although there was no significant difference between centres in Scotland ( $X^2=18$ , d.f=10,  $p<0.0634$ ).

Without knowledge of the age and ethnicity of the individual catchment areas and of local policies and constraints it is not possible to analyse the reasons for this variation in England & Wales. Nevertheless these variations are greater than would be expected from known variations in the age distribution of UK populations, and do not appear to relate to the ethnic distribution of patients accepted for treatment. It thus seems that differences in referral patterns and acceptance policies play some part in these observed variations.



**Figure 3.3 Median age of new patients in each unit**

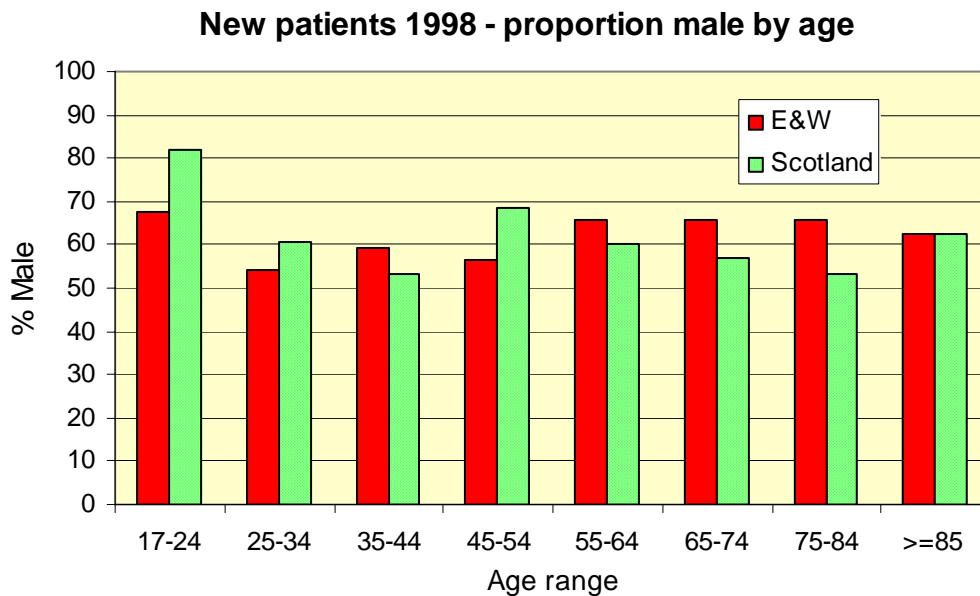
The relationship between the median age and acceptance rates for individual units is shown in Figure 3.4.



**Figure 3.4 Acceptance rate p.m.p. and age**

As discussed earlier, the acceptance rate for an individual renal unit is due to a combination of factors. Patient age, ethnicity and cross boundary flow due to lack of dialysis capacity influence this.

## Gender

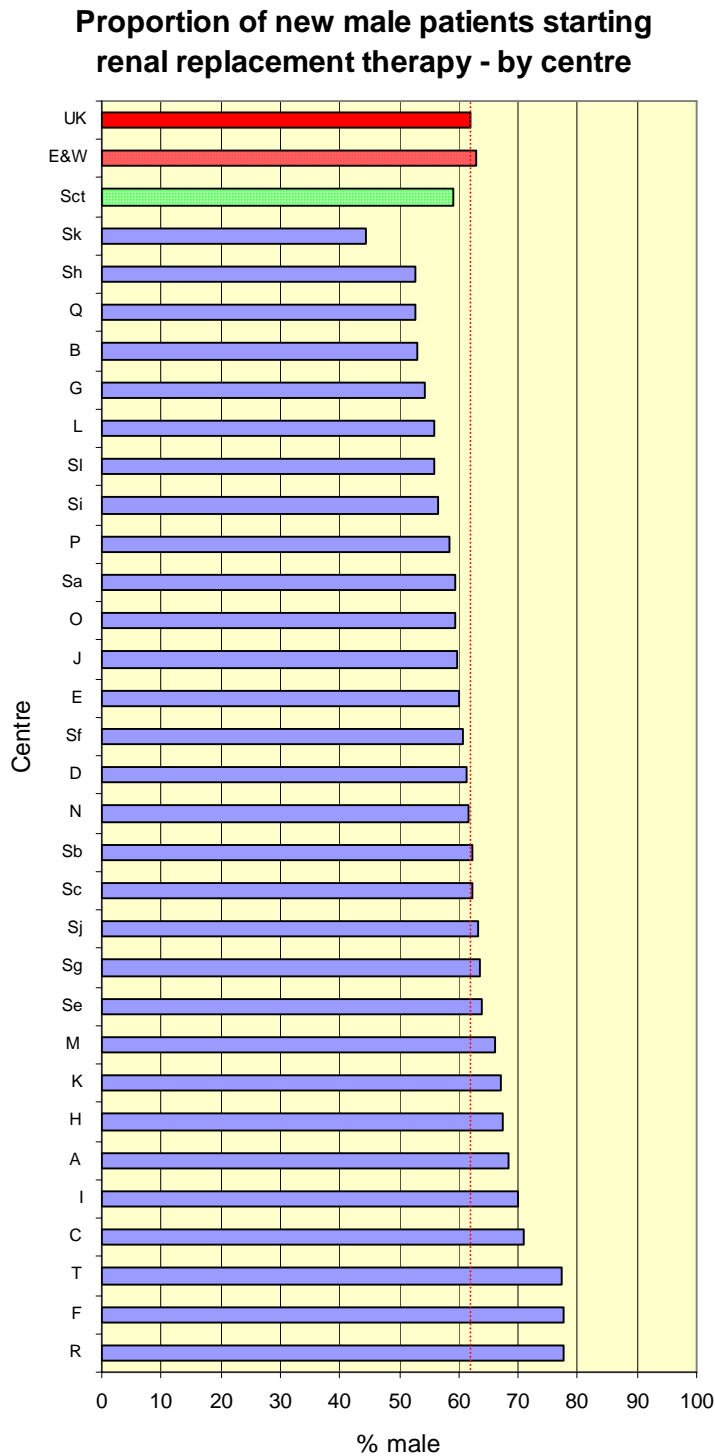


**Figure 3.5 New patients 1998 – proportion male by age**

The 11-24 age group contains few patients: no significance can be attached to the apparent high percentage of males in this age group for Scotland.

The male to female ratio for new patients was 1.64 (1.71 for England & Wales; 1.45 for Scotland). Despite the increasing preponderance of females in the older age groups in the general population, the proportion of males starting renal replacement therapy in the older groups does not reduce.

The variation between units in male to female ratio with age is illustrated in Figure 3.6.



**Figure 3.6 Variation between units in new male patients**

## Ethnicity

Ethnicity was recorded in 58% of patients who started treatment in 1998 in England and Wales, compared with 66% and 76% from the much smaller 1997 and 1996 cohorts. It is not yet requested for the database in Scotland. Of the 19 units from England & Wales, 6 units sent no ethnicity data at all, but data from 5 units had greater than 90% completeness. Of the 11 units with ethnicity data on at least 75% of their patients, the combined proportion of Asian and Black patients together varied from none to 27% of the new patients accepted for treatment (Table 3.2a).

	<b>% with data complete</b>	<b>% White</b>	<b>% Black</b>	<b>% Asian</b>	<b>% Chinese</b>	<b>% Other</b>
Birmingham	100	75.7	8.6	15.7		
Plymouth	100	100				
Sunderland	98	95.2	4.8			
Nottingham	96	87.3	5.6	7.1		
Gloucester	94	100.0				
Leicester	89	82.1	1.9	13.6	0.6	1.9
Bristol	83	91.1	5.0	3.0		1.0
Middlesborough	77	96.5		3.5		
Coventry	76	71.2	7.6	19.7	1.5	
Wordsley	76	100.0				
Carshalton	75	69	3	3		
Leeds, St James's	49	87.2	5.1	7.7		
Exeter	4					
Cardiff	0					
Carlisle	0					
Hull	0					
Oxford	0					
Sheffield	0					
Stevenage	0					
<b>E &amp; W</b>	<b>58</b>	<b>89.2</b>	<b>3.2</b>	<b>7.0</b>	<b>0.3</b>	<b>0.4</b>

**Table 3.2.a Ethnicity by centre**

Excluding centres with less than 85% completeness of ethnicity data, the most common cause of renal failure amongst the Black / Asian cohort is diabetes

	<b>White</b>	<b>Black /Asian</b>
No	450	50
Median age	64	61
% diabetic *	20.1%	38.9%

\* only includes centres with > 85% completeness of ethnicity

**Table 3.2b Ethnicity, age and diabetes**

## Primary Renal Disease

The details on diagnosis are summarised in Table 3.3. Information on diagnosis was missing in 14% of patients (17% from England & Wales; 6% from Scotland) compared with 7% of the new patients reported in 1997 (and it is absent in only 3.4% of prevalent patients).

	<b>% All</b>	<b>% Age &lt; 65</b>	<b>% Age ≥ 65</b>	<b>M:F ratio</b>
<b>Aetiology uncertain*</b>	24	19	30	1.88
<b>Diabetes</b>	16	19	11	1.31
<b>Glomerulonephritis</b>	9	12	6	2.89
<b>Pyelonephritis</b>	9	9	8	1.74
<b>Polycystic kidney</b>	6	9	3	0.94
<b>Hypertension</b>	5	5	5	2.53
<b>Renal vascular disease</b>	6	2	10	2.05
<b>Other</b>	12	13	11	1.27
<b>Not sent</b>	14	12	16	1.53

\* Includes those listed as glomerulonephritis without biopsy

**Table 3.3 Primary renal disease**

“Aetiology uncertain” was recorded in 24% overall, and 30% in those over 65 years old. Diabetes was the single most common diagnosis reported (16% of all patients) whereas for prevalent patients diabetes comprises 9.5%. For prevalent patients the single most common diagnosis is glomerulonephritis (15.7%) closely followed by pyelonephritis (15.5%). Of all the diabetics starting treatment in 1998, 66% were under 65 years of age, whereas 79% of prevalent diabetics are under 65.

### ***Treatment modality***

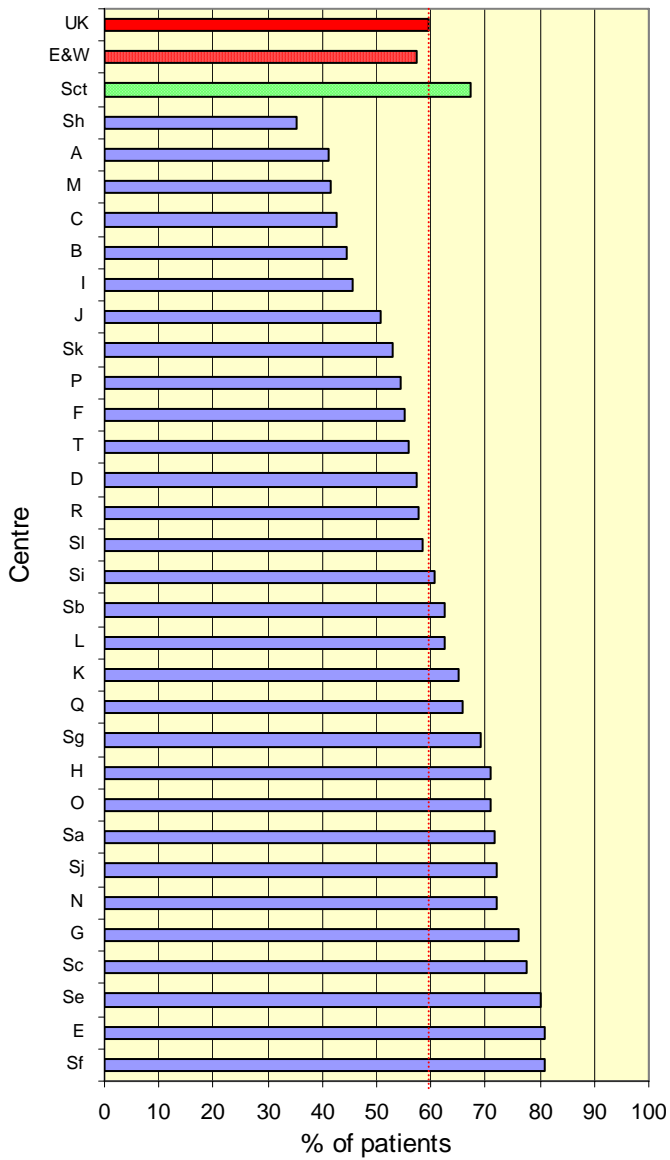
Many patients, especially those referred late to a renal unit, undergo a brief period of haemodialysis before being established on peritoneal dialysis. As an indication of elective treatment modality, the established modality at 90 days is a more clearly defined figure which is easier to derive: this has been used in subsequent analysis of elective modality of treatment of new patients.

On day 90 of treatment, 60% of patients were on haemodialysis. Table 3.4 shows that the proportion treated by haemodialysis was higher in Scotland than in England & Wales. It was also higher in older patients: 76% of dialysis patients in Scotland who are over 65 receive haemodialysis on day 90.

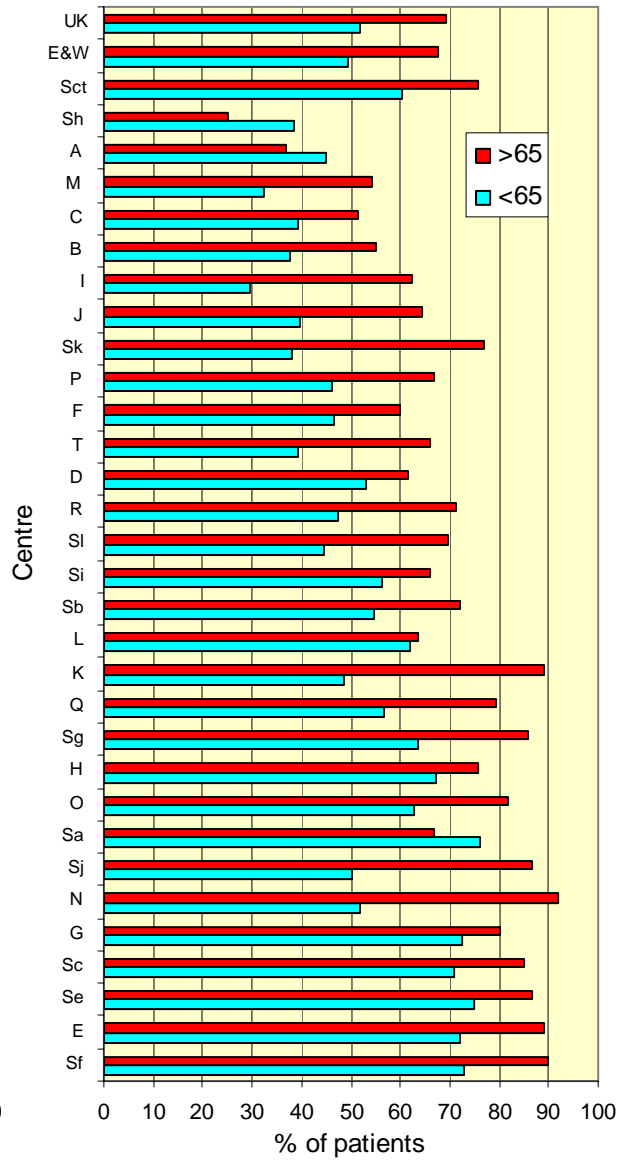
	<b>% of dialysis patients on HD at day 90</b>		
	<b>All ages</b>	<b>&lt; 65</b>	<b>≥ 65</b>
<b>U.K.</b>	60	52	69
<b>England &amp; Wales</b>	57	49	67
<b>Scotland</b>	67	60	76

**Table 3.4 Dialysis modality**

**New patients 1998 : Percentage of all dialysis on HD at day 90**



**New patients : % of all dialysis patients on HD on day 90, by age**



**Figure 3.7 % of patients established on HD at day 90 by centre and by age**

There does not seem to be any systematic gender bias in choice of modality (Fig 3.7)



### Percentage of new patients - male

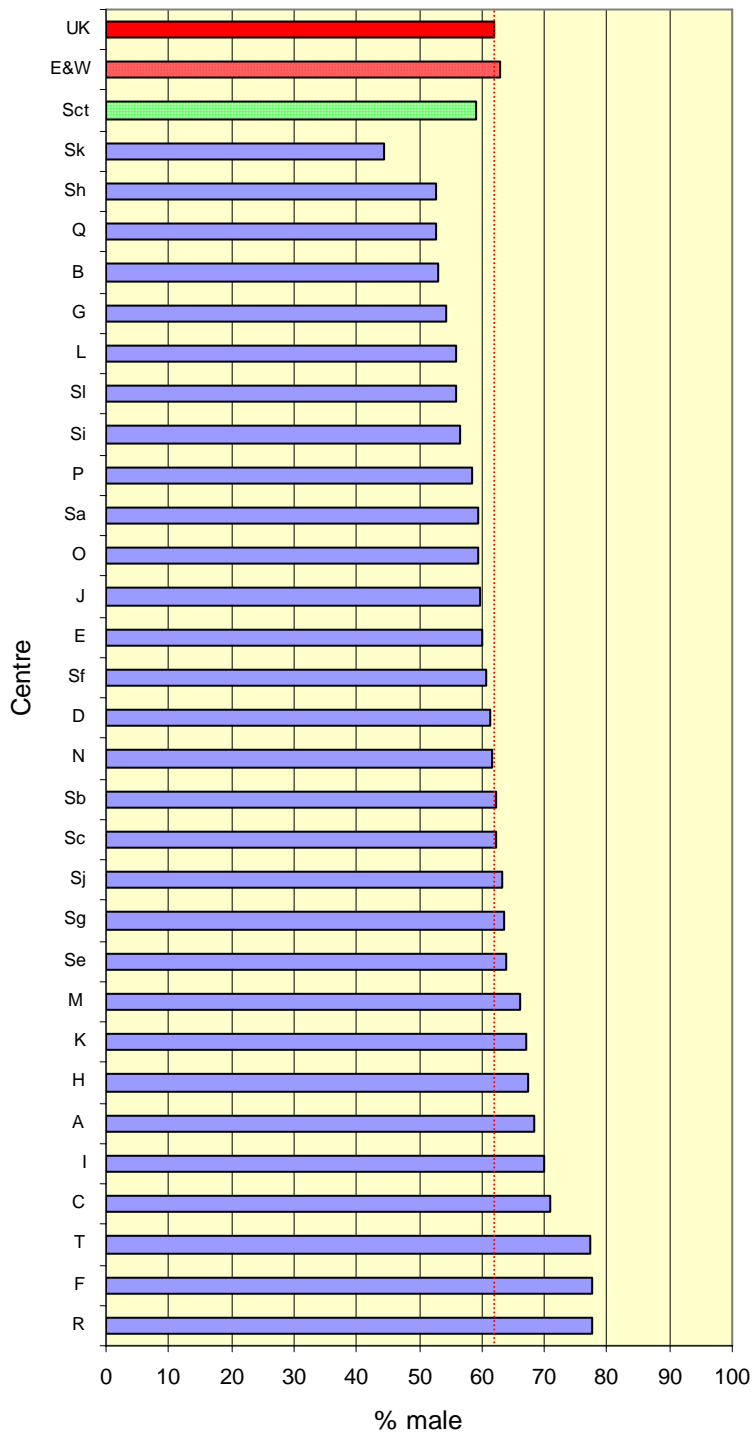


Figure 3.8 Percentage of male patients on each modality of dialysis

## ***The first change of treatment modality***

### ***Criteria for analysis***

The first change in treatment modality from the established modality at 3 months of therapy was analysed. The following criteria were applied:

1. A patient was classified as having changed to transplantation even if the transplant only lasted one day.
2. If a patient changed from haemodialysis to peritoneal dialysis the patient was classified as changed to peritoneal dialysis, independent of the subsequent length of time on peritoneal dialysis.
3. Patients on peritoneal dialysis who changed to haemodialysis for less than 31 days before changing back to peritoneal dialysis were classified as remaining on peritoneal dialysis. Those remaining on haemodialysis for more than 30 days and then changing back to peritoneal dialysis were classified as having changed to haemodialysis.
4. Patients who transferred out to a centre not on the Registry were categorised as unknown.

### ***Change of treatment modality in the first year***

This analysis includes the 912 patients from 12 centres sending data to the Registry in 1996/7 who started renal replacement therapy between 1/10/96 and 31/9/97, and analyses the first change of modality in 12 months from the established modality at 90 days of treatment.

The results are shown in table 3.5a and 3.5b.

<b>Modality</b>	<b>Haemodialysis</b>	
	<b>% all patients</b>	<b>no. of patients</b>
Remains on haemodialysis	68	329
Changed to PD	6	29
Transplanted	5	23
Transferred out elsewhere	.6	3
Recovered	`	6
Died (no change in modality)	19	98

**Table 3.5a HD patients at 90 days: changes in modality in subsequent year**

<b>Modality</b>	<b>Peritoneal Dialysis</b>	
	<b>% all patients</b>	<b>no. of patients</b>
Remains on PD	63	190
Change to haemodialysis	17	50
Transplanted	10	31
Transferred out elsewhere	1	3
Recovered	0.7	2
Died (no change in modality)	9	26

**Table 3.5b PD patients at 90 days: changes in modality in one year**

It is possible that some of the changes from haemodialysis to peritoneal dialysis were “elective”, some patients not having been established on their elective treatment modality by 90 days.

### ***First modality change over 2 years***

This analysis includes the 480 patients from 4 centres with returns from 1995/6 who started RRT between 1/10/95 and 31/9/96, and analyses the first change of modality in 2 years from the established modality at 90 days of treatment.

#### ***Patients who were on haemodialysis after the first 90 days***

There were 225 patients on haemodialysis after 90 days of renal replacement therapy.

<b>First Change in Modality</b>	<b>At end of 1 year</b>		<b>At end of 2 years</b>	
	<b>No. of Patients</b>	<b>% of Patients</b>	<b>No. of Patients</b>	<b>% of Patients</b>
Remains on haemodialysis	150	67%	105	47%
Changed to PD	11	5%	13	6%
Transplanted	21	9%	40	18%
Transferred out	1	0.5%	5	2%
Stopped Treatment (died)	5	2%	5	2%
Died (with no change in modality)	37	17%	57	25%
Total	225		225	

**Table 3.6 Changes in modality over the first 2 years for patients on HD**

#### ***Patients who were on peritoneal dialysis after the first 90 days***

There were 201 patients on peritoneal dialysis after the first 90 days of treatment.

<b>First Change in Modality</b>	<b>At end of 1 year</b>		<b>At end of 2 years</b>	
	<b>No. of Patients</b>	<b>% of Patients</b>	<b>No. of Patients</b>	<b>% of Patients</b>
Remains on PD	133	66%	84	42%
Changed to haemodialysis	23	11%	40	20%
Transplanted	23	11%	41	20%
Transferred out	1	0.5%	2	0.5%
Recovered	2	1%	2	0.5%
Stopped Treatment (died)	0	0	0	0%
Died (with no change in modality)	19	9%	32	16%
Total	201		201	

Note that patients are classed as ‘died with no change in modality’ if they died within 30 days of changing to haemodialysis: this applies to 13 patients.

3 additional patients died more than one month after changing to haemodialysis.

**Table 3.7 Changes in modality over the first 2 years for patients on PD**

## **Comment**

These data demonstrate the large number of changes of modality which occur in individuals, even during the first and second year of treatment.

There is a high rate of transfer from peritoneal dialysis to haemodialysis in the first year, which appears to continue through the second year. From the smaller early cohort, of those established on peritoneal dialysis 20% changed to haemodialysis within 2 years. However, of the larger recent cohort, 17% had already changed to haemodialysis within one year. In contrast, there are few changes from peritoneal dialysis to haemodialysis, and these virtually cease after the first year. In addition 6% of all peritoneal dialysis patients (68% of those that died) had a brief period of haemodialysis immediately prior to death. These figures emphasise the need for an adequate haemodialysis program to support peritoneal dialysis.

No significance can be attached to the higher death rate amongst haemodialysis patients as they are an older group of patients, and allocation to modality is not random.

## **New patient survival**

The only recommendation in the Renal Association Standards document is for a limited group of patients. The document recommends the following provisional targets may be set for mean survival:

*For all patients with 'standard' primary disease aged 18-55 years:  
1 year >90%; 5 years >80%.*

## **Analysis criteria**

Patients who later recovered renal function were excluded from the analysis.

Patients who transferred out of a Renal Registry centre without later transferring into another Renal Registry centre were censored when they transferred out.

To relate to the recommendations these analyses only considered patients who were aged between 18 and 55 when they started renal replacement therapy.

Analysis of patients with 'Standard Primary Renal Disease' only included those patients with EDTA codes between 0 and 49 for their primary cause of ESRF.

Analysis of patients with 'All Diseases Except Diabetes' also excluded patients with a diagnosis of 'Not Sent'.

Analysis of 'All treatments' did not censor patients when they were transplanted or changed dialysis modality.

For the analysis by modality of patients on haemodialysis and peritoneal dialysis, patients were censored when they changed treatment modality - even if the change in treatment modality only lasted a day. Patients were classified according to their starting

treatment modality – even if they only remained on their starting treatment modality for a day. Note that if a patient transfers out and then back into the centre later then it is assumed that the patient has remained on the same modality unless the timeline shows otherwise.

The Kaplan – Meier Method was used to estimate the percentage of patients surviving more than a year.

### **Comparison with the Standard recommendation**

One year patient survival was calculated for the groups of patients to whom the Standard applies.

This analysis considers patients starting renal replacement therapy treatment in 1997 from 12 Renal Units. These 12 Renal Units are the 9 Renal Units considered in the 1998 Report together with Hull, Sunderland and Exeter. Patients starting in 1996 at the 4 Renal Units for which 1996 data was also collected are also included.

First Treatment	Patients 18-55 - One Year Survival [95% CI]			
	Standard Primary Renal Disease		All Diseases Except Diabetes	
	Survival	No. of deaths	Survival	No. of deaths
All	97.2 [95.3 – 99.1]	8/284	94.4 [92.1 – 96.7]	22/393
Haemodialysis	96.8 [93.8 – 99.9]	4/173	92.2 [88.4 – 96.0]	15/244
Peritoneal dialysis	97.5 [94.1 - 100]	2/101	95.3 [91.3 – 99.3]	5/132

Note that the numbers are small when split by treatment modality. As the number of deaths are small and the numbers surviving are close to 100% some of the 95% CI are likely to be approximate and are most likely to be too narrow.

**Table 3.8 One Year Patients Survival – patients age 18-55**

These results fall well within the recommended standard.

### **Survival of all new patients**

The death rate per 100 patient years was calculated by counting the number of deaths and dividing by the person years exposed. This includes all patients, including those who died within the first three months of therapy. The person years at risk was calculated by adding up for each patient the number of days at risk (until they died or transferred out) and dividing by 365.

Results are shown in tables 3.9 and 3.10.

#### **90 day survival**

The 90-day survival is shown in table 3.9. The probability of a new patient aged under 65 surviving the first 90 days is 95%, compared with 81% for those aged 65 or over.

There is a relatively high early death rate. Of those who die in the first year, 50% die within three months. This is more marked in the older patients (54% deaths in 3 months) than in the younger patients (43%).

	<b>Deaths No of Patients</b>	<b>KM Survival Analysis</b>	<b>K-M 95% Confidence Interval</b>
< 65	29/547	0.95	0.93 – 0.97
≥ 65	81/437	0.81	0.78 – 0.85
All	110/984	0.89	0.87 – 0.91

**Table 3.9** Ninety day survival of new patients

### *One year survival*

	<b>At 3 months</b>		<b>At one year</b>		
	<b>Deaths No of Patients at 3/12</b>	<b>Deaths No of Patients</b>	<b>KM Survival Analysis</b>	<b>K-M 95% Confidence Interval</b>	<b>Death Rate Per 100 Patient Years</b>
< 65	29/547	68/547	0.87	0.85 - 0.90	13.6
≥65	81/437	151/437	0.65	0.61 - 0.70	45.7
All	110/984	219/984	0.78	0.75 - 0.80	26.3

**Table 3.10** One year survival of new patients, by age at start of therapy

### *Two year survival*

This was studied for the small cohort of 446 patients from 4 units recorded by the Registry as starting renal replacement therapy during 1996. Statistical techniques used are similar to those described for the one year survival estimates. There was a similar trend in early deaths. One year survival was similar to the larger 1998 cohort. Although it appears slightly better, with such a small number of patients in this cohort confidence intervals are wide and the differences are not significant.

	<b>Deaths / No of Patients</b>			<b>KM Survival Analysis</b>		<b>K-M 95% Confidence Interval</b>
	<b>3/12</b>	<b>1 year</b>	<b>2 years</b>	<b>1 year</b>	<b>2 year</b>	<b>2 year survival</b>
< 65	7	22	43/252	91.2	0.83	0.78 – 0.87
≥ 65	31	62	92/194	67.8	0.52	0.45 – 0.59
All	38/446	84/446	135/446	81	0.69	0.65 – 0.74

**Table 3.11** Two year survival of new patients

### **Comment**

The death rate for diabetic patients has not been analysed separately, as there were insufficient numbers to draw any conclusions. In future Registry reports when larger numbers of patients will be included, analysis of survival by diagnosis and other means of stratification, including co-morbidity and gender, will be possible. It will also be possible to study survival of new patients in smaller age bands.

The figures produced here are not comparable with those reported by the United States renal data system (USRDS) which excludes patients dying within the first 90 days of renal replacement therapy. The USRDS is unable to collect data with regard to the first 90 days of treatment as much of their data is collected by billing systems, and patients are not eligible for Medicare payment until 90 days of therapy have passed.