

Chapter 4: New Adult Patients Starting Renal Replacement Therapy In 1999

Summary

The estimated rate of adult patients starting renal replacement therapy (RRT) in the UK is 90 pmp indicating that approximately 5350 patients started RRT in 1999.

Haemodialysis was the modality of RRT at a day 90 for 58.8% of dialysis patients in England & Wales compared with 66.8% in Scotland

By the end of the first year 16% of patients starting on PD had changed to HD

The 90 day survival is 95% (95%CI 94-97%) for those aged less than 65 and 81% (95%CI 78-83%) for patients aged 65 and over.

The one year survival is 88% (95%CI 86-89%) for those aged less than 65 and 65% (95%CI 62-68%) for patients aged 65 and over.

The one year survival of the 1998 patient cohort on RRT was the same as the 1997 patient cohort even though there were 2 1/2 times the number of patients. This was also true when comparing the two year survival with that of previous Reports.

The consistency of many of these results from year to year, as more units join the Registry, gives grounds for confidence that the population of patients followed by the Registry is representative of the UK as a whole.

Introduction

In addition to bringing the information on demographics provided in previous years up to date, this chapter will give more detail on one and two year survival for the Registry patients. Where relevant, Registry information will be compared with the 1998 National Renal Survey in which details of activity, staffing and service provision were obtained from all 71 UK Units during 1998.

The 1999 data were from 35 renal units covering 47% of the UK, including all 11 adult Scottish Units, and 23 (40%) of the 57 Units in England and Wales (Table 4.1).

	England & Wales	Scotland	Estimated UK
No. of Units	23	11	
No. of new patients	1998	546	5350
Catchment population million	22.5	5.1	
New patients p.m.p. (95% C.I.)	88.7 (84.6 – 92.8)	107.1 (98.3 – 116.4)	90.4
New patients per Unit	86.9	49.6	

Table 4.1 Summary of new adult patients accepted during 1999

Acceptance Rates

The acceptance rate for Scotland has increased from 101 in 1998 to 107 p.m.p in 1999, although this is still within the 95% confidence interval from last year. These figures are accurate as all Scottish Units are included in the Registry. The estimated acceptance rate for England & Wales increased from 86.8 in 1998 to 88.7 p.m.p in 1999 but these figures are less reliable than those for Scotland because the catchment populations are less well defined, and the pool from which patients are drawn differs from year to year as more units join the Registry. The incidence of 86.8 p.m.p calculated by the Registry based on the 19 centres from England & Wales who contributed to the Registry during 1998 should be compared to that of 94.6 p.m.p obtained in the 1998 UK Renal Survey, which included all centres in England & Wales. The discrepancy between these two figures is probably caused by the higher acceptance rates in the London area due to the high ethnic minority population. London is relatively poorly represented in the Registry. Nevertheless the centres contributing to the Registry include a number of cities, large and small, in various parts of the country, with varying ethnic minority populations. Although there may be small errors in extrapolating epidemiological data from the Registry to the whole UK, the information appears to be largely representative of British nephrology, and will be more accurate as more units join the Registry

As shown in last years report, there is a wide variation in estimated acceptance rates between centres (figure 4.1). Once again it is stressed that these calculations are based on population estimates given by each centre, which may well be a major cause for the wide variation because of the unknown percentage of cross-boundary flow. Other reasons for this variation include differing population needs due to age and ethnicity, differing referral practices to the renal unit, and differing policies for acceptance for therapy which in some cases are driven by resource limitations.

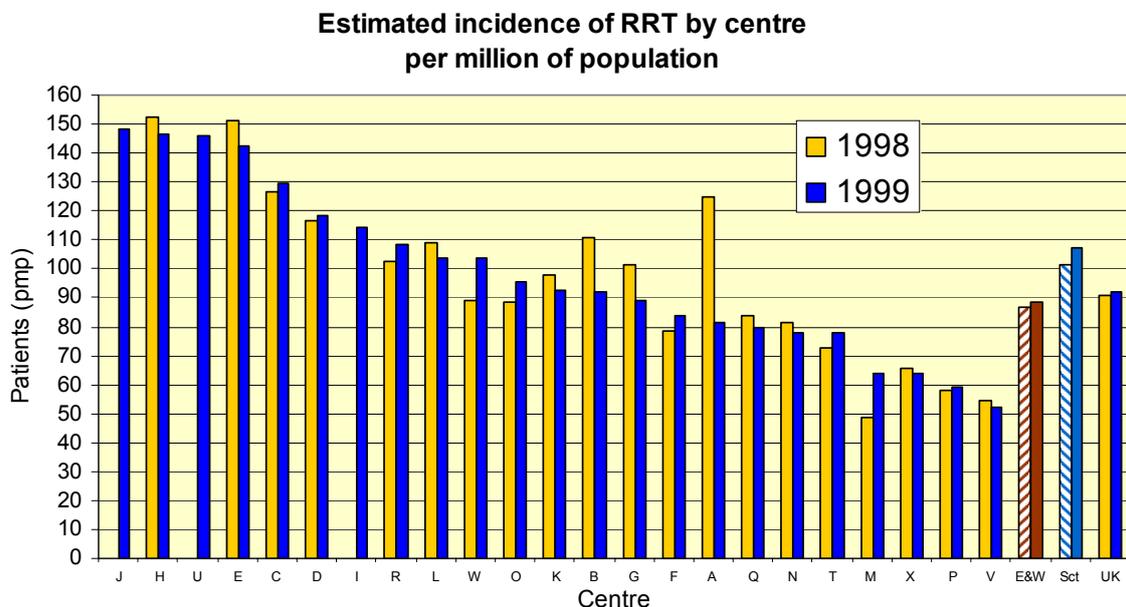


Figure 4.1 Estimated new patients starting RRT by centre per million of population

The changes in acceptance rates from 1998 to 1999 should be interpreted with caution from the point of view of individual renal units where the numbers may be small and confidence intervals large. When comparing the year on year national figures the possible effect of the additional centres who joined the Registry in 1999 must be borne in mind.

Calculation of incidence rates for the Scottish centres is not possible as the catchment populations by centre are not available.

When comparing the catchment data supplied in this report with that calculated by the National Review in 1992 centres B, C, F, G, H, I, J, K, M, P, Q, R and X have some discrepancy. Some of these centres appear as an over-estimate and others an under-estimate. The overall summation of these discrepancies appear to cancel each other out and does not change the total Registry coverage of 22.5 million.

Centre A is one of the smaller centres and the variation is within the 95% confidence interval..

Due to incomplete geographical coverage, it has not been possible to analyse acceptance rates by district health authority using postcode information. Each year as more renal units are included in the Registry there will be larger contiguous areas of the UK covered. The possible errors due to cross boundary flow and population estimates will be smaller, and the calculation of crude and standardised acceptance rates for individual Health Authorities from post codes, and age and national /regional age and ethnic specific rates, will be more accurate.

Incidence rate of RRT per million population by age

In 1999 the Registry covered an approximate population in England & Wales of 22 million. Data produced by the Office for National Statistics have been used to generate an approximate prevalent age distribution for England & Wales. The distributions for Scotland were obtained from the General Register Office for Scotland. The age distribution of the whole population in England & Wales compared with Scotland is fairly similar (table 4.2)

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
E&W	8.3	15.6	14.3	13.2	9.9	8.4	5.5	1.9
Scot	8.6	14.8	14.8	12.7	10.3	9.0	6.4	1.6

Table 4.2 UK population distribution by age group (% of total population)

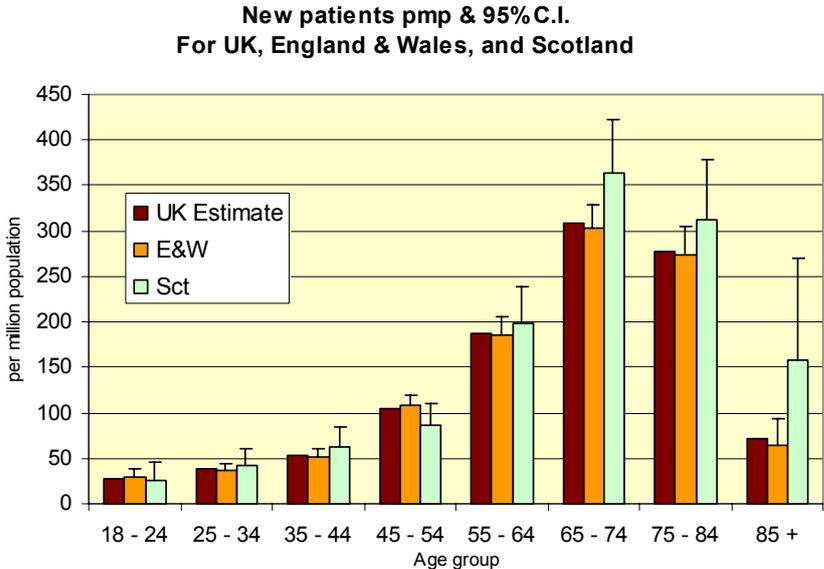


Figure 4.2 Estimated incidence per million population by age

The underlying assumption by the Registry in calculation of the acceptance rates for RRT shown in figure 4.2 is that the areas covered by the Registry have a similar age distribution to the overall population for England and Wales. The upper 95% confidence intervals are included. The differences between Scotland and England & Wales are not significant in any of the age groups. The acceptance rates peak in the 65-74 age group and then falls, which is contrary to the rising incidence of ESRF with age indicating the unmet need in the 65+ age group.

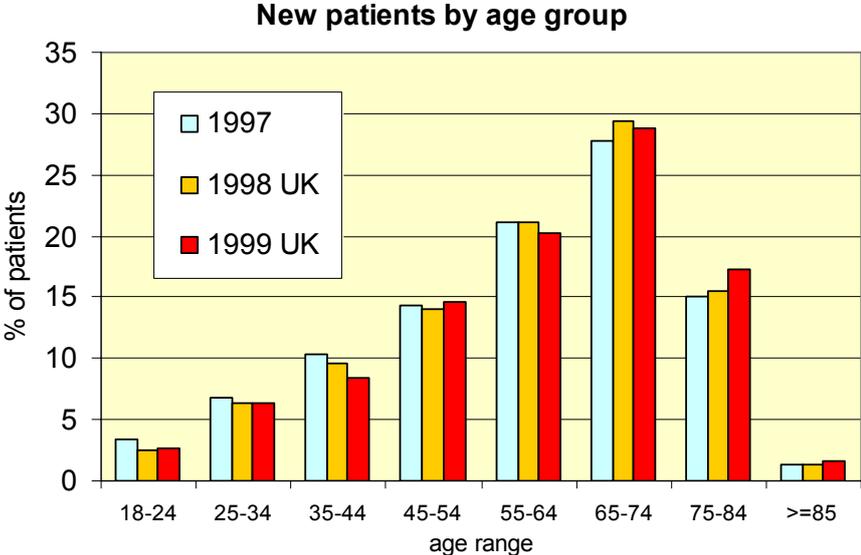


Figure 4.3 New RRT patients by age group for the UK

In England & Wales 44% of patients are over 65 compared with 50% in Scotland and 1 in 6 over 75 years of age at the start of treatment (Figures 4.2 & 4.3). In England and Wales the median age of patients starting renal replacement therapy in 1999 remained unchanged at 63.0, although in Scotland it increased from 64.0 to 65.0 years (figure 4.4).

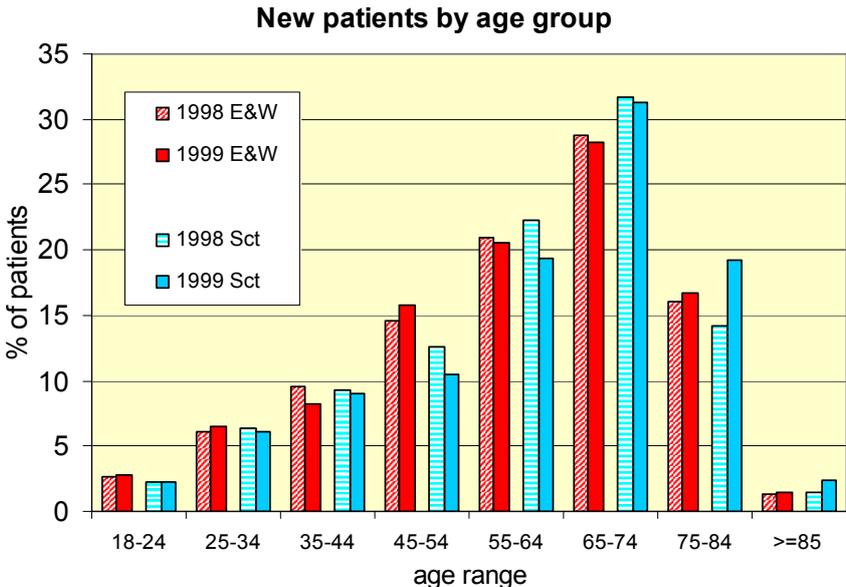


Figure 4.4 Changes in new RRT patients by age group – Scotland with England & Wales

There was a significant difference in the median age between England & Wales and Scotland (Chi squared $p < 0.01$) There was also a significant variation in median age between centres within England & Wales (Chi squared $p < 0.005$) shown in Figure 4.5. There was no significant variation in median age within Scotland (Chi squared $p = .33$). Perhaps surprisingly, there was no relationship between median age and acceptance rates (Figure 4.6).

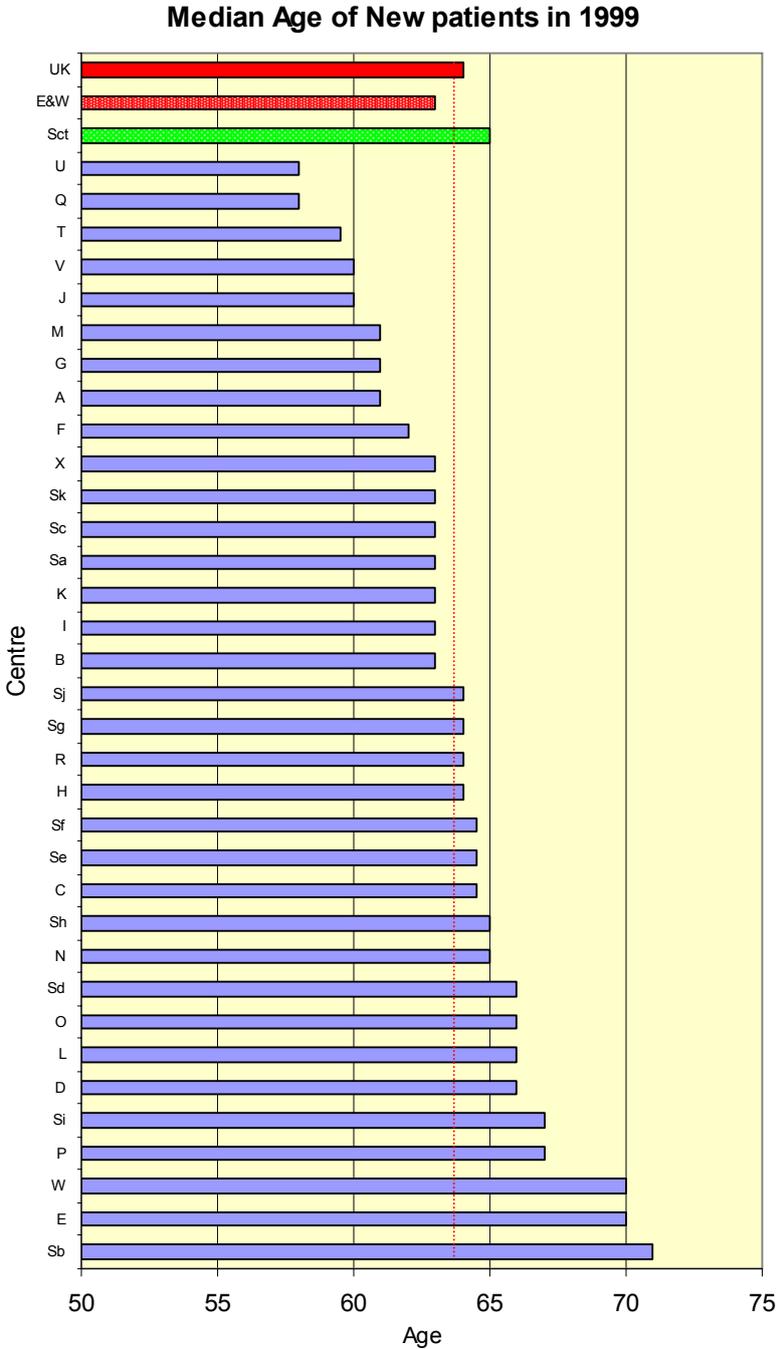


Figure 4.5 Median age of new patients in each unit

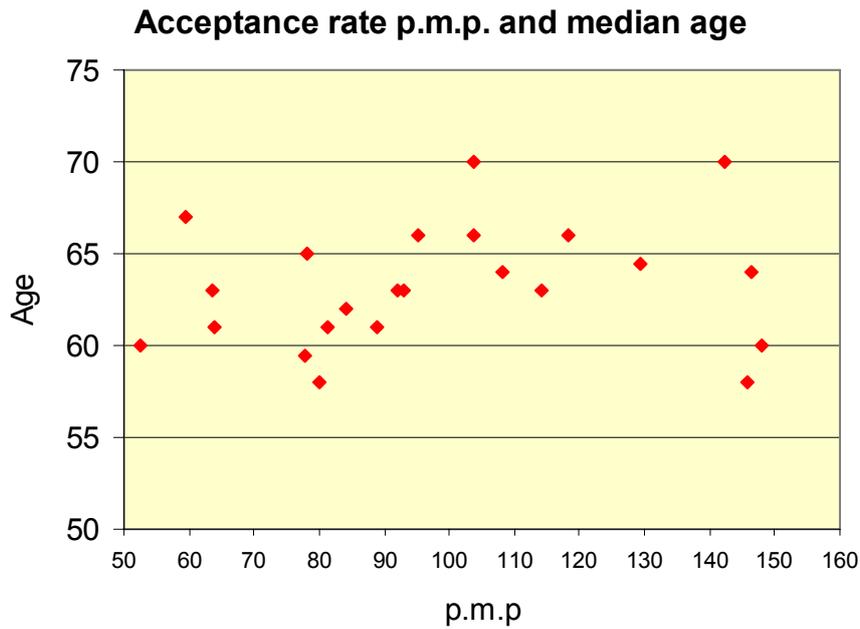


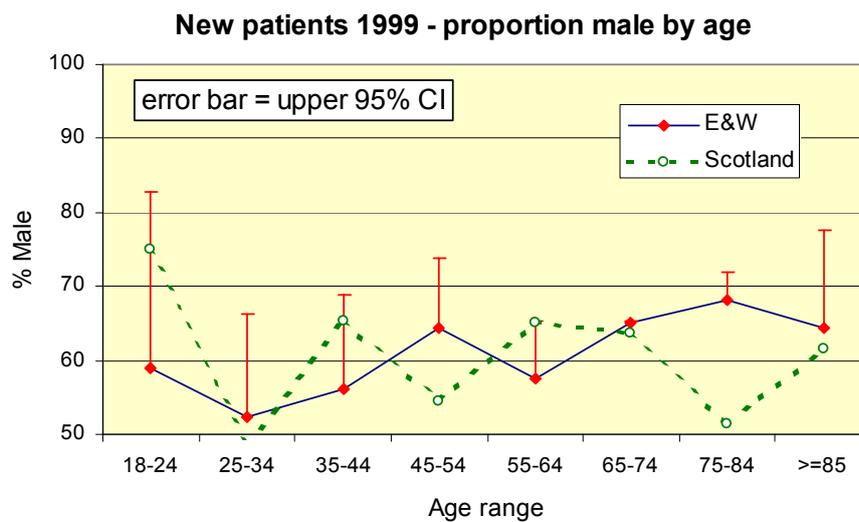
Figure 4.6 Estimated acceptance rate p.m.p. and age

Gender

Year	1997	1998	1999
England & Wales	63.1	62.8	62.2
Scotland		59.3	60.1

Table 4.3 Percentage of males accepted for RRT

From 1997 – 99 there was no change in the proportion of males starting renal replacement therapy (table 4.3)



For Scotland there are small numbers in each age band. There are thus wide confidence limits, and no significance difference from England and Wales.

Figure 4.7 New patients 1999 – proportion male by age

Ethnicity

Centre	%sent	White	Black	Asian	Chinese	Other
Sheffield	100	94	2	2	1	1
Nottingham	100	91	5	3		1
Stourbridge	100	85		15		
Birmingham Heartlands	100	76	3	18	2	1
Gloucester	98	100				
Plymouth	98	95	3	2		
Leicester	98	87	1	10		2
Sunderland	93	98			2	
Carshalton	93	76	4	6		14
Exeter	88	100				
Coventry	88	81	5	14		
Bristol	87	90	6	2	2	
Leeds, St James'	79	90	7	3		
Middlesborough	65	86		7		7
Hull	2	2				
Cardiff	0					
Carlisle	0					
Oxford	0					
Preston	0					
Southend	0					
Stevenage	0					
Wolverhampton	0					
Wrexham	0					
England	66					

Table 4.4 Ethnicity by centre

In those centres which sent ethnicity data, 12% of patients were from ethnic minorities. This is similar to the total of 14% in the 1998 cohort. Neither Scotland nor Wales collect ethnicity data within the health service as a matter of policy.

The median age of ethnic minority patients was 59.0 years (n=129) compared with 64.0 (n=1034) for white patients in England.

Data on ethnicity for England were missing in 34% of patients. The number of centres providing information on at least 85% of patients increased from 6 to 12 including 2 centres which provided no data last year. Seven centres in England provided no data or virtually none and this included all 4 of the new centres. All centres in the UK are encouraged to provide these data, which are very important for relating acceptance rates to local populations and planning service provision, and also for studying the pattern of disease in different ethnic populations.

Primary Renal Diagnosis

Diagnosis	E&W < 65	Scot <65	E&W ≥ 65	Scot ≥65	M:F (UK)
Aetiology uncertain and Glomerulonephritis not proven	16	13	23	31	1.6
Glomerulonephritis	13	15	6	7	2.2
Diabetes	20	21	10	12	1.4
Polycystic Kidney	9	10	3	2	1.1
Pyelonephritis	9	11	7	6	1.3
Renal Vascular disease	3	2	12	14	2.7
Hypertension	4	5	4	7	2.2
Other	12	14	12	9	1.5
No diagnosis sent	14	10	23	11	1.7
Total patients	1124	275	874	271	1.4

Table 4.5 % Primary renal diagnosis by age, and gender ratios

For the U.K. as a whole the single most common diagnosis was diabetic nephropathy (16%); this was even more commonly reported in those under 65 (20%). In the ethnic minority populations this accounted for 29% starting renal replacement therapy in 1999 and 32% including all those known to be from ethnic minorities who started in 1997-99. Once again there was a high proportion of diagnoses not returned, especially amongst the over 65 years old patients in England & Wales.

Unit	Not sent	Aetiology unc. Glomer. NP	GN	Diabetes	Polycystic Kidney	Pyelo-nephritis	Reno-vasc disease	Hyper tension	Other
A	0	23	15	19		12	23		8
B	37	15	13	10	4	8	1	4	8
C	18	20	9	20	5	14		7	7
D	0	45	8	10	6	10	10	1	10
E	14	19	8	17	6	6	9	2	19
F	7	30	10	9	3	6	8	1	28
G	8	28	10	16	4	11	9	3	11
H	1	21	10	19	7	10	10	7	16
I	0	30	15	23	8	8	15		3
J	0	16	4	28	7	12	9	12	12
K	0	18	10	15	8	10	5	15	18
L	42	17	13	15	7	2	1	1	2
M	2	16	9	26	8	5	6	9	20
N	12	22	13	19	6	9	6	1	13
O	53	6	5	14	2	5	1		14
P	72	6	2	8	2	2	4		5
Q	28	12	13	14	13	7	3	1	10
R	1	17	10	20	3	10	12	9	18
Sa	0	16	19	10	12	8	6	17	12
Sb	12	31	5	16	4	4	9	4	14
Sc	59	12	12			6	6	6	0
Sd	0	32	8	15	4	10	10	2	19
Se	2	24	9	28	9	11	4	7	7

Unit	Not sent	Aetiology unc. Glomer. NP	GN	Diabetes	Polycystic Kidney	Pyelo-nephritis	Reno-vasc disease	Hyper tension	Other
Sf	100								
Sg	0	35	11	19	11	8	5	3	8
Sh	0	24	14	24		10	10	10	7
Si	7	20		20	7	13	27	7	0
Sj	4	21	13	25	4	8	8	4	15
Sk	0	11	18	19	9	12	11	7	14
T	0	15	12	18	4	13	9	13	17
U	63	8	2	10	6	6			6
V	5	20	14	11	9	4	13	8	16
W	12	33	9	7	7	9	14	4	5
X	9	23	11	15	11	14	3	3	11
Sct	10	22	11	16	6	8	8	6	12
E&W	18	19	10	16	6	8	7	4	12
UK	16	20	10	16	6	8	7	5	12

Table 4.6 Percentage diagnostic distribution of new RRT patients by unit

This year the information is shown by individual centre (Table 4.6). The EDTA diagnostic coding categories for primary renal disease are used by all but one centre. This centre uses ICD9 coding which has been mapped at the Registry to EDTA. In the absence of reliable definitions of most diagnoses, except for biopsy proven glomerulonephritis, polycystic disease and to a lesser extent diabetic nephropathy and pyelonephritis, the variation between centres may reflect little more than the difficulty in categorising patients. This illustrates the need for more reliable definitions to enable meaningful comparison of outcomes in relation to underlying disease. These difficulties are compounded by the fact that many patients have multiple problems and there is individual variation in the use of invasive investigations to obtain a diagnosis in a predominantly elderly population.

Nevertheless there was a large variation from 7% - 28% in the reporting of diabetic nephropathy as the cause of end stage renal failure. With the Black and Asian population having a much higher incidence of diabetes than the rest of the population, the variation in ethnic minority mix will account for some of these differences.

Treatment modality

In 1999 haemodialysis was the very first modality of RRT for 58.6% of patients in England & Wales (57.7% in 1998) compared with 67.6% in Scotland (67.0% in 1998). Calculated as the percentage all dialysis patients 59.7% started on haemodialysis in England & Wales compared with 69.0% in Scotland. In many cases this was temporary haemodialysis whilst peritoneal dialysis was being established. The Registry therefore looks at the modality on day 90 as being more indicative of the elective modality for patients.

Haemodialysis was the modality of RRT at a day 90 for 58.8% of dialysis patients in England & Wales compared with 66.8% in Scotland (Figure 4.8). This is little changed from the initial treatment modality in England & Wales and Scotland respectively. The lack of change in these figures is probably hidden by the increased death rate in the haemodialysis patients (older patient group) and also the failure of PD in some patients.

By day 90, only 2.6% of 1999 patient cohort in England & Wales had received a transplant compared with 3.9% in 1998 while the corresponding figures for Scotland were 2.0% in 1999 and 0.9% in 1998.

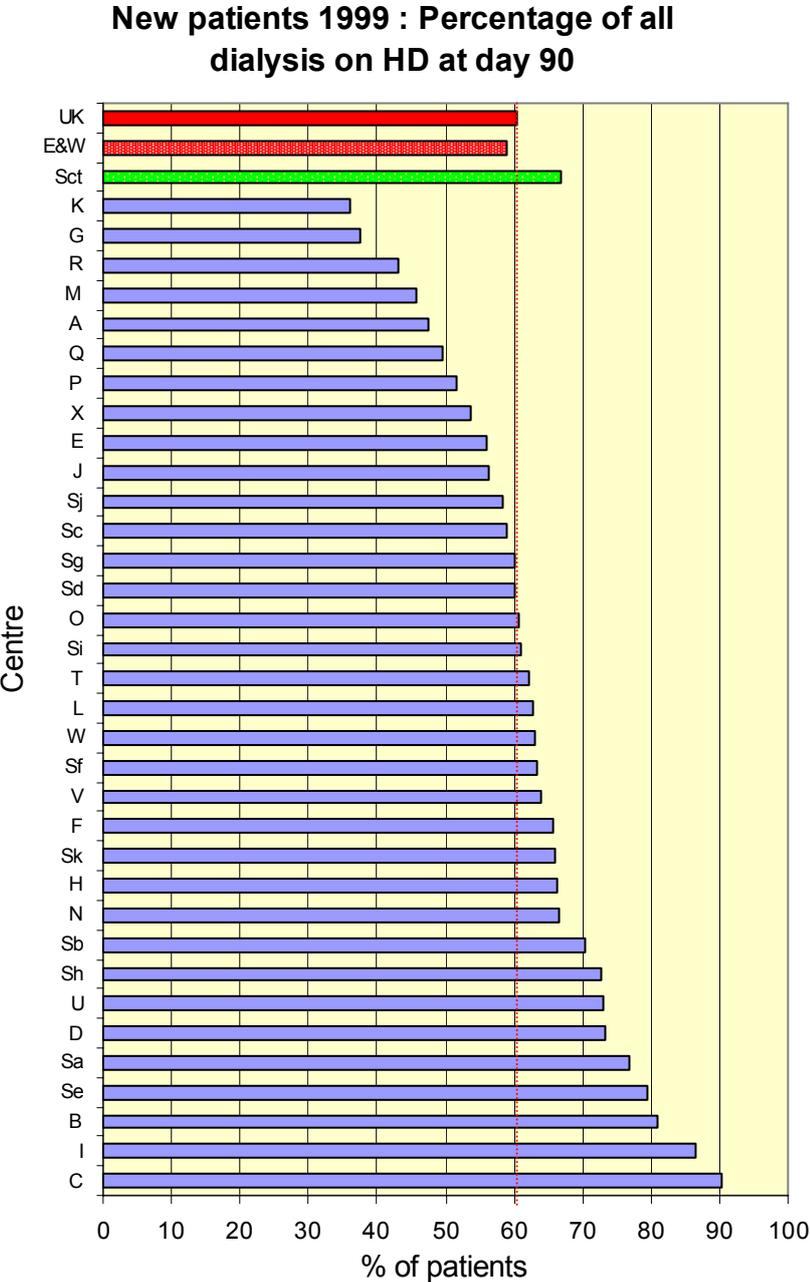


Figure 4.8 Percentage of patients established on HD at day 90 by centre

There were significant differences between individual Units within England & Wales (chi squared $p < 0.001$) in the percentage of patients on haemodialysis. This was not a significant difference within Scotland (chi squared $p < 0.05$). Peritoneal dialysis is more likely to be used in younger than older patients. Possible reasons for these differences include availability of treatment, patient and clinician preferences as well as differences in age and ethnicity.

New patients : Percentage of all dialysis patients on haemodialysis on day 90, by age

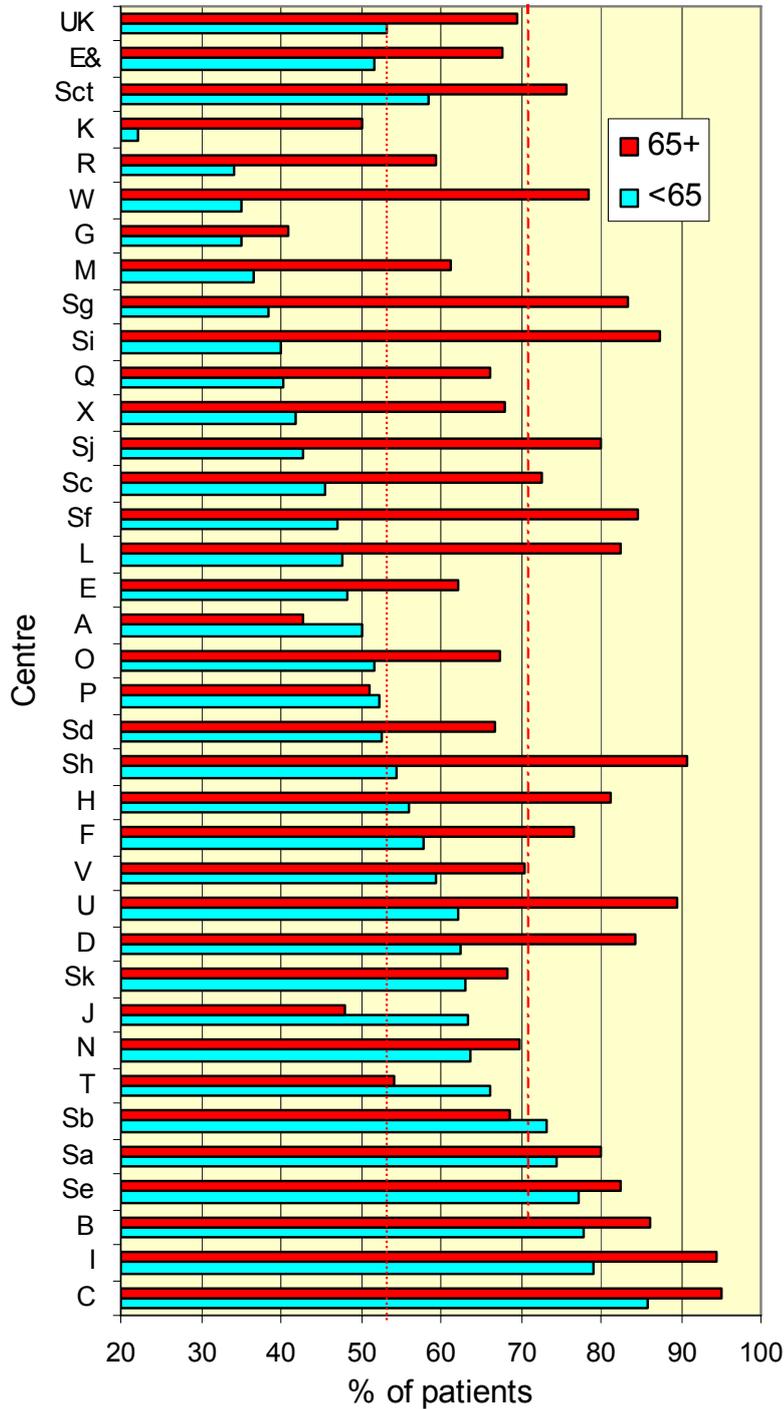


Figure 4.9 Percentage of patients established on HD at day 90 by centre and by age
 By day 90, 9.9% of patients in England & Wales had died (9.6% in 1998) compared with 12.7% for Scotland (13.6% in 1998).

The first change of treatment modality

This analysis includes the 2065 patients from the 19 E&W centres and 11 Scottish centres who started RRT on dialysis in 1998 and analyses the first change in modality in the 12 months from the established modality at day 90.

Change of treatment modality within the first year

Haemodialysis Modality	<i>No of patients</i>	<i>Percentage</i>
Remains on HD	849	70
Changed to PD	54	4
Transplanted	55	5
Transferred out elsewhere	9	0.7
Recovered	14	1.2
Stopped Treatment (died)	2	0.2
Died (no change in modality)	229	19

Table 4.7 HD patients at 90 days: changes in modality in subsequent year

The results in table 4.7 are almost identical to those in the 1998 Report although only 4% changed to PD in the first year rather than the 6% reported previously

Peritoneal Dialysis Modality	<i>No of patients</i>	<i>Percentage</i>
Remains on PD	545	64
Change to HD	135	16
Transplanted	76	9
Transferred out elsewhere	7	0.8
Recovered	1	0.1
Stopped Treatment (died)	6	0.7
Died (no change in modality)	83	10

Table 4.8 PD patients at 90 days: changes in modality in one year

The results in table 4.8 are identical to those in the 1999 Report.

The consistency of this data with the change from 912 patients to 2478 covering more varied regions of the country strongly suggests that this practice is reflective of the UK as a whole.

First modality change over 2 years

Only centres on the Registry in 1997 had a full annual cohort of patients available for a 2 year follow up period. The analysis includes 773 patients.

Patients who were on haemodialysis after the first 90 days

These figures are similar to those in last years Report except for a marked fall in the percentage of patients transplanted - from 9% at one year and 18% at 2 years down to 3% and

7% respectively. This fall is accounted for by the increased waiting lists for transplantation without a corresponding increase in the transplant rate.

First Change in Modality	At end of 1 year		At end of 2 years	
	No. of Patients	% of Patients	No. of Patients	% of Patients
Remains on HD	330	69	233	49
Changed to PD	28	6	31	7
Transplanted	16	3	35	7
Transferred out elsewhere	3	0.6	14	3
Recovered	4	0.8	5	1
Stopped Treatment (died)	4	0.8	4	0.8
Died (with no change in modality)	91	19	154	32
Total	476		476	

Table 4.9 Changes in modality over the first 2 years for patients on HD

Patients who were on peritoneal dialysis after the first 90 days

First Change in Modality	At end of 1 year		At end of 2 years	
	No. of Patients	% of Patients	No. of Patients	% of Patients
Remains on PD	196	66	122	41
Changed to HD	50	17	74	25
Transplanted	22	7	37	13
Transferred out	2	0.7	10	0
Recovered	1	0.3	1	0.3
Stopped Treatment (died)	0	0	0	0
Died (with no change in modality)	26	9	53	18
Total	297		297	

Table 4.10 Changes in modality over the first 2 years for patients on PD

Compared with last year there is a fall in the percentage of patients transplanted at one year from 11% to 7% and at 2 years from 20% down to 13%. This has been reflected in a greatly increased shift from PD to HD. The PD technique survival has effectively remained the same at 66% at one year and 41% at 2 years but this was maintained at the expense of an increased shift to HD from 11% to 17% at one year and 20% to 25% at 2 years. The continual future rise in transplant waiting lists will have HD resource implications. As patients stay longer on PD, more of the inadequately dialysed patients will have to be transferred to HD. Few centres appear to be recoding withdrawal of treatment prior to death.

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.

In the analysis against the Renal Association Standard patients were only included if they 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 no diagnosis recorded.

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

This analysis includes the cohort of 2347 patients from the 19 E&W centres and 11 Scottish centres who started RRT between 1/1/1998 and the 31/12/1998. The previous annual cohort of 984 patients is compared and then incorporated for further analysis. Results are shown in table 4.11.

First Treatment	Patients 18-55 - One Year Survival (95% CI)			
	<i>Standard Primary Renal Disease</i>		All Diseases Except Diabetes	
	1998	1997 & 1998	1998	1997 & 1998
All	95.8 (94.3 - 97.4)	96.0 (94.6 - 97.4)	94.4 (91.7 – 97.1)	93.8 (92.3 - 95.3)
Haemodialysis	92.7 (89.7 - 95.8)	93.1 (90.4 - 95.9)	88.6 (85.4 – 91.8)	89.5 (86.7 - 92.3)
Peritoneal dialysis	98.0 (96.0 - 100)	97.9 (96.0 - 99.7)	97.6 (95.7 – 99.5)	97.3 (95.4 - 99.2)

Table 4.11 One Year Patients Survival – patients age 18-55

These data are well within the Renal Association Standard and within the 95% confidence intervals of the previous year’s data. As the numbers of deaths are small in these categories, the data for 1997 and 1998 patient cohort have been combined to provide a more accurate figure and narrow the confidence intervals. The apparent better survival on peritoneal dialysis

is unlikely to reflect differential benefits of the treatment, as the patients are a selected group and are younger than those on haemodialysis.

Survival of all new patients – further analysis

Results are shown in tables 4.12 to 4.14

	1998 Deaths No of Patients	1998 KM Survival	1998 K-M 95% C I	1997-8 KM Survival	1997-8 K-M 95% C I
< 65	65/1268	0.95	(0.94 - 0.97)	0.95	(0.94 - 0.96)
≥ 65	206/1079	0.80	(0.78 - 0.83)	0.81	(0.78 - 0.83)
All	271/2347	0.88	(0.87- 0.90)	0.89	(0.87 - 0.90)

Table 4.12 Ninety day survival of 1998 and combined 1997-8 cohort patients

These 1998 patient cohort results are similar to those of 1997 produced in the 1999 Registry report, with 89% survival in the first ninety days.

One year survival

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 were 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 4.13 and 4.14

	At 3 months 1998 cohort		At one year 1998 cohort		Death Rate Per 100 Patient Years
Deaths	Deaths	KM	K-M		
/Patients	/Patients	Survival	95% CI		
< 65	65/1268	156/1268	0.88	(0.86 - 0.89)	13.5
≥65	206/1079	375/1079	0.65	(0.62 - 0.68)	46.3
All	271/2347	531/2347	0.77	(0.75 - 0.79)	27.0

Table 4.13 One year survival of new patients, by age at start of therapy in 1998

	At 3 months 1997 cohort		At one year 1997 cohort		Death Rate Per 100 Patient Years
Deaths	Deaths	KM	K-M		
/Patients	/Patients	Survival	95% CI		
< 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 4.14 One year survival of new patients from 1997

There are over twice the number of patients included in this analysis than in the 1999 Report, with similar results. This consistency suggests the Registry data are representative of the UK as a whole.

Two year survival

Only centres on the Registry in 1997 which had a full annual cohort of patients available for a 2 year follow up period ending 31/12/1999 were included. The analysis includes 987 patients and is shown in figure 4.15.

	Deaths / No of Patients			KM Survival Analysis		K-M 95% Confidence Interval
	3/12	1 year	2 years	1 year	2 year	2 year survival
<65	29	67	114/552	0.90	0.83	(0.79 - 0.87)
≥ 65	84	153	258/435	0.68	0.48	(0.43 - 0.53)
All	113/987	220/987	372/987	0.82	0.67	(0.65 - 0.70)

Table 4.15 Two year survival of 1997 cohort patients

Comment

These survival data are similar to that in the previous report. In a further 2 years a trend analysis will be possible to identify any changes in these patterns.

Comparisons of survival in different units are not shown at this point. To perform such comparisons it is essential to understand the influence of factors such as age, gender, social deprivation, and primary diagnosis on outcomes. One can then adjust the measured outcomes of each unit for these factors. In chapter 16 there is further analysis of factors influencing survival enabling some of these adjustments to be made. Appropriately adjusted survival for each renal unit is then presented.